Hearing before the United States Commission on Civil Rights

AIDS

Hearing Held in

WASHINGTON, D.C.

May 16–18, 1988

Civil Rights Aspects of Public Health Policies and Initiatives to Control AIDS

U.S. COMMISSION ON CIVIL RIGHTS

The U.S. Commission on Civil Rights is an independent, bipartisan agency first established by Congress in 1957 and reestablished in 1983. It is directed to:

- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, handicap, or national origin, or by reason of fraudulent practices;
- Study and collect information concerning legal developments constituting discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin;
- Submit reports, findings, and recommendations to the President and Congress.

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HEARING BEFORE THE UNITED STATES COMMISSION ON CIVIL RIGHTS
CIVIL RIGHTS ASPECTS OF PUBLIC HEALTH POLICIES AND INITIATIVES TO CONTROL AIDS

Monday, May 16, 1988

The U.S. Commission on Civil Rights convened at 8:30a.m., Monday, May 16, 1988, in the U.S. Department of Health and Human Services Departmental Auditorium, 330 Independence Avenue, S.W., Washington, D.C., Chairman Clarence M. Pendleton, Jr., presiding.

PRESENT: Chairman Clarence M. Pendleton, Jr.; Vice Chairman Murray Friedman; Commissioners Mary Frances Berry, Esther Gonzalez-Arroyo Buckley, Robert A. Destro, Francis A. Guess, and Blandina Cardenas Ramirez; Acting Staff Director Susan Prado; General Counsel William Howard, and staff attorneys Burt Balch and Michael Fumento.

PROCEEDINGS

CHAIRMAN PENDLETON. Anyone who is hearing-impaired please let the Chair know. We will have people here to communicate with you. In the absence of hearing-impaired persons, we will let the communicator rest.

I'd also like to note that, as is our custom, the record will be kept open for approximately 30 days after the close of this hearing, and those persons who would like to submit statements for the record can feel free to do so.

We have one statement from the American Bar Association that will be a part of the record. So if there are other statements, and if those of you who are here know other people who will want to make statements, certainly you are welcome to relay that information.

CHAIRMAN PENDLETON. With that, I would like the witnesses to stand before I give my opening statement and I will swear you in.

[David Pence, Jeffrey Levi, Jim Johnson, and Jay E. Menitove, were sworn.]

CHAIRMAN PENDLETON. I'd like to introduce my colleagues who are here this morning.

Commissioner Francis Guess, Commissioner Robert Destro. On my left is Commissioner Esther Buckley, and other Commissioners, I would assume, will be here in due time. I think, as constituted, we do have appropriate people here from both sides of the aisle.

COMMISSIONER DESTRO. Commissioner Berry is here.

CHAIRMAN PENDLETON. Commissioner Berry is here or on her way. I have an opening statement. I do want to say that the Chair is going to stick extremely close to the schedule, as petitioned by staff, to get all this information in.

Good morning. This hearing is now convened. I am Clarence M. Pendleton, Jr., Chairman of the United States Commission on Civil Rights.

During the next 3 days, the Commission will receive testimony on the important issue of civil rights aspects of public health policies and initiatives to control AIDS. For those of you who do not have copies, the agenda is available at the entrance to the auditorium. It is a balanced agenda, with a wide array of viewpoints represented, and I am sure the testimony will be interesting and enlightening.

As you observe these proceedings, I think you will find that among the Commissioners there is a wide variety of viewpoints. Those viewpoints are well represented here. We do, after all, represent two branches of the Federal Government. Four Commissioners are appointed by the Congress and four by the President. All told, four of us are Republicans, three are Democrats, and one is an Independent. Not too long ago it used to be the reverse, except for the Independent.

This hearing is comprised of 10 panels. The Public Health Aspects Panel, which we will hear from in a moment, consists of Dr. David Pence of the University of Minnesota Medical Center; Jeffrey Levi of the National Gay and Lesbian Task Force; Jim Johnson, head of a California-based AIDS hospice; Dr. Jay Menitove of the American Association of Blood Banks; and Donald Goldman of the National Hemophilia Foundation.

In the context of AIDS, the key question in assessing what measures should be taken to protect the public health involves assessing the transmissibility of the HIV virus and of infections secondary to AIDS. AIDS is first and foremost a public health issue. Thus, in drawing conclusions about whether particular actions would be impermissible discrimination or prudent protection of the public health, we must be bound by what we know about how AIDS is spread.

Our second panel will examine this issue. Dr. Anthony Fauci of the National Institutes of Health will speak first and offer a slide presentation; Dr. James Allen of the Centers for Disease Control will follow; followed by Dr. Rand Stoneburner of the New York City Department of Health; Dr. Stanley Monteith, a physician in private practice in California, and Dr. Alexander Langmuir, an epidemiologist at Johns Hopkins.

Having considered the degree and nature of the general risk of catching AIDS and secondary infections, we will examine in Panel III the subject of AIDS in prisons and mental institutions.

Panel IV will examine the disproportionate impact of AIDS on minorities.

Panel V will discuss AIDS, AIDS-related complex, and asymptomatic seropositivity, and the extent to which each of these is covered by the Rehabilitation Act of 1973.

Panel VI will look at discrimination in housing against persons with AIDS.

Panel VII will examine government testing for the HIV virus.

Issues surrounding seropositive children in schools will be the focus of Panel VIII.

The right of AIDS victims to health care and the right of health care providers to take steps to avoid exposure to HIV will be the focus of Panel IX.

And, finally, whether insurance companies should be permitted to test for the HIV virus before issuing new policies will be the topic of Panel X.

The panels will be followed on Wednesday by an open session at which members of the public may make a 5-minute statement on which there will be no debate and no questions.

Now let me say a word about what we are not doing here today. In a major newspaper a few weeks ago, homosexual rights groups criticized the Commission's hearing agenda. It didn't seem to bother them, or the reporter for that matter, that they hadn't even seen the agenda. We have also been told that homosexual groups plan to demonstrate in front of this building while we are holding our hearing. The truth is, homosexual groups are represented in this hearing, and therefore I am having trouble understanding what all the moaning is about. They are here to testify, and they should be, since they are the group most affected by the AIDS epidemic.

Let me say, however, that we are not here to listen to testimony about discrimination on the basis of sexual orientation. That issue not only exceeds the scope of this hearing, it exceeds the Commission's jurisdiction. These groups have been invited to testify on the extent to which certain of their members are being deprived of humane treatment, not only because of their sexual orientation but because they have AIDS.

Finally, I want to say something about the decision of the U.S. Supreme Court last year in *School Board of Nassau County, Florida* v. *Arline*. Those of you unacquainted with *Arline* will hear a great deal about it during the next 3 days, because although the decision dealt specifically with tuberculosis, it appears applicable to full-blown AIDS and AIDS-related complex as well.

The opinion, written by Justice Brennan, with Chief Justice Rehnquist and Justice Scalia dissenting, held that Gene Arline, a third-grade teacher who testified positive for tuberculosis in 1957, 1977, and twice in 1978, and who was discharged by her school in 1978, was handicapped within the meaning of Section 504 of the Rehabilitation Act. In doing so, the Supreme Court affirmed the Appeals Court order that the case be remanded to the District Court to determine whether the school could reasonably accommodate her.

Coincidentally, the remand is coming up in the District Court tomorrow. I have just learned that the School Board will present evidence, previously unknown, that 2 of the 19 children in Gene Arline's third-grade class tested positive for tuberculosis in 1978. That's 2 of 19. And you can be sure they didn't get it at home.

Did the School Board know this in 1978? Did the United States Supreme Court know this when it rendered its decision that persons with contagious diseases are handicapped within the meaning of the Rehabilitation Act? No.

Why not? Because I am told that the Florida public health officials were treating the positive test results as confidential.

It seems to me the fact that neither the School Board nor the United States Supreme Court knew that two of Gene Arline's third-grade students tested positive for TB may be evidence that the public's health in Nassau County took a back seat to some undefined notion of civil rights.

Should Congress reverse *Arline?* Frankly, whether it should or not, I don't think it's going to. Now that the Court has given the Rehabilitation Act new meaning, the Congress has acted to codify that meaning. You have doubtless heard all about Congress having to pass the Grove City legislation over President Reagan's veto. What you may not have heard is that Grove City may have codified *Arline*, an issue that we will be taking testimony on in the employment context.

The Rehabilitation Act now protects individuals who do not pose a "direct threat to the health or safety of other individuals" by reason of

their carrying a contagious disease if they can perform their job. I should also point out that the House Judiciary Committee recently reported out amendments to the Fair Housing Act, using language similar to the Grove City language, which would prohibit discrimination in housing against persons with contagious diseases who do not pose a direct threat to the health or safety of other individuals. It seems to me the National Institutes of Health may have to open a branch at the Department of Housing and Urban Development to assist the administrative law judges in handling their new caseload.

My discomfort with *Arline* does not stem from a belief that persons with contagious diseases ought not to have recourse to forums to determine whether their disease is a direct threat to the public health. To the contrary, they should have such a forum and, if they don't pose a threat to the public health, they should, of course, be permitted to live normal lives. I question, however, whether courts provide a better forum than public health departments. Put another way, sending the issue to the courts rather than to public health departments makes the contagious disease issue more a civil rights issue than a public health issue, the reverse of what it ought to be.

For my own purposes, I will assume that *Arline* is with us as a permanent feature of our civil rights landscape. The questions I will ask during this hearing will begin from that assumption and focus, in particular, on the appropriate burdens of proof in contagious disease litigation, and on specific language in the Rehabilitation Act or regulation.

I thank you all for coming.

COMMISSIONER BERRY. May I make a statement, Mr. Chairman, because I most certainly had not seen your statement and do not agree with it, and feel that it is entirely inappropriate for this Commission to make statements which are conclusions of fact before we even begin this hearing. We have not made any decisions, as you refer to on page 5 of your statement, about whether the Department of Housing will have to have a branch office of NIH to assist administrative law judges.

You are clearly commenting on legislation that is before the Congress and trying to imply—in fact you are implying—that that legislation somehow has implications that this Commission has not considered, has not voted on, has not studied, has not analyzed. You are continuing a previous pattern. If you speak for others on this Commission you certainly do not speak for me, and I want it known that this Commissioner feels that it is entirely inappropriate to make such statements.

Furthermore, on the case of *Arline,* I believe it is inappropriate also for you to comment on the evidence that will be presented in a District Court case as the Chairman of this Commission, leaving the matter open as to whether the rest of us agree with you about this evidence that will be introduced, what its meaning is.

And by the way, even if one assumed that you were correct about the evidence that will be introduced, it in no way is inconsistent with the Supreme Court decision in *Arline* which simply remanded it for such evidence, and it is no basis for anyone to conclude that the public health of Nassau County took a back seat to some undefined notion of civil rights, not even knowing what you mean by an undefined notion of civil rights.

I had great fears as we began this hearing, fear and trepidation, that one of the most unfortunate things I have done in my career on the Commission is to vote that there should be a hearing on AIDS, since I had hoped that my colleagues would proceed in a judicious manner on a matter of such important public concern without drawing conclusions and making inflammatory remarks at the beginning. It turns out that I was wrong.

So I want to completely disassociate myself from your conclusions of facts, statements, innuendo, and inflammatory remarks in my view, Mr. Chairman, and I still will try to keep an open mind as I listen to these hearings, even though I already know your views.

COMMISSIONER GUESS. Mr. Chairman.

CHAIRMAN PENDLETON. Mr. Guess.

COMMISSIONER GUESS. Mr. Chairman, I'd like to concur in Commissioner Berry's observations on your opening statement pertaining to the constitution of this hearing and consultation. More importantly, Mr. Chairman, I hope it does not forbode what we can anticipate during the next 3 days as you go about the business of conducting a hearing and consultation, and I also would like to disassociate myself from it.

CHAIRMAN PENDLETON. Ms. Buckley.

COMMISSIONER BUCKLEY. I have nothing.

CHAIRMAN PENDLETON. Mr. Destro.

COMMISSIONER DESTRO. I have no comment.

CHAIRMAN PENDLETON. Thank you. Dr. Pence.

Panel I: Public Health Aspects

TESTIMONY OF DAVID PENCE, M.D., DEPARTMENT OF THERAPEUTIC RADIOLOGY-RADIATION ONCOLOGY, UNIVERSITY OF MINNESOTA HOSPITAL AND CLINIC

DR. PENCE. Chairman Pendleton, ladies and gentlemen of the Commission.

In his book, *The Structure of Scientific Revolutions,* Thomas Kuhn explains that scientific facts are always interpreted within a basic framework of ideas and assumptions that he calls a paradigm. Paradigms are useful because they provide coherence for us in understanding observed events and they give us direction for our future research.

My presentation today to the Commission is about paradigms. I submit that the present framework in which the civil rights argument is being

presented to medical and public health professions has paralyzed effective public health measures in dealing with the HIV epidemic. Men of good will and honorable intentions have been mislead by a faulty paradigm.

So it is fitting—indeed, Ms. Berry, I think it is crucial—that the Civil Rights Commission and other traditional civil rights organizations contribute to public policy formulation by clarifying the intellectual content and the moral heritage of the civil rights movement.

Present policy in most States dealing with the AIDS epidemic has been shaped by public health officials, physicians, and gay rights activists. Many of the physicians who have become involved in the various AIDS task forces around the country are also proponents of the gay ideology. A recent survey from the Minnesota Public Health Department compared a random sample of physicians with physicians involved in AIDS patient care and discovered 10 times as many homosexual and bisexual physicians involved in cases reported as AIDS. This is not an accidental occurrence, and it has created a false bias from the medical profession in formulating our initial response to this epidemic.

As more physicians with less ideological interest become involved in the HIV epidemic, certainly we shall see advocacy of a more traditional public health and medical approach to contain this disease.

In a similar fashion, the civil rights movement has been poorly represented by sexual revolutionaries masquerading as civil rights advocates and AIDS task forces across the country. Traditional civil rights workers are well aware that in the 1970s the basic civil rights paradigm against racism was destroyed not by opposition but by dilution. The equation of gender differences with racial discrimination and the bizarre addition of sexual preference as a meaningful moral category has dealt the civil rights movement a blow from which it has never fully recovered. Its moral capital has been squandered by sexual revolutionaries who have subverted the social agenda of the poor with the middle-class ideologies of feminism and gay rights.

It is this fallacious caricature of civil rights which has created the many false dilemmas now perplexing policymakers as they approach the HIV epidemic. It should not be surprising, then, if traditional civil rights groups begin to clarify this debate. For we will be motivated by the daily observation of a paralyzed public policy making its preferential and horrifying claim on the women and the children of the urban poor.

Before explaining further the faulty paradigm which has compromised this policy, we should agree to certain basic facts about the disease and its spread. It is important to do this to clarify that the debate about public policy is not centered on a dispute about scientific facts.

When the medical community first labeled this disease as AIDS, it was not clear that it was caused by the HIV virus. Now we know that the

infections and cancers from which these first patients died were caused by a viral infection called HIV which weaken the immune system.

The virus is transmitted by sexual contact and exposure to infected blood or blood components and perinatally from mother to neonate, which means that a pregnant woman basically can pass the virus to her child. And about 50 percent of women, if they were pregnant, if they were HIV-positive, would pass it to their child.

When a person is infected by the virus, he does not become an AIDS case. However, he is carrying the virus, and he can now infect other people. It is crucial to understand this distinction. A person can be HIV-infected and look perfectly healthy. He is a carrier of the virus, and he is capable of spreading the virus. He is both infected and he is infectious. The great danger of this disease is that a person can have a long period of time in which he simply carries the disease and spreads it to others while appearing healthy. Thus, each individual who is infected can spread the disease to many others if he does not refrain from sexual contact or blood donation.

In terms of public health considerations, this would be a much less dangerous epidemic if the person were infected and died 2 weeks later. It's the long period of infectivity without clinical signs of disease that make the HIV epidemic such a momentous public health challenge.

For purposes, then, of public health policy, let us be very clear: It is HIV infection and not AIDS cases which are important. In fact, it would serve us all well if we remember that the AIDS terminology was developed when we did not understand the nature of the infection. By referring to this disease as the HIV infection, our language will become more rooted in the biological facts which must be understood to establish coherent policy.

If a person is infected with HIV, the chance is very high he will develop end-stage disease. The most likely progression rate now is that if a person is infected, after 5 years 10 percent of the people will take on end-stage disease; after 8 years, 30 percent; and after 10 years, 42 percent. It appears that this progression continues with each following year, and that after 15 to 20 years, over 90 percent of infected individuals will have end-stage disease.

No one can absolutely prove this, because we have not followed the disease for that many years. But our working hypothesis in shaping public policy should be that the great majority of people who are HIV-infected will eventually die from AIDS.

The basic assumptions, then, that I think public policy should be built on are:

First, the disease is spread through sexual contacts, perinatally, and through exposure to blood products. And let me make it very clear that I do not believe it is caused by casual transmission, and that is not the basis of my argument. The basic points that the NIH will put out about how this

disease is spread I totally agree with. I do not dispute that, and I think it is erroneous to try to dispute that.

A cure or a vaccine is not likely in the next decade.

The third principle that we have to base our policy on is the understanding that people infected with the virus showing no symptoms of disease—that is, asymptomatic carriers—are capable of infecting others for years if they have sexual relations, donate blood, or share IV drugs.

And, fourth, a very high proportion of people infected with the virus will die of the disease.

Now, let us also outline the basic principles which must underlie public health policy. An infectious disease—and I'm not talking about AIDS or anything like that, just a general infectious disease—which cannot be cured, can only be controlled by interrupting its transmission. This necessarily entails four basic steps:

First, case finding—the location of carriers of the infectious disease.

Secondly, contact tracing—the location of all individuals who have been exposed to the infected person in the manner by which the agent is known to be spread.

Third, the determination of whether carriers will continue the activity which spreads the disease and the isolation of those who will not comply with desist orders.

Fourth, the closing of public establishments which foster the activity by which the disease is spread.

And to the great credit of laboratory science, we have a task which can reasonably determine who carries the virus, even if the person does not appear ill. It is important to understand that for purposes, again, of public health policy, all rules and regulations should apply to carriers of the virus and not simply those of end-stage disease. Unfortunately, the scientific genius which has developed the diagnostic tests has not been matched by a corresponding wisdom in the political community.

Traditional public health measures are applied to a particular disease when the State public health authorities declare the disease to be reportable, communicable, or some other designation.

In almost every State in the union there are provisions for case finding, contact tracing, isolation of recalcitrant carriers, and closure of places of transmission, if the infection is put in the appropriate designation. Unfortunately, the great majority of States have not designated the HIV carrier state. So we have the cruel paradox, "the epidemic of the century"—and I believe it is the epidemic of the century—has been granted immunity from the protective measures of standard public health practice.

Let me illustrate the manner in which we have deviated from traditional public health policy. The first component of public health strategy is built on identifying individuals who are infectious. Again, for public health

purposes, a person who has early HIV infection, the carrier state, or end-stage infection, AIDS, that distinction is not important. The people who are infectious is anyone who is seropositive. In fact, it is the asymptomatic carrier who is the greatest danger as a potential source of transmission.

For the first time in the history of public health, anonymous testing has been allowed and even encouraged by public health officials. The early rationale for this was that anonymous testing would prevent people from going to plasma centers to find out if they had the AIDS virus. This is a rather tortured argument since plasma centers demand identification before testing. It was a good idea to set up testing centers, but it was a fundamental conceptual error to allow testing to be anonymous. Remember the crucial distinction. Confidential testing means that results are known to a patient, to a doctor, and if it's a communicable disease to public health officials. That is the standard practice throughout medicine. Anonymous testing means a person does not even give his name when he takes a test, and that practice is unique to the HIV infection.

Gay lobbyists have convinced officials that the government and the medical profession cannot be trusted. The nameless carrier of the virus, however, is to be granted total discretion in warning his sexual contacts and desisting from the behavior which spreads the disease. This policy displays an unfortunate naivete when we consider the addictive and compulsive behavior by which most HIV carriers contract the disease.

The second component of public health strategy, contact tracing, has also been largely abandoned in dealing with the AIDS crisis. And throughout the country there has been an irresponsible reluctance to take even minimal steps of closing down bathhouses and 24-hour book stores where we know acts of anonymous sodomy are occurring. We should think about this because those of us who have argued for this have been called homophobic, and yet we know that by closing places like this we would save the lives of men most likely to practice serial anonymous homosexual activity.

So we should think about this and ask who really speaks for the men who seek the environment for sexual contact. Is it the average citizen who just shows neglect? Is it the gay spokesman who defends his ideology at the expense of individual lives? Or is it the doctor, the minister, the policeman, or the public official who says, "Enough, enough; let us not lose one more life to preserve this commerce in misery and death."

We should know enough about the history of the civil rights movement to remember that black Southern Baptists marched for a right to vote, they marched for a right to own a home, to hold a job, to raise a family, to participate as policemen and firemen in the protection of their towns. The road to Selma did not lead to the right to sodomy. This cruel perversion of the civil rights movement, which intellectually marked the 1970s, now biologically confronts us in the 1980s. The civil rights movement must

regain its soul or lose forever its moral claim on the conscience of our people.

The consequences of inaction will fall on the poor and on the urban dwellers. After the young hemophiliacs are decimated, the children of the black community will pay for the inability of adults to fulfill our protective function.

Before we turn our attention to the growing number of pediatric HIV cases, we should reflect a moment on the present plight of hemophiliacs in America. How strange indeed it is that with so much written about the newly invented rights of virus carriers that so little has been written about the victimization of hemophiliacs and the failure of government to provide them protection from an obviously infected blood supply.

Hemophiliacs are born with the deficiency of clotting factors in their blood, and they need continual blood transfusions to supply these factors. Because of their exposure to large pools of blood, the rate of HIV infection among hemophiliacs is higher than any group in America. Of the approximately 12,500 hemophilia A patients, 70 percent are infected. Of the 3,000 hemophilia B patients, about 35 percent are probably infected.

It was clear in 1983 that the disease which was killing homosexuals and IV drug users in 1981 had spread to the blood supply and was now infecting hemophiliacs and others depending on blood products for their health care. Neither the government nor the medical profession responded to this crisis with the traditional public action of a political community. No law was passed. No law was passed prohibiting men engaging in homosexual activity or IV drug use from donating blood. Instead, in March of '83, the FDA suggested the cowardly compromise of self-deferral by donors in high-risk groups.

How many minutes do I have?

CHAIRMAN PENDLETON. You're about out. As I said at the beginning, we are trying to limit the discussion from panelists, other than the testimony you might submit, between 8 and 10 minutes to give us a chance to get through it all and have a chance for staff questions as well as Commissioner questions. Do you have some important points you want to tie up with?

DR. PENCE. Let me have just 3 more minutes, all right?

CHAIRMAN PENDLETON. Since I made the mistake, you can have 3 more minutes, but you're the last one who gets 3 more minutes.

DR. PENCE. Basically I will argue—and you can read through the paper—how the policy of self-deferral has worked and show you the amount of infections that have happened since we have had the policy of self-deferral. We still do not have any laws which prevent people in high-risk groups to not donate blood.

The overreliance on voluntary compliance to insure testing and to effect behavioral changes seems a strange mixture of naivete, ignorance, and

ideological self-interest. Both commonsense and recent data indicate that when the testing of select groups is voluntary, the most likely people to refuse testing are those most likely to be positive.

It should also be unsettling to us that public policy is so unilaterally grounded upon the good judgment of individuals who are afflicted with the disease which often manifests itself as progressive dementia.

Finally, the notion that only education and counseling can significantly alter the addictive behavior of IV drug users can only be understood as another capitulation of commonsense and the public health to special interest groups.

In the essential task, then, of educating our young, the civil rights movement must also lead the fight to recognize that our teenagers are moral beings capable of disciplining themselves to reject premarital sex and drug use.

The traditional civil rights movement must free itself from the ideologies of feminism and homosexual rights. Gender distinctions are fundamentally different from racial distinctions. Uniting these diverse phenomena under the analogy of oppression has tortured our language, twisted our law, and betrayed social reform. Homosexual behavior is a completely different category of activity which, again, cannot be seriously considered even an analogue of race or gender.

The freedom train has been hijacked. The new agenda of the civil rights movement will not be written until the philosophical and social tenets of the sexual revolutionaries are exposed as inimical to the poor.

Frederick Douglas said, "Unless the field is plowed, there will be no harvest." So it is with this epidemic. Unless the battle be engaged, the war will never be won.

To employ the paradigm, then, of a vigorous public health program, to intercept the transmission of this virus, we must restore the moral and intellectual paradigm of the traditional civil rights movement. When we do this, we cannot assume that the war against AIDS will be won. We will be assured, however, that the battle has begun.

CHAIRMAN PENDLETON. Thank you very much.

Mr. Levi, you are next.

TESTIMONY OF JEFFREY LEVI, EXECUTIVE DIRECTOR, NATIONAL GAY AND LESBIAN TASK FORCE

MR. LEVI. Thank you, Mr. Chairman.

I am sort of awed at the power that Dr. Pence thinks the gay community has, and maybe I should rewrite my testimony in that light. But perhaps my testimony will give you some idea as to what all the moaning has been about.

I appear before this Commission this morning with very mixed feelings. The issues before you are of critical importance to the 23 million lesbian

and gay Americans my organization represents. But the record of this Commission is one of abysmal disregard for the civil rights traditions of the last generation. Instead of standing with those who seek to move toward an ever more inclusive society, you have joined with those elements in American society that promote and encourage hatred toward the less privileged in our midst.

The overall response of this Commission to the concerns of gays and lesbians in particular does not give one hope that you will address with openness and sympathy the problems we face in the context of AIDS. We have been unsuccessful in getting this Commission to address the long-standing history of discrimination against lesbians and gays. Indeed, you have worked diligently and often gratuitously to exclude gays and lesbians from your consideration.

The most recent example of this is passage of a resolution favoring the Hate Crimes Statistics Bill, and then footnoting your support with a statement of opposition to collection of data about antigay and lesbian violence. This Commission, allegedly designed to protect people, will not even support collecting data about violence against a minority group.

With these demonstrated biases in mind, we initially looked with skepticism at this, your first effort on AIDS—7 years into the epidemic—skepticism that turned to outrage when the project proposal for these hearings was made public. Your proposal contains lengthy, offensive, and irrelevant condemnations of homosexuality. When 70 percent of the people with AIDS are gay or bisexual men, how can we trust this Commission's handling of AIDS discrimination issues when its own project proposal carries such homophobic rhetoric? Clearly, before we can take your efforts seriously, a retraction and apology to the gay community is necessary.

This is a civil rights commission, not a public health commission. It is appalling that a Commission with no medical or public health expertise is also considering issues concerning the transmissibility of HIV. These should not be issues of debate before this Commission, nor are they issues of debate within the public health community. They are, instead, appropriately raised simply as statements of fact by your counterparts in the Public Health Service.

To open up such issues as casual transmission for debate only serves to promote an unnecessary air of hysteria about the disease, and seems like a deliberate attempt to undercut the sound and rational policies of the Public Health Service in this regard. Instead, the focus of your deliberations should be on the civil rights violations that are often associated with this epidemic.

The very premise of what I have been asked to testify on—the alleged inherent conflict between civil liberties and public health—is a false one for this Commission, but it is one that has been raised again and again, and so I will take the time to respond.

As the most visible and organized group associated with this epidemic, implicit in this claim, and made explicit by Dr. Pence, is a charge that the gay community is placing its political civil rights agenda above that of the public health. Nothing could be further from the truth—or more offensive to a group that has suffered so much at the hands of this epidemic. This argument suggests that somehow we have been callous to all the dying around us. It forgets that we are the ones who are dying. We have never stood in the way of measures to stop the spread of this disease: for it is our lives that we are saving. What we have argued instead is much more complicated but important if we are to understand and halt this epidemic. It is that in the context of AIDS—and I would suggest most disease control efforts—good public health requires a healthy regard for civil liberties.

The positions taken by the gay community are consistent with the positions taken by the public health community. Public health experts understand that this disease will only be stopped by getting people to come forward and voluntarily participate in prevention efforts. Remember, this is a disease that is transmitted primarily by consent. If each of us is willing to take responsibility for our own lives, if each of us refuses to engage in activities that might expose us to the AIDS virus, then we need not worry about the infectivity of anyone else. We don't need to know anyone's antibody status or sexual orientation or drug-use history. Coercion or mandatory testing or quarantine become irrelevant issues when AIDS is considered in this light.

All of these coercive approaches are simply excuses to avoid facing the reality of AIDS: that we must each care for ourselves enough that we no longer engage in those activities that might place us at risk.

But changing behavior of a society—and particularly of those elements of society that have encountered a long history of discrimination and oppression—requires creating an environment where people are willing to come forward to participate in counseling and prevention programs. One of the groups that is a target of AIDS prevention efforts is the gay community. I would like you to take a moment to consider the context in which we who are gay are being asked to participate in the prevention effort. Put yourselves in the shoes of gay men, and ask yourselves these questions:

Would you come forward to be tested or participate in a prevention program if your identification with that test or program would mark you as gay, and therefore leave you open to losing your job, custody of your children, or your home?

Only one State, Wisconsin, and the District of Columbia, provide protection against sexual orientation discrimination. In all but a handful of cities and counties where protections do exist, and as well as in Wisconsin and D.C., it is perfectly legal for an employer or a landlord or a judge or

anyone else to discriminate against gay people—for whatever reason they may choose.

Would you, if you had a serious disease, speak frankly to government epidemiologists about how you contracted that disease, if the manner in which you contracted it is a felony in your State? In half the States and the District of Columbia, consensual sodomy between adults is still illegal.

Would you participate in AIDS control efforts if your identification with this disease would leave you open to violent attack? The incidence of antigay violence has increased dramatically since the outbreak of the AIDS epidemic, a fact this Commission would know already had it been willing to consider the issue of antigay violence as my organization has requested for over 4 years now.

Looked at from this perspective, it is amazing that, despite the risks to life and liberty, gay men have indeed said yes to these questions. We have come forward to help control and stop this disease in every way possible. But certainly the public health battle would be much easier and more effective if we did not have to filter out the noise that generations of discrimination and hatred have created.

This is where the civil rights agenda and the public health agenda merge: The society that now so fears AIDS is paying the price of its generations of discrimination against gays by having created conditions that make it less encouraging for us to participate in public health measures.

I am under no illusion that this Commission, given its history of neglect for the rights of all minorities, will suddenly wake up to the importance of the issues I have raised regarding sexual orientation discrimination. However, for the record—perhaps for the time when a more enlightened majority is appointed to this Commission in the next administration—I want to state what measures should be taken in the civil rights arena to make the work of the public health community easier:

First, we must eliminate the noise or underlying discrimination about this public health issue by repealing all sodomy laws and extending civil rights protections to lesbians and gays at the Federal and State levels. Most Americans rightly balk at the notion that the government should regulate their private lives, as do lesbians and gays, and the many heterosexuals covered by sodomy laws. Bringing a long-discriminated-against minority, homosexuals, into the family of minorities protected by our civil rights laws would go a long way to eliminating the fear that so many have of dealing openly with a disease that is so closely linked to homosexuality.

Second, we must deal directly with the discrimination that is related to this disease and not necessarily related to sexual orientation. The coverage under Section 504 of the Rehabilitation Act, as clarified in the Civil Rights Restoration Act, must be broadened to include private sector protections against discrimination based on handicap or HIV status.

I want to close my statement with a challenge, a challenge to this Commission to prove me wrong in my assumption that the pleas of the gays and lesbian community will go unheard by a majority of this body. If gays and lesbians have learned one thing in life, it is that we should never give up hope that people will overcome their fear and hatred of us, whether those people are our parents or, I hope, the U.S. Commission on Civil Rights.

CHAIRMAN PENDLETON. Thank you, Mr. Levi.

I will now move to Dr. Menitove.

TESTIMONY OF JAY E. MENITOVE, M.D., THE BLOOD CENTER OF SOUTHEASTERN WISCONSIN, INC., REPRESENTING THE AMERICAN ASSOCIATION OF BLOOD BANKS

DR. MENITOVE. Chairman Pendleton, members of the Commission. I am Dr. Jay Menitove, chairman of the Transfusion Transmitted Diseases Committee of the American Association of Blood Banks, a position which I have held for the past year. Prior to that I served as a member of that committee since 1982. I am the medical director of the Blood Center of Southeastern Wisconsin in Milwaukee, and have several appointments in medicine and pathology.

I welcome the opportunity to appear before you this morning to discuss the efforts made by blood banking organizations to control the transmission of AIDS as a consequence of blood transfusion, particularly during the period prior to the introduction of a specific test for AIDS. It is my understanding that the Commission is concerned as to whether or not all precautions were taken to protect public health.

The development of policies designed to protect the safety of the blood supply from AIDS began over 5 years ago when very little was known about this terrible disease. Today, using 20/20 hindsight, critics have asserted that we made mistakes, at the very best, or ignored facts in order to protect our self-interest at the worst. I am here today because we wish to set the record straight.

Today, all blood is tested with a highly accurate test for a number of transfusion-transmitted infectious agents, including the virus responsible for AIDS. Although the test for the antibody to HIV is not 100 percent effective, it is so good that very few persons risk contracting AIDS from a blood transfusion. The blood supply is safer now than ever before—so safe that the risks associated with the underlying need for a blood transfusion are always much greater than the risks of a blood transfusion itself. And we are constantly working to make the blood supply even safer.

Nevertheless, it is possible that as many as 12,000 people are alive in the United States who received transfusions prior to the implementation of the HIV-antibody test and were thus inadvertently exposed to the AIDS virus.

Almost all of this exposure occurred during the few years prior to the availability of the test in the spring of 1985. Some of these people will get AIDS. Could something have been done to eliminate or reduce this tragedy? Were all appropriate precautions taken to protect the public health?

In my opinion, blood banking and governmental organizations worked diligently and quickly, using all information available at the time, to respond to the threat of AIDS transmission via blood. The rapid development of safeguards for the blood supply, however, is surely one of the true successes in the Nation's efforts to deal with this devastating health crisis. When so few strategies were available to control the spread of this disease, it is ironic that some authors and critics have suggested that we failed to carry out our responsibilities as stewards of the Nation's blood supply—that is, we failed to be perfect.

The first official notification of a direct link between a blood donor and a transfusion recipient with AIDS was reported by the Centers for Disease Control [CDC] on December 10, 1982. The AABB [American Association of Blood Banks] acted immediately by notifying its members that AIDS might be transmissible by blood; that members should prepare to meet with concerned groups in their communities; and that two very important meetings were scheduled to deal with this subject less than 1 month later—the first, sponsored by the CDC on January 4, 1983, and another sponsored by the AABB on January 6, 1983.

As a result of these meetings, recommendations deemed to be prudent were made on the basis of available information. Additional caution in the use of blood and blood products and efforts to limit blood donation from high-risk groups were advised. These recommendations were issued in a joint statement dated January 13, 1983, to all blood-collecting units belonging to the AABB, the American Red Cross, and the Council of Community Blood Centers.

In addition to these organizations, the joint statement had input from other participants at the January 6 meeting, including representatives of the National Hemophilia Foundation, the Centers for Disease Control, the Food and Drug Administration, the American Blood Commission, and the National Gay Task Force.

The January 13 statement was issued at a time when evidence about the transmissibility of AIDS via blood was still speculative. We were in a state of constant flux; we had little information and it changed frequently. Few cases of AIDS with possible linkage to transfusions were known. No one had any proof that AIDS was caused by a virus. Suggestions of all sorts of causes, from the use of poppers to participation in certain sex practices, were proposed. Most authorities believed at that time that only very promiscuous gays were at risk.

In the midst of all the uncertainty and because no real understanding of the etiology was available, we were cautious in advising courses of action, such as nonspecific tests, which seemed speculative.

Although the January 13 joint statement specifically advised against recruiting high-risk donors, particularly gay males with multiple sexual partners, the more difficult question confronting us was whether direct and specific questions about sexual preferences and practices should be asked to eliminate gay males as donors. While we considered that direct questioning about sexual preference would be a violation of an individual's civil rights, our decision not to use such questioning was based on our belief in 1983 that it would be ineffective in protecting the blood supply. We were cautioned that direct questioning might actually encourage gays to donate purposefully. We were advised that a more positive and effective means of discouraging donations from those at risk was for gay organizations to voluntarily urge gays to cease blood donations. We believed that cooperation, not confrontation, would be the most effective course of action. Subsequently, blood donations by males in New York dropped dramatically.

A successful national blood supply, derived from volunteer donors, as mandated by the National Blood Policy, is only possible when there is a mutually satisfactory relationship between blood collectors and the donating public. We were concerned about the reactions of our donors toward policies that could be considered as discriminatory or offensive, and we believed it to be poor judgment to adopt such policies in the absence of supporting scientific evidence.

Our nation's voluntary blood donor system is based, in a bidirectional manner, on credibility and trust. We expect donors to provide complete and accurate medical history information and they, in turn, expect us to make decisions that protect their safety during the donation process and make judgments that maintain the safety of transfusion for recipients. These principles guided our decision in the crucial period during early 1983, as they do now.

Less than 2 months after the initial joint statement was issued, we again communicated with our members. On March 7, 1983, we told them they must prepare to screen high-risk donors in accordance with procedures as recommended by the Public Health Service [PHS] in a March 4, 1983, *Morbidity and Mortality Weekly Report.* The PHS did not recommend direct questioning about sexual practices. In addition, blood-collecting agencies were advised by PHS to inform donors that those persons at risk for AIDS should not donate.

In the absence of other more specific approaches in 1983, we prepared an informational message to be read by every donor in order to screen out high-risk donors. With few modifications, it is still an important approach which is currently being used. This was implemented within several weeks

of learning about the possible transmission of AIDS by blood transfusion. That is, the industry reacted by putting in place a donor screening procedure which was believed to be the most effective way of eliminating high-risk donors from the system.

Among the criticisms directed at us was that we could have implemented some kind of test to screen out potentially infective units of blood. There are inherent dangers in implementing a nonspecific, or surrogate, test in relationship to the Nation's blood supply.

First, any such surrogate test is likely to result in substantial amounts of blood being thrown away. Given the crucial state of balance in which the blood supply exists at all times, a decision to eliminate 3 to 5 percent of donated units can have serious repercussions.

Second, as with most surrogate tests, its nonspecific nature will mean many persons not in danger of transmitting a disease will be identified as potentially hazardous. Furthermore, there is an obligation to tell donors that they have been found positive and to notify them.

In January 1983, the cause of AIDS was unknown—and I'll paraphrase the written statement for you. Some people suggested that we perform surrogate testing, and at that time that was highly debated. The test that was recommended was a test for antibody against core of the hepatitis virus. It was our feeling that there was no evidence to suggest that people who would test positive for that had been exposed to the virus, and that people who had been exposed to the virus would not test positive.

We have later learned that 3 to 5 percent of nongays are positive for that test. That would mean that 240,000 to 400,000 donors would have tested positive by a test that would have been considered an AIDS test. Our question at the time, and remains, is: What would we have told those donors when we notified them about these test results?

In addition, we were concerned that the donor population would be screened by a test that perhaps would not be effective, and that additional thousands of patients might have been infected.

Let me stop at that point, Mr. Chairman.

CHAIRMAN PENDLETON. Thank you very much, Dr. Menitove.

Mr. Johnson, welcome to a fellow Californian.

TESTIMONY OF JIM JOHNSON, EXECUTIVE DIRECTOR, BEYOND REJECTION, INC., LONG BEACH, CALIFORNIA

MR. JOHNSON. Thank you, Mr. Chairman. I thank all the Commissioners for having me here today.

I would like to make one point of clarification—well, several, actually—because the statement is quite brief. That is, I am a homosexually oriented person myself, and I want to make that clarification so there would be an understanding from some of the statements that I make.

The other one is that the persons I have worked with for the last 3½ years are homosexually oriented persons, heterosexually oriented persons who are IV drug users, some prostitutes both male and female, the total number of which represents in-house approximately 107 that have lived in one of my programs. Outside of the program they number in the several hundred that I have dealt with, and I have had brief encounters in conversation with probably 1,500 to 1,700 people who are HIV positive, AIDS-diagnosed, or AIDS-related-complex diagnosed, in most of the major cities or at least five major cities in the United States, most specifically Los Angeles and San Francisco.

I am the director of Beyond Rejection Ministries, Inc., and also the founder of Providence House, a group of AIDS hospice houses in Long Beach, California. It is my observation, of the persons with AIDS with whom I have worked the past few years, that around 60 percent of the ambulatory have indicated to me continued sexual encounters. This includes HIV positive, ARC, and AIDS diagnosed. These persons have also indicated to me to approximately the same percentage that so-called safe sex became boring after approximately, I would say, an estimation of 3 months, and therefore so-called safe sex practices were no longer entertained.

The behavior I consider one of many manifestations of an arrested psychosexual growth. One simply cannot keep a child from its father.

Activist groups have gone to extremes to try and close our program. They have lied, deceived, and threatened our work. They have threatened the buildings, to bomb them, and they have threatened my person, all in an attempt to discourage us from continuing our program. As a point of clarification here, I will indicate that they are using tactics of saying that we're demanding repentance and last-minute recontents of homosexuality out of deathbed patients.

I consider their outbursts to be related to a defensive detachment from the same sex parent and a life-long ambivalent relationship with persons of the same sex. In this case directed towards me, I believe their root problem was my intention to change my sexual orientation, which was, of course, a personal choice. And although it's a long and painful process, I have found it a rewarding journey away from the narcissism and contempt of my earlier life. I have invested these traits in myself by serving other people rather than myself.

I have clarified some of this with major psychologists and psychiatrists throughout the world, and they agree with me that most of this data is correct.

CHAIRMAN PENDLETON. Thank you very much.

Thank you, panelists, very much for the enlightening testimony.

I will now turn to counsel to begin the questioning, and then we will turn to the Commissioners.

Mr. Goldman missed his plane and will not be arriving today, so that is why he is not here. We do have a statement from the foundation for the record, and that will be included.

MR. HOWARD. Thank you, Mr. Chairman.

Mr. Mike Fumento is going to ask questions on behalf of the staff.

MR. FUMENTO. My first question is for Dr. Pence.

Dr. Pence, you are a veteran of the civil rights movement of the early 1960s. You served a year's jail time for protesting the Vietnam War. Whatever one feels about your opinions, nobody can doubt that you have the courage of your convictions. Nobody doubts that you truly care about civil rights.

Now, one question we are always asking ourselves at the Civil Rights Commission is: What is a civil right? Can you tell us briefly what you believe a civil right is? Or maybe I can narrow it even further to ask you why there can't be at the same time civil rights protections accorded to victims of HIV infection and at the same time concern and efforts to control the epidemic through additional public health practices.

DR. PENCE. I'll answer that in two ways. First of all, when we talk about civil rights, I think we are talking about the rights that people have because they are part of a civic community. And when people lose that because of some distinction, then I think their civil rights have been abrogated.

I think a very important notion in the civil rights community, though, that we have lost—you know, the civil rights community did not become just sort of a glorified "do your own thing." That is not the end of civil rights, that we establish autonomy of the individual as the supreme value—not at all. Civil rights also has to do with the ability of communities to act as civic communities. The civil rights movement never was meant to strip the community from acting through its civic institutions to protect communities. In fact, we often appealed to one level of government to help—when we felt one level of government was abrogating civil rights, we would often ask—in fact, this Commission and Federal involvement in civil rights was the idea that government sometimes, through its institutions, must act to protect individuals.

So the general tendency of what I call arrested flower children, of trying to think that all civil rights means is just autonomy in any individual act, I think that philosophically is an incorrect idea of civil rights.

For the HIV epidemic, I think you cannot establish—the entire structure of public health law is built on making discernments between people who are infected and people who are not, between people who are carriers and who will participate in the activity that spreads the disease and people who will not. When he talks about his 60 percent of the people, that has been my experience, too.

Some carriers do not have to be isolated. There are a lot of people carrying the HIV virus that do not spread it. There is no reason to isolate them. It is the people who have the virus and who spread it that you have to find some mechanism to deal with them.

The whole structure of public health law is making discernments, making distinctions between people. It is wrong to try to take a civil rights paradigm which says "Don't make any distinctions about people" and apply it to this problem, because it will not lead us to what we need to do, which is to protect individuals and to protect the community.

MR. FUMENTO. One problem we have with HIV is that either we quarantine people who have the virus or we have to rely on their restraining themselves from unsafe activities. So if you are not proposing a quarantine, then it seems to me that you would have to have certain protections for those people.

DR. PENCE. Okay. You are proposing a false dilemma here, and that has been the whole problem in the way we have approached the HIV epidemic. We always propose two alternatives that are not really the two alternatives. It's not quarantine everybody who is a carrier versus just rely on personal goodness. That is not what we do.

What we do is—on the one hand we do educate and we do try to tell people, "Don't do this"; we do rely on personal compliance.

On the other hand, we also have to set up a governmental mechanism by which people who are HIV carriers—whether it be psychiatrists and doctors and public health officials, to make a judgment if a person is going to continue the activity that spreads the disease. All carriers will not continue to do it. The same thing with mental commitments, the same kind of models you can imagine.

Those are the kinds of models we are absolutely going to have to have with the HIV epidemic. Some of these people are sexual addicts. A lot of them are drug addicts. And you cannot assume, because you put up a big poster with an athlete on it, that you are suddenly going to educate people not to do something.

We are living in an Alice in Wonderland world. As far as the blood banks are concerned, I don't think the only alternative is—what are we doing right now? We're telling them self-deferral. I think that's a good idea, but that should be coupled with a law that says a person who has engaged in homosexual activity or IV drug use cannot donate blood, because they continue to donate blood.

Twenty-five hundred people donated blood in the last 2 years who are HIV positive, and 90 percent of them on reinterview admitted to risk behavior. There are 13 people who have just gotten infected by HIV-positive blood and they had tested negative, but we traced back the seven donors, and six of them admitted to high-risk behavior and the seventh wouldn't be interviewed.

So you have to couple education with enforcement. And if you don't, if you keep adding this false dilemma of, "Oh, we're going to quarantine the whole population," or, "we're just going to educate everybody," that's a false dilemma. There are some people you have to quarantine.

MR. LEVI. Mr. Fumento, one way I would agree with Dr. Pence is that you have indeed created only two options, and too much of your focus is on the person who is HIV positive. I certainly agree that society has a need to be able to deal with that occasional recalcitrant, and I would argue it is the occasional recalcitrant, who willfully goes out and infects other people.

But I also think—and it's something that I tried to make clear in my testimony—that it is extremely important for us to recognize how this disease is indeed transmitted. We don't need to worry about the person who is HIV positive if each of us refuses to engage in activity that might place us at risk.

So the responsibility is not just with the person who is HIV positive. It is with every one of us in terms of whether we share needles or what kind of sexual practices we engage in.

DR. PENCE. Mr. Levi, this is a governmental body. We're talking about government action. It would be nice if everybody in the world was beautiful. That is your basic solution. But let's be realistic. Everybody is not beautiful. If everybody wouldn't rape, rob, and mug, everything would be wonderful, but we still have a police force. And that's our problem here.

MR. LEVI. But I think what you are doing is creating the impression that there are massive numbers of HIV-positive people out there who are going out trying to infect other people.

DR. PENCE. They're trying to have sex. That's what they're trying to do.

MR. LEVI. And I think that we do have a responsibility as a society to protect ourselves, and that is indeed a government responsibility to educate people about their risk and how they can reduce the risk of becoming infected, not just of people who are infected infecting others.

DR. PENCE. People already have the knowledge in their heads, Mr. Levi. The problem is behavior is a very hard thing to stop, and you must be willing to exercise authority. This is our problem. The baby-boomer generation is in arrested adolescence, and they are not capable of functioning as authorities in government. That is our problem.

CHAIRMAN PENDLETON. So much for public policymaking, irrespective of which side the balance is on.

[Laughter.]

MR. FUMENTO. Mr. Levi, let's get to a specific area where the government could so something. Bathhouse closure has been a very heated issue since, I believe, 1982 or maybe 1983. Has your organization supported bathhouse closure and, if so, why or why not?

MR. LEVI. Our organization has not supported bathhouse closure, and the reason for that is twofold. One is I think it's giving a false notion that somehow if you close the bathhouses this activity will stop.

Secondly, bathhouses provide an opportunity to educate people and, indeed, to encourage people in a manner where you might not otherwise reach them to learn about AIDS and to learn about reducing their risks.

The truth of the matter is that the people who are least likely to be reached by the safe sex message are relatively closeted people who may, indeed, be using the bathhouses as their only release, as their only contact with an organized community. And if we close down that opportunity to reach those people, they will continue to have sex, but they also will not have an opportunity to be in an environment where reducing risk and stopping transmission of this virus can be encouraged.

DR. PENCE. Use the bathhouse as an educational center sort of; right?

Mr. Levi, this is an utterly ridiculous argument. Because people are closeted doesn't mean they haven't heard about AIDS. When they go to the bathhouse, the idea if we put up a few posters in bathhouses—I mean, can any reasonable person accept this torturing of human logic that you have used to keep bathhouses open? Would you put up in a bar, "Don't take another drink." and then say, "Let's leave them all open for alcoholics because this is the only place they get education"? This is ridiculous.

MR. LEVI. Except you are not closing bars to alcoholics. And I think that the issue—

CHAIRMAN PENDLETON. Mr. Levi, just to give you some time to get your point across, I think what we should do here, if you would—Dr. Pence, I can understand your anxiety and your point of view. I think Mr. Levi does have a point that needs to expressed here, and rather than having a debate between people if we, for the record, could get the questions up on the docket, then perhaps after this is all over you can have a chance to discuss it with one another, and I'm certain by that time the TV cameras will turn from us to you to engage in your debate. But for the time being, if we could just get the questions on the record—

DR. PENCE. I apologize.

CHAIRMAN PENDLETON. That's all right; I understand.

MR. LEVI. I feel I have answered the question, and I have answered it directly, and I think with a better understanding of the gay community than Dr. Pence has.

MR. FUMENTO. Mr. Levi, part of your program in the fight against AIDS is to call for the legalization of sodomy, and yet there would be no AIDS epidemic but for sodomy. That seems something of a contradiction.

MR. LEVI. Well, I don't know that that's true, and it depends also how you define sodomy. It is not necessarily the origin of the epidemic, and I think Dr. Fauci and others will be able to speak more directly to the science that is involved. Outlawing activity does not necessarily eliminate

it. Lots of heterosexuals engage in sodomy as well. They probably don't know that in half of the States they are breaking the law.

The point of my statement was quite simple, that if you treat people as outlaws they are going to be less responsive to your pleas to respond to a public health message. Why should I trust someone in the government and talk about my sexuality and learn about changing the expression of that sexuality from an authority figure who also has the authority to go in and prosecute me for a crime?

I think that there is obviously an underlying philosophical point there, which is that consensual sexual activity between adults should not be regulated by the government.

Now, if you disagree with that, obviously we have a problem. But as a public health measure, outlawing today has not made a difference. There is no distinction between the States that have sodomy laws and the States that don't.

MR. FUMENTO. On the other hand, sodomy laws are virtually never enforced, either.

MR. LEVI That, unfortunately, is not true. Not true in the sense that sodomy laws are used to deny parents custody of their kids, deny people jobs, and so forth, in a way that indeed forces people to go underground. When you are dealing with a public health epidemic that ultimately requires, short of quarantining everyone who is positive, which would also require testing every man, woman, and child in this country—and I don't think anyone at this table, at least, is proposing that—ultimately to control this epidemic you require the cooperation of the people most affected by this disease. In order to get their cooperation, you are going to have to create a climate in which they trust those authorities and those public health officials who are trying to get them to make those changes.

The existence of sodomy laws and the lack of antidiscrimination protections are, I would argue, major impediments to that level of trust. Why should I trust you in advising me about sexual expression when that very same authority figure would like to really prosecute me for my sexual expression?

MR. FUMENTO. I have never heard of anybody being clamped in nine irons because they admitted to homosexual activity at the time of being diagnosed for AIDS, and I would point out—

MR. LEVI. Excuse me, sir, but there is a long history—and there will be other people testifying before this Commission who can provide you documentation to that effect—of people being discriminated against both because they have AIDS and because of their sexual orientation, and, indeed, a result of their being public about such a diagnosis.

MR. FUMENTO. But not as a direct result of sodomy laws.

Dr. Pence, your head was shaking so much I'm getting dizzy, so I'll give you a chance to respond.

DR. PENCE. I'd like to say again, in Mr. Levi's argument—and this is what has paralyzed us; I mean this is what has paralyzed us—he brings up we have one of two choices—we test every man, woman, and child in America and quarantine everyone who is positive.

No. No one is arguing that that is a public health approach. That is ridiculous. That is not a public health approach. That is not the alternative.

Mr. Levi says that there is nothing that can show in States that have sodomy laws and States that don't have sodomy laws, that one has more or less AIDS cases. But, Mr. Levi, without any doubt, you take a map of the United States and you draw out on that map where people like yourself and the so-called gay movement have gained ascendancy in a cülture or in a city, and you draw over that map those cities, and that is exactly the pattern of spread of the AIDS epidemic. It's San Francisco, with the great powerful gay rights movement; it's New York City. It's all the places where this noting of homosexuality as being part of the civil rights movement has overtaken the civil rights movement. That is where we have AIDS. And the poor people are going to pay for this.

I just want to say—25 years ago it was southern bullies in jeans that we had to fight. Today it's northern smooothies in ties, who use middle-class conventions and niceties, to prevent us from using public health measures to protect the urban poor.

MR. LEVI. Mr. Chairman, I find what Dr. Pence said to be so deeply offensive that I really have to question whether I can continue sitting at the same table with him. He has just likened us in the gay community, who are trying to fight this disease, to the Ku Klux Klan.

DR. PENCE. You are not fighting this disease.

MR. LEVI. —and suggesting that we are trying to impose this disease on anyone else—

DR. PENCE. You are not fighting this disease.

MR. LEVI. —is so deeply offensive, Mr. Chairman, I ask you to ask Dr. Pence to withdraw that remark, because it is totally irrelevant to the subject at hand.

CHAIRMAN PENDLETON. Well, the record is the record, Mr. Levi. I understand what you are saying. I would just hope that in my previous comments we could add some balance to this, and perhaps we can have disagreements but not be disagreeable in the process of how we differ with one another. I would just ask that perhaps we can move on with this in another way so we don't have to have this constant debate, and I would ask you, Mr. Levi, to stay. I cannot withdraw a statment from the record, as I understand it.

MR. LEVI. You could certainly ask for an apology or state that this does not reflect the views of the Commission.

CHAIRMAN PENDLETON. Well, certainly anybody who sits here doesn't reflect the Commission's views. Even my opening statement does not reflect the Commission's views.

MR. LEVI. I have a feeling, Mr. Chairman, that if someone came here and made a racist remark, that you would disavow it and you would disassociate yourself from it. I think you owe the people who are most affected by this disease a similar apology.

CHAIRMAN PENDLETON. Mr. Levi, I have been called racist names by my own people for the last 6 years, and I have not disavowed a thing. I sit here as one who attempts to direct this discussion and debate, and I am not about to get into this discussion about what I should or should not reject.

I think at the same time we need to move on with this one in the best manner possible, but I would ask that we not engage in these kinds of dialogue. We can help this in the process. Let's talk about information. We are here primarily to talk about the public health implications of this, not so much whether or not one believes in the other one's right to do whatever he or she pleases to do. And I would ask we kind of confine our remarks in that respect.

DR. PENCE. If I personally said anything, I apologize if I offended you as a person. However, I will not withdraw the basic thesis that I'm putting forward, that if you want to have a public health policy you are going to come up straight against the gay pressure groups. I think that's the whole point. I cannot withdraw that. That is my basic thesis, that the gay pressure groups have stopped us from using effective public health policy, and they've done it in the name of civil rights. I refuse to withdraw that.

MR. LEVI. For the record I will add one comment, and that is this, Mr. Chairman. What is absent from your list of witnesses is a State health officer or a local health officer who would be here and testify very similarly to what I am saying, saying that the civil rights agenda and the public health agenda do indeed merge, and that the gay community has worked very closely with the public health community in trying to contain this epidemic. The very nature of this panel suggests you don't want to hear that.

CHAIRMAN PENDLETON. Mr. Levi, just so you're clear, I'm not so sure that what we hear is what we believe. We are taking testimony. I'm not putting any words in my colleagues' mouths up here, but we are taking testimony. Since we take yours, we can take his testimony. It does not mean we believe.

I would happen to concur with you just as a bit of information, that from what I read there have been steps taken, especially in towns like San Francisco, to make the move in the homosexual community that tends to minimize this impact. I can say that, but I'm not one to say here that his opinion is any more weighty or less weighty than yours is. But to say this panel here happens to believe what Dr. Pence says is just not true. It is

accepting testimony from both Dr. Pence and from you, and perhaps we need to get the other panelists involved here so we don't wind up in this fracas again.

MR. LEVI. I guess my point, Mr. Chairman, is you just said you want to talk about the public health implications of AIDS. Well, you don't have a single local public officer or single State health officer testifying.

MR. FUMENTO. Mr. Levi, we have two representatives of the New York City Department of Health. They will be appearing later today.

MR. LEVI. You have someone from the Office of AIDS Research, which is not someone talking about the public health control measures that would be appropriate in dealing with an epidemic of this nature.

CHAIRMAN PENDLETON. Mr. Levi, your comments are so noted and that is well-taken. Thank you, sir. I have some concerns, too, about whether or not this is a national policy or State and local policy we're talking about anyway.

Do you have other questions, Counsel?

MR. FUMENTO. Yes. Mr. Johnson, you in a sense have come from a farther distance than anybody here, so we would like to bring you in on this a little.

You mentioned 60 percent of the ambulatory is still engaging in sex, and unsafe sex at that—a very disturbing figure. What would you propose to reduce this number or eliminate it? What can be done?

MR. JOHNSON. I think we have to identify where the root problem is. It's undoubtedly a manifestation of an underlying neurosis for this kind of behavior. It is not normal behavior.

For instance, a heterosexual IV drug user recently crossed the border—this is not an uncommon occurrence for me to encounter—crossed the border after he got his check and went into Tijuana to have a sexual relationship with a prostitute in Tijuana.

MR. FUMENTO. This is a heterosexual male; right?

MR. JOHNSON. Yes.

MR. FUMENTO. So you're not just talking about homosexuals.

MR. JOHNSON. No, I'm not talking about homosexuals necessarily. I'm talking about male, female. It depends on the particular circumstances of the individual. Not all homosexuals are compulsively sexually behaved, and not all heterosexuals are compulsively sexually behaved. So we have to identify the scenario first to determine this.

Unfortunately, there is in the homosexual lifestyle a high level of compulsive behavior in all areas. We find this in the high number of alcoholics and those who participate in alcohol abuse and drug abuse in the homosexual community. I was one of them. During the course of 17 years with three lovers that I lived with, although we had no personal discriminations ourselves in our homes and in the neighborhoods that we lived, we had the interior discrimination between ourselves in the fight

with alcohol and drugs within our relationship, and that was a very difficult thing to overcome. It certainly accounted for a great deal of our behavior because we did not behave the same as we would have if we had not been on drugs or alcohol. That's logical there.

But because of the homosexual lifestyle, alcoholism has become a prevalence, and, therefore, the behavior is going to result or reflect whatever the particular behavior of that person is.

In the heterosexual situation that I'm discussing, this is not the first time I have had a heterosexual male cross over into Tijuana to engage in sexual activity. I took my staff there a little over a month ago so they could see the bordellos and see that the activity was, in fact, continuing or business as usual in Tijuana.

MR. FUMENTO. So you're talking about compulsive irresponsible sexual behavior or needle-sharing behavior, in fact, which crosses sexual preferences.

MR. JOHNSON. Yes.

MR. LEVI. Mr. Fumento, could we get for the record Mr. Johnson's qualifications to make diagnoses of neuroses and compulsive behavior, or would that not be a more appropriate question to put to someone from the American Psychiatric Association or the American Psychological Association, who could not only testify on those issues but also testify as to the dramatic changes in behavior that have occurred in the gay male community?

MR. JOHNSON. Mr. Levi, part of my problems are the manifestations of the erroneous information that those organizations produced for the public back in the early seventies. I am one of the people that suffered from that. For four decades I have involved myself with homosexual orientation. I follow the teachings of the Roman Catholic Church, who prudently pointed out the disorder, and I can now relate to that by looking at my own life in depth. I am very knowledgeable of the homosexual lifestyle. As I indicated, for 17 years I had three separate lovers, not counting the many hundreds of sexual partners that I have had in my life, Mr. Levi.

MR. FUMENTO. Mr. Johnson, is it true you are attempting to get government funds for your hospices and these attempts have been stymied by other groups?

MR. JOHNSON. Oh, definitely; definitely.

MR. FUMENTO. Why have they done that?

MR. JOHNSON. The predominantly homosexual community, known as the gay community of West Hollywood, have done everything they can, and the gay Catholics, known as Dignity, have gone to great measures to discredit our work. It's all documented, both on film and in the newspapers.

MR. FUMENTO. What is your work, Mr. Johnson?

MR. JOHNSON. The work of the AIDS hospices?

MR. FUMENTO. Yes. Do you take care of these people as they are about to die?

MR. JOHNSON. We have three levels. We have the ambulatory program; we have the semiambulatory program; and then, of course, the hospice which is for terminally ill that are dying. We try to service all these people because the gay community did not meet the need. They have met needs in other areas efficiently and effectively and were the first ones there, and they were the first ones to raise funds for their own. They have provided housing.

But with any Christian-related organization or when they found out that I had been involved in leaving the lifestyle and reidentifying my heterosexual identity, they wanted absolutely nothing to do with us, and that's when they started the pressure of closing us down.

MR. FUMENTO. Do you try to turn people against homosexuality, and do you think it matters if you do?

MR. JOHNSON. You can't turn anyone against homosexuality. Like I said, it's a manifestation of a detachment from the same sexed parent. It has to be dealt with with professionals. They are the only ones qualified to deal with this.

MR. FUMENTO. Would you see any purpose—use the term you would like, to try to pull people away from that lifestyle—do you see any purpose when somebody has AIDS?

MR. JOHNSON. When someone has AIDS, absolutely not, other than the fact to stop any compulsive behavior there might be. A person is only going to change their behavior if they want to. There is nothing outside of incarceration that is going to change a person's behavior unless they choose to do that themselves.

MR. FUMENTO. So the way you see it, at least, you are trying to help people who are dying; they've got a death sentence over their head, and you have other people denying you funds because there is other stuff concerned, being that you are trying to teach a Christian lifestyle or what have you.

MR. JOHNSON. We also have a homeless program, and we have no problems in that area, and we have people who come from all walks of life, including families. The homeless program—they come in all colors, all creeds, all backgrounds, all ages, all sizes.

MR. FUMENTO. Thank you.

Mr. Levi, why would any group want to deny funds to an AIDS hospice?

MR. LEVI. I think you just said it. You just said that Mr. Johnson is trying to promote a Christian lifestyle. It is my understanding that under the first amendment to the Constitution—and I do believe that falls within the jurisdiction, to some degree, of this Commission, even if sexual orientation discrimination does not—the government shouldn't be subsidiz-

ing in any way the promotion of certain types of religious orientation. That is essentially what it is about. And an AIDS hospice is not an AIDS hospice is not an AIDS hospice. You can have quality AIDS hospices and you can have hospices that make life more difficult and more painful toward the end.

I don't know the details of the funding battle in California over Mr. Johnson's hospices, but let me tell you, if I had to choose between dying on the street or going to his hospice, I'd choose dying on the street.

MR. FUMENTO. I hope you never have to make that choice, Mr. Levi.

CHAIRMAN PENDLETON. Mr. Levi, you agreed that we would be kind after your and Dr. Pence's last encounter.

DR. PENCE. We were all being so civilized.

CHAIRMAN PENDLETON. And I would hope you would keep to that. I understand where you are right now.

MR. FUMENTO. I'd like to bring Dr. Menitove in on this, too. We appreciate your coming out here from Wisconsin.

In Randy Schilts' book, which is one of the very few good books ever written about AIDS—and you answered this in part earlier on, at either the January 4 or January 6, 1983, meeting, that Dr. Roger Enlow, a New York homosexual physician and leader of the American Association of Physicians for Human Rights, said that in not asking sexual preference questions, "We preserve not just gay rights but the human right to privacy and individual choice."

That doesn't seem to be a public health consideration.

DR. MENITOVE. Well, as you remember, at that time there were very few AIDS cases. Those of us involved in blood banking at that time were interested in doing the best we could to get a handle on a newly emerging disease, one of which the etiology was not known, and yet at the same time we knew at least certain risks groups or people at risk, and our attempt at that time was to do something to have those people participating in those risks not donate blood.

It was a tough balancing act. We didn't have a test. We had educational methods available to us. And I think we did an excellent job getting the message across to volunteer, altruistically motivated blood donors.

MR. LEVI. Let me clarify some of the history or the rationale, and I'm not trying to explain Dr. Enlow's statement, but let me explain to you where some of this concern about specifying gay or bisexual men should not donate blood, et cetera.

I think, as the public health panel will probably make clear to you, we are not really talking about risk group; we're talking about risk behavior. And one of the problems with donor deferral guidelines, that say someone who is homosexual should not donate blood, is that a lot of people who engage in homosexual activity do not self-identify as homosexual.

So one of the reasons we talked about the guidelines—and these were worked out with the gay community—men who have had sex with another man since—I don't remember now the exact year but I think it's 1977 or '79—should not donate blood. The reason it says that is that a lot of people who engage in such activity don't self-identify as homosexual.

So they will see the deferral guidelines, and they'll even see there is a law about this, and say, "Well, I'm not homosexual. Yes, I've had sex with another man but I'm not homosexual."

There's a real difference between behavior and self-identification. So that is one of the reasons the guidelines talk the way they do.

But the second is that a lot of blood bank donations come in a group setting where there is a lot of pressure to donate. And if you have been donating blood for the last 10 years at your place of employment and suddenly there is a donor deferral guideline that says, "If you're gay, don't donate," and suddenly you are not donating—well, the first time you could claim you weren't feeling well, but a few times later down the road it becomes fairly obvious what is happening.

So there has been another way to get around that issue that the New York Blood Center started with—and I hope, despite stories to the contrary, they will continue—which is that there is an option in your donor card, in the information card that you fill out, to donate for research purposes only. That is, in a sense, a way of letting them know that, "You shouldn't transfuse this blood, but I also, for one reason or another, am not in a position to say, 'I will not give in this setting.'"

DR MENITOVE. Let me clarify the record because the question, I believe, was addressed to me. I appreciate some of those comments because they were helpful. But there were questions asked on the donor card that would allow people to have been so-called deferred at the time of the donation, even if they had presented themselves. Later on there were other measures taken, such as you just heard, that were additional and I think more protective measures. But there was a slowly escalating approach over the years by blood bankers to keep the blood supply as safe as possible.

MR. FUMENTO. We really only have a couple of minutes left.

COMMISSIONER BERRY, Mr. Chairman, could I please interrupt him. Could you please ask our counsel not to make statements when he asks questions, such as, "One of the few good books written about AIDS." We have not made any judgments at the Commission about anything good or bad, and he too obviously shows his own position—

MR. FUMENTO. You are absolutely—

COMMISSIONER BERRY. Will you let me finish, please? I'm speaking.

MR. FUMENTO. I'm sorry.

COMMISSIONER BERRY. — on the issues when he does that, and when he asks leading questions. That is not that purpose of this inquiry. So could you instruct him not to do that again, Mr. Chairman?

CHAIRMAN PENDLETON. Commissioner Berry, you have so instructed him.

COMMISSIONER BERRY. I'm not the Chairman. Will you instruct him?

CHAIRMAN PENDLETON. You are so instructed by Commissioner Berry with my assistance.

MR. FUMENTO. And Commissioner Berry is absolutely right.

I won't talk about books anymore, but I will ask for a final statement from Dr. Pence.

Mr. Levi spelled out what he thought should be done earlier in his address. If I were to appoint you dictator for about 60 seconds, what would your public health program entail?

CHAIRMAN PENDLETON. Just a second.

DR. PENCE. I would not accept being a dictator.

CHAIRMAN PENDLETON. You don't mean being a dictator, but you mean being an administrator?

MR. FUMENTO. He can make the rules he wants.

DR. PENCE. The proper authority is local public health officials. I think that's important—local public health officials. As we have already done in Minnesota, HIV carrier state is reportable. AIDS is reportable. We have a mechanism by which recalcitrant carriers are identified and can be confined, and that is people who are carriers but who continue to spread the disease, that there is a mechanism by which they can be confined. It has not been used yet.

We have begun putting pressure on the gay bathhouses. In fact, the gay bathhouse in Minneapolis just closed voluntarily bacause a law had just been passed in the city of Minneapolis to close it.

I would simply apply the already established paradigm of public health practices, make HIV carrier status reportable, and make determinations that people who are going to spread the disease, the people who continue the activity, either IV drug use or homosexual behavior when they're HIV positive, have to be in some kind of treatment centers to try to get them away from that behavior.

I also think there is absolutely no reason that we do not have laws—and this is again on the State level; you don't need a dictator—on the State level that says that people who have these activities—they've been with men, you know, the things that we've got written down right now for self-deferral and blood banks—that should be a law that says those people cannot, absolutely cannot, donate blood. It is unbelievable that we have still—it isn't just the blood bank's fault. The government has to make the law that says you can't do this. That's killing people.

MR. FUMENTO. Thank you.

CHAIRMAN PENDLETON. As we move to Commissioner questions, let me make one observation. I think perhaps what we have done in a sense here this morning, for whatever reason there may be, we may be putting too much emphasis in the discussion part about this on the homosexual transmission of this disease. Mr. Johnson has very ably talked about IV drug users and so forth.

So let us not leave, Mr. Levi, with the idea that this is where we leave this. I think some of my questions have to do with the other forms of public health policies that are neede, and I would not want to leave the impression at this point that what we are talking about solely is HIV as it involves the homosexual community alone, but there are some other serious problems here. And if nobody else asks questions about that, I certainly will when my time comes.

But I do want to talk about the other three modes of transmission as that impacts public health policy and what are the civil right implications of those modes of transmission or the civil rights implications of public health in those modes of transmission. So let's not leave here, Mr. Levi, with the idea that this is where we leave this. Not at all. There are some other thoughts, I'm certain.

Commissioner Berry, why don't you have the first question, or would you like to go last? Sometimes you want to go first and sometimes you want to go last. It's up to you.

COMMISSIONER BERRY. I'll go last. If somebody also asks a question I won't need to. I may need to clarify at the end, Mr. Chairman.

CHAIRMAN PENDLETON. Commissioner Destro.

Can we have 5 minutes at the beginning first from each Commissioner, and then we'll go around again if we have more time.

COMMISSIONER DESTRO. I think the discussion we have had so far points up the degree of sensitivity with respect to most of these questions. What I'd like all the witnesses to address, if they would, for a minute or two, is the degree to which coercive enforcement of civil rights law has to coexist with the hope for public or voluntary compliance.

It seems to me, observing other civil rights laws, including the laws in the District and in Wisconsin, as well as those laws which affect drug abusers, that especially in the case of drug abusers, using voluntary enforcement or the hope of voluntary enforcement becomes difficult, because you are indeed dealing with addictive behavior certainly with respect to heroin addicts.

So where is the proper balance—and I think this is really the problem that this Commission has to grapple with—between coercive measures which are designed not only to protect public health, but we also use coercive measures to protect civil rights. Where is the balance between voluntary compliance and coercive measures?

MR. LEVI. Just to clarify the question, because I'm not following you at all, are you creating dichotomy between coercive public health measures and civil rights protections? Because you have also talked about coercive measures to enforce civil rights laws, and I don't know where that fits into the equation.

COMMISSIONER DESTRO. What I'm asking about is: Where is the role of coercive or legislative enforcement with respect to what the public feels is legitimate behavior, whether or not it's drug abuse, promiscuous sexual activity of any sort.

MR. LEVI. I don't understand how there can be coercive enforcement of sexual activity or drug use.

COMMISSIONER DESTRO. This is the problem. We're talking about whether or not the debate is between the individuals who suggest, for example, passing out clean needles as opposed to actually arresting the drug abusers in the places where they are passing around the needle. There are all kinds of places where coercion has been suggested to be brought to bear to solve some of these problems, including, I might add, your suggestion, Mr. Levi—and I was not aiming the question at you; I was aiming it at everybody—that it seems to me the passage of gay rights legislation is itself the suggestion that behavior which we have decided is antisocial.

So my question really is: To what extent is coercion a legitimate subject of conversation in this debate, whether or not it's protection of HIV carriers, because that's what we're talking about with respect to civil rights laws, or the actual physical interdiction of people who have been identified to be irresponsible? Where is the dividing line between voluntary compliance—I know it's a hazy question, but it seems to me that really seems to be the crux of the controversy. To what extent do we use the coercive powers of government to change people's behavior?

MR. LEVI. I'll let someone else start because I'm still not sure I understand the question.

COMMISSIONER DESTRO. I know it's a tough question. Dr. Menitove, would you oppose, for example—let me give you an example—a law prohibiting someone who has engaged in high-risk behavior from giving blood?

DR. MENITOVE. I was hoping you wouldn't ask that question. It's almost impossible to answer, because that is exactly the goal that we want. On the other hand, I am not convinced the law will give us what we are aiming at. And I think we really are the model of the voluntary compliance versus the coercive measures type of scenario, because we are dealing with volunteer, altruistically motivated individuals who are donating blood presumably to help somebody else. And we need that confidential, accurate health history information given to us in private. If we don't get

that because of coercive measures or legal measures that might come back to haunt them, then we serve nobody.

It really is a tough balancing act. And I don't know that we have an answer at the current time.

DR. PENCE. I think your question is a very good question. I don't see why people are confused about this. It, of course, has no clear answer. But the answer is this—

CHAIRMAN PENDLETON. what was the clear question?

DR. PENCE. The clear question is: Where is the balance between education, getting people to voluntarily stop behavior, because like Mr. Levi said, if everybody just stopped doing certain things, we'd stop the epidemic tomorrow, and over here: When does government step in and start to do some things, because everybody is not stopping their behavior? Where is that balance?

That is exactly why the Civil Rights Commission has something to say about this epidemic, because right now, under the name of civil rights, people are saying any action that government takes is a violation of civil rights.

I think your question to him is exactly the perfect case. On the one hand, by interviewing people—and I've worked in a plasma center as a physician—you interview people; you try to get them to defer. That's the voluntary part. If would help a real lot if there was a little thing that said at a plasma center, "If you have had sex with a man since '83, if you've used IV drug use, if you are a partner of any of those people, you may not donate blood and it is against the law to do so."

That is absolutely appropriate, and I think we should not use the work "coercion." I think we should use the legitimate exercise of government authority. That's part of a democracy. Let's not be afraid of that. We are in a crisis, and we are going to have to act as a community.

COMMISSIONER DESTRO. Would Dr. Pence's suggestion—Dr. Menitove, do you think that would have a negative impact on blood donation?

DR. MENITOVE. I don't think it would have a negative impact. It's tough, though. We absolutely have to get that free exchange of information in a confidential setting. If that were to be guaranteed, then I think the other things would perhaps be window dressing, because I don't really know how effective they would be, but certainly we would not oppose it.

DR. PENCE. You already know that 2,500 people in the last year and a half, by the Red Cross, have donated blood who are HIV positive, and 90 percent of them are high risk. So self-deferral we know has a certain—

DR. MENITOVE. We know that. We report all—

DR. PENCE. You do need help from the government.

DR. MENITOVE. And we clearly ask for that in the State of Wisconsin, to make the donors who are found to be confirmed positive, to have their

names reportable to the State, for that reason in part, and also to serve the public health.

COMMISSIONER DESTRO. Mr. Levi, if I could ask you a question that goes to a slightly different aspect. What percentage of the membership of the gay community, to your knowledge, has sought testing or counseling for HIV status?

MR. LEVI. I don't know the answer to that question, to be honest, and I'm not sure it is relevant to the control of the epidemic. Let me explain to you why, from a public health point of view.

If I have chosen to stop engaging in behavior that might place me or others in risk, I don't need to know my antibody status—from a public health point of view. There might be arguments for being tested, after consultation with a physician, about my risk and whether I believed there were medical interventions for someone who is asymptomatic and seropositive, but that's a personal decision that doesn't play into the public health ramifications of transmission of the virus.

I would say that a significant number of people within the gay male community have indeed tested. But let me explain to you the conditions under which most of them have been tested.

COMMISSIONER DESTRO. Could I just interrupt for one second. The reason I asked the question is not really from the public health perspective at all. It goes to the provisions of some of the pending legislation on the Hill with respect to discrimination against people who have undergone testing, and the definition of the protected class is one who has sought counseling and/or testing for HIV status.

What I was trying to get a sense of from you, if you knew the answer—and apparently you don't, but if you can find it, it would be very useful for us—to see what kind of protected class we are dealing with by the enactment of laws which peg protection to seeking testing.

MR. LEVI. But relevant to that legislation, and relevant to the issue that you raise, is that I would guess that most of the gay men who sought testing have done so at anonymous testing sites which, Dr. Pence, notwithstanding, is not unique to the AIDS crisis. There has been anonymous sexually transmitted disease testing throughout the history of sexually transmitted diseases.

DR. PENCE. Anonymous?

MR. LEVI. Yes, sir.

DR. PENCE. Come on; come on.

CHAIRMAN PENDLETON. Time; time.

MR. LEVI. Let me explain one of the reasons for seeking that anonymity has been the concern about the reporting of names to public health officers, because the reporting of names to a certain extent is the creation of a list of gay men, and without protections against discrimination people are very concerned about that.

COMMISSIONER DESTRO. That leads me to another question for Dr. Menitove. There have been a number of cases that I have looked at with respect to blood donations. There is at least one in Texas and one in Florida involving access to donor records by individuals who claim to have been infected by the virus.

Does the AABB have a position on these kinds of access-to-records cases?

DR. MENITOVE. The official position on those cases—let me remind you that these are cases where the transfusions occurred in 1982 and 1983, prior to a lot of information being known about the epidemic and the transmission through blood transfusion. The position has been that the confidentiality of the blood donor must be guarded. And the reason for that is the so-called chilling effect it would have on blood donations. If donors did not know that the information that they gave us at the donor history taking would be held confidential, we perhaps would not get accurate information. And that is what we are really concerned about.

COMMISSIONER DESTRO. So basically the association then would oppose the granting of the opening of the records in such cases when records have been sought to be opened?

DR. MENITOVE. Yes. But let me confine this to those cases that occurred in the early part of the epidemic. I don't know that we all agree, perhaps, on what we would do at the current time. So I think we need to make a differentiation.

COMMISSIONNER DESTRO. My last question is: Mr. Levi, the last comment you made struck a chord with me with respect to the concern you have about discrimination and the maintenance of lists of potential victims of discrimination. What is your organization's position on contact tracing? Is that related to that same kind of fear?

MR. LEVI. It is related to that same kind of fear, but there is a balancing act that needs to be made. I don't feel there is any value in reporting the names of index cases, in other words, the person who is positive. You don't need epidemic, and that is really the primary reason for doing that.

Contact tracing, I think, falls into a hazier category, and I think as most sexually transmitted disease experts would testify and public health experts would testify, one does not always do contact tracing even if one knows the names of contacts. The position that my organization takes is in favor of a program where, as part of the counseling process for people who test positive, that they be encouraged to voluntarily notify their contacts. Where that is not done by the index case, by the individual who is positive, we are not opposed to a system whereby those doing the counseling provide assistance to that individual to do the notifying.

When it comes to the State actually going in and doing it, we make a differentiation between contacts who would otherwise have reason to believe they are at risk, and those who might not. So, for example, in the

gay male community in San Francisco, the odds are fairly good that a gay man in San Francisco knows that he is otherwise at risk. A heterosexual contact in San Francisco might not, and therefore contact tracing might be an appropriate vehicle there.

In other words, you make a distinction between high- and low-incidence populations, and therefore that would indeed carry over perhaps even into low-incidence gay communities and other communities other than San Francisco.

So it needs to be decided on a case-by-case basis essentially, with tremendous regard for the dangers that are involved, and also tremendous regard for the cost that is involved. Because if we really did extensive contact tracing around HIV, we might not have any other resources left to do the broader education and counseling that will reach a much larger segment of the population.

CHAIRMAN PENDLETON. Commissioner Guess.

COMMISSIONER GUESS. Thank you, Mr. Chairman. Mr. Levi, I have formed the opinion that you view with suspicion Mr. Johnson's program. Can you tell me succinctly what you feel is the problem with that program?

MR. LEVI. Essentially this issue is whether or not one looks at homosexuality as a disease and whether it is a form of behavior that needs to be repressed. It's good to know that Mr. Johnson at least acknowledges that it's an orientation that cannot be changed. All of the prevailing wisdom, shall we say, of the medical community and psychiatric community says that homsexuality is not a disease; it is indeed an orientation, and an orientation that overwhelmingly is not one that can be changed, and therefore is not one that ought to be repressed. That is the essential difference of opinion.

COMMISSIONER GUESS. You accept the proposition that it is not a disease, sir?

MR. LEVI. It is not a disease; that is correct.

COMMISSIONER GUESS. That being the case, do you think then that the protections under Section 504, for instance—

MR. LEVI. Section 504 does not cover homosexuality. Section 504 covers AIDS.

COMMISSIONER GUESS. No, no, that's not the question. Okay, I understand.

MR. LEVI. Mr. Helms may think that's what it says, but it isn't.

COMMISSIONER GUESS. Dr. Pence—

CHAIRMAN PENDLETON. Just a minute.

COMMISSIONER GUESS. I understood that.

CHAIRMAN PENDLETON. But I don't understand something. You're saying—

COMMISSIONER GUESS. We understand one another, Mr. Chairman.

CHAIRMAN PENDLETON. All right.

COMMISSIONER GUESS. We're talking about symptoms of an orientation as opposed to the orientation, and the symptoms of the orientation being the contraction of HIV.

MR. LEVI. Well, except I would not rate it that way. I really would not rate it that way.

COMMISSIONER GUESS. I understand.

CHAIRMAN PENDLETON. It gets better all the time, doesn't it—I mean clearer.

COMMISSIONER GUESS. Okay, Mr. Johnson, where am I wrong?

MR. JOHNSON. There is a difference between the orientation and the activity. The orientation is an underlying situation. It can be changed. It has been changed. It has been changed from a secular standpoint from secular psychologists and psychiatrists in professional practices without the use of any religious affiliation whatsoever. It is also becoming a phenomenon within the evangelical community, which I have nothing to do with, but I have studied many, many cases now for a number of years. It's becomes a very common thing for homosexually oriented men to change to heterosexual identity and to go on from there and marry and have children. They are all over the United States. There are scores of them now. It's becoming a phenomonen.

MR. LEVI. There's no point in debating this endlessly. It just isn't so.

MR. JOHNSON. No, because it's a fact.

CHAIRMAN PENDLETON. that's what you call balance.

MR. LEVI. no, it's not what I call balance. If you wanted to talk about the origins of homosexuality and whether it can be changed, you would have a psychologist or a psychiatrist.

CHAIRMAN PENDLETON. I wasn't talking about the content of sexuality. I was talking about the fact there's a difference of opinion in what you're talking about, Mr. Levi.

MR. JOHNSON. The activity is a separate situation, and if the compulsive activity is present it may be possible for transmission of HIV. That's my only point.

COMMISSIONER GUESS. Dr. Pence.

DR. PENCE. Yes, sir.

COMMISSIONER GUESS. I notice that our counsel and your curriculum vitae tends to certify you as an expert on civil rights because of your reluctance to accept induction in into the armed forces during the Vietnam War. Is it safe for me to conclude that you wear that refusal to accept induction as a certification for your being a civil rights expert on this matter, and that you do wear it as a badge of honor, sir?

Personally, as one who served over there, the only member of this panel who wears as his badge of honor the fact that he did serve in Vietnam, I'm offended.

DR. PENCE. I agree with you. I would be offended, too. Before I came here this morning, I went and visited the Vietnam Memorial. I do not in any way believe because I went to prison for refusing to go in the military that that was an exercise of a civil right or that it was part of the civil rights movement. My activity in the civil rights movement was in the antiracism part of the civil rights movement, and my activity in the antiwar movement was a different question of a public policy.

I think you have a right to be offended, and I would be offended. I don't think that is a civil right or was part of the civil rights movement.

COMMISSIONER GUESS. I don't have anything else, Mr. Chairman.

CHAIRMAN PENDLETON. Commissioner Ramirez.

COMMISSIONER RAMIREZ. I wish to dissociate myself from, first of all, the tone of our counsel's questioning. I think much of our difficulty in making progress—I have really gained very little from this discussion, and I think part of the problem is in the composition of the panel and the tone of some of the questioning. I wish to dissassociate myself from the notion that one group of individuals who suffer discrimination somehow diminishes the right of another to seek protection from discrimination.

I do not believe that the freedom train has been hijacked, nor that it can be hijacked. And I personally do not believe that gay and lesbian people are the cause of the continuation of discriminatory practices or the cause of the historical effects of discrimination suffered by minorities. That is my position.

I would like to ask Mr. Levi one question which has to do with whether he has any general sense—this is not a dissertation examination; you will not be held accountable for the specificity of your response. My impression is that the organized gay and lesbian community has been able to reduce the incidence of the spread of HIV through some rather aggressive and impressive practices—dissemination of information, education, and not just education in the sense of providing biologicals. Do you have any sense of the decrease in the incidence of the rate of the spread, if that's the right term?

MR. LEVI. I think that's very true. There has been a dramatic change in the behavior of the gay male community. In the best organized communities, where there has been the highest level of outreach and education, there has been a dramatic decline in the incidence of new infections. San Francisco is a good example of that, where there is evidence now to suggest that in a sense transmission may have stopped within the gay community.

It is a never-ending struggle because we are talking about people changing behavior and new people coming into a community and constantly needing to be educated. And I think the other issue is that a large part of those who are homosexually active are not part of the

organized gay community, so we have not necessarily reached all those people.

But, indeed, you are correct, and I appreciate your raising that issue, that the work of the gay community—and it indeed has been the work of the community because we, too, have not been able to get much in the way of government funding—has resulted in a dramatic change in behavior and a reduction of the transmission of this disease.

COMMISSIONER RAMIREZ. I wanted to ask also whether you believe that gay and lesbian behavior is compulsive and addictive. I believe that those were the terms Dr. Pence used. If it is addictive, I would like to understand in what way.

DR. PENCE. I think if you are going to characterize my testimony, ma'am, it strikes me that that is not what I said.

COMMISSIONER RAMIREZ. That is exactly what you said.

DR. PENCE. I said that some homsexual behavior is addictive, and I said that the behavior that spreads the disease, that a great deal of it is addictive—IV drug use, and a lot of the sexual behavior. I did not define male homosexuality or lesbianism as addiction. And I think you should totally separate male homosexuality from lesbianism. Lesbianism has nothing to do with AIDS.

COMMISSIONER RAMIREZ. But it may have something to do with compulsive behavior? Because that was the way I understood your characterization, that this was compulsive and addictive behavior.

DR. PENCE. There is something called sexual compulsive and addictive behavior, and there are many, many homosexuals who are involved in it. The definition of homosexuality, however, is not intrinsically tied to compulsive behavior. And if I said that, I apologize. That is not correct.

MR. LEVI. I think the point that ought to be made is there is no evidence that there is a greater level of sexual compulsive behavior among heterosexuals or homosexuals. And, again, one of the problems with statements like this is that we are in a sense sitting at the table without the experts on these issues.

COMMISSIONER RAMIREZ. Then let me get to a much more serious question, and that is around the issue of reporting and all the measures for reporting, if you would, the presence of the virus, and indeed the presence of the behavior. What, Mr. Levi, do you see as the consequences of that reporting in terms of the civil rights of any individual, or the civil rights of an American citizen in terms of the making known, if you would, of that behavior?

MR. LEVI. Well, the downside of reporting, I think, is primarily related to the fact that we would in a sense be constructing lists of people who have, because of their association with either homosexuality or IV drug use, or their association with AIDS, been the victims—it enables or would make more likely, I think, discrimination against those groups.

But really it comes a step before that, even before the list is actually constructed. And that is what I think is a legitimate fear on the part of gay men of having their identity known as gay people by the government. And that is what reporting is essentially about.

So what it does is it prevents people from coming forward to a testing site to be counseled and tested about AIDS. So we miss an opportunity to change someone's behavior. And it is that deterrent effect of reporting that is what worries me most, because it doesn't matter if we have the most wonderful reporting system in the world if people don't come forward in the first place to be tested.

COMMISSIONER RAMIREZ. I appreciate your position, but I think that this Commission's responsibility is one which has to do with civil rights. Obviously, one cannot detach the public health considerations from the civil rights considerations. But the fact of the matter is that our job as the Civil Rights Commission is to be aware and to present information on the consequences of discriminatory practices. The making of public policy by the elected and in some cases the judicial branch of government is one which must take into consideration public health issues, civil liberties issues, civil rights issues. Our job is to understand the nature and the consequences of discrimination. Therefore, you have not really answered my question, Mr. Levi.

MR. LEVI. Let me try it in a slightly different way and approach it from two points of view.

One is the fear of discrimination, as a result of reporting for public health purposes, is a result of the real experience of discrimination against gay people. So if you put into place laws and policies that would indeed prevent discrimination based on sexual orientation or HIV status, I don't think you would hear me saying—we may question it as being a valuable public health tool, but we certainly wouldn't raising the sorts of objections to reporting that we are.

I think what I'm trying to say is that a lot of the issues we are discussing around this table and debating around this table would not be issues were there adequate Federal, State, and local protections against sexual orientation discrimination and AIDS discrimination. And if we eliminated what I called in my statement the noise around this public health issue—and it's certainly been noisy at this table—then I think we could be looking at it—most of us wouldn't be at this table. This wouldn't be an issue, I think, for the Civil Rights Commission. It would be dealt with strictly as a public health issue. It still is being dealt with strictly as a public health issue that must take into account the context in which those who are most affected by this disease live.

DR PENCE. Ma'am, could I just make one point of fact about these lists. We already have lists of people who got gonorrhea, people who got

syphillis, and the people who got gonorrhea, males, who had rectal gonorrhea—that's a perfectly good list as a marker of homosexuals.

So this idea that reporting is something totally new, and reporting that shows you what kind of people's sexual behavior is is totally new—we have already got all of this stuff. When you say a disease is reportable, it doesn't mean you put it up in the *New York Times;* it means physicians and the public health officials have the names.

So I think, again, he's putting up a false dilemma here that doesn't really exist. We already have names of people. If you just took all the people who had rectal gonorrhea in different cities, you'd have a pretty good starting list of homosexuals, if that's what the government is looking for.

MR. LEVI. But the truth of the matter is that people aren't terribly interested in who has a sexually transmitted disease. People are much more interested in who has AIDS.

And I would point out to Dr. Pence that, if you look at the history of the gay movement and look at most of the communities around the country, one of the first organizations that has been formed has usually been a gay health clinic, specifically to deal with sexually transmitted diseases because of the fear that so many gay men had of the reporting of those diseases, and they were not seeking treatment rather than risk having their name reported.

COMMISSIONER RAMIREZ. How am I doing on time?

CHAIRMAN PENDLETON. You're just about out.

COMMISSIONER RAMIREZ. Then I will pass to others.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I hope I can get to two questions, so I would ask, if you could, to limit your answers so that I can get answers from all of you.

I bring to this panel a different concern. Last year half a million teenagers were pregnant. The incidence of penicillin-resistant gonorrhea and syphillis has increased since the AIDS scare rather than decreased. We know the HIV virus can be passed in body fluids. We know which sexual acts transmit this virus most effectively. We know once you have full-blown AIDS you die. We are not sure how long the period of latency is for every individual.

Last week I had a public health nurse come into a high school class and she told them, "If you're on the pill and have sex with a person who has gonorrhea, the chances you are going to get gonorrhea are very high." And it is working in reverse. "Being on the pill and having that contact, you will get it" was pretty much what she said.

Now, knowing this is happening in some of the sexually transmitted diseases, what should we do as a government, as a public policymaker, and as adults to protect our youth from what may take 10 years or even more to surface in their age group?

If you would take turns and give each other a chance to answer first.

DR. MENITOVE. I can be the most brief because this clearly is not my area of expertise. I would say, from a personal point of view, education would be the most important thing.

DR. PENCE. I would say from a public policy viewpoint that the people right now who are working in family planning clinics and who are working with teenage girls are going to have to totally reevaluate the overreliance on the pill as a way to deal with teenage female sexuality. The pill is setting the girls up for the pencillin-resistant gonorrhea. It is absolutely no protection for the HIV infection.

This is going to have to make us seriously consider that this is not the way to deal with teenage sexuality, because, really, the pill has been the major push that clinics use—and I've worked in community clinics. They try the IUD first and the pill. We have to totally reevaluate this.

I think personally the argument has to be for chastity. I just don't think there's any other argument.

But the people right now are pushing out pills, and that is the major way, that when young girls come to these clinics now, the major form of birth control that is being used is the pill. That is not going to help us a bit in this epidemic, and people are going to have to face that fact.

MR. JOHNSON. Mine would have to be a rather pastoral response. It is my understanding that approximately 57 percent of our nation's 17-year-olds have sexual experience.

CHAIRMAN PENDLETON. Is it that low? I thought it was a little higher than that.

MR. JOHNSON. It is probably higher than that. That is several years old, I think. This is the breakdown of the family unit, obviously, and I think we all know that. And until the family unit is reestablished in America, I don't think we are going to see any major improvement.

The problem is with intimacy. Therefore, from an educational standpoint, I feel strongly that intimacy is going to have to be encouraged from a nongenital perspective. Intimacy is extremely important to all of us—homosexually oriented, heterosexually oriented. We are all suffering from a lack of intimacy. So if we could educate from the standpoint with clearly defined consequences of genital activity, I think we would have some response.

MR. LEVI. I think you raise one of the most difficult issues that we face as a public health issue. Youth in particular think they are invulnerable, and the sorts of messages that we put out that we as adults might understand, teenagers may not identify with.

But I think a lot of what you said also relates directly to how there has to be a link between sexually transmitted disease prevention efforts and AIDS prevention. Because you're not going to convince teenagers that they are at risk for AIDS because they don't see a lot of teenagers around

them getting AIDS, but they probably know of a lot of teenagers who are getting other sexually transmitted diseases. And, in fact, the same prevention methods that you would teach people about other sexually transmitted diseases would also work for AIDS.

COMMISSIONER BUCKLEY. Just real quickly, there is an article in *Science Magazine,* January 22, 1988, by Allan Brandt, where he takes syphilis and correlates that to AIDS, and it goes through and outlines how the Surgeon General in the 1920s had a specific plan for dealing with syphilis. They went out; they did testing; they closed down a lot of red light districts. They did a whole bunch of activities that now we are saying are not suitable for AIDS.

Could you give us, from your perspective, say even in the blood banks—he just told me a little while ago he had hepatitis; he cannot donate blood. But yet, if you are in a high-risk group, we cannot make a law that does this.

Can you take some of these historical perspectives that we have? We had massive education programs in that period of time as well and it was not effective.

DR. MENITOVE. The question you raise is a good one, in terms of law or no law. Hepatitis is not something that has a "connotation" about it. You can get hepatitis in a variety of ways. So asking someone to give an accurate history of that is one matter.

On the other hand, you have seen the controversy and the heat of the discussion today. Getting someone to give us confidentially and accurate information on this subject, the AIDS subject, has just not happened. I think the discussion here sheds a lot of light on that.

Our approach to doing this—and again I must remind you that we are dealing with voluntary, altruistically motivated donors—has been to play on the emotions of why they are donating, and to say that if you're donating to help someone else, if you have engaged in these behaviors, perhaps you will not. Therefore, don't donate.

In addition, we have an excellent test today. It is not perfect but it is excellent.

So we take a multipart approach to what we are doing today. It's donor history; it's confidential self-exclusion where the donor can signify before they leave the donation site whether that unit can be used for transfusion purposes or should not be used for transfusion purposes, being the second part; and the third part being the test.

I think we have a handle on this issue. Whether a law is passed or not at this point I think is moot. I think we have taken steps, and I think they are very effective.

CHAIRMAN PENDLETON. Commissioner Berry.

MR. LEVI. Excuse me. Before we move on, this is really important to point out.

CHAIRMAN PENDLETON. Mr. Levi, let me say to you that we are trying to get through this as fast as we can and as much as we can, but if you are going to refute everybody's statement, we can't do that.

MR. LEVI. I'm not refuting someone's statement.

CHAIRMAN PENDLETON. Okay.

MR. LEVI. What I want to point out is that I am not sure Commissioner Buckley presented Dr. Brandt's position as he expressed it in that article. Yes, he makes comparisons to what happened with the syphilis epidemic, but his conclusion is that AIDS and syphilis are indeed not comparable for several reasons, two of which are the nature of the incubation period associated with HIV infection, and the fact that there is not a medical intervention for AIDS as there is for syphilis.

DR. PENCE. In 1920 what was the intervention for syphilis?

MR. LEVI. The methods that he was talking about of reporting and contact tracing and that sort of thing, he was talking about much more recent approaches.

CHAIRMAN PENDLETON. Commissioner Berry.

COMMISSIONER BERRY. Thank you, Mr. Chairman.

I have already disassociated myself with most of what has occurred, including the Chairman's opening statement, and I scrawled the remarks I made at that time on a piece of paper, which I ask be made available to anyone who is interested, since someone asked me. And I hope you can read my scrawling. So I won't take the time to try to disassociate myself from anything again.

I'll just say that, as I see it, what this Commission is supposed to be up to is a civil rights function, and the way I phrase the question is whether implementing policies based on the consensus in the expert medical-scientific community at every stage in dealing with AIDS and HIV would discriminate against certain people in ways that are inconsistent with civil rights protections under our Constitution. As I see it, that is our mission here.

I had always thought, from the things I read, from the President's Commission report and the testimony given in Congress and the briefing materials for this hearing, that there was consensus that we should follow the judgment of the experts in the medical-scientific community about how to deal with these issues, and then we would have only the task of trying to figure out whether that violated somebody's civil rights. And that's what I thought I was going to do here.

I did not know until I came this morning that there are people who believe the medical-scientific community has been so influenced by various people, including the gay and lesbian task force or lobby, that the medical-scientific community can't be trusted to make these judgments. I had intended to rely on them until I heard from Mr. Pence that they have been—what does he say?—"The gays say the docs can't be trusted." I

wrote that down so I know you said it. And, in fact, everything I heard was that they keep saying, and from Mr. Levi, that we ought to rely on what the experts in the medical-scientific community say about this issue as we make policies.

So in any case, that's the way I would frame the issue.

Now, based on what I have heard, do I understand that everyone on the panel who has any feelings at all about the subject would be in favor of legislation to end discrimination against gays, and legislation to reduce the use of drugs, even if it meant decriminalization if that could be shown to work, in order to reduce the supply; and that they would be in favor of more money being spent from government budgets and private funds for drug treatment centers and for treatment centers and the like, and that everybody up there agrees that that sort of thing should be done. Is there anybody who disagrees with that?

DR. PENCE. Well, those are two totally different questions, Ms. Berry.

COMMISSIONER BERRY. I know they are. Is there anyone who disagrees?

DR. PENCE. I absolutely disagree.

COMMISSIONER BERRY. Which one do you disagree with?

DR. PENCE. I agree with the second that we need drug treatment programs and we need probably sexual addict programs. And I absolutely disagree with the first.

COMMISSIONER BERRY. I beg your pardon. What was that word you used?

DR. PENCE. For sexual addiction. We need programs for that.

COMMISSIONER BERRY. What is sexual addiction?

DR. PENCE. I'm not going to give you a treatise on sexual addiction.

COMMISSIONER BERRY. Well, if you're not going to answer the question—

DR. PENCE. Just generally sexual addiction is people who have to compulsively behave in coital behavior outside of marriage, period.

COMMISSIONER BERRY. So you mean that anyone in American society who, by your definition, compulsively engages in sexual behavior outside of marriage is a sexual addict and we should have treatment centers for them?

DR. PENCE. That would be one definition, and most people are—

MR. LEVI. Within marriage it's okay.

DR. PENCE. Within marriage you can every day.

So the question of treatment programs for people—we can all be for that, and I'm all for that.

COMMISSIONER BERRY. Okay.

DR. PENCE. The other corollary, though, that really the big problem in America is that we haven't passed laws for gay rights—

COMMISSIONER BERRY. I didn't say that. I asked whether you were in favor, and you just said you're not, so could I ask my next question?

DR. PENCE. Good.

COMMISSIONER BERRY. Is there anyone else up there who is opposed to legislation to end discrimination against gays and lesbians as a way to make it more likely that people will want to be identified through testing and all the rest of it? Is anybody else opposed to that before I ask the next question?

MR. JOHNSON. I don't know that I would necessarily—I would have to see that legislation before I could conscientiously deal with that question.

COMMISSIONER BERRY. But in general; okay.

The other thing is that I understand that in the 1930s and the early history of epidemics in this country, about which I have read a great deal—I've had to lately for this hearing—that case finding and contact identification and all that business was designed in fact in part because for syphilis, gonorrhea, and the like, we finally found a cure, as it were, for them, and one of the things you do is identify people and then treat them. And in some cases you would isolate people who had certain diseases until they got some treatment.

You mentioned, Dr. Pence, gonorrhea, and you said that we already know from something about rectal something gonorrhea who the lists are of people who are likely to be gay men. Isn't the major difference between gonorrhea and AIDS, and being identified as having one or the other, that people know that gonorrhea can be treated successfully, so even if they are identified as having it, it doesn't mean everybody will go, "Wow, that person has gonorrhea; ah," as long as you don't engage in sexual behavior with them; whereas if you know they have AIDS, you know they can't be treated, or right now as I understand it we can't treat it successfully, or HIV, and you worry about whether you're going to get it. Isn't that a major distinction between those two? You don't think it's major?

DR. PENCE. No, ma'am, I certainly think that's a distinction. However, remember the argument people are using about not doing reporting is that the government cannot be trusted with lists of people who are homosexuals. And as far as that is concerned, as far as the government having a list of people who they know are homosexuals—rectal gonorrhea, they've got it, and they haven't done anything with it.

COMMISSIONER BERRY. Let me sharpen the distinction of my question. I know that there are lists. I'm not disputing that.

DR. PENCE. Yes.

COMMISSIONER BERRY. What I'm saying is: Wouldn't there be a heightened sense of awareness about what it would mean to not have confidentiality if what will become public is that you have something that people can die from and they might catch it from you, as opposed to something, however nefarious you might think it is, that can be treated, and you don't have to go around worrying about whether you in fact are going to get it. There's a distinction.

DR. PENCE. I agree with you that they are different diseases. However, confidentiality—I have never argued these names should not be confidential. I have said they should not be anonymous. Confidentiality will be respected. It's between the physicians and between the public health officials and only for public health purposes.

COMMISSIONER BERRY. We're talking about risks of betrayal of confidentiality.

I won't press the point. I think it's clear that there's a difference between somebody finding out something about you which makes them think they may die from being around you and there is no treatment—

DR. PENCE. It's precisely because of that, Ms. Berry, that we have to do contact tracing because HIV can kill people. Let's not be foolish.

COMMISSIONER BERRY. Let me ask this: If we were to go to a policy that you propose of contact tracing—

DR. PENCE. Standard public health laws.

COMMISSIONER BERRY. —and all the rest of that in the case of this disease, which is different, and the HIV phenomenon, in terms of its potential for treatment than others—you have already said that that's a case you agree—

DR. PENCE. Agreed.

COMMISSIONER BERRY. Would you be in favor of isolating people who have the disease if they refuse to become, in your words, "no longer sexual addicts," whatever that is, or if they refuse to stop taking drugs—are you in favor of isolating them in some place?

DR. PENCE. Yes, ma'am. People who refuse to stop IV drugs and the people who refuse to stop sexual penetration who are HIV positive should be isolated until they can refrain from that behavior, because that behavior can kill people, and we have an obligation to stop it. And that is the only group of people who should be isolated, but they absolutely should be. We are being completely irresponsible if we don't do this.

That is the reason that right now 1 percent of the babies in New York City are HIV positive because the drug-using partners of these women have not been found and have not been confined, and you are killing off a whole subset of our urban population, and basically black children. And I think we better do something about it.

COMMISSIONER BERRY. Are you in favor of isolating these people until they die? Is that the idea?

DR. PENCE. Let's not make a joke of this, Ms. Berry.

COMMISSIONER BERRY. I just want to know what you mean. Press your point.

DR. PENCE. What I mean is they go into a program and you try to deal with that behavior and try to change that behavior, and then you have to make some determination just like in many other processes that we have; you do it through a legal process. I'm not talking about posses—and in a

legal process you make a determination if the person will not participate in that behavior.

It's not perfect. No one can be perfect. No one can provide a perfect solution. I am trying to provide the parameters in which a reasonable, civilized response can happen to this epidemic. And part of that is going to be confinement.

COMMISSIONER BERRY. In your proposal—you or anyone else who cares to answer—how do you avoid the hidden infection problem, that is, that you aren't able to test people, if we made the policy the way you want it? How do we avoid the hidden infection problem, that is, people who don't get tested, who you don't find? How do we avoid that?

DR. PENCE. Well, we can't totally avoid it. There are certain places, however, that we can test people. For instance, people who come into the judicial system, people who are arrested for any kind of drug crimes or sex crimes—

COMMISSIONER BERRY. I know that. I'm talking about other people.

DR. PENCE. There is no perfect solution. We're not going to run out and test every person at every door, and I don't propose that. So there is going to be some hidden infection. Heck, there are some people you test and they've got the virus and you don't get it—very few people, but your test comes out negative and they've really got it. I'm not proposing any perfect solution. Every time someone does try to propose a public policy, when people say, "Oh, there's one person here in America you're not going to get" or "50 you're not going to get," that doesn't mean you shouldn't do something.

COMMISSIONER BERRY. You are prone to exaggeration, Dr. Pence. I noticed that in your testimony. We're not talking about there's one person we're not going to get. That isn't the point.

DR. PENCE. There may be thousands.

COMMISSIONER BERRY. Also, other kinds of statements you make, that people who complain—I wrote that down, too—that everything the government wants to do in this issue is a violation of civil rights. I haven't heard anyone complain that everything the government wants to do—

DR. PENCE. Not everything.

COMMISSIONER BERRY. Let's not overstate what the issue is, "Every single thing somebody proposes." That doesn't help the issue.

DR. PENCE. Thank you.

COMMISSIONER BERRY. The final thing that I would like to ask is: Do you agree—anyone except Mr. Levi because I already know you agree, but you may answer again if you wish—do you agree that the hidden infection problem could be reduced, the potential for people not wanting to be tested or not wanting to be followed up, if we were to pass laws ending discrimination against gays and lesbians?

DR. PENCE. That is not the way to stop the infection.

COMMISSIONER BERRY. I'm not asking just you.

DR. PENCE. I'll just answer your hidden infection. This bogeyman that you're putting up here, I don't really—the hidden infection problem is that people are walking in right now, being tested who are positive, and not giving their names. That's a hidden infection.

COMMISSIONER BERRY. The hidden infection problem I'm referring to is people who don't get tested and who wouldn't, no matter what you did, based on the history of other epidemics.

DR. PENCE. Well, passing gay rights bills are not going to stop that.

COMMISSIONER BERRY. I just want to know whether anybody up there agrees that that might be one way to reduce the possibility that people avoid things like being identified and being tested.

DR. MENITOVE. I wonder if you didn't answer your own question earlier with the treatment aspect, and I wonder if that's really the part of the puzzle that's missing. Once that occurs, then your question will be answered. Until then, my guess is it's going to be the same as it was in the twenties.

MR. JOHNSON. Civil rights legislation is not going to improve anything for the homosexual community. Basically I have to say that these are two separate issues. For instance, yesterday some information was given to me about pediatric migrant workers and the problem of incest creating HIV positive within these families. Now, that has absolutely nothing to do with the homosexual community, but it is a very serious problem from the information that was provided me yesterday. So I am more concerned about the civil rights of the incest victims of migrant workers right now than I am some other issues for myself and other homosexually oriented people.

COMMISSIONER BERRY. Would you like to testify about that? Go ahead.

MR. JOHNSON. About the homosexually oriented person?

COMMISSIONER BERRY. No, whatever it· is you said you are more concerned about.

MR. JOHNSON. No, I said I'm concerned about the children that are being born HIV positive in New York; I'm concerned about anyone that has AIDS. My work is not exclusively to the homosexual community. If someone wants to exclude themselves from my program because they feel I'm going to convert them or something, they have that option of not coming into my program. My program provides housing and emergency provisions for people that are HIV positive, people that have AIDS, or people that have AIDS-related complex. These are the people that I'm concerned about—regardless of their age, regardless of whether there are three people that have it in the family or whether there's a newborn baby with it.

COMMISSIONER BERRY. The last question I have, Mr. Chairman: Is everybody on the panel in favor of clean needle programs for drug addicts as a way to reduce HIV infection?

CHAIRMAN PENDLETON. You mean new needles or bleached needles?

MR. LEVI. Yes.

MR. JOHNSON. Yes.

DR. MENITOVE. Personal opinion on my part, no.

DR. PENCE. Absolutely not.

COMMISSIONER BERRY. You're opposed to it?

DR. PENCE. I have one question: How do we know it's the needles and not the syringes?

COMMISSIONER BERRY. Well, are you in favor of clean syringes?

DR. PENCE. I'm in favor of stopping IV drug use, ma'am.

COMMISSIONER BERRY. But you're not in favor of those—

DR. PENCE. Don't bleach the needles. That's not going to get you anywhere.

COMMISSIONER BERRY. I didn't hear you, Dr. Menitove. Are you in favor?

DR. MENITOVE. Just a personal opinion, no, I'm not in favor of giving out—

COMMISSIONER BERRY. Your organization isn't, either?

DR. MENITOVE. We don't have a position on that.

CHAIRMAN PENDLETON. I would presume you mean by "clean needles" either the bleach solutions or—

COMMISSIONER BERRY. Yes, there are programs where they do that. They distribute needles to people who are addicts.

CHAIRMAN PENDLETON. But there is more than one method to have clean needles, allegedly.

COMMISSIONER BERRY. Yes.

MR. LEVI. I think, Commissioner Berry, it is very important for us to be testing those types of solutions. We have to recognize that we don't have the infrastructure yet to get everyone treatment on demand, even if that were a public policy, and that isn't even a public policy.

So if you want to save lives, you have to take the steps that teach people how to shoot up safely. We may not want them to be shooting up; we may not want them to be sharing needles, but if we want to save their lives so when we do have enough places in treatment programs they will still be there to get the treatment, and we have to be providing the clean needles.

CHAIRMAN PENDLETON. Dr. Menitove, do you want to say why, as a personal opinion, you don't like this clean needle scenario?

DR. MENITOVE. Just because I don't think it would be effective. I'd rather see the time and the effort be spent on deterrence and stopping the problem rather than continuing it.

MR. JOHNSON. It's not effective. Speaking from the street level of practice at home, it is not now. There are differences in the IV drug use that are indigenous to the community that it is participating in and the socioeconomic conditions of that person. If they are in a lower economic condition, they are going to respond differently. They are maybe going to use fresh, clean needles that are provided to them today, and tomorrow when it's not available they are going to use whatever they can get.

CHAIRMAN PENDLETON. We have one question from Ms. Prado, and then I have just one or two questions to ask, so we can try to end this one on time. I didn't say on which note but on time.

MS. PRADO. Dr. Menitove, I am aware that you represent voluntary blood donors, and obviously the Red Cross program is also a voluntary donor program. I am aware that at least at one time there was a preponderance of paid donor blood banks. Do such paid donor blood banks still exist? If so, should they be outlawed?

DR. MENITOVE. I think they should be outlawed. I don't think they exist, or if they do it's such a minute part of the blood collection that it's almost zero. But I would personally feel that it should be exactly zero.

DR. PENCE. Plasma centers, you mean?

DR. MENITOVE. I'm talking about whole blood collection.

MS. PRADO. I know at least a few years back it used to be certainly something that skid row bums, people needing fixes, gave blood.

DR. MENITOVE. Then let me clarify the scenario. The whole blood that is collected for transfusion purposes is collected almost entirely from volunteer nonpaid donors. However, there is another part of the sector that collects plasma for further fractionation that does involve paid donors from all varieties of life. At this point in time, I guess, all of that plasma is further treated to inactivate viral transmission, and it's all tested as well.

There have been some disagreements, perhaps, on how effective the heat treatment or other treatment that is rendered to the plasma actually is, but from my point of view, at this point in time, it probably is very, very effective. I just don't want to deal with the plasma side of the collections.

MS. PRADO. So if blood donation was to be outlawed on a paid basis, you wouldn't include plasma donation? You would keep that separate?

DR. MENITOVE. I would keep that separate, yes.

MS. PRADO. Why is that?

DR. MENITOVE. One is a supply matter. The supply just isn't there, from what I understand. And the second is that the plasma is further treated to inactivate viruses.

So I think there's a protection there that is not available with red cell transfusions or platelet transfusions that cannot be inactivated vis-a-vis viral transmission.

MS. PRADO. Thank you.

CHAIRMAN PENDLETON. I just have a couple of questions that go to the entire panel.

Would the panel agree or not agree that the public policy imperative in the case of AIDS is the interruption and control of this disease? Would you agree or not agree?

MR. LEVI. Yes.

MR. JOHNSON. Yes.

DR. PENCE. Yes.

CHAIRMAN PENDLETON. There's general agreement to that; okay.

The next question is: Do you believe that civil rights laws or policies are helpful at the Federal, State, and local public health agencies in interrupting and controlling AIDS? What is the role of civil rights policies as we know them today, however you want to talk about it?

MR. LEVI. I think the answer to that is yes, and what I will offer to do is, rather than listening to me say this, I will submit for the record statements of the Association of State and Territorial Health Officers who are, indeed, the people on the front lines of this epidemic who have said the exact same thing.

CHAIRMAN PENDLETON. Just for this record, so we can hear it, can anybody tell me which policies or what policies will help in the interruption and control of this disease? I'm not talking just about gay men; I'm talking about the IV drug users and what other forms of transmission you want to talk about. What are those policies that this Commission should look at in terms of how we can interrupt and control this disease?

MR. LEVI. Well, my statement offered two categories. One was sexual orientation discrimination, and the other was extending the handicap protections and HIV discrimination protections into the private sector.

CHAIRMAN PENDLETON. I understand that. Are you saying, Mr. Levi, that you believe homosexuals should be a protected class similar to other protected classes as designated by the Congress?

MR. LEVI. Yes.

CHAIRMAN PENDLETON. Does anyone else on the panel believe that homosexuality should be declared a protected class?

MR. LEVI. Not homosexuality. Sexual orientation.

CHAIRMAN PENDLETON. You see, I don't know what "orientation" really means. "Orientation" could mean a whole lot of things.

MR. LEVI. As defined in a report of the House Judiciary Committee just a few weeks ago, sexual orientation means homosexuality, heterosexuality, and bisexuality.

CHAIRMAN PENDLETON. I come to the next point. If that is the case, do you believe that drug abusers should be a protected class the same as sexual orientation as you define it?

MR. LEVI. My understanding is—and perhaps some lawyers would help me on this—that IV drug users to a certain extent are already protected because it's interpreted as a handicap.

COMMISSIONER BERRY. You can't discriminate against them on the basis of—

CHAIRMAN PENDLETON. I'm just asking him a question.

COMMISSIONER BERRY. He said he didn't know.

CHAIRMAN PENDLETON. Back to another point. That means that perhaps there needs to be an affirmative action program for AIDS people like there would be for men and women and blacks and Hispanics—

MR. LEVI. Let me clarify that that has never been the position of my organization or our movement.

CHAIRMAN PENDLETON. I'm just asking a question. I'm not trying to be judgmental.

MR. LEVI. Right. We would argue we don't need an affirmative action program. We just need protection from discrimination.

CHAIRMAN PENDLETON. Okay. Any other response to that?

DR. MENITOVE. Let me clarify for the record that the American Association of Blood Banks does not have positions on these matters. If I'm on the panel, I don't want my organization to be on record when we don't have a position. We collect blood.

DR. PENCE. Mr. Chairman, I just want to say I respectfully ask you and other people who are part of traditional civil rights organizations not to make—we don't need more laws, but I hope you get into the public discussion and start revealing these arguments as being called civil rights arguments, because this is paralyzing us.

CHAIRMAN PENDLETON. Just one more question. It sounds redundant in a sense, but what public health policies at the State and local or Federal level now discriminate against AIDS victims?

MR. LEVI. That has not been the point of the argument.

CHAIRMAN PENDLETON. But it's the point of my question. If we're talking about discrimination, and we're talking about this in a public health setting, I'm trying to find out: Do you know of any public health laws at a Federal, State, or local level that discriminate against AIDS victims—whether that's IV drug users, whether those are babies, or what have you? I think this panel would like to know what those laws are. If you don't have the answer now, I'll be glad to accept that within a 30-day time period, if you don't mind, since we are talking about discrimination in this matter.

Just one more point. Dr. Pence, you raised the issue about babies and so forth, and maybe other members of the panel want to react to this.

It looks like babies now could have a hard time in terms of their prenatal and, for that matter, perinatal care. That is, from what this panel has heard before in our discussions and hearings on handicapped newborns, a baby

could be born with spina bifida or esophageal atresia or one of those birth defects, and also wind up being a drug addict and also wind up with AIDS.

Now, in that connection, what happens?

MR. LEVI. Chairman Pendleton, that is one of the tragedies of this crisis. There is a class or a group of kids with HIV infection who are known as border babies. These are babies born to HIV-infected mothers who also have the infection, and many of them go on to get the disease, whose mothers either don't want those kids or are not able to care for those kids, and they end up living their lives in hospitals because they can't be placed with foster parents; no one wants to care for them. That includes, unfortunately, a significant number of people in the health care professions as well.

One of the interesting and moving aspects of this situation is that Gay Men's Health Crisis in New York has a program where gay volunteers go to hospitals where there are border babies and visit and play with these kids, and very often that is literally the only human contact these kids have in their lives. And that is, indeed, a tragedy.

CHAIRMAN PENDLETON. Does anybody know of any denial of treatment of handicapped newborns in this respect, or of their parents or their mothers?

MR. LEVI. To the extent that they do not have the same access to the health care, to the same sorts of services that otherwise abandoned infants would, yes, that is discrimination.

CHAIRMAN PENDLETON. My final question is: There is this whole matter of public health cost. I'm not talking about insurance now but the public health cost of this.

Do you think that the public is going to be willing to pay the increased costs, or does that become competitive with the other kinds of public costs in this country? And where do you feel that should rate in the entire appropriation at the Federal, State, and local level process? Dr. Menitove.

DR. MENITOVE. The public, I think, has spoken in terms of the AIDS testing for blood donations. It probably costs in the neighborhood of $50 million a year or so, and it's a continuing cost and will be incurred every year, and the public demands it.

From a blood banking point of view, we are struggling with this issue, because there are other retroviruses that we will be seeing in years to come. Also, we are finding another test being proposed to safeguard the blood supply. And I think we do have to deal with this issue, and we do have to deal with it in an organized way, because it will come to pass that every time we hear a hint of something new, a test will be demanded for it. I don't think the public can forever bear that cost.

So if you can help in this matter, we would appreciate it, and that is to somehow or other organize an approach to the amount of testing that the public will need in order to feel satisfied that the blood supply is safe.

CHAIRMAN PENDLETON. I guess I'm in a sense reaching a little bit, as the lawyers would say, but is a denial of payment a denial of civil rights? I think we heard some time ago some testimony from someone that said they figured the cost of treatment and the like would be so astronomical that potentially this could make the riots of the "60s look like a picnic, and that might be to some extent reaching.

I guess my question is: How do you feel? Is there some point that we can say, "We have to weigh these costs to see how far we go." And if the public does not want to go farther, what do we do about the people that you know about, the drug addicts, the ones you know about in your hospice—what happens to those people if there is not the allocation of public resources?

MR. LEVI. I'd be more than happy to encourage the Civil Rights Commission to declare that access to quality health care should be a civil right, but I have a feeling that's a little bit far afield from this hearing.

COMMISSIONER BERRY. Mr. Chairman, I know you didn't ask me, but we already know that in many States it's a matter of public record; it's all in the papers where they make decisions about medical treatment of people and taxpayers' funds, whether it's organ transplants or other kinds of medical treatment. The public has a right to make that judgment about how it wants to spend its taxpayers' funds.

We even know in Federal law that we have something, an amendment, on a subject which we are not supposed to discuss in the Commission about the Federal Government not paying for poor women to have a certain kind of medical response to a condition which causes the protuberance of one's abdomen in a certain way, which I can't mention in the Commission, and that there was a Supreme Court decision about whether indeed the Federal Government had to pay.

DR. PENCE. We got what you're saying, Commissioner Berry.

COMMISSIONER BERRY. So that, indeed, the public makes a judgment about how it wants to spend taxpayers' money, and that you only discriminate if you do make a policy to spend money for something and then refuse to spend it equitably to other people.

DR. PENCE. Can I say one word about the money question. There is no question—

COMMISSIONER BERRY. May I just finish what I was saying?

DR. PENCE. I'm sorry.

COMMISSIONER BERRY. So I hope that the question really is whether the public will decide it wants to pay all this money, for whatever it costs, before we can figure out how to treat it.

I'm finished, Dr. Pence.

DR. PENCE. Thank you, Ms. Berry.

Three sentences. It's going to cost a lot of money; the public is going to have to pay for it; and we will find that some of the people who will be

competing for the money, competing for the money that should be going to governments to do enforcement, will be gay rights lobby groups who want the money given to them for education, and that will underlie the ideological debate that goes on.

CHAIRMAN PENDLETON. Mr. Levi, do you want another word with that?

MR. LEVI. That's the whole point. Public health control efforts should not be a substitute for education. They should be a part of and not a substitute for these efforts.

But I want to answer more specifically your question in terms of AIDS, and that is the funding of AZT under Medicaid. AZT is the only licensed intervention for AIDS. In fact, some States do cover it under Medicaid; a handful still do not. Texas, for example, was very late in getting around to covering it, even though it's one of the higher incidence States.

That, to me, is indeed a civil rights issue, that if I happen to live in the wrong State, even though I am equally poor, I can't get the one form of medication that might prolong my life.

CHAIRMAN PENDLETON. I have more questions but we have to stop here and take a break and then move to the next panel.

Thank you very much, gentlemen, for coming this morning.

[Recess.]

[Anthony S. Fauci was sworn.]

Panel II: Transmissibility

TESTIMONY OF ANTHONY S. FAUCI, M.D., DIRECTOR, NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, BETHESDA, MARYLAND

CHAIRMAN PENDLETON. Do we dim the lights now, or what do we do in this process? We have to have the presentation.

DR. FAUCI. I think you will be able to see the slides pretty well without turning all the lights off. We just tested it. I don't really think you need to turn all the lights off.

CHAIRMAN PENDLETON. Go right ahead, sir.

DR. FAUCI. Mr. Chairman and members of the Commission, what I'd like to do over the next several minutes is just very briefly outline for you some of the substantive issues in the AIDS epidemic.

[Slide.]

They can be generally broken down when we speak of the current issues in AIDS—it could be AIDS research or just a study of AIDS—into five empiric areas:

From epidemiology and natural history, which I think is the area that is probably most relevant to this particular Commission.

The etiological agent.

Pathogenesis or how this virus destroys the body's defenses.

And then two areas which are of current great interest in this country and worldwide, namely, the development of therapy for HIV, which is the human immunodeficiency virus, as well as for vaccine development.

And as I mentioned, I'll just take each of these and very briefly bring you up to date on where we stand on these.

[Slide.]

The projections for the number of individuals who have full-blown AIDS is right on the mark of what it was a couple of years ago when the Public Health Service projected that by the year 1990 there would be about 270,000 cases. Currently in the United States—this slide is a couple of weeks old—there are about 60,000 cases of full-blown AIDS cumulatively. Over half of those have already died.

Interestingly, the breakdown of cases, as you can see in the upper line: homosexual or bisexual men is still around 60 to 65 percent; intravenous drug abusers, about 18 percent; homosexual men who are also IV drug abusers, 7 percent; hemophiliacs, 1 percent; transfusion, 2 percent; and heterosexual contact, 4 percent.

I must emphasize something that is often misconstrued in the public, that these are the number of cases of individuals who have been sick with HIV infection. We'll get to the number of individuals who are infected in a moment.

Also of growing importance in this country are the number of infants and children who are infected with HIV. There are now in this country approximately 1,000 infants and children who have full-blown AIDS. It is very clear to us in the field that this number is probably a very gross underestimate of the number of individuals, infants and children, who are not only infected but who are either on their way to getting sick or who do have some symptoms.

One of the difficulties in assessing the numbers of full-blown cases of AIDS in infants and children is the vagueness of the criteria of diagnosing AIDS in children as opposed to adults in which you have very strict and set criteria, because infants react differently to this virus. There is still not universal agreement regarding the diagnosis of AIDS. But certainly there are thousands of children who are infected with the virus who do not yet have the full-blown disease.

[Slide.]

This is a picture of what we frequently call the iceberg of HIV infection. It is probably one of the most important concepts to put forth to you this morning. If you will look at the tip of the iceberg on the top, that in white, where it says "full-blown AIDS," that's the 60,000 patients that I alluded to just a moment ago. It is estimated there are about another 150,000 Americans who are infected who are ill in some respect but don't have the full criteria of full-blown AIDS.

The terminology "ARC" or "AIDS-related complex" is used for these individuals, but we are getting away from using that terminology since the revised definition of the Centers for Disease Control now includes individuals who previously were not in the major definition, namely, individuals with AIDS dementia and individuals with a wasting syndrome.

But clearly most important of all is the 1 to 1.5 million people in the dark blue who are infected with the virus who have absolutely no symptoms. These are important for a number of reasons. Most of them do not know that they are infected with the virus. Almost certainly they can transmit the virus by practicing high-risk behavior, which I will get into in a moment.

And, thirdly, given the fact there are drug trials now which are trying to answer the question of whether or not, if you treat someone who does not yet have AIDS but who is infected, with a drug such as AZT or alpha interferon, can you block the progression to full-blown AIDS? We don't know the answer to that, but if in fact we can, then it is going to become very important to understand the full scope of those people who are infected, who are well, and who do not yet know that they are infected.

[Slide.]

This is a diagram which is one that can really explain why there is much confusion in this country as to how many people will ultimately get AIDS who are infected. The closed circles are the real data, not projections from that data. As of May 1988 we know that approximately 30 percent of individuals who are infected with the virus, who are asymptomatic—namely, they feel well—30 percent of them in 5 years will develop AIDS. What we don't know is how many of them will develop AIDS in 10, 15, 20, 25, and 30 years. That's the reason why I have the open dots that either plateau or that have a linear curve.

The best scenario would be that there is a plateau there, that you won't have any more than 40 or so percent developing full-blown AIDS.

The worst-case scenario would be that it's a straight line, that sooner or later everyone who is infected will get sick from the virus. And preliminary data that we have on immunological function, namely looking at laboratory tests which give you subtle indications as to whether someone is getting a harmful effect of the virus, indicates in a study from the Walter Reed Army Medical Center that close to 90 percent of individuals within a period of 3 to 4 years will have some form of deleterious effect of the virus, even though they remain completely asymptomatic.

So although this doesn't give us the answer to that question posed on that slide, it strongly suggests that unless therapeutic intervention comes in, you would have virtually everyone who is infected with the virus over a period of whatever—20 years or so—ultimately develop the disease. That is why it is imperative to identify and counsel and treat individuals if,

in fact, treatment of individuals who are asymptomatic proves to be effective. And as I mentioned, we don't know that yet, but the studies are being conducted.

[Slide.]

This is a breakdown of the seropositivity in the United States, and I show it to indicate to you that the prevalence of infection among individuals who practice certain risk behavior varies greatly. It varies greatly among individuals and it varies greatly depending upon where in the United States you are.

For example, if you are a homosexual man in San Francisco, there is greater than 50 percent chance, if you have been practicing high-risk behavior, that you're infected with the virus. If you are, for example, in a small town in upstate New York, it may be closer to 10 or 20 percent.

IV drug abusers the same. If you're from Newark, New Jersey, or Miami, there's a 70 percent or so chance that you're infected. If you come from the central part of the United States that doesn't have much interaction with the New York, Brooklyn, South Bronx, Miami access, the chances are much less that you will be infected.

Spouses of infected males also varies.

And I think the last two lines there give us some important information, and that is what I am going to address now.

A question that is often asked—and the public is very interested in this—what is the prevalence of infection in the general population, and what are the chances of the infection actually running rampant in the general population?

We learned two things from our broadest surveys. One is among blood donors, people who donate blood to the Red Cross or to their blood banks, and the other are military recruits.

Blood bank donors exclude by their own will individuals who are male homosexuals or IV drug abusers. So it gives you a good cross section of the population, excluding IV drug abusers and male homosexuals. And of that group it has been consistent over the past 2 or 3 years that less than 0.02 percent of the general population is infected.

However, the data from the military is somewhat concerning. That is, if you look at sexually active young men and women, usually between the ages of 18 and 30, who are applying for the armed forces, the broad number of the United States is 0.15 percent. So it is significantly greater, at least five times greater, than the general population.

But of great concern is that if you look at various parts of the country, the pockets of infectivity among individuals who are not IV drug abusers or male homosexuals is very high in areas that are in areas of high IV drug abuse and very low in areas that are not.

For example, if you are a young white woman in the central part of the United States where there isn't much IV drug abuse, in Iowa or what have

you, there is a chance of maybe one in 2,000 that you are infected. If you are a young black man, living in the South Bronx, there's about a one in 50 to a one in 100 chance that you are infected, indicating that the pockets of spread in the general population heterosexually are focusing around the IV drug abuser population in places like South Bronx and Newark and Miami or what have you.

And that is something that really needs to be addressed when one thinks in terms of how and where and when you're going to have spread into the general population. Because the numbers from the blood donor pool indicate that, in fact, we are not seeing widespread entrance of the infection into the general population.

[Slide.]

Another very good example of this is this slide, which is taken from a report of the number of seropositive babies in New York State, and in almost 20,000 infants who were tested you can see in New York City one in 61 babies are born infected with the virus—one in 61. And the breakdown again reflects the distribution of IV drug abusers is greater in the Bronx with one in 43, less in Manhattan, a little less in Brooklyn, less in Queens, and much less in Staten Island, which is precisely again the breakdown of the IV drug abuser population in that city.

And all that tells us is what I just mentioned to you a moment ago, that spread into the heterosexual population by heterosexual sex will occur through the IV drug abuser population predominantly—not exclusively by any means—and predominantly 75 percent of infants who are infected with the virus who develop AIDS will be of parents who are either infected or at risk for getting infected. So the chances, again, of an IV drug abuser mother or a mother who is the sexual partner of an IV drug abuser is the greatest risk for an infant getting infected.

[Slide.]

Why are we not seeing spread of the infection into the general population the way we are seeing it in Africa? The reason is there are three major factors that are involved in the spread of this infection sexually.

One is the prevalence factor. Again, in the general population, the prevalence is still very low. It's high in the South Bronx among IV drug abusers. That's the reason why they get infected much more frequently than anyone in the general population sexually.

In addition is what we call the promiscuity factor, which is a bad word to use because it's judgmental. It really means the degree or the number of sexual contacts. In general, people in the United States are a relatively monogamous population, despite the fact that the United States thinks they are generally a swing society. They are not, compared to some of the other societies in which multiple sexual partners is part of the sociologically acceptable norm in society—and I'll mention that in a moment—when you talk in terms of Central Africa.

Secondly, other cofactors, such as other sexually transmitted diseases, play a major role in whether or not, if you get exposed to someone who is infected, that you will in fact get infected. So the greater the chance of having another sexually transmitted disease, the greater the chance of getting AIDS or getting HIV infection if you are exposed to it.

[Slide.]

This is a comparison of a city in Central Africa, Kinshasa in Zaire, where approximately 10 percent of the general population are infected with the virus, as opposed to 0.02 or 0.03 percent in the United States. Again, the prevalence is very high in that country, and that's the reason why you're seeing the spread of infection.

[Slide.]

Now, this is a picture of the AIDS retrovirus, which we call the human immunodeficiency virus, budding off one of its target cells. It is important to point out that this virus has a particular life cycle. For those of you who are not familiar with this, I don't want to go through and explain this whole thing, but it merely shows on the right-hand part of the slide that when the virus enters the cell, it goes through a variety of changes where it uses enzymes, such as reverse transcriptase, to turn itself into a molecule that could enter into the genes of your own cell.

Now, it can either stay there or it can then reproduce itself and make another virus. When it stays there, that's what we refer to as viral latency, namely someone is infected; they are not actively making a lot of virus, and they can go on for years without getting sick. They can still be infective, however, because if those cells are transmitted to another person by blood or blood products, by sharing a needle, by semen or vaginal secretions in a sexual contact, even though a person is perfectly well, they still can in fact transmit the virus.

[Slide.]

This is another schematic diagram of the virus on the right-hand side attacking a particular cell type.

I could probably spend 45 minutes with you going through the mechanisms of how the body's defenses are destroyed, but I think I could tell it very clearly on this next slide, which shows in a schematic way that the cell in the middle, which is essentially the conductor of the symphony of the body's immune system—and the body's immune system is the defenses of the body. The reason why you and I don't get infected and die from any common infection, and why we recover from viruses, is that we have a defense mechanism called the immune system, which protects us against these infections.

Somebody who is infected with the AIDS virus has that central cell, the helper-inducer cell, destroyed. That is essentially like removing the conductor of a symphony orchestra away and having the orchestra just play in a totally discombobulated way, or it's similar to taking an important

micro chip out of the computer and then seeing the whole computer break down. That's the reason why individuals who are infected with the virus have a deterioration of their body's defenses and they wind up getting a variety of opportunistic infections and tumors.

[Slide.]

These are the ways the virus is transmitted—still now, several years after we discovered the virus, and 8 or 7 years after we know that the disease AIDS exist. There has been no change in how we know the virus is spread.

By homosexual or heterosexual contact.

By blood or blood products.

Intrauterine, to a baby from the mother.

Or needle sharing.

The evidence for breast milk transmitting it is small. There are isolated cases of women who have gotten transfused during child birth because of a complication who then nursed their child and the child got infected. That's only one or two cases, so there aren't a lot of them. I just put it up there to be complete.

But the three major ways are: blood and blood products, sex, and mother to child.

Now, there is no evidence whatever that the virus is transmitted by casual contact. You have been hearing this for years. And when I say no evidence whatever, I'm talking about a variety of studies. And these are the titles representative of many, many studies in the literature now, which studied the families of people who have AIDS or an AIDS-related complex who live in the same house, share the same utensils, eat with each other, spend time with each other, use the same towels. There is zero incidence of transmissibility of the virus that way.

In addition, health care workers who have been taking care of AIDS patients, who have constantly been sneezing and coughing and what have you on health care workers—none of those have been infected except by direct inoculation of a needle that is contaminated when you're drawing blood from the patient.

So the evidence that this virus is transmitted by casual contact is really zero. And this obviously has important implications.

[Slide.]

This again is a slide of the life cycle of the virus. The arrows are shown in areas where they are vulnerable to attack by a number of drugs. For example, the drug that you have heard about, AZT or azidothymidine, has the ability to block that enzyme right there in the middle, reverse transcriptase.

We are working now in research capacity on a number of drugs that have the capability of blocking other components of the virus.

[Slide.]

Now, as you can see on the right-hand side, when there is latent infection, as I alluded to, there is nothing to attack, because the virus isn't multiplying itself. Only when the virus multiplies itself can you block it.

The reason I bring that up to you is that when people ask us, "When will you get a cure for AIDS?" we are not thinking in terms of a cure in the classic sense, when you come in and you wind up getting a pneumococcal pneumonia and your doctor gives you penicillin and he completely eliminates all the bacteria from your body. What we hope to do with drug development is suppress the active replication of the virus so that someone can lead a normal life to the point where, whenever the virus starts to replicate, the drug can suppress it. It is very analogous to insulin. It doesn't cure diabetes, but someone who is a diabetic, if taking insulin properly, can lead a reasonably normal life.

Antihypertensive agents do not cure blood pressure problems, but it controls blood pressure enough so you can lead a reasonably normal life.

That's the kind of scenario we are aiming at in the development of drugs. And as I mentioned, azidothymidine is the only drug now that is licensed for use in AIDS which has been shown to be effective in prolonging the lives of individuals who are infected with the virus.

[Slide.]

This is just a diagram of the number of individuals in the NIH clinical trial groups which are being tested in clinical trials with a number of other agents. So although you have heard and read about AZT—and it certainly still is the best we have—there are a number of drugs that are being tested right now that have some promise in the possibility of being used alone or in combination with AZT.

[Slide.]

And finally, on this last slide, there are a number of approaches for vaccine development. Rather than go through all of these, which really have a lot of words which aren't of much meaning to you, let me say that there are two vaccine trials going on in the United States, one right up here in Bethesda at the National Institutes of Health, and they are using a vaccine in what we call a Phase I study. That is to ask, one, is it safe to give and, two, does it induce an immune response?

We are not even talking at all about whether it's protective, because vaccine development in AIDS is going to take years and years, even if we are lucky. In other words, before we have a vaccine that is available for widespread use, even if we are lucky enough to be testing that right now, it won't be until well into the 1990s, probably the mid-1990s, before we have one that is available for widespread use. And the reasons for that are many—scientifically, logistically, as well as the fact that the virus has spread by a behavioral component and not, for example, as influenza is spread, where you can determine in one winter season whether the flu

vaccine is effective. It is going to take years to determine whether an AIDS vaccine is effective.

So in closing, there are a number of issues in AIDS ranging from the basic research on etiology and pathogenesis up through the more practical and understandable natural history in epidemiology. I have described each of these very, very briefly, and I'd be happy to answer any questions on these if you have any.

Thank you.

CHAIRMAN PENDLETON. I don't know how many of us are intimidated either by you or by your slides or whether we're just scared, but that is very impressive.

I have one or two questions, but I'll wait until my colleagues who might have questions. Do you have a question?

COMMISSIONER BERRY. I have questions but I'll wait.

CHAIRMAN PENDLETON. It's your turn.

COMMISSIONER BERRY. Thank you very much, Dr. Fauci.

Let me just ask, in anything you said to us in your presentation, and the slides you showed us and so on, whether you and your statement here, as well as the work at NIH that you do on this issue, is influenced at all by the activities of lobby groups on various aspects of the persons who might be identified as highly probable to have HIV or AIDS. Have you been in any way influenced?

I ask that—you might think that's a ridiculous question, and you may not have been here for the earlier panel.

DR. FAUCI. No, I wasn't.

COMMISSIONER BERRY. But there were all kinds of assertions that the public policies on this subject and the physicians who are involved in this issue—and you are a physician and researcher; is that right?

DR. FAUCI. Yes, I am.

COMMISSIONER BERRY. —have been influenced to take the positions they take in the policy debate by lobby groups who have certain positions, and it was always my understanding that that wasn't the case. So I wanted to find out whether you feel there has been some kind of influence from organized lobbies in your research or to make you take a position on transmissibility which would be otherwise or not.

DR. FAUCI. That's a very easy question to answer, and that is that the Public Health Service, of which the NIH is a part of, has approached from the beginning, and still does approach, the epidemic from a public health and scientific standpoint. It is totally preposterous to even imagine that any scientist that I know of, certainly not myself or the people that are involved in my own group as the coordinator of AIDS research in the NIH, would take a stand on how the virus is transmitted based on pressure from anyone other than the scientific evidence at hand. And the scientific

evidence at hand is overwhelming in telling us how the virus is transmitted and how it is not transmitted.

COMMISSIONER BERRY. Let me ask you another question. The way I have seen what this Commission is about in these hearings, since we are a Civil Rights Commission, I have sort of framed for myself the question of whether implementing policies based on the consensus and the expert medical-scientific community at every stage in dealing with AIDS and HIV would discriminate against certain people in ways that are inconsistent with civil rights protection under our Constitution.

Do you think that it is appropriate for me to rely on the judgment of the expert medical and scientific community in dealing with this disease or this epidemic or whatever as I go about trying to make my judgments about the civil rights implications? Should I rely on the judgment of the medical-scientific community or not?

DR. FAUCI. I think you should. It depends on what you mean by the medical-scientific community.

COMMISSIONER BERRY. Experts.

DR. FAUCI. That's the problem. There are a lot of experts around, as I'm sure you are aware.

COMMISSIONER BERRY. Which ones should I depend on?

DR. FAUCI. They seem to grow and sprout forth as weeds in a garden. I think what you need to do, when you talk to an expert, is make sure the person is an expert in the area they are talking about. We often have an expert in one area, a basic science area, making a proclamation on natural history and epidemiology, or someone who works in vaccine development talking about molecular biology or pathogenesis.

I think it is very clear that, for example, the ad hoc groups, which the Public Health Service calls together when we do our planning for the kinds of research and things that are done, takes a good cross-section of people who are recognized experts in the area. If you listen to those people, I think you can probably formulate a sound civil rights policy, because civil rights would be compatible with the scientific data, and the scientific data, I think, in no way at all would discriminate against anyone. It is just important scientific data. You make your policy decisions based on what the data is.

For example, if the virus is having a predominant spread among a particular group that needs special attention and help, I think that will be very, very clear. There are very good examples of that right now. It is very clear that right now the virus is spreading rather considerably among the IV drug-abusing population, and IV drug abusers have their own special problems. You can't just go over to an IV drug abuser and say, "Stop using drugs." You've got to help the person. They are ill. You've got to treat them for their IV drug abuse and then, with that as a background, try and stop the spread of HIV among that population.

COMMISSIONER BERRY. Are you the appropriate person to ask as an expert about whether case finding or contact tracing or isolation are appropriate ways of reducing the transmissibility of this? Or is there some other kind of expert I should ask?

DR. FAUCI. Well, I'm part of the Public Health Service Executive Committee, so I have been sitting in for years on all of the deliberations in this regard.

Specifically, the most appropriate group for you to ask that of would be a representative of the Centers for Disease Control, the CDC. But I can tell you there is universal agreement among Public Health Service officials that testing someone, and then if they are positive isolating them, quarantining them, is totally, one, not logistically possible and, two, incompatible with the Public Health Service component of what you're trying to do.

The Public Health Service has—and I can speak for them in this regard—in the past, and still does recommend more widespread voluntary testing associated with counseling, both pre- and post-testing counseling, so that you might help the individual who turns out to be positive: one, to help themselves to see what they can do to prevent themselves from going on to develop the disease, as well as to help them prevent the spread of infection by counseling them about how they can prevent the spread among their loved ones, their sexual partners, giving them counseling, for instance, if they are women of child-bearing age, about the dangers of getting pregnant, or what have you.

COMMISSIONER BERRY. But you do not propose isolation of people who are either drug addicted or, quote, "sexually addicted," until they desist from this behavior as a way of controlling the spread of this disease?

DR. FAUCI. That's a different story. You will always find the rare sociopathic individual who is infected and knows he is infected and deliberately goes out and infects other people. But I can tell you from my experience with a large number of AIDS patients and people who are infected with the virus, that is a very, very rare event. If, in fact, you have someone who still persists in doing that, I think that becomes a judicial problem more than a medical problem.

COMMISSIONER BERRY. Thank you.

CHAIRMAN PENDLETON. Any questions, because I have a couple.

Bob.

COMMISSIONER DESTRO. I just wanted to follow up on the last question. You answered with respect to isolation of the compulsive. There are actually two questions. One is: What about the contact tracing of people who have been found to be positive and information and the breach, if you will, of confidentiality with respect to the sex partner?

DR. FAUCI. That is such a complicated issue that, even if I were to give you an opinion of what I thought, there are so many problems associated

with that that need to be worked out before you can have a coherent and cohesive policy on that. When you talk about sexually transmitted diseases, there is precedence for doing contact tracing, but it's almost always in association with a situation where you find the sexual partners, you identify them, you treat them with a shot of penicillin, and you've done them a very great service. You've gotten rid of their gonorrhea or you've gotten rid of their syphilis.

At the present time that is not the case with HIV, because even though AZT has been shown to prolong the lives of individuals who have serious HIV infection, we're certainly not nearly at the stage, as it were, that we are with penicillin and syphilis or gonorrhea. So that is one issue that's a confounding issue in the answer to your question.

The second issue is the whole idea of confidentiality and the protection of persons' rights. It is a very rare event in history that someone finds out that they're positive serology for syphilis and they get a shot of penicillin and they wind up losing their job, their health insurance, and getting their houses burned down.

It's really a different situation when you talk about identifying people who are infected. So although from a medical standpoint it would be very nice to be able to identify an infected person, counsel them, treat them, or what have you, there are so many other issues that need to be addressed that I don't think I can answer your question and give you a firm recommendation on that. That really is very much of a multidisciplinary thing to consider.

COMMISSIONER DESTRO. Actually, that was part of the ploy, to get that point that it's multidisciplinary on the record.

The other part of that, though, is that much of the commentary that I've seen from the multiplicity of disciplines which have commented on this issue, is that it is a mistake—some people say it's a mistake; other people say it's the appropriate way to look at it—to focus purely on the person with HIV; that part of the reason for tracing and/or isolation—and when we deal with drug abusers it's even more clear, I think, than with sexually transmitted HIV—that one of the reasons you might isolate and/or contact trace is to get these people to stop whatever behavior they are doing in order to prevent other people from catching the virus.

To what extent epidemiologically would those types of behavior further the lessening of the spread of the virus?

DR. FAUCI. Probably very little, because once you have a situation where you're testing people and tracing partners, what you will probably do is have an impact on a disincentive or discouraging people from being tested, and then therefore cutting off the tracing of their partners. If someone knows that there is a possible negative component to being tested or to have their sexual partner tested, you will then drive underground the

very people that you're trying to bring out and test and counsel. That's a big problem.

COMMISSIONER DESTRO. Did you want to follow up on that? Because I have one other question related to the vaccine. Actually they are related points. One is—the vaccines won't prevent the transmission of the disease, as I understood it.

DR. FAUCI. Vaccine does prevent transmission of infection. There's vaccine and there's treatment. If you vaccinate someone who is not infected and you have an effective vaccine, when they get exposed they won't be infected. Vaccine is useless in the classic sense for someone who is already infected.

COMMISSIONER DESTRO. I see. The other one is: If civil rights protection is key to seropositivity status, then would an effective vaccine in effect give you seropositivity status?

DR. FAUCI. Yes, it would. It would give you seropositivity, but it depends on the vaccine that is used. Let me try to make it as simple as I can.

If someone gets infected with the virus in the wild state, namely gets it from a contact, their antibodies will show a pattern that will be multiple components of the virus. In fact, if you take the pattern of someone, it looks like this [indicating], if this were a Western Blot. If someone were infected they'd have all of these bands being positive. If I vaccinated you with a purified component of the virus the way we're doing now in Bethesda, the only thing you would have would be these two bands. So I could tell you by definition that you got that positivity by a vaccine and not by getting infected. In fact, to protect the rights of the people in our NIH vaccine program, we are giving them a certificate saying they are in fact a participant in a government-sponsored vaccine trial, and if they want they can actually get a copy of their Western Blot which would prove that in fact they are not infected.

COMMISSIONER DESTRO. All right. Thank you.

CHAIRMAN PENDLETON. Dr. Fauci, could you go back to your slide about New York? Is that somewhere not too far away?

DR. FAUCI. Sure. About the babies in New York?

CHAIRMAN PENDLETON. No, about different neighborhoods in New York.

DR. FAUCI. That's the baby slide.

[Slide.]

CHAIRMAN PENDLETON. How did you get those numbers?

DR. FAUCI. That was a statewide survey that was conducted by the Department of Health of the State of New York looking at hospitals in various locations as sampling representative hospitals in a variety of locations, including New York City. That is the result of looking at individuals, for example, in general hospitals in the Bronx versus

Manhattan and what have you, and taking a sample of blood, which you take of children anyway when you do a test for a particular metabolic disease on all infants who are born, and applying that to the HIV. That's how you got that. That was on the front page of the *New York Times* about 4 months ago.

CHAIRMAN PENDLETON. Tell me, how confidential is this collection process?

DR. FAUCI. How confidential?

CHAIRMAN PENDLETON. Yes. What is the confidentiality mechanism in this process?

DR. FAUCI. There were no identifiers in that particular study. In other words, the people who did the test didn't know who they were doing the test on, and if the result was positive they didn't know. They only were able to develop quantitative numbers. For example, if every baby in the hospital gets a heel stick and blood is put on a paper and they test it on all the papers, at the end of the week they say, "We have 20 positives." They have no way of identifying who the positives were and were not.

CHAIRMAN PENDLETON. But you have some way of identifying what the universe is. Of all people that were in the hospital that week, you'd know how many babies were delivered that week; therefore, you might know.

DR. FAUCI. Right.

CHAIRMAN PENDLETON. So could that be a problem later?

DR. FAUCI. I can't imagine how it could be a problem. There would be no way of identifying those individual babies.

CHAIRMAN PENDLETON. I guess my other question is this: It looks like we are in a kind of a race in the treatment of this disease. On the one hand you're racing to develop vaccine and so forth. On the other hand, there's a race to see if we can't interrupt the transmission of this disease. Do you have any idea when those things might come together?

There are two sides to this public health question. One is the question about: What do we do about public health policies other than the ones you operate, by which you do the research and obtain the vaccine. Is there any projection when those might come together?

DR. FAUCI. I think you are starting to see results in both of those areas right now. If you talk about education and risk reduction, right now there is clear-cut evidence that a risk-reduction campaign is having very important results. For example, the incidence of new infection among male homosexuals in high-risk cities is very, very low right now compared to 1983 and 1984. It was 10 or 12 or whatever percent per year. Now it's less than 1 percent per year among male homosexuals because they are quite well educated now about what they need to do to avoid infection.

In addition, we know that the incidence of other sexually transmitted diseases, which is a good indicator of change in sexual behavior and sexual

habits, is very, very low among male homosexuals. The incidence of rectal gonorrhea in certain major cities is down by 75 to 85 percent. That's a very important indicator that this risk reduction public health type policy that you're talking about is already starting to reap benefits.

With regard to the basic science, it depends on what you're talking about. If you're talking about drugs, as I mentioned, we already have a drug, AZT, which has some benefit. It certainly isn't the cure and it isn't the answer. I would project, though these are just guesstimates, that within the next 2 years we will probably have other drugs that will be used alone or in combination with AZT that will have even better results than we are seeing now. And as I mentioned, vaccine is going to lag behind all the others.

CHAIRMAN PENDLETON. You're saying that the educational efforts among high-risk populations and the counseling is beginning to pay off?

DR. FAUCI. Yes, among certain high-risk populations.

CHAIRMAN PENDLETON. Among certain high-risk populations.

DR. FAUCI. Some are more difficult, like the IV drug abuser population.

CHAIRMAN PENDLETON. I want to get to that point. Since IV drug users are, in a sense, a more captive or dependent audience on drugs, isn't it much more difficult to reach the IV drug user, and don't we stand a chance of having an increased spread of the virus because of IV drug use as opposed to homosexual activity among men?

DR. FAUCI. There is no question that at the present time, in 1988, the greater risk of spread into the general population would be through heterosexual contact with IV drug abusing cohorts than from male homosexuals.

This is something that has been recognized and addressed by a number of groups, including the President's Commission on AIDS, who made just that statement, that that is a target population that needs to be looked at very carefully. One of the recommended ways to get around the recalcitrance and the difficulty in dealing with IV drug abusers is to implement drug treatment programs, to get them into treatment programs, which would be a very good way to get them away from sharing IV drug needles, which is the spread of HIV.

CHAIRMAN PENDLETON. I guess my final question is there has been a lot of talk about the allocation of public resources for research and for public health activities. What do you think is an adequate allocation, at the Federal level at least, for this? I realize that most of this is a local responsibility. How much money is needed?

DR. FAUCI. You try to make a best estimate based on the state of the art, for example, in research—and I can only speak to the research area—the state of the art, the number of individuals who can and will be working in this area. And I can say from the National Institutes of Health standpoint that the amount that is being proposed for the 1989 budget I believe is an

adequate amount. It's $587 million—$588 million—which I believe from a research standpoint is enough to do the job that we have to do.

CHAIRMAN PENDLETON. My final question is this: If we don't spend the $587 million or some other number, then how much do we lose on the other end in terms of lost productivity from people who can't go to work and who need transfer payments on Medicaid to make sure they can be cared for? What would you estimate the loss to be if we didn't spend this kind of money? Do you have any idea at all?

DR. FAUCI. There are wide ranges of estimates of how much, for example, by 1990, when you expect to have a cumulative number of 270,000 cases in the United States—the number varies with a great margin of error, but certainly it is measured in health care costs and other costs of well into the $20 to $50 billion. It's going to be a lot of money.

CHAIRMAN PENDLETON. Do you have any other questions?

COMMISSIONER GUESS. Could I hear that figure again?

DR. FAUCI. Somewhere between $20 and $50 billion of all health care costs, lost productivity—those are very, very rough estimates—by the year 1990, if we have 270,000 people cumulative who develop it. But that's a number that's not a surprise. This has been kicked around and discussed in many fora.

COMMISSIONER BUCKLEY. How many would still be alive that would be costing this money? You say 270,000 cumulative?

DR. FAUCI. Right. About half of them probably will have been dead by then.

CHAIRMAN PENDLETON. I'm talking in terms of lost productivity.

DR. FAUCI. I can't give you a number on that.

CHAIRMAN PENDLETON. These are people who can't go to work, who are dependent on the public for their health care and the like, so there's a productivity loss that way.

DR. FAUCI. I don't have a solid number for you on that.

MS. PRADO. As a point of clarification on that slide, was that survey taken of all hospitals in the city or just public?

DR. FAUCI. Just public hospitals.

COMMISSIONER RAMIREZ. Why don't I let—this is a followup question?

COMMISSIONER GUESS. It's on the question on the incidence of HIV transmission being attendant to the intravenous drug user. I'm understanding you to say that we anticipate the primary source of transmission between now and 1990 is going to be from that population.

DR. FAUCI. Transmission. I didn't say primary. I'm saying that it's going to be a major source.

COMMISSIONER GUESS. What would be in your prognosis the primary source?

DR. FAUCI. Again, I think you are going to still see a degree of homosexual contact, probably less and less as the years go by. And I think

you are going to be seeing an increase in IV drug abuse, and heterosexual contact that is secondary to the IV drug abuse, namely, someone who is the lover of an IV drug abuser. You're going to be seeing an increase in infants who are born of infected mothers, who are either IV drug abusers or who are the sexual partners of IV drug abusers.

So I think it would be correct to say that, given the decrease in spread of infection—not disease, because the disease is still going to be male homosexuals, because in 1990 the people who are going to get disease are going to be the people who were infected 5 to 6 years before, so you are still going to see an increase among male homosexuals for disease, but new infections you're going to see a shift over towards the IV drug-abusing population as the predominant group.

COMMISSIONER GUESS. Is it safe for me to conclude as a matter of public policy that there should be a correlation between this country's inability to hamper the importation of illegal drugs as well as the health effect it's having in terms of the transmission of AIDS?

DR. FAUCI. Well, I don't know if I can answer that because I don't know what the relationship between hampering the importing of drugs and use, et cetera—that's in a different area of expertise than mine. I think if you cut down IV drug abuse, you certainly will cut down transmissibility of infection. Whether stopping drugs at the border is the answer is something that is not in my line of expertise. But certainly if you stop IV drug abuse, you are going to stop transmissibility of the virus.

CHAIRMAN PENDLETON. Commissioner Ramirez.

COMMISSIONER RAMIREZ. Let me just try to restate the context for my questions.

We on the Commission obviously have a civil rights rather than a public health function. It is very difficult for us to continue to focus on civil rights concerns when there is so much that needs to be understood about the public health concerns.

But I am violating my own rule in asking you a question which has more to do with perhaps a public health issue. I would like to know whether, in terms of your understanding of the transmissibility, the method of transmission question has been resolved. Or rather, do you anticipate that it is likely that there would be any other methods of transmission that would come out of research? Is there research being done?

DR. FAUCI. No.

COMMISSIONER RAMIREZ. Do you understand my question?

DR. FAUCI. I understand the question, and the question is that the amount of data that has confirmed the three major methods of transmissibility, which I mentioned—blood, blood products, sex, and mother to child—is an overwhelmingly large amount of data. On the other hand, the amount of data collected to indicate that casual contact is not a form of transmissibility is also rather compelling data.

So scientifically we certainly don't anticipate that we are going to all of a sudden come up with a new way the virus is transmitted that we haven't recognized up to now. You are going to see a fluke case, a one in a million somewhere someplace, and that always happens in biology. Nothing is 100 percent. But I don't think there's any chance you're going to see a major revelation about a new way that the virus is transmitted.

COMMISSIONER RAMIREZ. Our focus on civil rights and, indeed, our reason for holding these hearings, in part, have to do with the fact that up to this point the populations which were infected or who surfaced with the problem of AIDS and HIV infection are populations that have themselves over the years been victims of discriminatory practices, and have themselves continued to operate in the society with a predisposition to bias against those populations.

Do you believe—this may be out of your area of expertise—that that reality of having these less desirable, if you would, in historically less desirable populations being the object of this disease—does that in any way affect the way in which public health strategies are implemented or viewed in terms of trying to resolve the public health issue?

DR. FAUCI. In my opinion, absolutely not. I have been working on the AIDS problem since the summer of '81 when it was first recognized, as a researcher and a public health official, and I could say never once in all of the years that we have been working on it, at the level of research, public health, or what have you, has the fact that the major group that is infected in this country, male homosexuals or IV drug abusers, influenced the direction of research or public health opinion or policy or what have you.

COMMISSIONER RAMIREZ. Two other questions.

CHAIRMAN PENDLETON. We have to hurry and get out.

COMMISSIONER RAMIREZ. I'm trying to be fast.

When we talk about IV drug users, is the transmission of the disease significantly more prevalent among low-income minority IV drug users, or is it found among all of the IV drug-user population?

DR. FAUCI. Well, the only handle that one has on the IV drug-abusing population in this country indicates that they are predominantly minorities, blacks and Hispanics in this country. Whether or not you will have an upper middle-class person who is shooting heroin that they are buying at the top of the drawer highest prices, no one even knows about them. The ones you know about are the ones who get arrested, the ones that you see in the streets, the ones that go to the clinic. And the majority of those are of the low socioeconomic group and are minorities. So, in fact, they are suffering unduly from both the drug-abusing problem and HIV among drug abusers.

CHAIRMAN PENDLETON. I would just submit, Commissioner Ramirez, that people who are drug users are not necessarily low-income people.

COMMISSIONER RAMIREZ. Well, that was my point.

CHAIRMAN PENDLETON. I mean those who are considered to be low income are not really low income, because you can't really have a habit if you have low income.

COMMISSIONER RAMIREZ. But it is the use of infected needles that is the issue, and obviously if you can afford to buy clean needles—

DR. FAUCI. If you're sharing a needle in a shooting gallery in the South Bronx, there is a greater chance of your getting infected with HIV than if you are on 73rd Street and Lexington Avenue in an apartment shooting up by yourself with a needle that you got from a physician that's clean, of course.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I'd like to go back to that one. These are May '88 CDC statistics, and of IV drug abusers that have been identified, 6 percent were white, 37 were black, 38 were Hispanic. You might be able to look at that and determine that it may not be the low income that is the factor in this case. It may be the shooting gallery situation that would be involved.

I'd like to come back to what she was saying. The public health issue is very interesting and the scientific aspects of this, of course. We could spend a lot of time on it, but what I'd like to do is come back to the civil rights aspect of this.

From what I keep hearing, if the general public were to know more about the disease, about the progress, about the latency period and the transmissibility of it, do you think that if we continue massive educational programs we could control it to where the discrimination aspect associated with AIDS could be controlled without requiring going into a legislative activity at this point. Do you think we could keep discrimination out of the picture and deal with a public health issue first if we were to continue with education? And then what educational programs would you advocate, from different government agencies, of course?

DR. FAUCI. I don't think there is any question that the more education you have, the greater people will understand the illness and the infection, and the more they understand it I think you will see a lessening of discrimination. I don't know, and I don't think I am qualified to answer whether or not education of the American public is going to eliminate discrimination. From what I know of my experience in life, it probably will not eliminate discrimination. But nonetheless, I think it will help.

One of the things you are going to be seeing soon is the mailing to all of the households in the United States the brochure on AIDS. There are going to be over 100 million mailings that are going to go out, and I think if people read that brochure they will learn a lot about what's going on and how it can and cannot be transmitted, and about what it means to be infected. I think that will help against discrimination.

CHAIRMAN PENDLETON. One question from counsel, and then Commissioner Berry has a brief question. Go ahead.

MR. FUMENTO. For clarification, no question. The percentage breakdown you have is 4 percent for heterosexual transmission.

DR. FAUCI. That's right.

MR. FUMENTO. Does that not include 2 percent heterosexual contact and about 2 percent born in nations where heterosexual transmission is thought to be from?

DR. FAUCI. Yes, it does.

MR. FUMENTO. In other words, Haiti and Central Africa.

DR. FAUCI. Yes. But it's almost certain that those are heterosexual contacts from our epidemiological surveys, both in Central Africa and in Port-au-Prince in Haiti.

MR. FUMENTO. My question, Dr. Fauci, concerns—you and Jeff Levi in a previous panel talked about education as having resulted in a marked decrease in new infections in the homosexual community. About what year do you think that education really kicked in enough to make a difference?

DR. FAUCI. Well, probably around 1986, I would think. If you look at the curve of new infections in San Francisco, you have new infections of seroconversions in '82, '83, '84, and '85, and then right after that it starts to come down, '86, '87, and '88. It's a combination of the fact that when the virus was recognized as being the cause of AIDS, people were convinced that they had a transmissible agent here that you could avoid by behavioral change. There was a lot of wishful thinking in the community, then, that it wasn't an infectious agent, and then when it became very clear that it was, and that word was being spread by the gay groups among themselves, that they began to change the level of high-risk behavior.

MR. FUMENTO. The data I have here is somewhat confusing. What I have here is table 12 from a November 30 report that was sent to the Commissioners in their first mailing—I'll show the cover so they know what I'm talking about.

According to table 12—and I assume this is where you are getting your information from. These are cohort studies done from around the country—there are two from San Francisco—that show blood being tested as early as 1978, all the way up to the present. What you're talking about, it shows every year it goes up a little more and a little more, and then it really goes up, and then it declines rapidly.

The problem, Dr. Fauci, is that the peak in the main San Francisco study, the one with the most individuals and the one that went all the way back to 1978—in 1980, 11 percent seroconverted became HIV positive; in 1981, 14.8 percent became seropositive; in 1982, 20.8 percent of the cohort became seropositive. By 1983 it dropped to 2.1 percent; in 1984 it was 2.1; and in 1985 it was 2.1, and now it has gone down even lower. In other

words, about 4 years before you said education kicked in, it seems like there was a tremendous drop-off.

And the other studies seemed to show this, too. It seems they might have hit a saturation point before that.

Do you see my point? Is that correlative?

DR. FAUCI. You always have to balance the possibility that you're saturating the population; that's why you're not getting new cases. You also have to factor in that, even though the agent was not identified then, there was a great suspicion among us that there was an infectious agent. We were laboring under the presumption that it was an infectious agent for several years before.

So your figures are making it earlier than I had said. I didn't have the numbers in front of me. But it's probably an awareness of the fact that it's very likely that this is an infectious agent, combined with the saturation factor. I don't think there's any question that there's a saturation factor there.

MR. FUMENTO. So perhaps the education aspect has been somewhat overplayed in showing the greatly reduced incidence—

DR. FAUCI. Well, no, let me give you some other data that says it isn't overplayed. That is, if you look at the incidence of rectal gonorrhea in sexually transmitted disease clinics and compare it, '83, '84, and then '85, '86, and '87, you have anywhere from a 75 to an 80 percent decrease in rectal gonorrhea, which is telling you that risk-behavior of rectal intercourse or unprotected rectal intercourse clearly has to be going down. It's a good proxy indicator of sexual activity that is a high-risk activity.

So I think your point about saturation is true with regard to HIV. It has to play some role, the extent to which I am not certain. But it doesn't tell you anything at all about rectal gonorrhea. Rectal gonorrhea decrease is clearly a behavioral change.

MR. FUMENTO. Thank you.

CHAIRMAN PENDLETON. Commissioner Berry.

COMMISSIONER BERRY. Dr. Fauci, you said it was all right to ask you questions about controlling use of drugs as opposed to drugs coming in the country, so I'll ask you about that.

Do you think that clean needle programs help in terms of keeping down the transmission of HIV through the needles that the addicts use, and do you support such programs?

DR. FAUCI. That is something that is actually being looked at very carefully now, about trying to get information from the programs that are already existing, for example in England and in other areas, as to whether or not that has any negative effect on people's drug abuse, namely, do they abuse drugs more, or do they abuse drugs the same or less?

So I think it's something that at least should be considered in investigating the data that is already available. If it looks like there may be

a situation where it could be helpful, I think it would be worthwhile in a pilot project. That is not government policy I'm talking about. I'm not speaking now of the policy of the Public Health Service. But I think we should at least look at the data that is being accumulated from the programs that are already going. It might turn out to be a good thing. I don't know that right now.

COMMISSIONER BERRY. Are you also looking at decriminalization as a means for encouraging people seeking treatment, and therefore indirectly having some influence on transmissibility?

DR. FAUCI. No, I'm not. I have enough things to do without worrying about decriminalization.

COMMISSIONER BERRY. Not you personally, but has the Public Health Service, to your knowledge, or any of the folks—

DR. FAUCI. No, the Public Health Service is not involved in it. They are mostly involved in the public health components and not the legal components.

COMMISSIONER BERRY. Finally, Mr. Chairman, the issue of money for research. You said something like $589 million—

DR. FAUCI. $588 million.

COMMISSIONER BERRY. —$588 million proposed for FY what? '89?

DR. FAUCI. This is for the year '89 for the National Institutes of Health.

COMMISSIONER BERRY. For research?

DR. FAUCI. For research. $1.3 billion for the Public Health Service.

COMMISSIONER BERRY. And you said you thought that was sufficient money, if I understood you correctly.

DR. FAUCI. Yes.

COMMISSIONER BERRY. And since you are one of the few public officials that are researchers who I've ever heard say there was sufficient money, are you saying that because, indeed, the capacity to use the money—

DR. FAUCI. That's it.

COMMISSIONER BERRY. —that there wouldn't be enough research projects that you could fund that would make any contribution to this, that it's just not possible to use it? Or what is the basis?

DR. FAUCI. I think if you ask any researcher—and I also am a researcher myself, in addition to administering science—you will always be able to come up with someone asking for more, that they think they could do a little bit more. You've got to make some sort of a reasonable estimate based on what you think can be done with the money that is available. And based on the kinds of ad hoc groups we have brought together to see what is the pool of investigator out there, what are the projects that are ready to be done—that figure is about the right ball park. I'm sure someone is going to come up during the fiscal year that we're talking about with projects that actually might need more money, and that's when you reconsider it with

either amendments—at the time it won't be an amendment; it will be a supplement.

COMMISSIONER BERRY. And really finally, Mr. Chairman, would you support a proposal to have us fund, as taxpayers, through our budget, research proposals, even if they were from researchers from abroad who are in other countries, and to do that systematically, wherever they are throughout the world, to the extent that they have proposals, as just a matter of policy? What are we doing about that, and would you support extending an effort in that regard?

DR. FAUCI. That's easy, because in fact it is a policy of the National Institutes of Health that we will fund research proposals from foreign investigators in foreign countries if, in fact, it is clear there is a level of expertise in that particular area that it can be done better by them, as opposed to a researcher in the United States.

If you have a proposal from someone from Italy or from Germany or what have you, and you have proposals of the same type with an equally competent person in the United States, without question we will fund the one from the United States. But there are exceptions where you have a particular technique, a particular approach by a foreign investigator, that is worthwhile for the effort. Our policy is that we will fund those research grants.

COMMISSIONER BERRY. And your answer, then, about sufficient money includes your awareness of the potential throughout the world for researchers to be funded to work on this subject?

DR. FAUCI. That's right.

CHAIRMAN PENDLETON. Thank you very much.

These hearings are recessed until about 1:15.

[Recess.]

Afternoon Session, May 16, 1988

CHAIRMAN PENDLETON. I'm going to ask us to reconvene.

Gentlemen, if you would all stand and be sworn.

[James R. Allen, Rand Stoneburner, Stanley K. Monteith, and Alexander Langmuir were sworn.]

CHAIRMAN PENDLETON. Thank you very much. Have a seat, gentlemen.

This afternoon we continue into the discussion of transmissibility.

Let me say from the outset—and maybe one of my colleagues might want to make a comment later—there is some question about why we are studying transmissibility. We are studying transmissibility because we want to understand this disease and how it is transmitted. There are all kinds of discussions about that. In order to make an accurate decision on what policy recommendations to make to an administration and to a Congress, we would certainly have to have the best data available to us.

As I said to one reporter just now, if we didn't study transmissibility as well as the public health implications of this disease, someone would say we are doing sloppy work. On the other hand, we cannot take the term "discrimination" as an assertion and it is so. In order to make rational recommendations, should there be any, we have to be an informed Commission and to have an informed record. And that is exactly what we are trying to do here today, and we will continue in that vein.

I would say to those who feel as though they are not a part of the record, every American, in a sense, can be a part of this record, and if anybody would like to send us information, the record will be left open for 30 days, and we would be glad to accept recommendations or papers from anyone and make those a part of the record.

I would ask that the panelists this afternoon follow what we followed this morning, and that is we'd like to have some of you on this panel, especially who have presented papers, give an 8-minute-or-so summary of what it is that you have given us for the record, and give us a chance to ask questions. That is the best use of our time, and we'd appreciate your cooperation.

We will start with you, Dr. Allen. Dr. James R. Allen is from the Centers for Disease Control, and we would be glad to have a summary of what it is you'd like to say to us.

TESTIMONY OF JAMES R. ALLEN, M.D., ASSISTANT DIRECTOR FOR MEDICAL SCIENCE, AIDS PROGRAM, CENTER FOR INFECTIOUS DISEASES, CENTERS FOR DISEASE CONTROL, ATLANTA, GEORGIA

DR. ALLEN. Mr. Chairman and distinguished members of the Commission, thank you for the opportunity to present before you. I am sorry that I was not here this morning to hear the comments by Dr. Fauci and others, and I hope this is not repetitive.

Human immunodeficiency virus, which I will call HIV, is the virus that has been isolated and characterized as the cause of AIDS. The reservoir of HIV is humans. We estimate that in the United States there are approximately 1 to 1.5 million persons infected with HIV today. There are many millions more in other areas of the world.

I would like, therefore, to discuss the means of transmission of HIV from one person to another because that is how the virus is transmitted or spread.

HIV has been isolated from blood, from other internal body fluids such as spinal fluid and pleural fluid, from human milk, semen, cervical secretions, saliva, and urine.

Epidemiologically, only blood, semen, cervical secretions, and rarely human milk have been implicated as the means of transmission of the virus

from one person to another. HIV has been documented to be transmitted from an infected person to a person who is not infected by three routes:

First, sexual intercourse, whether from a heterosexual person to another heterosexual person, or from a male homosexual to another male homosexual.

Secondly, by parenteral inoculation of blood, most often among drug users who share syringes and needles for injection. In the past, in the United States, transfusion of blood or blood components, such as platelets and plasma, or of selected blood products, such as the clotting factor concentrates administered to hemophiliacs, also cause transmission of the virus. Today, because of technical improvements and screening in the blood supply, these sources of infection are not of primary significance.

Third, transmission can occur by the congenital or perinatal route from an infected woman to her fetus or newborn.

I would like to focus on potential areas of transmission, however, that have transfixed the public and the sensational media, since these areas often prove most disruptive in efforts to establish a rational approach to working with persons with AIDS and to control of the problem.

The risk of HIV infection to health care workers, including physicians and nurses who are taking care of persons who have AIDS or are infected with HIV, is extremely low. The number of AIDS cases reported in health care workers is proportional to the adults employed in the health care settings, and 95 percent of the persons give a history of specific risk of infection unrelated to their employment.

Six prospective studies have evaluated more than 2,400 health care workers who have been exposed one or more times to blood or other potentially infectious body fluids of persons with AIDS or HIV infection. Most of these workers were exposed to blood from an infected person, and most had sustained a needle-stick injury. Only four workers from these studies are known to have seroconverted to HIV, all following a needle-stick injury. And one worker was found to be seropositive 10 months after exposure. In this individual, sexual transmission could not be excluded.

No health care worker in these prospective studies has seroconverted after mucous membrane exposure such as to the mouth or to the eyes, or cutaneous exposure, or after exposure to any secretions or excretions from an infected patient, only percutaneous or needle-stick exposure to blood.

A study in dentists has found a similarly low rate of HIV infection. Overall, the risk of HIV infection after direct exposure by needle-stick to blood or bloody fluids from an infected person is well under 1 percent. The risk from other types of exposure, including of nonintact skin or mucous membranes, appear much lower.

Much of the concern about the risk of infection in the health care setting has arisen from case reports of infection after exposure. In addition to the cases reported in the prospective studies, six health care workers and one

research laboratory worker who was cut while working with concentrated virus—these individuals from the United States and four from other countries have been reported to have seroconverted after exposure.

Five other health care and one research laboratory worker who have not reported other risks for infection have been found to be infected, although seroconversion, proximate to a specific injury where exposure was not documented.

Three of these health care workers apparently became infected after contact with blood from an infected patient onto nonintact skin, such as dermatitis or abrasions. Two of the health care workers who became infected were providing nursing or home health care without following recommended precautions. And I think it is these cases that have created a lot of concern about the potential for so-called casual transmission. One was a mother who was assisting with the care of her child, who had unknowingly been infected with HIV through blood transfusion. The mother had extensive contact with the child's blood, secretions, and excretions during a lengthy hospitalization of the child, although she did not wear gloves and often did not wash her hands immediately after exposure.

Almost 500 families or household members of persons with AIDS or HIV infection have been followed and evaluated. HIV was transmitted from an infected person only by sexual contact or sharing of equipment for injection of drugs. HIV was not transmitted by close household or family contact in these studies, even by sharing of personal items such as razors, toothbrushes, towels, clothes, eating utensils, and drinking glasses, or of beds and bathroom and kitchen facilities. Family members helped the infected person bathe, to get dressed, and to eat, and interacted with hugs, kissing on the cheek, and kissing on the lips.

One of the studies included the family members of 35 children, mostly infants, who had been infected through transfusion. And another included 15 infants or children less than 4 years of age who had both clinical and serologic evidence of HIV infection.

In the former study, 31 siblings lived with the infected children, and in the latter study 90 children lived in the families with infected adults and children. None of these children became infected, even though they shared toys and other items, slept in the same beds on occasion, and participated normally in family activities and interactions, including hugging and kissing.

One case report, however, does indicate the transmission within a household setting might occur, although the means of transmission from a young boy infected through transfusion at about 18 months of age to his brother, who was about 4 years older, is not known.

Other reports definitely indicate that biting has not transmitted HIV from an infected biter to the person bitten. In one report 30 health care

workers were bitten and/or scratched by a neurologically impaired adult, the injuries often resulting in puncture wounds to the skin. All workers were seronegative at least 6 months after exposure.

No studies in the literature or cases reported suggest transmission of HIV by urine, feces, saliva, tears, or sweat. Similarly, no studies or reports have suggested the transmission of HIV in school or day care settings, or during contact sports such as football, boxing, or wrestling.

Finally, let's briefly examine the potential for transmission of HIV by insect vectors such as mosquitoes. Laboratory examination of several species of potential insect vectors to date do not suggest a transmission from this source is likely. Most important are the epidemiologic studies and observations that do not suggest insect-borne transmission.

In 1986 investigators from the Florida State Department of Health and CDC conducted a study in Belle Glade, Florida, to evaluate the frequency of HIV infection in that town. Of 523 persons between the ages of 18 and 59, 26 or 5 percent were found infected. This population was sexually active, and some persons injected drugs. Of 121 children between 2 and 10 years of age, and 94 adults 60 or more years of age, none were infected. If mosquitoes or other insects were a prominent means of HIV transmission in this population, it would be highly unlikely for these younger and older populations to be totally spared.

In summary, we have had more than 61,000 cases of AIDS reported in the United States. Many more people are sick and infected with the virus. The means of transmission of the virus has been well-defined: sexual transmission, parenteral exposure to infectious blood or bloody fluids, and congenital or perinatal transmission from an infected woman to her fetus or newborn.

Thank you.

CHAIRMAN PENDLETON. Thank you, sir.

Dr. Stoneburner is the director of AIDS Research for the New York City Department of Health.

Thank you, sir.

TESTIMONY OF RAND STONEBURNER, M.D., DIRECTOR OF AIDS RESEARCH, NEW YORK CITY DEPARTMENT OF HEALTH

DR. STONEBURNER. Thank you. I'd like to thank the Commission also for inviting me to present the data on the AIDS epidemic in New York City, present and future trends. I will do my best to stay to the 8-minute limit but will have to edit as I go.

Certainly monitoring the AIDS epidemic is critical to prevention strategies in New York City and in other parts of the country, as well as for planning for delivery of health care services. The tools used to assess the AIDS epidemic includes AIDS case surveillance, seroprevalence

studies of HIV–1 infection among selected populations, such as persons attending sexually transmitted disease clinics, as well as reviewing mortality trends to determine the spectrum of HIV disease in certain populations, as adequately identified by the CDC case definition.

The overall epidemic of AIDS in New York City as of mid-April is as follows:

Over 14,000 cases, 25 percent of the national total.

Approximately 7,500 deaths.

An average number of 300 cases diagnosed per month, 88 percent male, 12 percent female; 43 percent are among whites, 32 percent among blacks, and a quarter among Hispanics.

CHAIRMAN PENDLETON. What are those numbers again?

DR. STONEBURNER. Forty-three percent among whites, 32 percent among blacks, and 25 percent among Hispanics.

New York City has 42 percent of the Nation's parenteral drug users, and 34 percent of cases who are black and Hispanic.

New York City's AIDS epidemic is complex because of the heterogeneity of the epidemic and the populations affected, and it is best to consider two major epidemics: one among gay and bisexual men, the other among heterosexual parenteral drug users, with a closely related epidemic of heterosexuals in children. I will briefly describe them.

The epidemic among gay and bisexual men is shown in the first figure that I distributed to you. Approximately 7,500 reported cases, 61 percent of our total. Sixty-five percent are among whites; 35 percent are among blacks and Hispanics.

This epidemic has decreased as a proportion of the total, as a percentage of cases among parenteral drug users has increased. Studies of cohorts of this population in New York City have shown dramatic decreases in new HIV infection rates, and data from trends of gay-related sexually transmitted diseases in New York City and nationally suggest that risk-reduction efforts have been successful. However, recent data from our research unit has shown a disturbing disproportionate change of high-risk behavior among males by race and age. It appears that older white males who are homosexual have changed their behavior much more than younger minority males.

The second epidemic is among parenteral drug users, mostly heterosexuals. Based on our surveillance data, this accounts for 5,200 cases or 37 percent of the total AIDS cases. Eighty percent are black and Hispanic. And among women this accounts for 60 percent of all cases. However, the AIDS epidemic among parenteral drug users in New York City is greatly underestimated by the CDC case definition.

The last figure that I have handed out to you shows trend in narcotic-related deaths from 1978 to 1986. While AIDS deaths increased from nine in 1982 to 905 in '86, other causes also increased in epidemic proportions.

Investigation of these deaths suggest that many are due to non-AIDS infectious causes, and over 40 percent have evidence of HIV-related disease at the hospitalization of their death.

We believe these deaths are HIV-related to disease that are not presently captured by our AIDS surveillance, and we believe these deaths underestimate the AIDS epidemic in New York City by as much as 50 percent overall, and 130 percent among intravenous drug users. Since the majority of these cases, 80 percent, are among minorities, blacks and Hispanics, these deaths greatly underestimate the impact of AIDS among minorities.

The epidemic of AIDS in children in heterosexuals are closely linked to the epidemic among parenteral drug users. New York City has 293 reported pediatric AIDS cases, 31 percent of the national total. Among the maternally transmitted cases, 92 percent are among minorities, and the risk factors of the mother in 72 percent of the cases are intravenous drug use, and in 3 percent sexual contact with either an intravenous drug user or a bisexual man.

Lastly, the epidemic among heterosexuals who are not parenteral drug users, from surveillance 368 cases have been reported among persons whose only risk reported has been sexual contact with a person in an AIDS risk group. This is 360 females and 8 males. This represents 2.6 percent of all of our cases. However, it represents 22 percent of all female AIDS cases.

The risk of the sexual contacts have been 85 percent intravenous drug users and 11 percent bisexual men. Most cases have reported long-term sexual relationships with risk group members.

Cases with no identified AIDS risk, the group that could compose persons who possibly acquired infection heterosexually or through other means but weren't aware of the AIDS risk of their partner, have remained at less than 1 percent throughout the course of the epidemic among males, and 2 percent among females.

Some hypothesized that surveillance data may underestimate heterosexually transmitted AIDS because of the long incubation period. Thus, these cases may represent transmission in the past, and current transmission patterns may be different. This may be true.

In order to assess risk for HIV-1 infection, not AIDS, which may represent more current infection, we have conducted studies of risk factors for HIV acquisition at New York City sexually transmitted disease clinics. Participation in these studies was voluntary. A detailed questionnaire about risk factors was administered to each participant by a trained interviewer before and after antibody testing. Preliminary results reported in October are shown in the attached Tables 1 and 2.

Among 440 males, 63 or 14 percent were HIV antibody positive; 89 percent of the positive males were gay and bisexual or intravenous drug

users. Five of the 63 were men who had had sex contact with female intravenous drug users. So it was sexually transmitted.

Two of 248 persons who did not identify any AIDS risk were positive, and that is approximately 1 percent. Among the 196 females, 19 or 13 percent were positive, and all were either parenteral drug users or sex partners of risk group members.

Analysis has now been completed on over 1,100 participants in this study, and the distribution by risk is similar. We conclude that in this population there is little evidence to suggest spread of HIV beyond gay or bisexual men and parenteral drug users and their sexual partners of these groups, both male or female.

In conclusion, the future of the AIDS epidemic is difficult to predict. Seroprevalence studies now under way in different subpopulations will give us insight into further spread and the numbers of infected.

In New York City, the epidemic among gay or bisexual men will probably plateau first, though we don't know when that will be, though the disproportionate change in sexual behavior among minority men may prolong the spread among certain minority populations.

The greatly underestimated epidemic of AIDS among parenteral drug users continues. Though stable HIV seroprevalence, between 50 to 60 percent suggests a saturation of this population. There are new parenteral drug users who continue to enter this pool and thus sustain the epidemic.

The epidemic of heterosexually transmitted HIV to sex partners—since the mode of transmission is primarily linked to sexual intercourse with parenteral drug users, I see this epidemic paralleling that of IV drug use. Although there is scant evidence of large-scale heterosexual transmission beyond this group, the sex partners of risk group members, the potential may exist, coupled with the concurrent epidemic of syphilis or other genital ulcer disease, sexually transmitted diseases, for further significant spread into certain subpopulations.

In summary, the future spread of AIDS in New York City, I believe, will continue to disproportionately impact on minorities. The epidemic of parenteral drug users will surpass that of gay men in the future. The epidemic among heterosexuals, though largely confined to sex partners of risk group members at present, has a potential for further spread, primarily in certain subpopulations, and suggest that targeted prevention efforts to drug users and their sex partners may prevent this further spread.

CHAIRMAN PENDLETON. Thank you.

Dr. Langmuir, please.

TESTIMONY OF ALEXANDER LANGMUIR, M.D., M.P.H, DEPARTMENT OF EPIDEMIOLOGY, JOHNS HOPKINS SCHOOL OF HYGIENE, BALTIMORE, MARYLAND

DR. LANGMUIR. I appreciate very much the invitation as a retired civil servant to participate again in this very, very major problem. I have no direct access to any special information.

[Laughter and applause and demonstration from audience.]

VOICE. Pick up a newspaper.

VOICE. Why are you there if you don't have any information?

VOICE. Spin the wheel.

VOICE. How many more have to die?

[Continuous repetition of: "How many more have to die?"]

VOICE. What if your family were dying?

VOICE. While Reagan's panel keeps debating, 8 years later we're still waiting.

[Continuous repetition of: "While Reagan's panel keeps debating, 8 years later we're still waiting."]

CHAIRMAN PENDLETON. The protesters are here. This is an American way to do business. We would ask you to be patient and be respectful, and allow us—

VOICES. Eight years of patience.

[Simultaneous remarks and demonstration from audience.]

CHAIRMAN PENDLETON. We're going to ask one more time for you to please be quiet. If not, we'll have to ask you to leave.

Dr. Langmuir, we'll try again.

DR. LANGMUIR. I have given a handout for you, and there are a number available, I think, for the press, which is a considered analysis that I have made of the AIDS information over the last year. Since there are some mathematical projections, which take a little time to explain, I will have to just say this is my projection. It is different from the others, but I don't expect you to have a critical judgment of it.

Let us go straight to the last two figures, figure 1 and figure 2, which merely show the incidence trends. These are broadly known, although not very often portrayed, and these are carefully adjusted for the lag in reporting, particularly for the cases in 1986 and '87, so I believe they present rather clearly the trends of AIDS in the United States.

They are graphed on what is called ratio paper. We are all familiar with this. This is the way the Dow Jones is compared to the Standard and Poor.

[Laughter and demonstration from audience.]

DR. LANGMUIR. You will note that the carrier for the homosexuals is the highest and up into the range of 5,000 cases in a 6-month period.

VOICE. Homosexual men. Get it straight, stupid. There are no lesbian transmissions data.

DR. LANGMUIR. There is a constant curve toward a bending over.

[Laughter and demonstration from audience.]

DR. LANGMUIR. If you look at the intravenous drug abusers, the curve is well below the homosexuals.

VOICE. Homosexual men. Get it straight. Be factual.

DR. LANGMUIR. Those that are both homosexual and IV drug and cannot be distinguished are also following the same curve. And really those three curves should be combined together as indistinguishable, and this amounts to 90 percent of the total AIDS cases in the United States.

Then we have dots of the heterosexual cases, which has been brought out very clearly that half of these are foreign-borns and therefore really a distinct group, and half are heterosexual contacts largely of IV drug users. If you corrected that curve, the heterosexual contacts of the IV drug users would rise in exact parallel with the other curves.

The last two curves, serotransfusion and hemophiliac cases, making not more than 5 percent of the total, and they generally follow the same curve.

The point is that this curve is bending over, and as an epidemiologist who has spent his life in this kind of data analysis—I was an epidemiologist at the CDC for 21 years. My interpretation is that this curve is progressing steadily to a peak, and then it will progressively go down. This is a different point of view from that presently at CDC, but I believe there is sound basis for it.

I would like also to go to figure 2, which shows you the total AIDS cases by geographic region. These are the larger cities in the West. That would be Los Angeles, San Francisco, Seattle. In the Northeast would be the New England cities and New York, Newark. The South represents, of course, Miami, Atlanta, New Orleans. The Mid-Atlantic represents Philadelphia, Baltimore. And the Central States, of course, are clear. And the bottom line are the areas in the country, about half the total population, which has no city of over a million.

Note that these curves also curve in exactly the same way. And I believe, my projections, that we are about at the crest of AIDS cases. They will peak probably this year or next. There will be some variation by region, not much, some variation by classification and transmission categories, but not much. And my projections are that the [mean] incubation period of this disease, contrary to what has been normally said, is at least 8 years and may go on as far as 30 years.

VOICE. When will you do something?

DR. LANGMUIR. What we are seeing here this year are largely individuals infected back in 1980, '81, '82, and now reaching the incubation period we are going to see more cases. But I believe the evidence was brought out this morning quite clearly that the spread among homosexuals is greatly reduced to a point of really being a very minimum number. That's more than 65 or 70 percent of the total. We don't know the level of

the IV drug abuse, and this is a serious worry, although the evidence that it is spreading wildly is not there.

The blood transfusion and hemophiliac cases—new cases stopped back in 1985, and they will continue now because they started somewhat later. They will peak maybe in 1989 or 1990, but then it will come down according to the incubation period curve. I believe the problem has been grossly exaggerated. Furthermore, my study of the published information—

VOICE. Who are you?

DR. LANGMUIR. My analysis of the published information, now quite extensive, is that this disease spreads by inoculation of blood or the inoculation of semen very dominantly by receptive anal intercourse, and almost no other way. That is a conclusion, I think very abundant. A number of studies have shown this very persuasively. It is not talked about much, but facing the facts as epidemiologists should, this is my conclusion.

[Inaudible remarks from audience.]

DR. LANGMUIR. In conclusion I'd like to point out that if my projections are correct—and I believe they are—inside of 2 to 3 years, the number of deaths of the present cases will exceed the number of new cases reported. This will vary enormously in different areas. New York City and San Francisco will get the brunt of it. Other big cities the main brunt.

VOICE. You're wasting time.

DR. LANGMUIR. And they are measured in figure 2 rather clearly. These curves are all going in parallel. Therefore, it is going to be possible to project rather precisely the number of AIDS cases that will occur.

[Inaudible remarks from audience.]

DR. LANGMUIR. This is a different point of view than usual. Instead of the scare tactics, this means that in 2 years it will be possible to sit down, and every community can estimate what its projected problem is going to be.

VOICE. Three percent of the babies in the Bronx are born with HIV infections. Did they get that from anal intercourse? Where are your facts, sir?

[Inaudible remarks from audience.]

VOICE. In conclusion, you've done nothing.

VOICE. Believe it or not, there are experts. Why don't you get one?

DR. LANGMUIR. In each of these areas in figure 2, it will be possible to project what the load will be. It becomes a serious but a manageable problem. It becomes something where the resources necessary to meet the need can be identified and planned for. This is not an easy problem because each of these areas—after all, many different jurisdictions, even several States are involved. This is a Federal problem. This is one that can be carefully projected. It should be handled in a very simple way. Medicare takes care of the kidney dialysis problem. It helps take care of the

hemophiliac problem. This should be taken over on a Federal basis. Again, the Medicare law should provide for AIDS care, and it is going to be well within the range of manageability.

CHAIRMAN PENDLETON. Dr. Langmuir, thank you very much.

We now move to the last panel member, Dr. Monteith. Go right ahead, sir.

TESTIMONY OF STANLEY K. MONTEITH, M.D., SANTA CRUZ, CALIFORNIA

DR. MONTEITH. I would suggest all of you get a chance to read this book. I see that Mike has a copy of it. It is written by a homosexual activist from San Francisco, and it's called, "And the Band Played On."

VOICES. We've read it.

DR. MONTEITH. For as the Titanic was going down, the band played on.

CHAIRMAN PENDLETON. Just a minute, sir. What we are trying to do here is to collect—

[Inaudible remarks from audience.]

VOICE. Justice.

VOICE. Polarization.

CHAIRMAN PENDLETON. At some point our patience begins to wear.

VOICE. It's been collected a thousand times. Why are you doing—

[Simultaneous remarks from audience.]

VOICE. We know where the clowns are.

CHAIRMAN PENDLETON. I wish they'd all leave with you. We'd be much happier doing our work here today.

[Simultaneous remarks from audience.]

CHAIRMAN PENDLETON. We're going to have a 10-minute recess—just a recess.

[Recess.]

CHAIRMAN PENDLETON. We're going to try to get back to business. We will have Dr. Monteith's testimony. We would hope that would be without rancor. I have no choice but to ask that the room be cleared, that you leave peaceably if you do not wish to give the witness the respect that all witnesses deserve and let him give his testimony.

This is not an action that one takes lightly. I happen to believe that people should be able to protest in an appropriate manner. I think the fact that you're here is an indication of that belief, and we want to continue with the testimony, and we hope that you will bear with us.

VOICE. Are we having any testimony from Leviticus?

VOICE. Do you want us put to death, Clarence? Why don't you answer that question? It was in your opening paper in winter. Do you still want us put to death? It's in Leviticus. Answer the question, sir.

CHAIRMAN PENDLETON. Dr. Monteith.

DR. MONTEITH. In the forward to Randy Schilts' book he makes this statement: "The bitter truth was that AIDS did not have to happen. It was allowed to happen by an array of public institutions, all of which failed to carry out their assigned task to protect the public health."

VOICE. And continues to do so—continues to do so.

DR. MONTEITH. "The legacy of that failure will haunt Western civilization for decades to come. There was no reason at this time in this nation for this epidemic."

And ladies and gentlemen, that is entirely true. There was no reason at this time in this nation that this epidemic ever should have reached the proportions that it has, or that two-thirds of the homosexual population in San Francisco, at least according to the cohort study, carry a virus that will ultimately kill them.

VOICE. It doesn't have to kill us.

DR. MONTEITH. Now, to give you some idea of what the situation is in Africa—

VOICE. [Inaudible]. It's supposed to be disseminated among the population.

DR. MONTEITH. To give you some idea of the magnitude of the problem that we face today, if you go to Uganda or northern Tanzania in any of the major cities, and you go to the maternity wards, you will find that 35 percent of the women there carry the virus.

Now, what does it mean when you carry the virus? If you carry the virus, in all probability you are going to die. We don't have any long-term series of what happens, but every appearance is that if you carry the virus, whether it's 5 years or 10 years or 15 years down the line, 95 or 100 percent of the people are going to die.

As a result of this, most of these women's husbands are going to die, half their children are going to be born with the virus and they are going to die. And there is going to be a major depopulation of Central Africa.

Now, the tragedy of this situation is that in Africa they don't have the money. They don't have the money, in many instances, to check blood transfusions and do the simple tests that we do here routinely. They don't have the money for public health followup of any of the cases. In fact, in most of these instances they do not even bother to tell the women that they carry the virus so they can warn their cohorts and their husbands. They don't warn the mothers not to breast feed because there is no other means of nutrition other than breast milk.

The tragedy, as these gentlemen behind me have pointed out, is that some of these same very things are happening in America today.

[Applause.]

Because in America we have vast amounts of money we spend to protect the public health. We have statistics on measles, we have statistics on mumps, we have statistics on all sorts of communicable diseases.

But, ladies and gentlemen, let me point out to you that there is a very definite effort to confuse people about the magnitude of the epidemic. There is no AIDS epidemic. AIDS is the terminal stage of an HIV disease.

VOICE. Thirty-five thousand people are dead.

VOICE. How many more have to die?

VOICE. This is a charade.

[Simultaneous remarks and demonstration.]

[Continuous repetition from audience of "Shame, shame, shame."]

DR. MONTEITH. As I was saying, before I was so rudely interrupted, the disease is HIV disease. The terminal stage of that disease is referred to as AIDS. AIDS occurs somewhere between 5 and 10 or a longer period of time after an individual is infected with the virus. AIDS is characterized by the breakdown of the immunological system, by your susceptibility to cancer, by progressive neurological and mental deficiencies, paranoia, forgetfulness, your inability to concentrate. In fact, 90 percent of the patients with terminal AIDS are found to have changes within the brain. AIDS is a horrible situation.

But the epidemic is HIV. And that, tragically, is not in any way being monitored in America today. In fact, I could point out to you that in only 13 States is HIV considered an infectious disease, and only in a few of those States are any standard public health techniques being used to either identify in confidence who carries the virus or do the contact tracing that will be necessary to begin to bring this epidemic under control. We are doing as little in America to bring this epidemic under control as they are doing in Africa, and it didn't have to happen. As a result of this, millions of Americans are going to die unnecessarily.

Now, I'd like to address some of the common misconceptions that are put out.

First of all, we have statistics on the incidence of AIDS. The CDC told us 2 years ago we had a million to a million-and-a-half people with HIV infected. Two years later we have a million to a million-and-a-half people with HIV. Was the CDC wrong 2 years ago? Is the CDC wrong today? Is it perhaps that they have no idea what the incidence of the disease is?

We know that during the same period of time, the incidence in the United States Army went from about 1 in 1,200, despite an extensive educational effort, to 1 in 700—almost doubled within those people within the Army itself.

I would suggest that perhaps the CDC is doing exactly what Randy Schilts suggested in this book—and if you have not read the book you must. The basic theme at the CDC was, "Don't scare the horses. Don't scare the public. Don't let them know what's really going on."

You see, we over and over again hear that, well, 20 to 25 percent of people get AIDS if you have the virus, and another 25 percent get ARC, and another 20 percent will get some other symptoms. They do not tell

you this is a 100 percent fatal disease or a 95 percent fatal disease, because they don't want people to panic.

Now, this disease has to be approached from three points of view, from the point of view of research, which is vitally important, although the outlook for coming up with a vaccine or treatment is very, very slim. And the problem is that you can vaccinate people and get a positive antibody test, but that doesn't protect you against the virus because the virus becomes part of the gene itself, different than other viruses. This gene goes into your chromosomes and becomes part of your genetic code. Retroviruses are entirely different from regular viruses, and just because you have antibodies doesn't mean you have any protection at all to the disease. In fact, the disease eventually overwhelms the entire immunological system.

The problem that we face today is that doctors across this Nation have been effectively blocked from doing what doctors know needed to be done to bring this epidemic under control.

Yes, Mr. Pendleton.

CHAIRMAN PENDLETON. You have another minute or so.

DR. MONTEITH. All I've got is another minute or so?

All right, fine. I can tell you, as a member of organized medicine, I have been in a situation where I have had an opportunity to be a delegate to the California Medical Association. I led my delegation to the House of Delegates, which is the ruling body of organized medicine, for years. The doctors in the State of California want to treat this as a communicable disease, but a few people within the hierarchy of organized medicine have effectively blocked this. In 1986, and again in 1987, doctors voted that we wanted things to be done, to begin treating this using standard public health techniques that have been used so effectively in the past. And organized medicine, a small clique of people, have effectively prevented this. Doctors have been threatened. I have personally witnessed this. I have been told by other doctors of the threats that have been made against them.

The question was asked this morning: Do you know of any pressure brought to bear? Yes, I can tell you—and if I had the time I would list case after case of doctors being silenced, being prevented from passing out information, being threatened, even from the highest echelons of our government.

I would point out in the defense of the current administration, however, that I had the unique opportunity of going to the White House and interviewing one of President Reagan's highest public policy advisors. His remark to me was, "I don't understand the CDC and I don't understand why the CDC is doing what it's doing." They are going into the heartland of America where they know the incidence of this disease is the lowest, and they are doing their testing. They are not releasing the testing from New York and San Francisco where we know it is indeed much higher.

To give you some idea of the magnitude of this disease, let me point out I had the opportunity of talking with Jay Liebenfarb, who is the administrative assistant to Assemblyman Liza who is the chairman of the City Health Commission in New York City. You heard the statistics that one in 60 children born in New York City carry the virus, but if you go to Bellevue Hospital it's one in 25.

And according to Jay Liebenfarb, the administrative assistant to the chairman of the City Health Commission, in some blocks, five or six blocks square, one person in 10 carries the virus. In some areas, four or five blocks square, one person in four carries the virus and they're going to die. And yet in the State of New York, HIV infection is not considered an infectious disease, it is not monitored, it is not treated, and nothing is being done to stop the chain of death, the march of death, the chain of transmission.

This is unconscionable. We have better statistics in many respects coming out of Africa than we have coming out of America.

VOICE. You are presenting wrongful information. It's a disgrace and a shame that this poor Commission has to listen to it and we have to suffer it. Get your facts straight.

VOICE. People are being treated in New York.

CHAIRMAN PENDLETON. Go ahead, sir.

DR. MONTEITH. What we need to do is to begin treating HIV infection as a communicable disease. It should be required that it be declared a communicable disease, that it be reported in confidence to public health officers, that we begin doing the standard public health followup that has been used so effectively in past epidemics.

Now, you say the public health organizations come out against it, and I will tell you that one reason is because many public health officers are afraid to speak up. In fact, I was going into the meeting in Reno recently where I would be debating this with such prominent people as Merv Silverman, who heads the AIDS Foundation, one of the AIDS foundations, the man who failed to close the bathhouses in San Francisco, and as a result of this almost 20 to 25 percent of the population there incurred the disease while he was playing politics because he didn't want to stand up against the sort of demonstration you have just seen.

A public health officer came to me and said, "Stan, I agree with everything you've said, but I'm not going to get up and say it because our organization has been threatened, and we have been told if we go to Sacramento and if we go to Washington, D.C., and ask that this be declared an infectious disease and start using standard public health techniques, these people will go and demonstrate and cut off all of our funds for all public health. We will lose the ability to monitor measles and mumps; we'll lose everything. I'm not going to stand up and say that you're right."

And I had to get up and debate the public health officers, those who are intent upon not treating this as a communicable disease, and other people sat in the audience knowing full well we were right but wouldn't stand up.

One of the most courageous people I know was an orthopedic surgeon named Lorraine Day. She's chief of orthopedics at the University of California.

CHAIRMAN PENDLETON. Please wind up, sir.

DR. MONTEITH. All right, sir. Maybe during the questions and answers we can tell about the threats that have been made against her.

COMMISSIONER BERRY. Mr. Chairman, I object to Dr. Monteith taking up more time than these people who are experts from the CDC and the New York Department of Health and continuing to speak and speak and speak with innuendos about this group and that group without identifying them.

[Applause.]

I don't see why he deserves more time than the man from the CDC or from the New York City Department of Health. I mean, who is this guy?

CHAIRMAN PENDLETON. He had a problem with the disruptions, so just wind up, Doctor. I think you're about to get through.

DR. MONTEITH. I think I'm just about through. Thank you so much, sir.

CHAIRMAN PENDLETON. Thank you.

Counsel.

MR. FUMENTO. Dr. Monteith, even before Ms. Berry's statement I was going to ask you to talk about your credentials, where you have spoken on this subject.

DR. MONTEITH. Oh, I have testified before Congress. I have addressed members of the legislature in Sacramento. I happened to lead my delegation from my county to the California Medical Association. My expertise is in the politics of AIDS and the fact that there has been a conscious, organized, orchestrated effort all across America to keep HIV from being considered an infectious disease. I have had the opportunity of going to the White House. I'm a member on the board of one of the AIDS organizations, and you take that newsletter. I happen to be a member of Americans for a Sound AIDS Policy, the California Physicians for a Logical AIDS Response. I have spoken many times on the same podium with Mr. Gann, who as you know is an AIDS victim because of a transfusion, and is trying very hard to leave a legacy behind that will save lives of countless people by beginning to address HIV infection as a public health rather than a political issue.

MR. FUMENTO. Could you address for us—

COMMISSIONER GUESS. Point of order, Mr. Chairman. And I can conclude that what counsel has done is certified Dr. Monteith, as a result of that question, as an expert on AIDS as defined in our project proposal?

CHAIRMAN PENDLETON. We have to ask counsel that.

MR. FUMENTO. I'm getting to that with the next question.

COMMISSIONER GUESS. Are you concluding, as a result of that question, you are certifying to this Commission, as you have done in inviting Dr. Monteith, that he is an expert on the question of AIDS as defined in our project proposal?

MR. FUMENTO. Mr. Commissioner, we needed somebody who would testify as to the possibility of casual transmission.

COMMISSIONER GUESS. So Dr. Monteith is an expert on the possibility of casual transmission as it relates to the transmissibility of AIDS?

MR. FUMENTO. From what I have seen, he has spoken on this as much as anybody in the United States.

VOICE. Where is his research if he's an expert? We didn't ask for his opinion. Where is the research?

MR. FUMENTO. I don't know of anybody in the United States who has spoken on this more than he has.

COMMISSIONER GUESS. You're certifying to this Commission that no one in the United States is better qualified to speak on the question of casual transmission of AIDS than Dr. Monteith before this Commission?

MR. FUMENTO. To take his position, that is correct.

COMMISSIONER GUESS. Is Dr. Monteith also a congressional candidate?

MR. FUMENTO. Are you still a congressional candidate?

DR. MONTEITH. Yes, sir.

COMMISSIONER GUESS. Is he running as a Democrat or a Republican?

VOICE. It doesn't make any difference.

DR. MONTEITH. Does that make a difference?

COMMISSIONER GUESS. I would like to know.

DR. MONTEITH. I'm running as a Republican, but I'm basically and philosophically a Libertarian.

But since you brought this up, the reason I am willing to give up my medical practice, which I love, and enter into politics, which I really don't want to go into, is because I feel that millions of Americans are going to die unnecessarily, and as a moral individual I have no other alternative but to try to get someplace where perhaps we can have some impact and get this message out. I would far rather be home being a surgeon than give up my very lucrative practice for a job I don't want. But I feel that, faced with an epidemic of this proportion, I have no other alternative. And I know other doctors who feel this same way. We have given our lives to healing. But unfortunately, politics has placed a barrier in our way so that we can't do that.

CHAIRMAN PENDLETON. Can we continue? Mr. Guess, were you through?

COMMISSIONER GUESS. Frankly, Mr. Chairman, I would like to hear Dr. Monteith's testimony pertaining to casual transmission. I haven't heard it yet.

MR. FUMENTO. That was the next question.

COMMISSIONER GUESS. What has he been talking about?

[Laughter and applause.]

COMMISSIONER BERRY. Mr. Chairman, could you have Dr. Monteith's summary of his credentials, which is only one page, read into the record at this point so we can judge for ourselves whether he indeed is an expert on this subject.

CHAIRMAN PENDLETON. It will be in the record.

COMMISSIONER BERRY. Because as I look at it, I don't see any research or practice. He's an orthopedic surgeon, it says here, and I just wondered. I think you ought to note that, at least, at this point.

CHAIRMAN PENDLETON. Counsel's question is getting to the point you're raising, I think.

MR. FUMENTO. Dr. Monteith, you have stated before, and I quote: "Today individual Americans have little chance of getting the disease by casual contact, although casual contact certainly has been demonstrated. But what will happen when 50 or 100 million Americans carry the virus?"

Do you really believe that up to 50 or 100 million Americans can carry the virus? And can you provide evidence of casual transmission?

DR. MONTEITH. Well, sir, there are many, many instances of casual transmission. First of all, we have to describe what casual transmission is. This is intentionally confused. Is casual transmission sitting next to somebody who carries the virus? No. But, for instance, as a physician, can I get this from doing surgery on a patient, from sticking myself with a needle, from getting their blood on my skin? Yes, I can.

It was said that you couldn't get this by mucous membrane transmission, but there was an instance—and it's reported in this book and actually comes out of the CDC material, but you can get the reference to it here—where a woman who was drawing blood happened to splash blood onto her eye and into her mouth, and that was apparently the source of her getting the disease.

VOICE. It's not casual; it's occupational, sir.

DR. MONTEITH. It is occupational; that's true. And so is defining the terms we speak of as far as casual transmission is concerned.

There are instances we could mention of the mother taking care of the child who came down with it; the little boy who lived with his brother who had gotten the virus.

There are other instances which the CDC doesn't list. There's a case in Brodsheadville, Pennsylvania, which is under litigation at the present time, where a mother supposedly got AIDS from a transfusion. The father got it from the mother. The little boy got it living in the family.

Now, because this case is in litigation at the present time, the judge has sealed the record so nobody can find out how that little boy got the case, and the CDC doesn't mention it. But this is another of the instances that

we find where anybody who suggests the possibility of casual transmission is immediately said to be an extremist.

Now, I think casual transmission is extremely rare. I think that the danger is to health care workers. I think it is a travesty of justice that we are not testing health care workers for HIV. In fact, of the three so-called splash cases that we have—in other words, a woman put her finger on the skin where there was some bleeding, the individual who splashed it onto their mucous membranes and eyes, and one other case—none of those were picked up by routine testing, because we don't test medical personnel and we don't know the incidence in the general medical population.

But we do know this: Two of those three people got it when they went to give blood. That's how it was picked up. We are not monitoring health care personnel. Here is where I am concerned.

But let's imagine what happens when we have 5 or 6 million people who carry the virus, because it is moving into the heterosexual population. At that time does it change?

MR. FUMENTO. We'll be taking testimony tomorrow, I believe, on health care workers, so we will get into that subject.

But, briefly, you aren't saying that it can be passed through, say, saliva or through close contact—holding hands?

DR. MONTEITH. I do not believe it can be passed by holding hands. Saliva—I think there are varying interpretations of that. I do know of one case of a doctor—will you give me 2 minutes to tell you the story?

CHAIRMAN PENDLETON. Just a minute. I think we have to make this as brief as we can. We're going to run out of time.

We have two more panels to go through, and I think we get the gist of where we are, but I'd like to sort of wind up with Dr. Monteith. I'm sure Dr. Allen over here is chomping at the bit to say something about the Centers for Disease Control, and possibly Dr. Langmuir.

Are you through?

MR. FUMENTO. Yes.

Dr. Allen, is there evidence that this virus can penetrate through the mucous membrane or does it need a porthole into the body as seems to be commonly believed?

DR. ALLEN. I don't think we have an absolute answer to that one way or the other. For the most part, we believe that the penetration, at least through skin, has been through breaks in skin. In terms of penetration or infection through mucous membranes, very clearly the type of sexual transmission that occurs, whether it is through receptive rectal intercourse or receptive vaginal intercourse, for the most part does represent transmission that is occurring through mucous membranes.

If your question is: Does it occur through mucous membranes in the mouth, we don't really have a clear answer to that.

MR. FUMENTO. Dr. Stoneburner, to switch the subject a little to secondary infections, you are something of an expert on the subject of tuberculosis in AIDS. You have studied tuberculosis in AIDS in New York City. Tuberculosis, now, is casually transmitted, maybe not easily so but you can catch it by being breathed upon.

First, first of all, can you tell us how coincidental are AIDS and tuberculosis? How often do you find tuberculosis in an AIDS patient? And is the increase in the last couple of years of tuberculosis in the country as a whole related to the AIDS epidemic?

DR. STONEBURNER. First I would like to maybe address one point that you made when you make a reference to casual transmission of tuberculosis. That may be misconstrued. I think tuberculosis is an airborne infection. It is not casually transmitted like the common cold or influenza. One has to have a prolonged exposure to an airborne route to somebody who is infected and has tuberculosis before transmission will occur. So it is not casually transmitted as, say, the cold virus is.

As far as increasing tuberculosis and its association with the AIDS epidemic and HIV infection, I think there is now compelling evidence to suggest that in certain areas of the country, particularly in New York City, the increase in TB incidence that is being identified is related to HIV-related immunosuppression.

MR. FUMENTO. Do these people who have more of a tendency to have tuberculosis because they have AIDS, the question I think we might be concerned with—I won't say we should be—if we assume that an office worker with AIDS or with HIV does not pose a threat of transmitting that HIV to a fellow office worker—and we're going to be discussing seropositive children—is there still the possibility that this individual might be able to transmit tuberculosis, or can you name other secondary infections that fall into that category?

DR. STONEBURNER. If somebody has HIV infection or does not have HIV infection and has prior evidence of tuberculosis infection and develops tuberculosis, they are at risk to transmit that to close contacts. I think that it is tuberculosis, though, not HIV infection, that puts them at greatest risk.

MR. FUMENTO. What are the other secondary infections? I believe cytomegalovirus and toxoplasmosis are two of the others. Are there other infections that an AIDS patient is more likely to have that they are more likely then to transmit to other people more easily than they could transmit the AIDS virus itself?

DR. STONEBURNER. Well, I think that tuberculosis is probably the best example, though I reiterate that it is difficult to transmit. There are, in the expanded-case definition, enteric diseases, such as salmonella, that can be transmitted, but it is unlikely.

CHAIRMAN PENDLETON. Do you have any more questions?

MR. FUMENTO. I have a couple. If you really need the time I can give it up.

CHAIRMAN PENDLETON. I think we're going to need it. You can have one more question.

MR. FUMENTO. You put me on the spot.

CHAIRMAN PENDLETON. We might get back to you.

MR. FUMENTO. Well, I will just ask a question of Dr. Langmuir, who is by far the most optimistic person, and, of course, we all hope he's right. You believe how many people will die of this virus, Dr. Langmuir, by the year 2000, 2015?

DR. LANGMUIR. My projection is in the table at the beginning, table 3. My estimate for homosexuals in the United States in the second decade of the epidemic, by the year 2000 is 131,000, which is much lower than the present projections for 1991. These are homosexual cases in the United States. Since they have been 65 percent right along, one can make a rough estimate that there will be about 200,000 total cases of AIDS.

This, I agree, is optimistic. Just last week a man said the difference between an optimist and a pessimist is that they both can be wrong equally often but the optimist has much more fun in the process.

I am well aware that I am on the extreme side of optimism. I have been on this side since 1985, and I have found nothing in the developments that changes my optimism.

MR. FUMENTO. Thank you.

CHAIRMAN PENDLETON. Mr. Destro.

COMMISSIONER DESTRO. A couple of questions, first for Dr. Allen, and maybe Dr. Langmuir would be willing to comment on it. By way of precursor or comment to the question, I just wanted to ask Dr. Langmuir to clarify for the record, which he so kindly did for me during the break, what your figures reflect. Do they reflect HIV infection, or do they in fact reflect actual cases of end-stage AIDS?

DR. LANGMUIR. The 200,000 total cases is AIDS cases, and I accept that all of them will die.

COMMISSIONER DESTRO. Dr. Allen, you gave a speech before the American Bar Association, and you gave somewhat of a rule of thumb, and you said—and I quote: "For every person who has AIDS, we estimate that 10 to 20 people are infected with the virus and are clinically ill but do not meet the formal definition of AIDS. In addition, for every person who has AIDS, we estimate that 50 to 100 people are infected with the virus but are asymptomatic"—end of quote.

Do you still go by that as your rule of thumb with respect to projections today?

DR. ALLEN. The ratio of the numbers probably is shifting, but it is very hard to get hard enough data on which to base an exact ratio. A lot varies. It varies from one area of the country to another. It depends on the

maturity of the infections. In other words, in an area where there are much higher proportion of recently infected people, you will find a much higher proportion of people who are asymptomatic compared with those who have progressed onto disease. If you look at a relatively closed population, such as the cohort of gay men in San Francisco that the City-County Health Department and CDC have been following, one finds a very high proportion of disease in comparison to those with, at this point, asymptomatic infection.

So it is hard to come up with any exact ratio. I think that was almost 2 years ago that I did that presentation. There is still a ratio. It depends on many, many different factors as to exactly what it is, however.

COMMISSIONER DESTRO. Now, my understanding is that CDC is doing a nationwide seropositivity study. Could you explain for the Commission how that is done and who it looks at?

DR. ALLEN. There are several components to the seroprevalence studies that are being funded and directed by the Centers for Disease Control. The one that is currently underway is what we call a 30-city—basically it's a metropolitan area—family of surveys, in which rather than trying to do household-by-household studies or population-based sampling, we are looking at selected population groups. These would include clinics that provide services for gay men. They would include clinics or other facilities that provide services for intravenous drug abusers, for persons regardless of sexual orientation who have sexually transmitted diseases. It includes prenatal clinics, family planning clinics.

We are in each of the metropolitan areas attempting to contract with one or more hospitals to provide blinded seroprevalence data about the frequency of infections in the populations being served by that hospital.

So we are trying, in other words, in each of these 30 metropolitan areas, to obtain data about the frequency of infection from a variety of populations who may be at varying degrees of risk.

In addition to that, in many of these areas, accepted on a statewide basis, the departments of health are taking blood samples available from every newborn, blood samples that are obtained to do other types of testing such as testing for phenylketonuria, which is a metabolic disease that is almost universally screened for in the United States. We are taking the same blood specimens and doing blinded seroprevalence studies in many of these areas. So we will get a much better idea about the frequency of infection in the mothers of the infants. The antibody, of course, is in the infant, but it's antibody that comes from the mother, so it's a proxy for the infection in the mother.

In addition, the National Center for Health Statistics, which is one of the components of the Centers for Disease Control, is contracting with a private organization to do pilot studies on the feasibility of doing a

household survey. That will be carried out in one city initially. Depending on the results of that, probably in two other cities later in '88 or early '89.

And if those are successful, then sometime in midyear 1989 we will undertake a nationwide seroprevalence survey based on households. The problem, of course, with that type of study is that it will significantly underestimate the risk of infection in persons who have transient households or who are more difficult to reach, and we are very concerned because obviously a large proportion of the population that would not be reached by that type of study are the drug users.

COMMISSIONER DESTRO. I guess this would be addressed generally to the panel. My perception, as one who is concerned about civil rights enforcement, is that the public may have a misimpression about the degree of risk faced by the general public, and that much of the discriminatory activity that is being complained of is based on lack of information. And correct me if I'm wrong, but what I thought I heard you say is that you're looking at high-risk populations and that you are contracting with hospitals to do studies on their populations.

My understanding is that CDC has some key hospitals around the country where you just look at whatever comes in. Are they also just taking random blood samples from people who come in to check and see what's going on?

DR. ALLEN. Yes. We have a contract that was initially initiated with four hospitals. I assume those are among the group that Dr. Monteith was criticizing CDC for going to the heartland of America for. We put out a bid nationwide, hoping to get a much larger number of hospitals. We had four hospitals that responded to the request, and we were able to get a contract with each one of those four hospitals. We would have liked to have had many more. We are in the process, as I indicated, in getting at least one hospital in each of the 30 metropolitan areas, so we will in the future have much more broad-based information.

In addition, we have information being given to us by the American Red Cross, by some of the other blood-collecting organizations. So we're looking at antibody testing being done on 8 million U.S. citizens annually through blood-collection facilities.

We are getting information from the U.S. military on their recruit applicant populations. The problem with this latter group is that the followup information in terms of risk for infection is not uniformly obtained. However, we are also working with the military to try to get additional followup information on the recruit applicants who have been tested to identify risk-factor information and to assure that the young people are put into appropriate follow-up.

COMMISSIONER DESTRO. My last question is for Dr. Stoneburner. Do you have any data that would give an answer to the question of whether or not in your high-risk populations, where it's showing up a lot, with the IV

drug users and certain minority populations, whether or not there is any indication that it is spreading outwards through heterosexual transmission from those populations into the population at large? Or is that largely a confined phenomenon?

DR. STONEBURNER. I think in the data that I presented—unfortunately, I had to run through it too quickly—but the data from the sexually transmitted disease clinics I think will address that question, where we interview people about their risks and test them and were able to identify risks in the vast majority of persons who were HIV antibody positive.

Studies like that repeated, and also repeated in the same clinics, over time will tell us if there are more people who turn out to be antibody positive without identified risk or whether that is stable. And I think it is studies like that that will give us better answers to that question. But based on our work so far, it doesn't suggest that there is a lot of spread beyond the sex partners of the major risk group members in this particular population. That does not mean there are not tertiary cases as defined, but that it's rare.

COMMISSIONER DESTRO. It doesn't appear at this time to be a big phenomenon?

DR. STONEBURNER. Not in these populations.

COMMISSIONER DESTRO. Thank you.

COMMISSIONER RAMIREZ. I want to apologize for not having been here for all of the presentations, but the thing that I would like to have answered, maybe by Dr. Allen and by Dr. Langmuir, is what you consider to be the significance of your differences in terms of how the Nation responds from a civil rights perspective, and also from a perspective of solving problems or dealing with problems in a way that is just.

What is the significance of your differences?

DR. ALLEN. I think we may have some differences but I'm not sure we have differences on that.

Alex, I'll let you go first.

COMMISSIONER RAMIREZ. Let me be very clear. Do the differences in your numbers have implications for how we deal with this problem both in terms of public health and civil rights and where those come together?

DR. LANGMUIR. I like your word "just," and I believe my final statement—if you didn't fully understand, I understand.

COMMISSIONER RAMIREZ. This is very difficult for us.

DR. LANGMUIR. I understand. But my projection is obviously the most optimistic one, I think, of any responsible person—I hope I'm a responsible person—in the country. I don't advocate that you adopt it, but in your deliberations you should consider it as one of the possibilities if it comes anywhere near the truth. My basic point is that we can be exceedingly just and well within our budget and our traditions, because we already are

taking care of a large number of patients, not perfectly, but we are doing a pretty good job, particularly in San Francisco.

VOICE. Yes, 20 beds in New York City. You don't know what the hell you're talking about. Thank God there's one Commissioner who had the guts and determination to stand up to this farce, and I hope to God the rest of you have enough conscience to be able to do what you have to. This is supposed to be human and civil rights.

DR. LANGMUIR. I am advocating, I think, support for your point of view, namely that this should be something that is taken on on a national scale and managed, because it will be within our range to project it rather carefully, and each community can know what its problems are. And if we do it on a Federal basis, standards can be set for quality.

I think this is very much in the tradition of this country. We do it for kidney dialysis, we do it for hemophilia. We've done it a number of times. We did it for polio. This is well within the tradition of this country. And it is, if my projections are anywhere near right, optimistic. This crisis which has been fanned out of all proportions to what I think the facts are, will soon cool down, and then I think the civil rights issues will be much less severe than they are now.

COMMISSIONER RAMIREZ. Dr. Allen, would you please comment on that?

DR. ALLEN. I think Dr. Langmuir has focused on aspects of health care planning and a community approach. I won't disagree with any of what he has said or his approach. He has put an emphasis on one aspect of things. I believe in my presentation I was attempting to look at the way in which people respond to the information about the means of transmission of the virus.

Essentially for people who know how the virus is transmitted—and I am fully cognizant that for many people they don't understand that the information and educational materials that have been put out have not been adequate, have not reached them; that particularly if you already are using drugs intravenously, the fact that you may learn more about transmission of the virus may not alter your patterns of behavior much at all. And I'm cognizant of all that. I think we need to deal with all of that aspect of it.

But for a person who is educated today, essentially becoming infected with the virus is a voluntary action. We decide who our sexual partners are; we decide whether or not we are going to inject drugs in a fully rational society. And I recognize that that is not—

COMMISSIONER RAMIREZ. If you don't know that your partner is infected, then it's not a voluntary action.

DR. ALLEN. That's right. The point is that we need to help people to understand that there should be no sharing, whether it's because of HIV or hepatitis B virus or cytomegalovirus or Epstein-Barr virus or any of the

other potentially infectious diseases that could be transmitted through sharing—quite apart from that.

COMMISSIONER RAMIREZ. I won't quibble.

DR. ALLEN. I would hope that we could get to the point, however, that we deal with this disease, regardless of whether we've got an epidemic that is going to be terminated in the near run or whether we've got something that will be with us on into the next century; that we've got to learn how to deal with this and with people who are infected in the same way that we deal with other things.

My concern is that if there is a very definite evidence, let's say, of transmission in a school setting, we may well find that infected children nationwide are thrown out of schools. On the other hand, we are all aware of the tragedy of the adolescents killed in the church bus crash within the last couple of days. I don't think that stops people from driving in cars and buses.

I think we've got to learn—from the data I presented, I tried to show that the risk of so-called casual transmission or transmission by routes other than the standard means is extremely low. It is not zero. I think Dr. Monteith reemphasized some of the same cases that I pointed out. The risk of so-called casual transmission is extremely low, but it is not zero. And we somehow have to learn how to accept that and live within that without abridging the civil liberties of people.

COMMISSIONER RAMIREZ. So what I hear you saying is that the objective of controlling the incidence of panic, if you would, whether it's around casual transmission or around gross numbers, is our ability to control that level of panic—which may be an extreme term but is inversely proportioned to our ability and willingness to respond in a way that is both effective and just.

DR. ALLEN. Yes, I think that's a fair statement.

COMMISSIONER RAMIREZ. So all of the numbers questions that keep going around become important within that context of political will to be just and to be effective; is that right?

DR. ALLEN. Yes. I think if we were all certain that the problem would go away in the next 2 years, the response would be very different than if we are certain we are going to live with this on into the future. We will have infected people with us for a long period of time. Even if we are able to bring transmission down to zero today, we will have a large group of people who will continue to become ill over a period of time. And I think that is a fact that needs to be dealt with. We can take care of these people; we can integrate them into our society. There is no reason not to from the fear of transmission point of view.

COMMISSIONER BUCKLEY. That answers some of the concerns that I have, coming back to the civil rights issue—mainstreaming them into

society. If they live with us for 10, 15, 20 years, then what would be our concern?

One thing I was wondering about—say in New York City, and I know this is not necessarily the topic you are here for, but because we won't have you back, New York City and CDC, have you picked up any reports in your people that you do treat or deal with on refusal of health care because of AIDS? In dealing with the clinics in New York City, have you had a problem in giving adequate care for these individuals when they come to your hospitals the first time because of the scare of transmissibility, the fear that is there?

DR. STONEBURNER. I can't give you specific incidences of this or numbers, but I am certainly aware of people who have lost their housing because of fear, and other types of discrimination because of undue fear, where they have lost their jobs. So I know it is happening. There is no question about that.

COMMISSIONER BUCKLEY. Dr. Allen?

DR. ALLEN. I cannot cite you specific examples. I am also aware certainly of physicians and some other health care personnel who have indicated that they will not take care of a person who is infected.

I'm sure it is difficult for some of them to be treated in some areas. I think potentially it's a problem. It's hard for me to give you an estimate of how severe a problem it is.

CHAIRMAN PENDLETON. There are two more of us left, Commissioner Berry, you and I. I'd like to break in about 10 minutes to give our reporter a chance to crack her fingers, if that's possible, and end this panel in about 10 minutes if we can.

Go ahead, Commissioner Berry.

COMMISSIONER BERRY. Thank you very much.

First of all, Dr. Langmuir, based on your long experience as an epidemiologist and the testimony you have given today, are we dealing with the AIDS HIV situation much as we have dealt historically with epidemics and outbreaks of this kind? Is there anything in the pattern of response from a public health standpoint that seemed to you to be anomalous or to be something completely different from what happened before? Or are we simply responding much in the same way at different stages as this proceeds or not? What is your view of that?

DR. LANGMUIR. Oh, I think the record of response in the whole country—the CDC, the NIH, all our medical schools, our doctors—has basically been exemplary, from a difficult problem of a kind of cancer in Los Angeles, and then to a strange pneumonia that we knew about in leukemic patients and so on. I learned about it sitting in my retirement home in Martha's Vineyard and I said, "My, that is a serious problem." And in an amazingly rapid time they identified the blood transfusion problem, they identified the hemophiliac problem. They got research on it

in France and this country together, and in no time after they got the virus they got a test, and it turns out to be an exceedingly good test. They can protect the blood.

The record of achievement is as fast as it was, say, with polio or with Legionnaire's disease, a much more simple problem. The only difference is that my interpretation of the data which CDC provides is somewhat more optimistic. But otherwise I'm in excellent communication with my friends down there, and they say time will tell.

COMMISSIONER BERRY. I see. I just wanted to make sure there wasn't anything curious about their response.

DR. LANGMUIR. Not at all. I am totally impressed with the quality of the work and the extent, and of the cooperation between CDC and all the States in providing information. The reporting I believe is extraordinarily good, and the investigation of each of these 50,000 cases—that's just a lot of investigations. In spite of Dr. Monteith, I just don't think he is the professional in the area that I am.

COMMISSIONER BERRY. Let me ask Dr. Allen—I asked this question of Dr. Fauci this morning, so I'll ask you pretty much the same one.

Is anything you've said to us today in your testimony been influenced by or affected by some lobbying group that intimidates you or makes you feel you ought to say certain things? And how much have the activities of the CDC have been controlled, in terms of what you recommend to the public or the data you put out, by some organized lobbies? Could you tell us about what they've done to you and how what you have said today has been affected and whether we can rely on what you said?

Do you understand the question?

DR. ALLEN. Sure.

CHAIRMAN PENDLETON. Are you going to go back home after today and say, "We got some pressure, and we have to change our policies because of the pressure we received today?"

COMMISSIONER BERRY. What influence does pressure have on what you folks are doing, and who are these lobbies who keep intimidating you?

DR. ALLEN. Maybe I'm the wrong person to answer this. I personally have not felt intimidated or threatened or coerced by any lobby or pressure group. As we have witnessed today, I have been in a few situations where I have been shouted down or otherwise people have disagreed with me. That has not influenced my views. To the extent that I am aware, it has not influenced the views of any of my colleagues, nor of the Center itself. We try, as one of the major agencies of the U.S. Public Health Service, to be a professional organization. I am extremely impressed with the quality of my colleagues. We try our best to get the best data available. We try to evaluate it rationally, and often under a great deal of time pressure to come up with the best recommendations.

If there is an element of pressure, I think it is the element of time, where we are struggling to evaluate the data and come out with the best possible recommendations that will be sustained over time, and yet to do it in such a rapid fashion that we are not being accused of covering up the data and sitting on it.

I take disagreement with some of the previous statements about CDC sitting on data and covering up. I invite any of you, as has Congress and others, to come and take a look. I am extraordinarily proud of the record that CDC has accumulated over the last 7 years.

COMMISSIONER BERRY. Let me ask both you and Dr. Stoneburner, who I think are in the best position to probably answer this kind of question: How do you deal with the problem of hidden infection? We had some discussion this morning about contact tracing as a way of reducing the impact of HIV and AIDS, and the issue was raised. Some people want that done, and then isolation of people who in fact turn out to be HIV positive, we heard this morning, until they are trained or educated not to engage in the behavior that transmits the disease, whether it's sex or drugs or so on. Are you in favor of that as a policy?

DR. ALLEN. Let me go back to your first question, which was contact tracing, or the term I prefer is partner notification, whether it's sex partner or drug-using partner.

Partner tracing, particularly sex partner tracing for other sexually transmitted diseases, has had a very long and I think impressive history, although by itself it certainly has not controlled the problems with sexually transmitted diseases that have plagued humankind.

It is one effective tool when it is applied appropriately. It can be done with confidentiality; it can be done with great discretion. I think that Dr. Stoneburner can address the way in which local health departments apply it. State health department personnel, obviously, or local health department personnel—not CDC personnel—are the ones who carry out the notification and tracing. It needs to be done properly. It is not a coercive thing. I cannot force anyone to tell me who their sexual partners are. This is a voluntary, cooperative effort. And then a notification is done essentially in an anonymous fashion. The sexually transmitted disease investigator does not go out and knock on somebody's door and say, "So and so," whether it's the spouse or a friend or whoever, "tells me they gave you gonorrhea," or whatever. That simply is not the way in which it is carried out.

In terms of HIV, I think it has to be used very selectively. If we are talking about people who have had large numbers of partners, most of whom they had one or two relationships with, and they often don't know the name or the address or the telephone number, they have no other information, partner tracing is not going to be of much use.

Where there are a limited number of contacts, especially where the contacts are very close or whether it's been a continuing relationship, I think partner tracing can be a very useful tool in identifying people who may be at risk or who may be infected, and being able then to reach them with the counseling and education that are going to help in the process of behavior change.

COMMISSIONER BERRY. How about isolation?

DR. ALLEN. I have much more difficulty with isolation being very useful. The only potential in which I could see its perhaps being useful would be in limited circumstances where somebody has been warned and has been provided with education counseling and continues to place other people at risk because they refuse to change behavior. I think it has to be applied very, very carefully under very stringent circumstances, carefully defined and with the approval of court authorities. I don't think that this is something that health officials by themselves ought to have the liberty to carry out without there being appropriate court authority.

COMMISSIONER BERRY. Dr. Stoneburner, do you want to say anything about any of that?

DR. STONEBURNER. Just a few comments. New York City does have a partner notification service, and we encourage people who are HIV tested and found to be positive to notify their partners. We offer a service that will assist those, who are unwilling to do that or reluctant to do that, to notify their partners. This is anonymous, and it has been in effect for over a year now.

It is very difficult to determine how successful an intervention approach like this is. But I think if we review the epidemiology, particularly in New York City, one can see that the vast majority of sexual transmission is among gay and bisexual men. There has been a tremendous decrease in transmission due to education, and I think that is key. I think the reason we may not be seeing it among blacks and Hispanics as we are seeing it among whites may be a communication problem, that that message has not gotten to that population. But I think if that message gets through, the effect will be stopping transmission or reducing transmission. And that is what the goal is.

For intravenous drug users, their problem is addiction. Contact tracing—to notify somebody that they're sharing needles, if they are addicted, without offering them treatment, is not going to be very effective.

COMMISSIONER BERRY. Are you in favor of clean needle programs, both of you—you know, giving people syringes and needles? I've forgotten whether you do that in New York now.

CHAIRMAN PENDLETON. As opposed to bleach.

COMMISSIONER BERRY. So that they will have clean needles. I guess they call them clean needle programs or distribution.

DR. STONEBURNER. Needle distribution programs.

COMMISSIONER BERRY. Will that help? Either one of you.

DR. ALLEN. It should include syringes also.

COMMISSIONER BERRY. I mean syringes and needles, yes. We've had that joke twice today. Yes, syringes and needles.

CHAIRMAN PENDLETON. Maybe the pusher should give out needles.

DR. STONEBURNER. I think the intravenous drug users in New York City are quite knowledgeable about how one gets AIDS and through needles. The problem is that they still have an addiction that hasn't been dealt with through drug treatment.

COMMISSIONER BERRY. So are you for it or against it?

DR. STONEBURNER. I think the distribution of needles, without expansion of treatment, which we have not seen, that this is an effort—it's much more than symbolic; it is a definite effort to attempt to interrupt transmission, but I think the ideal—there may not be an ideal solution, but it needs to be coupled with access to drug treatment for intravenous drug users.

COMMISSIONER BERRY. Do you agree with that, Dr. Allen?

DR. ALLEN. Yes, I believe we have to be very aggressive in defining and carrying out research strategies, including distribution programs. I'd like a very good study. And it sounds like a delaying tactic, but I think we need to look very aggressively at a number of ways to deal with this problem. We need to look at ways to prevent our young people from starting drug use. We need to look at ways to deal with those who are already hooked. And that may well include a needle and syringe exchange program. It also must include programs, such that if they are carrying on their person injection equipment, whether it's needles and syringes or bottles of bleach to sterilize equipment or disinfect equipment, that these not by themselves be presumptive evidence of drug abuse that can be applied by police, because anything like that that would again discourage people doing it is going to decrease the effectiveness of the program. So we're talking about community education.

CHAIRMAN PENDLETON. We have to get out.

COMMISSIONER BERRY. Last question.

CHAIRMAN PENDLETON. Please, spare us.

COMMISSIONER BERRY. Last question. In the policies that you make and implement, where do you take into account the rights of people who do not have HIV or AIDS? How do you balance in the equation, of what you propose as a matter of public policy, their needs? And is there some kind of process for doing that, the desire of people not to be exposed to these things?

DR. ALLEN. I think that education about ways to avoid being infected is the most effective.

COMMISSIONER BERRY. Okay.

CHAIRMAN PENDLETON. Bob, did you have any questions?

COMMISSIONER DESTRO. No, I didn't, but that raises the related question. I was going to ask the question: How many people actually refuse, when you give them assistance, in terms of warning partners? How many people refuse? And if they refuse, would you support any kind of coercive measures to go ahead and force them to disclose so that persons could be warned?

That's actually two questions. We talked about balancing voluntary programs with coercion. First of all, how many people really do refuse, and do you see that as irresponsible behavior on their part?

Dr. Stoneburner.

DR. STONEBURNER. I don't have the figures from our program, so I can't tell you what our refusal rate is. Personally, I think that coercion could very well work against the goal of prevention of transmission, in that one person coerced, one person isolated, could drive thousands away from education and anonymous testing. And I think that is the major concern here.

CHAIRMAN PENDLETON. Could I just ask one question here?

We have heard conversation from the press and from the protesters and the like about us studying transmissibility—not studying but having a section on transmissibility. Would you agree or not agree that we have to understand transmissibility, which is part of what you said, Dr. Langmuir. If we can understand what transmissibility is and how the disease is or is not transmitted, we might be able to reduce some of the fear that results in discrimination. Is that an accurate statement, or should we not have studied transmissibility at all.

DR. LANGMUIR. I am a student of the published information. I am in contact with the group at Hopkins that has a very large study. Although their latest results won't be released until the Stockholm meeting, it is quite clear among those that I respect as most knowledgeable that the evidence focuses on receptive anal intercourse as the way this disease is spread. Heterosexual spread is so low as to be inconsequential. Frankly, I think the pornographic magazines, the Playboys and the Penthouses, are onto this already, and they are doing the education for us. As an old health officer, I don't approve of that as a method, but I look at it with a wry smile because I think this is what is happening.

CHAIRMAN PENDLETON. I guess my question was just a little bit different. Do you want to answer that, Dr. Stoneburner? Should we be hearing evidence about transmissibility, as we begin to look at what the civil rights aspects of managing and controlling this disease are?

DR. STONEBURNER. I think it is important, because I think as the public is knowledgeable about how AIDS is transmitted and how it isn't transmitted and how difficult it is to transmit, that fears, hysteria, anxiety

will be allayed. And I think it is important to address that in a Commission like this.

CHAIRMAN PENDLETON. Commissioner Ramirez, I hope it's just one question because we want to get on with the next panel.

COMMISSIONER RAMIREZ. Mr. Chairman, I have one question for Dr. Stoneburner. I will accompany it with my comment in order to reduce the time that it takes.

I am interested in knowing whether you have any information about the spread of the disease from IV drug users to their non-IV-drug-using mates, as compared to the spread of the disease among situations where both partners are IV drug users.

I have listened carefully to the issues related to the dimensions in that problem, but in places like—let me be specific. In the Hispanic community, you see a higher incidence of the maintenance of the family when there is drug abuse by the male partner; the woman will stay with her partner, sometimes under great coercion; she has few options. And it seems to me if we are to understand that dynamic, it becomes necessary to think about an impediment to the future spread of the disease, not only in terms of the treatment of the drug-abusing condition in the males, but that there have to be options for that woman also to get herself out of the situation she finds herself in, so she also needs treatment.

If you could comment very quickly on that, I would appreciate it.

DR. STONEBURNER. I think if there is any misconception about how important male-to-female transmission is around IV drug users, I'd like to clear that up. As I said before, among women, over 20 percent of cases have been sexual contacts with intravenous drug users. We know that this is a heterosexually transmitted disease, and women in New York City and women who are sexual partners of intravenous drug users primarily are at high risk for this. Most of them are probably long-term sexual relationships.

And I think you're right. If we can access intravenous drug users through education or treatment for their drug abuse problem, it could be through these channels that we would also access sexual partners for AIDS risk reduction.

CHAIRMAN PENDLETON. The last question is from Ms. Prado.

MS. PRADO. Very quickly, Dr. Stoneburner. You rattled off a number of statistics that were frightening as well as impressive. You said something—I don't want to misquote you—about what you saw as an increase, a trend, I believe, in young minority males. Can you clarify what that is? What is the rate of spread and means, and what should be done about it?

DR. STONEBURNER. Was this about the assessment of high-risk behavior among gay men?

MS. PRADO. I believe so. I was trying to remember the context.

DR. STONEBURNER. Yes.

MS. PRADO. You said that you were identifying, the rate was increasing in young minorities.

DR. STONEBURNER. I'm sorry I had to go through that so quickly.

Early in the course of the epidemic, there has been good data from sexually transmitted disease clinics throughout the country showing sexually transmitted diseases that occur commonly among gay men decreasing as a response to the risk-reduction message through AIDS education. Many of them have not looked at their data by race and by age. We were able to dissect our data by race and age and found, yes, there was a profound decrease overall, but that it occurred more commonly among whites who were older than among minorities who were younger. So it suggests that there still needs to be a lot of risk reduction in the gay community, and particularly among the minority gay community.

MS. PRADO. What did you suggest we should do about it?

DR. STONEBURNER. I think we use the same education—well, not use the same education channels because they obviously have not been as successful, but we need to see what the obstacles are in certain subpopulations to our risk-reduction message.

MS. PRADO. Thank you.

CHAIRMAN PENDLETON. Thank you very much.

Thank you, Panel.

We'll take a 10-minute break and then move to our next panel. One of those panel members will be on by telephone. The other one will be here. Is that correct? Three persons will be here and one will be on telephone.

[Recess.]

CHAIRMAN PENDLETON. Mr. Rideau, how are you? Can you hear me?

MR. RIDEAU [via telephone]. Yes.

CHAIRMAN PENDLETON. It's good to have you with us.

The hour is going to creep up on us when we are going to be evicted this evening from this building, so the Chair is going to be a little more dictatorial or something with the presentations so we can complete two more panels.

Panel III is Prisons and Mental Institutions. We will start with Mr. Wilbert Rideau by telephone, who is editor of *The Angolite.* He's an inmate at the Louisiana State Prison in Angola.

Panel III: Prisons and Mental Institutions

TESTIMONY OF WILBERT RIDEAU, EDITOR, THE ANGOLITE, ANGOLA PRISON, LOUISIANA STATE PENITENTIARY

CHAIRMAN PENDLETON. Mr. Rideau, welcome to the panel, and we'll be glad to have your 8-minute-or-thereabouts statement. Thank you for sending material to us ahead of time.

MR. RIDEAU [via telephone]. Eight?

CHAIRMAN PENDLETON. Eight; yes, sir.

MR. RIDEAU [via telephone]. You should have told me that in the beginning.

CHAIRMAN PENDLETON. I'm trying to.

MR. RIDEAU [via telephone]. I said you should have told me that in the beginning.

What am I supposed to talk about, aside from AIDS?

CHAIRMAN PENDLETON. I assume you're going to talk about AIDS in prisons. We figured you could give us a summary statement of about 8 minutes, and we'll probably have some questions to ask you after we get through the other three panelists.

MR. RIDEAU [via telephone]. Okay. I'll skip everything you already know.

The current policy is an insistence by those who advocate integration, no testing, and no segregation that all medical information concerning AIDS in affected prisoners be kept confidential. I'd like to point out, number one, that introduces a certain paranoia. It adds an entirely different dimension to prison life and the stress of prison life. It introduces paranoia, and a lot of people who have sores or what have you on their bodies, it subjects them to social avoidance, suspicions, stigmatization. That's because of the secrecy. Nobody knows who has AIDS so you suspect anybody.

Also, I'd like to point out that I understand you're trying to make rules or guidelines. Prison is a peculiar world, and it's one in which the problem will generally take care of itself without rules. Those infected inmates who behave responsibly will get away with it until the illness becomes obvious, in which case security authorities generally will move on their own accord to protect them, as they normally do in cases requiring protection. On the other hand, those who behave irresponsibly will be removed eventually by security authorities or be ejected or killed by the inmate population.

I think the issue of whether to integrate or segregate is bigger than the reality of the situation, because you've got both security authorities and even the infected inmate himself acting to protect him from violence. And every inmate knows how to do that. Of course, the reason for a lot of the violence is that we don't always act upon that knowledge, and we end up dying.

I think, based on who you have on the panel, that we're going to hear pros and cons about testing and nontesting and protecting the rights of the AIDS-infected prisoner. And I'd like to point out not to protect noninfected populations as well—I mean, protection can't be one-sided. You've got conflicts of interest here. The American way has always been to balance out those interests whenever there's a conflict. And there's going to be the issue of education. Education is the key.

This is a peculiar world and it's different from yours.

Are my 8 minutes up?

CHAIRMAN PENDLETON. You've got a few more.

MR. RIDEAU [via telephone]. Let me tell you something about this education bit and my own reaction as a prisoner. I'm a rational, reasonable, and thinking individual. I'm fully aware of the problem, and I'm mindful of the needs and the rights of the infected and the noninfected. I hate the thought of someone being punished and treated unjustly just because he is ill. That's an awful injustice to anybody.

But the greatest injustice, not only to me but to many other prisoners, is to spend an eternity in the prison jungle locked in a perpetual struggle to survive gang wars, bullets and knives, and all the grubby gut of violence, and then to wake up one morning and find it's all been for nothing, that you're going to lose your life to something you can't see or touch to fight.

Now, I know everybody throws out that the key is education. I know the government and the medical community say how it's transmitted. I'm well aware and knowledgeable on the subject. For your information, I have never engaged in homosexuality, nor have I ever used any kind of dope, and I never will. If that's what protects me from the virus, I don't know.

You see, the problem here is not the lack of education and knowledge. In fact, I don't know of a prisoner in this prison who hasn't heard about AIDS and how to protect himself from it. The medical authorities at the prison have literally force-fed us that information. The problem lies in the reality that, unlike the general public, governments and authority and penal administrations generally have no credibility with the prisoners. Prisoners more than any other class of people have experienced being lied to by government and authorities throughout their entire prison experience, and now you're going to ask them on an issue of life and death to accept the government's word that AIDS is what it says it is, and there is no danger to them if they do this or if they don't do that.

You've got the same problem now that negotiators have trying to resolve a prison disturbance. You've got to convince the inmates that what you're saying is really what you say it is. That was just an example of the Cuban takeover in the Federal prison system. You had to bring in outside people, persons of credibility, to intervene.

Now, you can say they're being unreasonable, but they're not in 27 years' confinement. I've seen government and power do all the things they condemn prisoners for, and lying not only to prisoners but personnel as well, as they go on pursuing the manipulation of some Machiavellian scenarios. I'm a rational and intelligent man, and because I am, I have a problem with accepting government's word at face value. Besides, I'm not so certain that the medical community and the government knows enough or is on top of this virus well enough yet to give me any promises or

assurances, especially when I read constantly about how many medical practitioners themselves refuse to treat AIDS patients.

Now, these are the medical experts, and they are avoiding AIDS patients. But you want us to trust and embrace them with our lives on the line, and we've got to gamble that you're telling us straight. I think you're going to have a difficult time selling that to noninfected prisoners. And the problem is more than a matter of education, it's one of credibility, and I don't know how you're going to resolve it.

CHAIRMAN PENDLETON. Thank you very much. If you'll stay on the line with us, we're going to have some other testimony, and then we'd be glad to have you participate in the questioning period.

Before you give testimony, gentlemen, would you please stand and raise your hands and be sworn in. I forgot to do that originally.

[Alvin J. Bronstein, Anthony P. Travisono, and James T. Havel were sworn.]

CHAIRMAN PENDLETON. Mr. Bronstein.

TESTIMONY OF ALVIN J. BRONSTEIN, EXECUTIVE DIRECTOR, THE NATIONAL PRISON PROJECT, AMERICAN CIVIL LIBERTIES UNION FOUNDATION

MR. BRONSTEIN. Apparently what the Commission wants to hear about today, at least from this speaker—and I confirmed this with Mr. Travisono—is the best kept secret in Washington because neither of us were able to elicit from the staff what you want to hear about, but we will do the best we can.

The problems you have heard about earlier today, and will no doubt hear about over the next 3 days, are magnified geometrically in our jails and prisons. These are institutions that function with a great deal of fear and paranoia. There's an extreme lack of privacy and confidentiality, a good deal of forced single-sex sexual activity, sometimes rape, sometimes just coerced; a great deal of consensual single-sex sexual activity, the inability to obtain informed consent in these closed institutions, severely stressed medical delivery systems because of overcrowding, and then the overcrowding itself, which exaggerates everything else. So all the problems you hear about are really magnified a great deal in these institutions.

Let me give you two examples of what's going on in the country, and then perhaps what you want to hear is what I see as civil liberties issues, and I will do that quickly.

Just to indicate the kind of paranoia that exists, the South Carolina legislature last week passed and sent to the Governor a bill which would require the Department of Corrections to retain every sentenced prisoner after they complete their sentence—retain them in custody after they complete their sentence—and release them only upon a certification from

the local medical authorities that they can be cared for and watched in the community. That's a little bit of a civil liberties problem there, if you keep people after their sentence expires.

On the other hand, the kind of problems that exist are exemplified by the New York system. The New York prison system death rate from the disease AIDS is twice as fast as it is in the free community. In other words, people who contract full-blown AIDS are dying in half the time in the New York State prison system as they are out on the street.

The issues as I see them—and I should say there is very little civil law on any of these issues because most of the cases, to the extent they have been litigated, have been litigated pro se by prisoners without counsel, without experts, and there are new issues arising every day.

The first one is obviously the issue of mandatory or universal testing, which I see as raising a lot of serious problems—privacy, due process, possible fourth amendment unlawful search and seizures. It is expensive. There is no medical justification for it. Yet, many jurisdictions are doing mandatory testing, which then leads to the privacy problem, because of the lack of confidentiality in prisons, the so-called prison grapevine, and the understandable requests from correction officers who want to know who in their ward, who in their dormitory, who on their cell block, have tested positive. This information, once it is available, is spread throughout the system, in spite of promises of confidentiality.

The testing and the lack of confidentiality then leads you to custody and housing decisions, the creation of what I call leper colonies, segregation of prisoners who test positive, not because of any medical reason but either a fear on the part of officials or other prisoners of transmission, a fear of inability to protect the seropositive prisoner from other people, or just because of paranoia and the feeling that that's the right thing to do.

And, of course, segregation in most cases becomes punitive. When a prisoner is segregated in a special housing unit, they often lose access to programs, work release, family visits, recreation, and a whole variety of other ordinary rights or privileges. I think there are serious legal problems which are currently being litigated around those issues.

The medical care is another serious issue. Because of the overcrowding, the traditionally poor medical care systems in most prisons and jails, which have been upgraded substantially over the last 15 years with the recognition that you really have to do it—those are being taxed to the extreme. This is costly and expensive medical care when a person is really sick with AIDS or is seropositive and symptomatic, and therefore it's costly, it's time-consuming, and it's very difficult for most systems to keep up with the needs of the medical care.

There the Supreme Court has already spoken, not only in the context of AIDS, but the constitutional test is deliberate indifference to serious medical needs. If you can establish that there is deliberate indifference,

then you have an eighth amendment violation. And certainly when a person has AIDS or is symptomatic with HIV testing and they develop symptoms, it is a serious medical need. And most systems, unfortunately, can't provide the kind of medical care that is required.

You have a very complicated issue of third-party notification, the so-called, Tarisoff issues named for a Supreme Court of California case. One is the obligation of the prison officials to notify the spouse of a prisoner, John Doe, that they know is seropositive and is being released next Tuesday. What is the obligation to notify prospective employers by the probation department or the parole officer? Should the obligation be measured by local medical standards? Should it be a corrections decision? Should it be a decision of the paroling authority, the releasing authority? Very, very complicated decisions. My own feeling is that they ought to be medical decisions and not decisions made by corrections people.

Two other issues that are arising—and these are quite new; one just came out to the forefront about 2 weeks ago. As you may know, in the late seventies the Department of HHS—its predecessor—and Food and Drug Administration, promulgated regulations which prohibited the use of prisoners for biomedical experimentation, the so-called guinea pig theory, except if they could meet very stringent requirements or criteria. And there is not a jail or a prison in this country that can meet those criteria.

So medical experimentation and the abuses that went with it have evaporated in this country—until recently. We now know that in violation of those regulations, this kind of experimentation is going on by drug companies in prisons and jails in this country.

Question: Should the regulations be changed, given the fact that you have a controlled high-risk population in a controlled environment and with a great need to discover information about medicine and drugs to deal with this disease? The National Institute of Justice has put up some money to have a 2-day conference next month in June to begin to look at this issue.

Finally, there are legal issues arising under the Rehabilitation Act of 1973. The Civil Rights Restoration Act, which was passed on March 22 of this year, creates, I believe, a cause of action for a person who is either seropositive or has AIDS against governmental officials, jail and prison managers or operators, for failure to treat them and to discriminate against them in any way. All of these issues are now being tested in the courts and will now be tested in the courts in cases involving lawyers and experts and not just *pro se* prisoners.

Let me stop there so we can save as much time as possible for discussion.

CHAIRMAN PENDLETON. Thank you.

Mr. Travisono.

TESTIMONY OF ANTHONY P. TRAVISONO, EXECUTIVE DIRECTOR, AMERICAN CORRECTIONAL ASSOCIATION, COLLEGE PARK, MARYLAND

MR. TRAVISONO. Thank you, Mr. Chairman, ladies and gentlemen.

The corrections industry—I would like to use that term because it is an industry—is being put upon like no other industry that I am aware of with the number of people being sent to it and the growth of what we represent as the American prison today.

MR. RIDEAU [via telephone]. I can't hear.

MR. TRAVISONO. You can't hear?

Mr. Rideau. I'm just picking up snatches of what is being said. It echoes and it's very low.

MR. TRAVISONO. Sorry about that.

It almost seems from our perspective that we—Americans now—are creating a new welfare system behind the walls of institutions, that so many people are coming into our institutions that the profession is not prepared to handle the number that the American public wants to send through its courts.

So when we take a look at the AIDS problem we see the entire system being somewhat out of control and AIDS being a symptom of this out-of-control business because many people have different answers for what they want the correctional professional to do.

I provided you with some information early on from the three national studies that we did from 1985, '86, and '87.

The reason we were so quick to jump on this—when I say "we," I mean the Federal Government in relationship with the American Correctional Association—is that many people expected the prisons of America to become cesspools for AIDS transmission. And unless Mr. Bronstein can tell me any differently, we are not aware of one case of transmission while in prison at the moment, the oldest case being in New York of 7 years, and CDC indicating that that transmission may not have happened in prison; it could have happened on the outside. So with that, we still have the difficulty of understanding the number of cases we have being brought to us when we do some testing.

Now, there is no mandatory testing. There is no nationwide Federal law to allow corrections to follow it in any way. There are 50 States, five territories, and all of the various counties—3,200 counties—that have jails. And the American Correctional Association tries to provide guidelines, as does each of the various States' health departments.

So with all of that, the background to that is that in the 3 years that we have been keeping track of the AIDS cases in the institutions, we have 1,320 confirmed cases in 39 States in Federal systems, and in addition 644 in 31 large city and county jails. All of the jails have not been surveyed.

Most of the jails in America are 20 to 30 population, and we have a whole host of mega-jails in the very large cities.

The public rate has gained about 61 percent over the same time period, and the correctional gain of active AIDS patients has gained about 59 percent.

So in one sense, with 3 years of tracking, so to speak, without mass testing, without mandatory testing nationwide, we are two points less than the general public. So it made us in some way feel good that we were not the cesspools that some people predicted we would be because of the general heterosexual problem and the general problem of drug use.

Now, the great majority, about 92 percent, I believe, of AIDS patients are drug abusers. And many of them are Hispanic. Most of them are Hispanic. There are very few whites, and some blacks. Most of them are from New York, New Jersey, Florida, California. Seventy percent of those come from four States—73 percent, I should say—and about 12 percent from some of the larger jails.

So with that as the background, Mr. Chairman, the American Correctional Association has been working for a year-and-a-half now to try to provide what we call a policy resolution for what we would ask our Nation's prisons and jails to follow, since there is no nationwide program by which we can follow. We like to think we should not take the lead in this because CDC is that agency that we look to for guidance in this area. CDC generally joins with the correctional community and suggests that mandatory testing is not the way to go, particularly since we wouldn't know what to do. If the rules came down that segregation, isolation of some sort, was going to be what we were looking for, the correctional community could not handle something like that.

So isolation is not a part of HIV logic at the moment, although those who are infected with AIDS are immediately sent to hospitals, either in New York City or in the Federal system, in their own institution, and in California a couple of their institutions.

So we are trying to follow the CDC and having them help us figure out what to do. There are only a handful of States that are doing mandatory testing at the moment. There is a political drive that is being established to have mandatory testing. And until those are passed by some law in a State government, the correctional community will resist.

The reason why is it is very difficult, as I said earlier, to do anything with it, once we have that information and, secondly, we don't have the money. Corrections doesn't have its fair share of the pie to spend on testing when we don't have enough, as Mr. Bronstein said earlier, just taking care of people in an institution with their ordinary medical problems.

So it is a major problem to us in the industry. It is a growing industry. It is growing larger than most people would ever expect it to grow, and the

AIDS situation is not growing as rapidly as one might expect, and it's staying just a few paces below public indications.

CHAIRMAN PENDLETON. Thank you, sir.

Next we go to Mr. Havel.

TESTIMONY OF JAMES T. HAVEL, DIRECTOR OF GOVERNMENT RELATIONS, NATIONAL ALLIANCE FOR THE MENTALLY ILL, ARLINGTON, VIRGINIA

MR. HAVEL. Thank you, Mr. Chairman and members of the Commission.

Before I make my formal remarks, I'd like to endorse the comments made by my two colleagues at the table, because increasingly correctional facilities are institutions not by choice, perhaps, but of first entry into the institutional setting for many people who are mentally ill. We think that is an unfortunate consequence of the institutionalization, but it is something of grave concern to us, and the remarks that I make in relation to mental institutions I think parallel some of the suggestions made in the correctional facilities, and I'd like to associate myself with their remarks.

Mr. Chairman, you have heard a great deal of expert testimony today. I'd like to bring a different perspective because I don't pretend to be an expert in this at all. I'm a family member. The organization that I represent, the National Alliance for the Mentally Ill, is a national network of support groups for persons who have mental illness in their families, primarily parents, but also siblings, children of persons suffering from serious mental illnesses, primarily schizophrenia, and major depression bipolar disorder.

CHAIRMAN PENDLETON. Would you put the microphone close to you, sir.

MR. HAVEL. So it is as a family member that I bring my remarks before you today, and it is as a family member that I have a direct and immediate concern with the kinds of policy issues that you are deliberating today.

Most of the members of my organization, which now is over 65,000 families strong, have had some experience with mental institutions. It is the nature of mental illness that periodic recycling into and out of institutions is part of the course of the brain disease in many instances, and so we have had that direct contact and we know if our loved one is not now in an institution, some time in the future at least a portion of our membership will again experience that sad event.

As we talk about mental institutions, I think it is important to recognize the difference in the character of the mental hospital today as opposed to, say, 20 years ago. The institutionalization has had a very dramatic impact on the nature of mental hospitals. In 1963 there were half a million persons who were long-term residents of mental hospitals around the Nation. In

1984 that number has dropped to 116,000 individuals, still a significant number but a major decrease.

But offsetting that decrease has been a concurrent rise in the number of individuals who have been committed to mental hospitals for short-term stays. In 1955 there were 178,000 individuals who were admitted to mental hospitals for short-term stays, and in 1984 that number had risen to 332,000 individuals. So what the Lord giveth with one hand, he taketh away with the other, I guess, and we see that there is that recycling effect of individuals going into mental hospitals for short-term stays.

One of the things that I'd like to point out is the concern of our members deals with those individuals who suffer from mental illness first. They may be gay and they may be HIV positive; they may not be HIV positive or they may not be gay. But the one salient feature that unifies the population of our concern and for whom we advocate is the fact that they have mental illness, and mental illness primarily in the first instance rather than as a consequence of AIDS infection.

We were disturbed when we first began to consider this issue by the absolute dearth of information that was available to tell us just what the magnitude of the problem was. So when I said that I would bring you a new perspective as a nonexpert, I trust that you will find yourself in that same position, that there will simply not be the data available at the present time to tell you how serious the incidence or prevalence of AIDS might be within mental hospitals. So we can have a discussion, I guess, on the mutual grounds of ignorance, if you're comfortable with that.

But we would urge and advocate that you support the development of incidence and prevalence data in terms of mental institutions and do that through the Centers for Disease Control, or through the National Institute of Mental Health, on a blind test that would be anonymous in nature, that would test several institutions around the country and give us some idea of how serious the problem is.

We were led to our interest in this by our knowledge of the behavior of our children or our parents or those of our relatives who are mentally ill. We know that the mentally ill tend to be a highly vulnerable population. Frequently they self-medicate. They will medicate through the abuse of alcohol or through the abuse of drugs.

For those who suffer from bipolar disorder in their manic phase, they may in fact be hypersexual and engage in a great deal of sexual activity. For others they may be very passive but easily victimized. They tend to live in congregate facilities when they are not living at home or to live on the streets. Shelters and the streets are not the ideal place for one to protect themselves against possible sexual aggression or contamination through needles.

So we have reason to believe that this population may be a population that merits closer examination than it has received, and our plea to the

Centers for Disease Control and NIMH and to you is that you direct some of your attention to the mentally ill in the institutional setting.

We have adopted a policy that is preliminary, and it is intended to inspire, I guess, some discussion of issues in this area, even though we lack the kind of foundation that we need in terms of data. So, we have addressed, and I think you had presented to you the statement that was adopted by our board of directors in January addressing the issues of testing, of isolation, segregation, the issues of education, prevention, and our belief that all individuals have a right to treatment, whether it be for their mental illness or for their AIDS, and that it ought to be in an appropriate facility.

I'd be happy at the appropriate time to answer any questions you might have, Mr. Chairman.

CHAIRMAN PENDLETON. Thank you.

Mr. Bronstein, you indicated in the beginning you didn't know why you were here. I find that interesting. Did you and counsel talk before you came, and you did not know what—you did very well, by the way—you did not know what we wanted you to do today; is that correct?

MR. BRONSTEIN. Well, my office has made four calls to counsel in the last 3 weeks to find out, other than AIDS in prisons, specifically what we were going to talk about, and we were unable to reach him or get a return call with any information from counsel. It took us three calls just to find out where and what time this hearing would be held, and we never got the letter we were supposed to get confirming our appearance and describing the hearings.

CHAIRMAN PENDLETON. Did you have that problem, Mr. Havel or Mr. Travisono?

MR. TRAVISONO. Unfortunately.

MR. HAVEL. As to the general subject nature of the hearing.

CHAIRMAN PENDLETON. Does counsel want to make any statement? We have a record here that we didn't contact someone. Do you want to clear the record?

MR. FUMENTO. Mr. Bronstein and I talked a couple of months ago. I thought it was definite, but apparently I was mistaken.

And Mr. Travisono and I also did talk much more recently.

MR. TRAVISONO. But we expected a letter to come to confirm this whole thing, that's all. We had no letter.

CHAIRMAN PENDLETON. Well, we want to thank you for coming, and we are glad you were able to talk to us about where things are because of your interest in these matters. I just wanted to make sure whether we had a problem with communication here. Now I understand and hope that wasn't too inconvenient for you, and we appreciate your coming to spend time with us and give us your testimony.

I just have, I guess, one question, and it even goes to Mr. Rideau who is there [indicating telephone].

How are the civil rights of AIDS victims in prison protected? We just read a story here in the *Washington Post* about New York on Saturday, and Mr. Rideau talked about people don't last very long sometimes. This information here indicates that once they find out that somebody has AIDS, they first throw water into that person's cell, and when he is not there, if that doesn't work they burn out the cell.

I'm trying to find out how are AIDS patients in prisons—and if that's the same case in mental institutions, how are their civil rights protected in terms of, I guess, equal protections? They are prisoners. I realize they are in a confined environment, and you indicated that there can't be that much isolation because you don't have the resources to do that, and that creates other problems. But can you tell us something about what happens?

MR. BRONSTEIN. I can, Mr. Chairman, and what I say is not in any way to be construed as suggesting that prison officials are being evil or malevolent or unwilling to do what is right. The problem is that their resources are generally as overtaxed as can possibly be, and in some cases they are directed by their legislatures to do things which are contrary to their own beliefs.

Let me give you a specific example of how civil rights are handled in one State, Alabama, where the State legislature passed a law requiring the Commissioner of Corrections to test every prisoner coming into the system and to test every prisoner then in the system, against the Commissioner's own beliefs and against CDC suggestions. The legislature also required that the Commissioner segregate every person who tests seropositive, and that's what they're doing.

The result of that is that both women prisoners and men prisoners in Alabama who have tested seropositive—and there are about 90 of them—are housed in very, very punitive segregation units. When they move they're put in restraints as though they were people who had done terrible things, although unrelated to any disciplinary problems. The medical care is abominable because most of the staff—low-line staff—who have not been sufficiently educated, are concerned about providing medical care. So you have what I think is a gross abuse of their civil rights. That issue is being tested in court.

To the contrary, States like New York, which has a huge population, and a huge population which suggests that they have a high-risk population, given the fact that 70 percent of the prisoners in New York State today have a history of IV drug abuse, and they have reportedly the highest number of seropositive cases, the highest number of AIDS cases, the highest number of deaths from AIDS.

By the way, the correct update, if I may correct Mr. Travisono's figures, our national study is more current than his last one. As of April '88, there

were 1,650 cases of confirmed AIDS in prison. And mass testing—13 States do it.

In any event, in New York the Commissioner there, contrary to that story you saw in the paper, at least from a policy point of view, tried to protect the civil rights of the prisoners. They try not to segregate, unless there is some other good and sufficient reason. If you have a prisoner who is seropositive, and there's a history of predatory behavior, it would segregate that person, irrespective of whether they had AIDS or not.

They are trying to provide the best medical care. They try, whenever possible, if there's a full-blown AIDS case, to move the person out of the system. Mother Theresa has a hospice specifically for AIDS patients in the New York State correctional system. There is also a hospital in New York City which takes prisoners from New York State, when they are fairly seriously ill.

So there are many States that are trying. The numbers, the sheer overcrowding, is what creates an awful lot of the violation of civil rights.

CHAIRMAN PENDLETON. Mr. Rideau, you heard what Mr. Bronstein said. How do you feel about that?

MR. RIDEAU [via telephone]. Again, I just caught snatches of it.

CHAIRMAN PENDLETON. He is really saying that the overcrowding conditions in prisons in many cases cause—I hope I'm saying it right—the violation of prisoners' civil rights with respect to them being seropositive or having full-blown AIDS—that their civil rights really aren't protected because of overcrowding conditions or the resources available to correctional agencies; is that correct?

MR. BRONSTEIN. That plus the impact on correctional officials of the so-called policymakers who don't have to run these difficult institutions but who make these bizarre policies, like the South Carolina legislature I mentioned before or the Alabama one, which direct them to do things.

CHAIRMAN PENDLETON. This is also saying that policymakers don't care who goes to prison as long as they go to prison. They've satisfied their obligation, and the prisons are apparently saddled with people who might have a series of debilitating or social conditions. Do you want to react to that?

MR. RIDEAU [via telephone]. What he says about policymakers essentially is true, except here in Louisiana our corrections officials have been crying in the wilderness for the past decade pleading with the public and the lawmakers to stop sending everybody to prison.

What he says is essentially true. The public wants people locked up, and they generally don't care what happens afterwards. But the overcrowding condition adds an extra dimension to the normal situation, and it's a problem. It compounds everything, because it imposes on what usually are just meager resources. Particularly here in Louisiana we have a situation where the State is broke, and to do mass testing, who the hell is going to

pay for it? I mean they can't afford it. They're cutting education, health services, and everything else in this State.

But it's not always that. I don't know what the situation is in New York, but I recently read a report about AIDS cases in New York, where they revealed that infected prisoners there live half as long in prison hospitals as those free on the outside. It's a report that points to the possibility of deficient medical care provided for them.

Now, let me tell you this about prison medicine. Prison medicine—and I guess it's the same way everywhere else, but it's more than a matter of technology and money and ability to do it. The delivery of it rests primarily upon the attitude of the deliverers more than anything else. And when you're talking about AIDS, remember a lot of medical people in your world don't want to treat AIDS patients.

Now, the flip side of that is, keep in mind that in today's America prisoners are generally a despised class of people. We're the new social lepers. There is so little empathy. So attitude has a lot to do with it.

I'm not going to say—I'm not agreeing with him entirely but I'm not going to put all the blame on overcrowding. We can stretch that out. It's like you've got a lot of penal administrators who say they can't control the violence in their prison, but yet it took the bloodiest prison in the Nation, which was right here at Angola 10 years ago, and they made it the safest maximum-security prison in the Nation.

My position has always been that any time a penal administrator says he can't control violence or he can't do this or can't do that—that's an excuse. In fact, corrections is the only field of endeavor in the United States where they've got a readymade excuse—I mean they're not accountable. They can excuse failure. My position has always been, to give an excuse, you should be fired.

CHAIRMAN PENDLETON. Thank you, sir.

Mr. Travisono.

MR. TRAVISONO. To further your question, we recommend education, as most people do, to try to understand this problem. But when you get into an environment such as a prison, and when you don't have a nationalized standard of education where we are trying to develop one, it is very difficult to have everyone be on the same wavelength. You take inmates—they are all different from one another. There is no such thing as a prisoner all looking the same. They are different people, each with his own understanding, each with his own level of education.

So it gets to the point if you want to believe what the authorities are telling you, then your behavior immediately improves. If your behavior and your thought process says you want the worst to happen and you don't want to be influenced by education, then we're going to have some of the things happen in every prison in the Nation that you read about in New York, because that's the nature of how it is inside of particularly male

institutions. So you have that major problem to deal with. Education is a significant component. But it is not equal across the land. And unless we have it equal, we won't have this equal protection in any given way.

The scare tactic still lives and breathes in a community of prisons by prisoners, and in some instances by a staff. That's going to take a long time to erase because we began this whole process of AIDS education through scare tactics.

CHAIRMAN PENDLETON. How about mental hospitals, Mr. Havel?

MR. HAVEL. Mental hospitals are very dangerous places many times. People can be assaulted. We get continual reports of people committing suicide because they are unsupervised. Sexual abuse occurs. The whole range of abuse and neglect that you find in correctional facilities you also find in the mental hospitals. And, again, much of that is attributed to the inadequate staff, and the fact that staff is frequently overworked and underpaid.

But just as we would not urge any discrimination against AIDS victims within the confines of a mental institution, so we would generalize the problem of protection of human rights, and not advocating anything specific for persons with AIDS and that nature, but say we need to address the problem for all persons who are in institutions.

CHAIRMAN PENDLETON. Let me try one more thing here. We are talking about adult correctional facilities now.

MR. BRONSTEIN. Which house many people who are not adults.

CHAIRMAN PENDLETON. Right. I was going to ask you that point. The other point is: What is your experience, even with mental institutions, for adolescents? Is there any information about that at all? It looks like now where we are increasing the IV drug use among adolescents for all kinds of reasons. Can we look forward to an increase in AIDS transmission or admission of AIDS or seropositive persons to youth correctional facilities or to adolescent mental health institutions?

The other part of my question is this: What happens with all of this 5 years from now, if what we hear from the transmission people that the chances are moving from being seropositive to full-blown AIDS—it looks pretty good—then what kind of epidemic are we looking at around 1991 and 1992 in the prisons and mental institutions as well as everyplace else if you want to talk about that?

MR. BRONSTEIN. In answer to your second question first, I think with respect to prisons you are looking at a crisis of enormous proportions. We know that there are very large numbers of people in institutions today who are seropositive. We know there are many who are in the dormant stage who will test seropositive over the next few years, and I think you will have that, combined with the overcrowding, creating a problem that Mr. Travisono and his colleagues are going to find extraordinarily difficult to manage.

With respect to the youth facilities, that is something that has just begun to get the attention of the various authorities and the health authorities, and they are beginning to recognize that there may be a very serious problem of infection among facilities housing kids between 15 and 21 or 15 and 22, which are generally youth facilities or younger offender facilities, and some controlled confidential testing is beginning to take place to see what the rate of seropositivity is. I suspect it may be as high, if not higher, than some of the adult facilities.

CHAIRMAN PENDLETON. Just one more question, and then my colleagues want to ask some questions here.

Let me ask you this: In your estimation, especially in the prison population, is there kind of a rap on AIDS people as there is on child abusers and the like when you go to prison? Child abusers, as I understand it, are pretty much marked once they go because there does seem to be some ethic about that.

What is the ethic, if you can tell us, about AIDS, full-blown AIDS people, not the seropositive people? Or do full-blown AIDS people go to prison and we don't know it? What is that situation?

MR. BRONSTEIN. Well, 1,650 have died in prison so they're there. They may not go to prison with full-blown AIDS, although there have been some cases of that, but they develop it.

I think Mr. Travisono ought to first take a crack at the other question. I'm sure we'll agree on the answer.

MR. TRAVISONO. They are at the bottom, there is no question about it. The crime is at the bottom, and the child molester along with the person—the person is at the bottom if he is suspected of having something—little difference.

But I don't think a major tradition has moved into the system yet, because the numbers aren't there. So you have, say, the drug abusers in New York. They are drug abusers to begin with. A certain number of them have contracted AIDS. The others haven't heard the news yet. So there may not be as strong a power as there was with child molesters.

MR. BRONSTEIN. You see, paranoia and hysteria take over. Two years ago a prisoner died in Mr. Travisono's old system, the Rhode Island system, of AIDS. I got a call about 6 hours after that from the *Providence Journal,* the largest newspaper there, asking me to comment on the epidemic of AIDS in Rhode Island's prisons.

And I said, "What epidemic?"

He said, "Well, we have 31 cases of full-blown AIDS and hundreds of people who are seropositive."

It was one case of AIDS, and they didn't know who was seropositive because they weren't testing. But by the time the information passed on, it was an epidemic.

And that is true of correctional officers, particularly line staff, as well as prisoners.

CHAIRMAN PENDLETON. I want to do a lot more, but I want to yield to my colleagues.

COMMISSIONER RAMIREZ. I would like to clarify one point. I thought I heard Mr. Travisono say that there was not one case of AIDS transmission within prisons, that there was one case that was referred to but he believed that that transmission had occurred outside the correctional institution. So if AIDS is not being transmitted in correctional institutions—

MR. BRONSTEIN. They're two different things.

COMMISSIONER RAMIREZ. No.

MR. HAVEL. Yes, they are.

MR. TRAVISONO. Yes, they are.

MR. BRONSTEIN. You have two different things. Not one known case, but AIDS is being transmitted. They just haven't turned seropositive yet.

COMMISSIONER RAMIREZ. They haven't tested it.

MR. BRONSTEIN. That's right, or even become infected. It can take years while the disease grows and then shows.

COMMISSIONER RAMIREZ. Yes, but transmitting the virus—you're not equating transmitting the virus with transmitting the disease. Is that the difference?

MR. BRONSTEIN. No.

MR. TRAVISONO. No, I am suggesting, by CDC and others that have looked at this, that we have yet to confirm one case of transmission from one inmate to another while they are both in prison.

MR. BRONSTEIN. But we know that it is happening and has happened. They just haven't tested positive yet. It can take from 4 months to years before the incubation period is over and seropositivity occurs.

COMMISSIONER DESTRO. In other words, it's safe to assume that transmission is taking place—

MR. BRONSTEIN. And has taken place.

COMMISSIONER DESTRO. —but just has not shown up yet.

MR. BRONSTEIN. That's right.

COMMISSIONER RAMIREZ. Let me clarify the numbers again. You said there were 350 more or less cases, and you say there are 1,600—

MR. TRAVISONO. It's 1,300 as of October last year, and he's got his April figures.

MR. BRONSTEIN. April '88.

MR. TRAVISONO. And then 600 in the major jails.

COMMISSIONER RAMIREZ. Now, you also said that the AIDS, the illness, rather than the testing positive for the virus, was overwhelmingly Hispanic?

MR. TRAVISONO. Yes.

COMMISSIONER RAMIREZ. Do you have any explanation for that?

MR. TRAVISONO. No, I don't. They are mostly from New York City, and the courts have sent them. I don't know whether that translates that Hispanics are using and being caught quicker than others or not, but I'm talking basically—

CHAIRMAN PENDLETON. You mean being caught with the virus or being caught and put in jail?

MR. TRAVISONO. Put in jail, charged. Of the 300 cases that were there a few months back, I think 280 were Hispanic.

COMMISSIONER RAMIREZ. But that would not correlate to the presence of the illness among the general population.

MR. TRAVISONO. No.

COMMISSIONER RAMIREZ. Blacks and whites have—what are you comments on that?

MR. BRONSTEIN. Our information is a little different. Our information, as of April '88, is that New York State shows 45 percent of their prisoners with AIDS are Hispanic, and 45 percent are black. In Ohio the numbers aren't big enough. In Texas, a total of 64 cases—24 white, 34 black, and only 3 Hispanics.

I think what it says is that it is directly related to numbers of people who are coming in with a history of IV drug abuse. You have a big Hispanic population in the Texas prison system but very small numbers of them who are IV drug abusers. In New York State, you have a large number of Hispanics who are IV drug abusers.

California is another State. They don't break it down, however, between black and Hispanic. We don't have that.

The only other data I have, if you might be interested in it, is that the rate of incidence of women prisoners with AIDS is very, very low, even though there is a lot of very high incidence of IV drug users.

COMMISSIONER RAMIREZ. Getting back to the issue of transmission within prisons, at this point you would have no reason for implementing segregation policies, for example, or any other punitive policy on the basis of transmission, because you don't know what transmission is occurring; is that correct?

MR. TRAVISONO. That's a thought. It's not necessarily a reason.

COMMISSIONER RAMIREZ. Do you agree with Mr. Bronstein that once AIDS is identified, that the individuals are treated punitively by the system?

MR. TRAVISONO. In some systems, yes, that is correct. It is either State-mandated by law or a policy of the department. But it is not nationwide.

I think we have to continue to segregate seropositive versus illness. Once an illness is detected and AIDS symptoms show up, those men and women are transferred to hospital settings. They are not kept in punitive in any place in a prison system, to my knowledge.

CHAIRMAN PENDLETON. Just let me ask you this: I have read Mr. Rideau's letters and the like. He is a little bit more—

MR. BRONSTEIN. —conservative.

CHAIRMAN PENDLETON. Yes, and descriptive about what goes on. And I assume you have read his material.

MR. BRONSTEIN. Yes.

CHAIRMAN PENDLETON. Anyway, can we wind up with a crisis in the correctional system and in mental institutions that's similar to the crisis that's a microcosm of the broader society? Is that correct?

MR. TRAVISONO. I think so.

CHAIRMAN PENDLETON. I'm not reaching too far with this one?

Then it looks like we don't really know what to expect, except the worst, 5 years from now or less. And then the social and financial costs of treating that might be more than we heard this morning in terms of dollars.

When I asked that question of Dr. Fauci, he indicated that the lost revenue costs, or the loss in productivity costs, could be somewhere between $20 and $50 billion; that is, people that don't have jobs, people who are incarcerated, people who can't go to work, people who have exhausted all their employment and insurance benefits, and this gets to be mostly a public cost. When you weigh that against what other public costs might be, we are in difficulty.

Would the panel agree or not agree?

MR. BRONSTEIN. I would agree.

MR. TRAVISONO. I would agree.

MR. BRONSTEIN. By the way, that's in the context of already vastly expanding budgets for correctional departments because of a variety of circumstances, including the overcrowding.

CHAIRMAN PENDLETON. Well, in my State of California, we are always fighting. I mean, I live in San Diego, and there's always this hassle about the bond issue or the no-bond issue, and whether or not we can raise the money out of general funds, or do obligation bonds—I'm sure you know all about that.

MR. BRONSTEIN. I can tell you, sir, the politicians in California are mortgaging your future and that of your children and grandchildren with their current prison expansion plan. They are spending $2.8 billion, which will cost them $8 billion to finance, and they are planning more of that, without even the operating costs. They will not be able to run their schools in 10 years because of the cost of their prisons.

CHAIRMAN PENDLETON. What is the cost of building a jail—cell cost? Is it about $40,000 per cell?

MR. BRONSTEIN. That's low.

MR. TRAVISONO. It's $80,000 to $100,000.

CHAIRMAN PENDLETON. To build a cell?

MR. TRAVISONO. To build a maximum-security cell. To build a medium-security cell, we're talking $50,000 to $60,000.

CHAIRMAN PENDLETON. That's a little bit more than we spend for a luxury hotel in downtown New York.

MR. BRONSTEIN. Then you have to multiply the building cost by four to figure out the debt financing—still not operating, just financing the debt on that $50,000 or $80,000.

CHAIRMAN PENDLETON. What is the operational cost per cell per year?

MR. TRAVISONO. It's about $16,000 a year.

COMMISSIONER DESTRO. Per prisoner?

MR. TRAVISONO. Per prisoner per year.

CHAIRMAN PENDLETON. If we took your $16,000 figure, we can multiply that by—

MR. BRONSTEIN. —570,000 in the State and Federal system.

MR. TRAVISONO. No, 600,000.

CHAIRMAN PENDLETON. Six hundred thousand with AIDS in the Federal system?

MR. BRONSTEIN. No, no.

MR. TRAVISONO. Prisoners, gross prisoners.

CHAIRMAN PENDLETON. You mentioned how many have AIDS?

MR. TRAVISONO. We have about 2,000.

CHAIRMAN PENDLETON. So 2,000 times 16,000, times the number of years, gives us a pretty good figure, doesn't it? $32 million, my calculator over here says.

MR. BRONSTEIN. Of course, conversions are taking place all the time. The numbers of people who are seropositive and converted to AIDS between the last two surveys is quite an important number, and it's growing.

CHAIRMAN PENDLETON. I'm sorry to be long, but I'm trying to get to a point of public cost in these things.

What about your institutions, Mr. Havel?

MR. HAVEL. I wish, Mr. Chairman, I could agree with your view of offsetting costs as it relates to the mentally ill.

CHAIRMAN PENDLETON. What kinds of costs?

MR. HAVEL. The offsetting costs. But the reality is that for most persons with mental illness, they are unemployed. They have long since exhausted their insurance coverage, if they ever had it, so a lot of those kinds of offsets are just nonexistent.

CHAIRMAN PENDLETON. Yours is going to be a public cost.

MR. HAVEL. That's right.

CHAIRMAN PENDLETON. Bob.

COMMISSIONER DESTRO. I'd like to address my first question to Mr. Rideau and tell him at the outset how informative his articles were.

What I would like to ask you is the degree to which you perceive, as an inmate, the amount of high-risk behavior going on in the prisons. What would you say is the amount of high-risk behavior going on?

MR. RIDEAU [via telephone]. Keep in mind I can only speak about the Louisiana State Penitentiary.

COMMISSIONER DESTRO. Understood.

MR. RIDEAU [via telephone]. Contrary to popular perception, the majority of the prisoners here at the State penitentiary do not engage in homosexual activity, and this would have to be an assumption on my part. The highest risk would have to be drug abusers, and that is merely a subjective assumption on my part, because the level of homosexuality is pretty low.

But we have had five deaths over the past several years here in Louisiana of AIDS-infected prisoners. Only five people have died. Two were black, three white, and four of them were drug users. As Mr. Travisono pointed out—and it's the same here—all of them were believed to have contracted the disease prior to entering the prison system. In fact, even here at the penitentiary we have a surprisingly low incidence, at least to the extent that anybody knows because there is no mass testing or anything like that, but we have a surprisingly low number of inmates who test out positive.

When we did an article back in July and August last year, we found that there were approximately 38 or 40 here at Angola, and once they were doublechecked to make certain, less than 15 percent of that number were found to remain positive. The rest were false positives.

So it is surprisingly low here, and the people at least who are known to be positive or suspected to be positive are all new people. It's the new prisoners who are bringing the virus into the system. The people who have been here for any length of time don't have it.

So, there is no transmission—well, I'd better not say that. Nobody knows if there is any transmission because current medical policy is to keep the identities of the people who test positive secret, and they integrate them into the prison. Nobody knows who they are. So whether or not they are transmitting AIDS or not is something we are going to find out at some point in the future.

But one of the things I'd like to point out is the biggest problem, more than anything, is the fear of AIDS. I heard someone mention about education and all that, and I spoke about it earlier. We are all educated. They educated literally everybody here, both employees and inmates. They force-fed it. They made it mandatory. And we know it; everybody knows it.

But in the two instances I know of here at the prison, two people suspected of being AIDS-infected, the reaction was unreasoning fear. What you've educated them to do—they observe all the precautions that

the Surgeon General and everybody says to do, and if they're going to catch AIDS they're not going to catch it that way.

But there is that unreasoning fear—and that's what I was talking about earlier—you know, they don't want to gamble. How do you know that the medical community is not going to turn around next week and say, "Well, the virus is a little more complicated than we thought. You can catch it another way."

These guys just don't want to gamble, and for the most part—mind you, I'm not advocating mass testing, because the tests are too unreliable, as our experience here has shown, and I'm not advocating segregation or integration. That's a problem you're going to have to deal with and other people are going to have to deal with.

But the corrections authorities and medical authorities see no value in mass testing and all that, and the flip side of the coin is all the prisoners that I know of and all the inmate leaders that I know of want everybody tested and segregated. You have two opposing perspectives there, but the prisoner's reaction is one of fear. And right now the way the authorities are handling it, one guy is locked down, as much for his irresponsible behavior as for protection from the other prisoners. The other one is in a trustee housing unit. In fact, he's in my dormitory, and he is allowed to live among the rest of us. He's just suspect. Nobody knows for certain. But he has all these sores on him.

But I'm straying away from the question. Like I say, I'd have to assume it was from drugs, not homosexuality.

COMMISSIONER DESTRO. Thank you very much. That was an informative answer.

Mr. Havel, you made an interesting comment about the deinstitutionalization problem or, I should say more appropriately, the problem facing deinstitutionalized people and how, as long-term commitments have gone down, short-term commitments have gone up.

Now, you appeared to see that as being a negative. My question to you is: With respect to the most vulnerable people in our society, to my mind it is not as much a question of their rights as it is a question of what duty do we owe to them, and what kind of a policy would you suggest with respect to the mentally ill that would both take into account their need to be free to the extent to which they can take care of themselves, and their need to be institutionalized and at the same time be protected against the threats to their health posed by this health problem.

MR. HAVEL. If I left the impression at all that I saw those trends as negative, then I need to correct myself, because we are strong supporters, as an alliance—and I am personally—of the idea of community-based care. I guess I hold negative feelings towards the process of deinstitutionalization, which has resulted in taking people out of the back wards and onto

the back streets. I think that has been unacceptable to us, but that has been one of the consequences.

What we need in this country is an opportunity for individuals to remain within their communities and live lives with dignity and opportunity. And that exists almost nowhere in America for a person who is mentally ill. So I have very strong feelings about that.

The short-term stay, though, does impact upon your policy deliberations, when you look at mandatory testing, for example, because individuals will go into an institution. If they are tested upon admission, they may be gone long before you get the test results back and know what they mean. Individuals may be, as part of their therapy, released to home visits and have opportunity to make contacts which would infect them with HIV. And the question we ask ourselves is: How many times do you have to test an individual in a mental institution? Do you test them when they come in? Do you test them when they go out? Do you test them every time they take a leave? Do you test them whenever they walk around the grounds?

Certainly we don't want to leave them in confinement in the mental institutions so they have no liberties at all. We believe it ought to be a therapeutic environment, one which helps them to restructure their lives and reenter society. So we think mandatory testing is inappropriate and impractical.

CHAIRMAN PENDLETON. Thank you very much.

Ms. Prado.

MS. PRADO. Mr. Havel, I'm sure you've seen on a local channel the series—I've only seen one—showing abuse of the mentally retarded, which I know is slightly different from what you are representing, but the problem it seems to me is no less different. And I assume the inference is clear that the reporter is suggesting that the retarded men who were abused have contracted AIDS from the caretaker of the home that they were placed in. I did not see the whole series, so I don't know what conclusions they came to or what they were advocating.

But could you comment on that very quickly? You raised it earlier, the potential of abuse and what you think should be done about this.

MR. HAVEL. I think there are many fine adult foster care homes in the country. I think there are also a large number that constitute a national disgrace.

When I was with the Oregon legislature, for the first time in the State's history we passed licensure legislation. Prior to that we didn't even known where those homes were and who was taking care of individuals. We simply placed them out in the community and forgot about them. We had many, many instances reported to us of sexual abuse, of confiscation of personal property of residents in the homes, of opening of mail, of

compulsory attendance at church, or whatever it might be, but it was one abuse after another of a person's civil liberties.

As part of the consequence of the cutback in funding for social services, one of the first things you do, instead of monitoring a facility every year, you monitor it every other year, and pretty soon you're monitoring it every 3 years. And as that kind of a plan to govern intervention to insure quality takes hold, you find a diminution in that quality, a very significant diminution, because there will always be people out there who will take advantage of opportunities to make a quick buck at somebody else's expense. And the mentally ill and the mentally retarded are two of the easiest marks in town.

CHAIRMAN PENDLETON. Thank you very much.

COMMISSIONER RAMIREZ. I have one question I really would like to have Mr. Havel address very quickly. It has to do with the fact that this morning we consistently heard testimony about voluntary acts, voluntary behaviors. And as I listened to you, I kept thinking about a relative who is in a mental institution, who is clearly incompetent to protect himself, and whose acts probably would not be judged as voluntary in the traditional sense of the word.

We also consistently hear about education—education of the individual, the exercise of responsibility, et cetera, et cetera.

It seems to me that the issue of what we do in mental institutions at first blush for me is a very difficult one in the sense that you may have two individuals who are not responsible for their acts, and the question of protecting both from their acts. How is it that you reconcile issues of both civil liberties, civil rights, in that kind of a situation?

MR. HAVEL. Not easily. It's a very, very difficult issue. We wrestled with that, particularly in terms of consensual sexual activity. Ultimately we came down on the side that most mental institutions now have policies and procedures in place which, on a theoretical basis at least, address the issue of consensual sexual activity among patients. Where it does occur, and it's inappropriate in a therapeutic context, it occurs because of the inadequate staffing. And rather than addressing one evil by creating another, that is, by segregation or isolation or some other means that would seem to be to us to be more deleterious in the interests of the mentally ill, we believe you need to advocate for adequate staffing in the institutions and adequate supervision and adequate therapy.

CHAIRMAN PENDLETON. Thank you very much, panelists, and thank you for coming to spend time with us. In spite of our communications difficulties, we had a good panel, and thank you for spending time with us.

We will have our next panel after a 5-minute break. If you will assemble, shortly I'll swear you in, if they're all here.

[Recess.]

[Dr. Herbert Nickens, Sunny Rumsey, and Elvira Rosales Arriola were sworn.]

CHAIRMAN PENDLETON. Our final panel for the day is on the impact of this epidemic on minorities. We have three well-qualified people to speak to us this afternoon, and we can start with you, Dr. Nickens. Go right ahead. Take about 8 minutes or so and summarize, and then we'll have some questions from counsel and questions from my colleagues.

Panel IV: Minorities

TESTIMONY OF HERBERT NICKENS, M.D., OFFICE OF MINORITY HEALTH, U.S. PUBLIC HEALTH SERVICE, WASHINGTON, D.C.

DR. NICKENS. Thank you for the opportunity to testify here today.

The Office of Minority Health was created to oversee and to insure the implementation of the report of the Secretary's Task Force on Black Minority Health. That 1985 report provided the most exhaustive documentation ever done of the health status disparity in America between Asians, blacks, Hispanics, Native Americans, compared with the white population.

I'll give you an example. Of the 140,000 black Americans who die on average every year prior to age 70, about 59,000 or 42 percent would not die if black Americans had the same death rates as white Americans.

As a generalization, minority Americans die from the same causes as do white Americans, only more so. About 80 percent of excess deaths among minorities are from just six causes: cancer, cardiovascular disease and stroke, chemical dependency, measured by death due to cirrhosis, by the way—we don't have to worry about the other drugs to kill plenty of people; diabetes, infant mortality, and violence.

The full task force report runs about 3,000 pages. The magnitude of the minority health problems detailed by the report, as well as the large number of recommendations it contained, made it clear that some implementing mechanism was required. The Office of Minority Health, or OMH, was created in December 1985.

For a variety of reasons, the task force report did not include a discussion of AIDS. However, soon after the office was organized, the data made it clear that AIDS must be added to the other six causes of death with which OMH is concerned. However, from our perspective, AIDS is but one of a cluster of severe health challenges that confront minority Americans.

In the Office of Minority Health, we believe that health education and empowering minority communities around the issue of health is essential to both amplify the salutary effects of the health care system as well as to blunt the adverse health effects of poverty.

In order to achieve this, we believe the direct funding of community-based organizations with technical assistance as appropriate is a powerful tool to improve minority health. AIDS, albeit in a compressed time frame, presents similar challenges and requires similar solutions, as do the other so-called Big Six causes of death.

For the Office of Minority Health, the following considerations shape our view of the problem with AIDS in minorities:

1. As you know, blacks and Hispanics are disproportionately represented among persons with AIDS. However, AIDS among whites overwhelming occurs among homosexual or bisexual males. On the other hand, among minorities, homosexual or bisexual males represent the most common mode of transmission, but only about half of current AIDS cases among minorities.

Transmission through the sharing of needles and works and heterosexual spread are also very significant. As a result, among minorities, AIDS is also a disease of families—men, women, and children. Therefore, the behavior change challenge required for effective prevention is by orders of magnitude more complex.

2. It is true that persons who contract AIDS do so because of behaviors, not because of membership in any racial or ethnic group. However, in organizing response to AIDS, we must recognize that racial and ethnic considerations are powerful determinants in our society and must be explicitly factored into proposed solutions to the AIDS problem.

3. Having said this, stigma and discrimination are a constant danger, especially when one combines minority status with AIDS.

4. Our national minority AIDS prevention strategy should utilize the analytic and communicative techniques developed by the advertising industry, including but not limited to identification of and research on market segments, which include variables such as race, ethnicity, language preference, age, sex, and HIV transmission risk groups.

5. Indigenous minority institutions and leaders are essential to credible communications and must be empowered and trained regarding health in general and HIV infection in particular. Examples of such institutions are churches, schools, fraternal organizations, as well as other community-based and national minority organizations.

6. More traditional public health related agencies and organizations—for example, public health departments, hospitals, health professional and voluntary organizations—must be encouraged to become full partners with those minority institutions described above.

7. Particular attention must be paid to achieving behavior change among intravenous drug abusers and their sexual partners. Otherwise, without an effective treatment or vaccine, this group could provide a permanent HIV reservoir.

8. Finally, many of the same organizations and efforts described above must also be enlisted and empowered if a rational and humane HIV infection service delivery system, which effectively serves minority populations, is to be constructed.

These eight considerations shape the Office of Minority Health AIDS programs as well as shape the input we provide to the department as a whole on the problem of AIDS in minorities.

In the time remaining, I will summarize quickly the Office of Minority Health AIDS programs and activities.

In the spring of 1987, the Office of Minority Health convened a small group of minority professionals on the front lines in the fight against the HIV epidemic to advise us regarding the specific needs and problems faced by minority populations.

In June of 1987, the Office of Minority Health organized a minority leadership forum on AIDS, which brought together three groups for a 1-day meeting.

First, the leaders of about 40 national minority organizations; second, HHS officials; and, third, minority professionals who work daily with the problem of AIDS. This meeting provided a trialogue as well as revealed a substantial amount of activity and interest in AIDS on the part of these national minority organizations.

In August 1987, CDC, who had also cosponsored the June meeting, and OMH, cosponsored the meeting, "AIDS in Minority Populations in the United States" in Atlanta. This meeting drew over 1,000 people and was a watershed in expanding interest and an awareness of the minority AIDS issue. At the meeting, Asian, black, Hispanic, and Native American caucuses prepared lists of concerns, which served to open bilateral communications.

In addition, OMH has provided small amounts of funds and/or technical assistance to a substantial number of minority organizations around AIDS. Two examples are the Southern Christian Leadership Conference, SCLC, and the Coalition of Hispanic Health and Human Services Organizations, or COSSMHO.

Now, in fiscal 1988, Congress appropriated $1.5 million within fiscal year '88 funds to the Office of Minority Health to, quote, "assume a more active role in the AIDS epidemic, specifically with regard to targeted education." And with that money we plan to do the following things:

We are going to give some HIV infection education and risk-reduction grants. We are planning to support HIV infection education and risk-reduction programs through small grants to minority community-based organizations, coalitions of community-based organizations, and national minority organizations.

The second thing we are going to do is technical assistance. We recognize the need to build the capacity of minority organizations to

design, implement, and evaluate the effective prevention-intervention programs. OMH is planning a technical assistance effort which will be in a central part of our program. We intend to provide direct technical assistance to potential grantees, and in addition we will hold or have held a series of seven grantsmanship workshops around the country in seven different cities. They will be finished by June of this year.

Finally, we are going to do a model program evaluation. There is evidence that community-mobilized HIV infection education and risk-reduction programs have been effective in changing behavior to reduce risk for HIV infection among gay populations. However, little is known about effective risk-reduction strategies for minority populations. OMH plans to review and evaluate various HIV infection, education and risk-reduction programs throughout the country that target minorities, and identify the central components of successful programs.

In closing, AIDS, unfortunately, is affecting minorities disproportionately, and AIDS is itself a stigmatizing disease. Therefore, we are confronted with a volatile combination that invites exclusion and discrimination. The quality of our civilization is being sorely tested, and history will judge us harshly if we are found wanting.

Thank you.

CHAIRMAN PENDLETON. Thank you, Dr. Nickens.

Ms. Rumsey.

TESTIMONY OF SUNNY RUMSEY, OFFICE OF AIDS RESEARCH, NEW YORK CITY DEPARTMENT OF HEALTH, NEW YORK CITY

Ms. RUMSEY. My name is Sunny Rumsey, and I'm the project coordinator for AIDS outreach for the New York City Department of Health. We have 15 units throughout New York City, distributing an average of about 20,000 pieces of literature in a given month, providing technical assistance and presentations to these diverse populations. So what I'm going to talk to you about today is the responsive AIDS from the community's perspective, and maybe just give you some things to think about.

In making the laws and policies, we need not just tell the various ethnic groups our policy, but listen to these communities and hear or feel how they see the issue of AIDS. It is quite different from the official story.

We must realize that many of these groups that we are trying to reach do not believe us nor do they believe the message we are giving them. They have already fallen through the cracks of our society, and again they fall. Between the combination of AIDS infection and the overuse of drugs in many of these communities, and in particular crack, we are witnessing the absolute destruction of some of our cultures and the inability of some of these cultures to go on into the year 2000 because of this infection rate.

I wish to highlight the current feelings and trends within the various minority communities and talk about how they see it, which may be sometimes differently than how we are looking at the issue, and how for the most part—if they are ill-prepared in large cities such as New York, you can imagine the effect this will be on smaller communities, which are not even beginning to address many of the issues that we are seeing happening all at once in the city.

In defining minorities, I will not give it the most narrow definition, which most of us think of only by color of your skin, but I will expand it further to understand that there are many ways of looking at minorities, and to understand that there are many different levels of minorities; that there are minorities within minorities, and they overlap depending on which issue we are talking about, and many things in particular around AIDS.

So when we are starting to look at the policy of minorities, I will not define it just by race but also by age, by sex, by region, and religion, sexual preference, and also language barriers, because all of these things combined impede them or restrict them from hearing the message that we are giving.

There are many different issues that we are talking about now that are affecting the minority community that they have actually had very little say in. So I will just highlight some of them.

One of them is around the issue of testing and who it will affect more. Right away we must understand that although we set up a policy, we do not perceive it as being racist or discriminatory. The community does not necessarily see it in the same way. If you set up a policy that basically is affecting one particular ethnic group, then they see it as affecting them directly, not in a total sense.

An example around testing that we have in the military—I have had many soldiers who have asked me to come and give this testimony—that after they have been tested, many of them are asked to leave the service with a minimum amount of counseling being given to them. Some of them have been in the service for many, many years. Their pensions are in question. They are just completely ill-prepared to go back into the community to even discuss what has happened to them, especially if they have been career people. We have no place really to refer them once they get back on the outside.

Children that are in the foster care system—many policies right now around testing them—almost all these children are black and Hispanic, and therefore the community says, "Why do you test them? You're just testing them because they are black and Hispanic." And if we have other reasons we really do not define them clearly when we approach the community with these ideas.

Testing in prison in New York City and New York State—again, they see this as racial because over 85 percent of the men in prison right now are of color. I believe many of them are there not only directly from IV drug use but from crimes to support the IV drug use, and have serious problems in realizing that they themselves are not growing the drug in their community, and they feel that there has been a concerted effort to introduce the drug into their community. I then set up this scenario.

We want to do testing of prostitutes. On prostitutes, I think I need to explain that I see different levels of prostitution going on. I was giving a lot of technical assistance to madams who run houses who are working only with men that are in private industry or in government. These women 2 or 3 years ago had already set up the tone. They didn't wait on anybody else. They tested all their women. If they were positive, they were thrown out of the houses. They have very strict controls. The men who come into these places must use a condom. There is no discussion on this.

If we look at some of the women who have been out on the street or men who have been on the street for a while, I see that sometimes they carry more condoms than I do. You know, they'll open up a whole bag for me. So they are very much aware of the message and, if they can, try to control the situation.

The largest group with the least amount of control is the adolescent population, and in particular if they're out on crack. They are being paid more money not to use the condom, and I have yet to see a 5-foot-2 woman drag down a 6-foot-4 man and make him engage in sexual intercourse, and yet we put all of this on the prostitute and what are we going to do about her, not realizing that we're also going to have to deal with the other side of it.

Also, most of these prostitutes are not all women. A large percentage of them are men—boys, actually, many of them under the age of 15. If we look at these kids and see where they're coming from, all of them are not coming from a small city setting. Many of them are hooked up to what we could call some type of government agency, such as foster care or belonging technically to someone. They have completely fallen through the cracks.

As a 14-year-old prostitute told me, who made an average of $50 on a blow job, and more if she engaged in menage-a-trois, she told me, "Why should I give up this behavior? I am too young to even get a work permit to go to McDonald's and kill myself for $100 a week."

That is the logic they use, and therefore there is just too much money being made on the street.

Also the general economy we're looking at—the infrastructure is being pulled out in particular minority communities. We do not have programs. Many of these programs have dried up that we would traditionally send these children to learn whatever minimal skill there is.

Right now crack is the income of the minority community. And clearly when you have kids on the street who are being seduced through the media or through whatever method as to getting into this material lifestyle, how else do you think they will get into it when they can't even afford to make a minimum wage? They may have reading disabilities; they may have already dropped out of school; they're pregnant; they've already had children. They have no problem being employed in the crack industry. Many of these kids under the age of 14 or 15 who will not go to jail can get $200 or $300 a week just by standing on the corner telling somebody else that a police officer is coming by.

When we look at problems in our drug treatment programs, we see that there have been no facilities really being built in the last couple of years, so there is a tremendous overcrowding in some of them. With crack it has just absolutely aggravated the whole situation, because you have this absolute flooding now of already strained resources.

In particular, we also have a double-edged sword, because many of the counselors themselves are also at risk, so there is nothing to deal with death-and-dying issues for them. As they see many of their clients die, they see themselves in their client. It's just an absolutely horrendous position to put these people in to provide counseling, and yet, themselves, they have no counseling.

But it becomes increasingly aggravated because most of these facilities do not have any type of child care facilities set up for them, and if they do go into these programs they have to then sign their children away and many of them will not do that. Even though we perceive that these women don't care about their children, many times they care very much about them and will not go into these programs because they have several children; they do not have someone to take care of them, or their family members are far away.

One of the interesting things that we are seeing happening is that as these populations are getting sick, we realize that a large percentage of them do not come from the New York City area. Many of them come from the Caribbean Islands, and they want to go home to die. Or they come from different regions of the United States, and they want to try to desperately go back to this family that they might not have seen for 5 or 10 years, and yet there is no mechanism to allow this to happen. We will give these children, if they are abandoned by the parents or the parents become too sick to take care of them, we will pay strangers more money than we will pay family members.

One of the other groups that we have is grandparents in general. Many grandparents have said to me they want to take care of the kids, but if they are on public assistance or under SSI they will get their benefits cut back. And we do not allow for the fact that if they have two or three children to take care of, we expect somehow this 70- or 80-year-old woman, who is

living under whatever kind of conditions, to do the washing, do the laundry, not only for herself, and feed everybody, but to make sure everybody goes to different school districts, because sometimes these things happen very rapidly and we see that one kid is in Head Start around the corner, the other kid is 14 blocks away in a two-fare zone, and there is no one there to help this person straighten this mess out.

Also, for home health care, we see problems around that we have no one to take care of the minority community. Many times they are held in hospital situations for a long period of time because they cannot go back home, not because someone isn't going to be there to take care of them or because they don't have an apartment, but because they do need some type of care.

So we need to look at that issue. And to me one of the best ways of solving it is if you know you're not going to start going into the minority community, pay the minority community more money, and I think they will then be willing to take care of AIDS patients. Clearly if we start paying people minimum wage, we can't expect them to work between 12 and 16 hours a day, which many times is what the paraprofessional or home health aid is working. If you give them $7 or $8 and give them a little training, I'm quite sure they would be more than glad to make more of an effort.

So when we look at different policies, one of the other hot issues we see is around testing HIV women and also around advising them on abortion. Clearly women see this as a reproductive rights issue, which has been in the long line of many issues around this area, and yet for the most part it is being discussed by men and very rarely—not only not men of color but not even women are involved in this.

So there is a strong movement on the part of women to have more say in this. We do not make this policy around any other genetically transmitted virus or any type of material. Yet for some reason we have decided that for all women who are HIV positive, we should do something with them, not realizing that this transmission rate is only 50 percent, and we do not have support systems really in place in the communities to help them.

Another area that I just wanted to highlight quickly is the adolescent population. There are certain groups that we see isolated. Why I highlight them is that if we see this in New York City, clearly you will see this being played out all across the country, and you're just not going to be prepared for it because there is no place for these people to go to and deal with these situations as they arise.

In particular, isolated groups would include gay and bisexual men of color and women of color. Because of the homosexuality issue, there is tremendous resentment in the minority community toward these groups, even more so than they have against the IV drug community. So what we see happening is that they will stay in the closet a lot longer, do not

necessarily hook up to gay-related organizations that are existing in the city that could service them and would be more than glad to service them, so when they do appear and do seek treatment they are usually very sick at this point.

Sexually active adults that are residing in group home settings. Outside of YAI, which is a very large organization nationally, most of these programs do not have any policies set up to do sex education for the mildly retarded, the adult who is also sexually active. Many of these programs are headed by religious organizations who receive funding, and because it's a religious organization they will not give them information around using condoms and such, but that does not stop the sexual activity.

As one of the clients told me, "Why should I make $24 a week at Goodwill when I can make that much standing on the corner for 15 minutes."

And they are also a very high-risk group because people will seek them out, because everybody wants to be loved.

Another group would be siblings, older siblings who are watching not only the younger siblings die but their parents. We are seeing them go absolutely through the cracks, because when they actually are displaying death and dying and grieving issues, the school system is not prepared for this. There is no place to refer them. There is no one there to talk to them about it. So we are seeing them hopped around, ending up many times in the foster care system, and then just going through that, and they're ending up on the streets or just wandering around someplace. There are a tremendous number of problems around that that no one is looking at yet.

One of the groups I would have to mention is definitely the Native America population. When we say "minorities," we just assume everybody is going to be black and Hispanic or other. We forget that that "other" represents large sections of the Native American population and the Asian community.

And particularly the Native American population I highlight because, whether they are on the reservation or in a city, many times they are absorbed within different groups and they are not appearing anyplace. They do not receive good education; they do not have any kind of videos or films or literature geared specifically for them by tribe. And clearly when we start to get into how the community feels about it, I'm going to address the issue of genocide from the minority perspective. The Native American community we cannot ignore, because some of these tribes are very small populations as it is. The child-bearing-age women are also a very small group within these subgroups, and we must then make much more of an effort to educate them to clearly see how they are being put at risk because they don't necessarily see it as the general population goes.

The other issue I want to address is this concept of genocide, and why I bring this up here is that in New York City I believe the black community

will and is setting the tone for the rest of the Nation. And if we do not understand at least why they say the word "genocide" or feel the need to say the word "genocide," I don't think we're going to be getting too far into this community as far as educating them. Thirty or 40 years ago, when we saw basically black and Hispanic communities isolated, it was very easy to see that whatever happened in New York would not affect what happened in Philadelphia. This, unfortunately now, is not the case. What happens in New York is instantly being relayed, whether it's in Philadelphia or Kinshasa.

So when dealing with the issue of genocide, I'm just going to highlight how they perceive this. Genocide by benign neglect. Clearly they believe that there has not been enough attention given to them on the issue of AIDS. In New York City there has only been literature geared for them in the last 2 years of the epidemic that has been here at least 7 years. If you had gone to the black community in New York 4 years ago or 3 years ago to look at what was going on with AIDS, even though we have the stats to show that they would be at risk, the only thing they had was posters in their communities that said this was germ warfare. So that's where they started out from right from the beginning. They weren't watching the MacNeil-Lehrer report and they didn't read the *Times*. That's what they heard and they fed into it. And many people said, "Why would they feed into it?"

Well, they'll refer you back to the Native American history and germ warfare.

If you say, "Why don't they trust you because you're from the government?" they refer you back to the Tuskegee experiments when they had 400 black men who were infected with the syphilis virus and let die in an experiment that lasted over 20 years.

Why are they jumpy over the people who head these committees? In New York City, Dr. Sencer, who was one of the health commissioners over AIDS when it first started, before Dr. Joseph came in, was affiliated with the Tuskegee experiments. Clearly when we look at the community's response, they see this as a very systematic approach gearing into their community.

During Dr. Sencer's reign at the Department of Health, the movement was not, let's say, aggressive into the minority community. So clearly now that you have a very large pool of infected people, everybody is running out to this group saying, "You're infected. What are you going to do about it?" and they are having a problem even understanding how they are infected.

The minority community still does not quite understand how they got infected all of a sudden, when for the last 5 years someone told them about a green monkey, and everybody said that everybody was a gay white male,

and all of a sudden it switched the last 2 years. They need to have time to play out this process.

Also I'd have to throw in at this point that the fact that Africa was highlighted and Haiti was highlighted as sources of initial infections just did not sit well in the minority community at all. Clearly they saw this as a racist attempt by the government.

So when we look at these different factors, we have to take into consideration that if we want to understand what is going on in the minority community and to help the minority community and to know about the issue of AIDS, if we understand what Dr. Koop has said about the issue of AIDS, we need to understand what Dr. Frances Westling has said about the issue of AIDS, because the minority community is not listening to Dr. Koop; they will listen to her, and she is clearly giving very strong evidence to the issue of genocide with very strong documentation, that even if this is not true, perception is everything.

And there isn't any counterbalance to it. There has been an uneasy relationship traditionally between the minority communities and the government, and it has definitely been aggravated by the comments that were made by our mayor in the recent elections. Believe me, it did not help it. Therefore, they are very leery of someone coming in.

Even my group—my group is a multicultural, trilingual group that is in the community. They know these communities. When we approach them, they have no idea we're from the Department of Health or from INS, so they don't stop to find out. Yet, this takes time to get over this, to try to get them to even look at us. And many times if we go to a presentation or we go into an apartment to talk to someone, there may be an official person in residence, we find three other families that are there representing maybe two or three different Caribbean islands or two or three different spots, and then they will start to come out and speak to us.

So it is very difficult in a short period of time to go through everything, but I hope I at least gave you some more insight or just some other ways to try to look at this issue a little bit differently and realize the effect some of these policies will have on these communities.

I just want to end with a quote for you. This is from a book called "Plagues and People" by William H. MacNeil, and on page 61 it talks about the effects of what happens to a culture when they come up against an unknown substance such as a virus, that they are completely unprepared for for the first time. And this would be us.

> The disruptive effect of such an epidemic is likely to be greater than the mere loss of life, severe as that may be. Often survivors are demoralized and lose all faith in inherent custom and belief which had not prepared them for such a disaster. Sometimes new infections actually manifest their greatest virulence among young adults owing, some doctors

believe, to the excessive vigor of this age group's antibody reactions to the invading disease organism.

And, of course, in New York City right now, AIDS is the leading cause of death among men and women between the ages of about 25 to 35. Population losses within the 20-to-40 age bracket are obviously far more damaging to society at large than comparably numerous destruction of either the very young or the very old. Indeed, any community that loses a substantial percentage of its young adults in a single epidemic finds itself hard to maintain itself materially and spiritually. When an initial exposure to one civilized infection is swiftly followed by similarly destructive exposure to others, the structural cohesion of the community is almost certain to collapse.

Thank you.

CHAIRMAN PENDLETON. Thank you very much.

Ms. Arriola, thank you for coming.

TESTIMONY OF ELVIRA ROSALES ARRIOLA, ASSISTANT ATTORNEY GENERAL, NEW YORK STATE DEPARTMENT OF LAW, CIVIL RIGHTS BUREAU

MS. ARRIOLA. Good afternoon, Chairman Pendleton, and honorable members of the Commission. I'm going to talk to you about the discriminatory impact of AIDS on the men, women, and children of our Nation's Hispanic communities, although many of the comments I will make do apply in general to a problem of the discriminatory impact of this disease on our racial and ethnic communities around the country.

The concern I express today is that of an activist, civil rights lawyer, and a Latin woman who is deeply disturbed by the increasing number of AIDS cases in our Spanish-speaking neighborhoods. Hispanics have the highest cumulative incidence of AIDS of all racial and ethnic groups in the United States and yet are among the least informed about the deadly virus and about prevention.

While Hispanics represent only 7.9 percent of the national population, they account for over 14 percent of the over 50,000 reported cases of AIDS in the United States, a figure that is expected to rise, particularly among heterosexual women and children. On a State-by-State basis, the rate of growth of Hispanic cases in States with large Latino populations continues to outpace that of non-Hispanic whites.

In the Latino communities AIDS is considered a family disease. It is now the highest killer of women between the ages of 25 to 35, and most of these women are black or Hispanic. The highest risk of transmission of the virus is occurring today from men to women through heterosexual intercourse. Most of the women getting the virus through sexual transmission are minority women.

Over 90 percent of the pediatric cases involve black or Latin babies. A conservative estimate by the New York City Department of Health indicates that by the end of this year, that city will see about 800 babies born with the HIV virus. A large number of these cases of prenatal transmission involve women who simply didn't know how to protect themselves in sexually intimate situations with a partner who may have been bisexual or an intravenous drug-using man. The statistics on pediatric cases alone urges that we examine the kind of orientation we are giving to the families in these communities about AIDS. Every case of a mother passing on the virus to her child during pregnancy or after is simply attributable to the lack of access to adequate AIDS education and counseling.

Why does the picture look so different when it applies to racial and ethnic minorities? Two years ago that question was brought to my attention by an activist man dying of AIDS who very bluntly said to me, "As you and I speak right now, there are approximately 300 black and brown babies dying alone in city hospitals. Their parents are probably dead by now, and their biological relatives are too afraid of AIDS to take over as caretakers. So there will be no one to care for those babies in their last days. And there will be more cases like this, many more; they are the product of ignorance, poverty, and lack of cultural sensitivity in existing AIDS-related education and services."

Mr. Lester, may he rest in peace, asked me not to turn away from the reality that there is something gravely wrong in a society that would allow 300 black and brown babies to die alone in city hospitals, and that this year will have 800 babies in one city affected by the HIV virus. We need to ask ourselves: What factors led to the statement by a doctor that, "After diagnosis, the average lifespan of a white person who has AIDS is two years, but the average lifespan of a black or a Latin person with AIDS is approximately 19 weeks."

These statistics represent a tragic picture of pain, suffering, and early death that will continue unless we understand the factors that contribute to this discriminatory impact of AIDS on people of color.

For Latinos or the members of other bilingual and bicultural social groups in this country, the question of what we need to do to alleviate this crisis appears to be answered almost always the same way: Get AIDS service providers, whether public or private, to provide culturally meaningful and sensitive AIDS education, to increase the number of bilingual/bicultural health care professionals, to improve the access to AIDS counseling and education, to assure racial and ethnic diversity in experimental AIDS treatment programs, and to provide greater relief from AIDS-related discrimination.

The history of this country has certainly made us a nation of minorities, and that same history demands that we accommodate the cultural

differences of the various racial and ethnic groups in this nation to whatever health services, funding, research, or literature exists now or may exist to fight AIDS. The discriminatory impact I have illustrated in the above statistics urges that cultural sensitivity be made a priority now by any public or private entity giving or receiving funds to fight AIDS at the local, State, or national level.

Cultural sensitivity: It means recognizing that immigrants and their descendants bring traits and attitudes from their homelands that foster racial or ethnic identity and pride. These same traits, however, should not become a barrier to safe and successful adaptation to living in a country that has such a high number of AIDS cases. In parts of the country having large immigrant populations, health officials should be making a special effort to study the age, class, generational, and other social distinctions within immigrant groups that influence intimate behavior and may be discouraging people from learning more about AIDS.

Education about the precautions a person needs to take with respect to their intimate behavior, whether sexual or not, reduces the number of AIDS cases. But from the rising number of Hispanic cases, it is clear that the information is not getting to these communities. There is no other reason which accounts for the greater impact on Latin people than lack of information about AIDS that is tailored to subtle but very powerful cultural attitudes that differ from those of a predominantly white community.

Culturally sensitive AIDS education would take account of those differences, and assure that every man, woman, and child gets the message about AIDS.

For Hispanics, the attitudes that nurture resistance and fear are often the by-product of religious and cultural values that govern our community life. Hispanics unite, for example, around beliefs and traditions that are heavily influenced by Catholicism. Sexual matters are not openly discussed. We do not deal openly with matters about homosexuality or bisexuality. Men and women are socialized from the time that they are young among very rigid social and sexual roles, so any talk about sexual practices or ways of living that threaten these attitudes or values are considered taboo. The taboo nurtures resistance to admitting that sexual differences may exist within the community. It also fosters denial.

The community's denial that AIDS could be a problem in one's own home or in the home of a relative or in the neighborhood is closely tied to these cultural attitudes. Denial has in turn fostered mass confusion about how the virus is transmitted. It has produced discrimination against those perceived as having a disease that they continue to associate with homosexuality. Hysteria and fear has led to attempts to evict persons with AIDS or their families from their homes, to children being kicked out of

private schools, and to the denial of such essential goods or services as funeral homes, ambulance rides, or foster care.

Even AIDS Buddies, people who volunteer to help a person with AIDS or her relatives, often suffer the AIDS stigma because people within the community do not understand that it is not spread through casual contact. So this denial by the community surrounding issues of sexuality or problems of drug abuse, and then the fear of being stigmatized within one's own community, is keeping men and women from reading AIDS literature, from going to clinics, from joining support groups, or even becoming political about the rising death rate in the Latino communities.

Take, for example, the special considerations that apply to the Latin woman who is deemed at risk. Latino women are generally not expected to be well-versed sexually; they are also viewed as submissive to their partners. These factors make it especially difficult to reach some women to discuss their sexual conduct or to get them to take an assertive role in their relationships to modify high-risk behavior. They may also be in denial about whether they are in a high-risk relationship. So we can't assume that a bilingual pamphlet on AIDS and sex at the door of a local clinic is going to be enough to reach that woman.

I think this Commission should support the funding of outreach programs that are sensitive to cultural differences or fears within our racial and immigrant communities. It should support efforts to cut across the language barriers with public multilingual campaigns that will reach these people. Unnecessary and harmful discrimination could be avoided if the Federal Government would simply state to the public clearly that AIDS, or perceived AIDS, or seropositivity of the HIV infection is a disability, and that it is illegal to discriminate against someone with AIDS or perceived as having AIDS.

I also urge the Commission to submit a Federal antidiscrimination bill that is AIDS-specific that will encourage other States and local jurisdictions to provide protection to those who are unfairly stigmatized. It should also help coordinate efforts between public and private service providers and relevant community groups who can help to fight the confusion that is creating resistance, denial, increasing death, and discrimination.

I want to comment briefly next on the Centers for Disease Control's continued use of the term "high-risk men or women" in its policy recommendations regarding transmission of the virus. I believe there should be a greater emphasis by the Federal Government or any entity on high-risk behavior and education to change conduct that puts anyone at risk.

Instead, I continue to see use of the term "high-risk groups" which feeds alarmist suggestions that AIDS is somehow a problem confined to social groups identifiable by certain characteristics or behaviors. The term fosters

prejudice against those defined as high-risk people: homosexual persons, sexually active black and Latin women, drug users, immigrants.

By abusing that label "high-risk groups," one is allowed to think that AIDS is someone else's problem. It not only stigmatizes certain people; it obscures the health issue, that AIDS is transmitted through high-risk behavior that cuts across age, class, race, sex, creed, national origin, or sexual orientation differences. Given the widespread use of the CDC's recommendations in this country, and the high presence of AIDS in blacks and Hispanics, a statement that suggests, for example, the testing of "high-risk women," or testing at places where "high-risk women will be found" encourages discrimination that is akin to mandatory testing of only black, brown, and poor women. Public health concerns must be balanced with an equal concern for such values as the freedom from discrimination, right to privacy, and free choice.

A further example of this insensitivity appeared in the recommendation that so-called high-risk women delay or interrupt a pregnancy until more is known about the AIDS virus. A woman bears a 50-50 percent chance of passing on the virus to an unborn child. Many Latino women are socialized to value closely knit families and children, and some strictly abide by the religious prohibition against contraception and abortion. That fact should urge caution in the way health providers are asked to counsel a seropositive woman who bears a high risk of having an HIV positive child about her options concerning contraception and/or abortion. Her constitutional right to privacy includes her right to make a free and fully informed choice.

Health counselors must be educated themselves to know that some women in these communities may think that they have to obey a medical suggestion, or that some women may simply resist hearing about contraception and/or abortion options because they're concerned in dealing with the fear and the guilt of violating a strong cultural and religious taboo.

So cultural sensitivity, again, means making sure that a woman knows she has the right to make an informed choice, and that there will be help for her if she fears losing the support of a spouse or a family or her own community for making what appears to be an unconventional decision.

I therefore urge the Commission to monitor AIDS services in the minority communities to determine if women are getting enough information, if they are not why, and whether their rights to privacy and freedom from discrimination are being respected.

My final comments surround the issue of mandatory testing, which I know has been covered by other speakers, but I am going to focus on it in the particular context of immigration policy.

The influx of immigrant groups in this country is certainly not something new, nor is the phenomenon of nativism that nurtures

sometimes that prejudicial attitude that some other one, who is dark or who is different or who speaks a different language, is responsible for a current problem in the country.

The Public Health Service has recently published rules regarding the medical examination of aliens seeking permanent resident status. Under current rules, HIV infection is a dangerous contagious disease for immigration purposes, which must be reported to the consulate or INS officials and disqualifies a person for admission to the United States.

The government's enforcement of a mandatory testing program is highly questionable when currently available HIV testing methods continue to show a high rate of false positives even under high quality control performance standards. The justifications for the program also appear to be filled with contradictions that show that they probably originated in political thinking and not much medical wisdom about how to stop the spread of the virus. While mandatory testing is to be applied to anyone who applies for admission, it is not required of those who seek temporary admission to this country, nor is it required of American citizens returning from travel overseas. But the program is rationalized on the ground that it will stop the spread of the disease. Selective screening is perceived in these communities as undermining the public health justifications, and it is seen as discrimination and xenophobia.

I recently attended a symposium with over 100 Hispanic activists from around the country who are attempting to cope with the problems of AIDS in their communities, and they all agreed that mandatory testing by the Immigration Service must be vigorously opposed. They agreed that the mandatory testing program is only perpetuating a vicious cycle of poverty and discrimination in our Hispanic communities. Resources that could go into better AIDS education are wastefully going into expensive testing and retesting procedures to confirm the accuracy of testing methods.

Therefore, the greatest impact is on health facilities that should be treating patients or counseling but instead are burdened with a questionable identification and exclusion program. When they could be counseling on AIDS prevention, they are instead dealing with someone who is confused or concerned about his or her rights under the amnesty program developed under the 1986 Immigration Reform and Control Act. Test results must be held confidential, apparently, under that act only by the Federal Government. So anyone who takes the test, the test is also faced with the additional risk of rejection by family or discrimination within the community should they find out the results.

The threat of HIV seropositivity and excludability or deportation or plain stigma has discouraged undocumented immigrants from coming forward and have driven many further underground. If an HIV positive undocumented immigrant were to return to another country without

education and counseling, then all we have done is spread the epidemic throughout the world in countries with fewer resources to handle the problems.

The long-term resident, on the other hand, is unlikely to return to his or her country of origin, and is more likely to remain underground as an illegal resident, possibly with a communicable disease.

Neither of these results allows either the immigrant family or the immigrant community or the public at large to really confront the AIDS crisis. Worse, the message is given to the public that identification of seropositivity is enough to stop AIDS, and it is clearly not.

This program is encouraging the creation of an underclass of persons who could receive counseling and treatment, if necessary, but who instead have burrowed into the underground economy and made themselves vulnerable to exploitation and disease. It is a mark of hypocrisy in the face of the expressed legislative intent to legalize large numbers of people who were deemed productive contributing residents under the Immigration Reform and Control Act.

I believe the Commission should therefore oppose the continued use of mandatory testing by the Immigration Service.

Undocumented immigrants already in the United States do not present a greater risk than the population at large. Those who engage in high-risk behavior would already be screened out under existing immigration law because drug addicts and narcotics offenders and persons who commit crimes of moral turpitude are already excludable under the act. Mandatory testing will not stop or retard the spread of AIDS. What it will do is drive people underground and away from the health care system. People are vulnerable to AIDS because they engage in conduct that places them at risk. Only widespread and mandatory education and counseling will accomplish this goal.

Thank you very much.

CHAIRMAN PENDLETON. Thank you. I might say this has been quite an enlightening panel. I think most of us here or all of us here feel that way.

Just let me raise a question, if I may.

Ms. Rumsey, I identify with a lot of what you're saying in terms of how you begin to get different groups in the community and so forth. Dr. Nickens is attempting to do some things with groups, and both you and Ms. Arriola talked about counseling and education.

How do you interrupt the existing behavior of the clientele that you know about long enough to allow this process of counseling and education to work? It seems to be a critical juncture as to how you get information out with the kind of cultural or ethnic sensitivity that Ms. Arriola is talking about.

But from my understanding of the drug culture, there is not much time between activities to be able to do what it is that needs to be done.

I would agree that education—and I think you spoke eloquently about the whole matter that there are different groups and how blacks especially have a kind of an underground education system that is saying, "No, because of Tuskegee, because of my links to Africa, and because of my links in terms of pigment." But I don't know quite how we interrupt the existing activities in communities for survival. There is no question in my mind when you can pay a kid 12 years old $300 a week to be a lookout for the narcs and that is a direct infusion of cash into his or her pocket, that certainly outweighs the potential for taking a minimum wage job that probably takes a lot more time and a lot more of everything to do.

But how is that going to be done? If we don't interrupt the behavior that exists now, how can information be gotten out, regardless of whether it's churches or fraternal orders or families? How do we interrupt that behavior?

Ms. RUMSEY. I think you can do it. I just think that, first of all, we have to be more realistic about what we are really trying to do. One factor that I think is holding that up is really the minority community has not had enough time to understand what is happening to them with AIDS, and AIDS is not their top priority. They weren't waiting for us to come into the community to tell them about AIDS. So you have so many other different factors there that AIDS is the least of their worries in some of the cases. This is something that may happen down the line.

Also, they don't really see AIDS that much in the minority community yet to really scare them into saying, "Oh, this is it." And why I say that is because, if we look at the gay and bisexual males, they are so far in the closet for the most part, when they come home—you know, when they're down in Manhattan on the gay parade, they can be gay and, "I'm out of the closet" and all that other stuff, but when they go uptown to their mothers and they're sitting down at the table eating rice and beans and chicken, everybody's straight, and we talk about why they're still single. So it's hard to identify this population.

Also, when we look at the IV drug population, they are always a transitory population. IV drug users are always skinny. So the fact that they're walking around coughing, with swollen glands someplace, really means nothing to them, because they could be moved at any time to any location.

New York City is going through a lot of regentrification, so who was in upper Manhattan now is now maybe in Staten Island or Rockaway because nobody is trying to get into upper Manhattan.

Another factor is I think we put the emphasis on the wrong side. We put women in the position of defending a policy that they themselves do not believe. Women do not wear condoms. So as long as we put this responsibility on women to make them put these condoms on, it's always going to fail.

I think traditionally in the society we have had a problem dealing with men of color, regardless of where they are, whether they're in the prison system or working now on a job. And I think we need to be more creative on looking at the issues as to why they are so resistant to it.

Clearly if we tell them to put on the condom, their response is, "You are limiting my numbers." This is what we call genocide. If they don't put on the condom, it is a double-edged sword. If they do not adapt, many of them will die. But right now they do not see it. I think in a way this is their form of denial, but traditionally we have not gone out of our way to reach them. It's a lot easier to get a woman who is in a WIC center, sort of trapped in a clinic sort of situation and throw a whole bunch of condoms at them and say, "Go get him to do something." We know where these guys are, but we really don't want to address the issue.

Plus when we call in people to give us advice, many times if we look at who do we call in, they don't really represent the communities anymore that they're trying to reach. They are more removed than many of the whites, let's say, that are on the committee. We always say the official black folks are whiter than the whites. Therefore, you call them in to ask them for advice, and they may be just as homophobic as anybody else. They're living out on the Island just like everybody else. They don't know the difference between the Rastofarians and the 5 percenters or anybody else, either, and could care less. So when you ask them for advice, they give you the traditional answers, which means nothing to the people on the street.

I think we are going to have to do—first of all, you cannot do outreach from behind a desk. So we see a lot of people who want to do all this stuff and pay someone $4.00 an hour to run around and give them brochures. We want to have a generic program, because basically the government doesn't want to spend a lot of money if they don't have to. And we are going to have realize there isn't any one approach to these communities. We're going to have to do multilevel approaches, I think, in a lot more smaller group settings, and to work with the men to really let them understand that this is a good thing. We have to make this a positive thing, that this is a manly thing to do, that you would care for some woman so much that you would want to protect her womb, whether she has children or not, the right to protect it. Because clearly when women get infected, it's two generations at once.

And we just don't interact with men like that. And I say why it can be done, because when we do one on one in the street with the men, or in the prison system—we have a separate program that just goes into the prisons, like Rikers and such. When we sit down with these men and we talk to them, that's the first time anyone has had that much eye contact with them in almost all their life, that they believe someone almost cares about them,

to actually show them how to use a condom. Lots of times guys don't even know how to use a condom. They have all this resistance to it.

What we see happening is that the counselors many times have a lot of hang-ups themselves which impedes upon the ability to get out there. If you're more worried about your pocketbook than the client, then you don't need to do AIDS outreach. The running joke was when you used to have the programs in the communities in the sixties, you'd have this influx of, say, white teachers coming into the black community, you had to walk them from their car or from the subway to the building; you had to watch them all day; you had to pay somebody for the car to take them back to Long Island again.

This is what we see happening.

CHAIRMAN PENDLETON. If the car was there when they got back.

MS. RUMSEY. Yes. So all of these things come into play for them.

So I think you can break the cycle, but I think we really need to make much more of a concerted effort to give them more diverse types of messages and use different types of media. Like my colleague said, just a piece of literature and make more of a strong commitment of the government saying, "I care for you," because minorities believe the government doesn't care.

A good example would be like what happened in Florida. Here you have a white family [the Rays] that had these two [three] kids who were hemophiliacs burned out of their house. Who is leading them but the minister? And the word on the street was, "If they treat white folks like that, what do you think they're going to do to us?"

So where was the government who came in and said, "This will not happen; we will protect them; we will build a house; we will make sure these kids go to school." It didn't happen.

So I think a lot of it is this natural resistance that we don't see that tremendous response coming in from the other end to say, "I'm going to give you my hand and I'm going to go into the fire with you. I care for you enough to want to do that." I think if we could convey that, that's almost half the battle.

CHAIRMAN PENDLETON. He's going to answer for himself subsequently, but is what he doing appropriate?

MS. RUMSEY. I think so.

CHAIRMAN PENDLETON. But he's suggesting the same group you're talking about that you're saying are not representative of the community, out in the street. You talked about some black folks being whiter than white folk on these matters.

MS. RUMSEY. Yes.

DR. NICKENS. We didn't talk to those people.

CHAIRMAN PENDLETON. What I'm hearing here is maybe what he's doing is not what you want to get done or what Ms. Arriola wants to get done. Is that right or is that wrong?

MS. RUMSEY. We have a program that is similar to what he does. We acknowledge the fact—

CHAIRMAN PENDLETON. Does he give you any money? Why don't you ask him for some right now?

MS. RUMSEY. I would.

No, I think it's clear what we need to realize is that there isn't any one particular spokesperson that will represent all these communities, that we have to really go across the spectrum and pull in people who represent different levels of it. If we have policies around adolescents, we are going to have to incorporate adolescents in the policy. We can't tell kids to say no when half of them said yes and we don't have anything as a middle ground for them.

DR. NICKENS. I think one of the things that AIDS has done is nakedly revealed inadequacies in our society that were there all along, but AIDS has revealed them. I think one of the things we haven't had all along is an infrastructure to reach grassroots people in minority communities with any kind of information, whether it's AIDS or anything else.

So I think we're starting from scratch. And what you see, if you are in cities that have creative and good contacts with their minority communities, they get good programs going very rapidly because they have the people and the relationships all ready to do it. If you have cities that have had very distant relationships, then they have serious problems. And I don't think that there is a quick fix if you don't have those relationships, because the minorities have been through too many up-and-down cycles of boom and bust, of coming into fad with a disease or a problem and then having it go out of style. So there's a lot of cynicism.

So I don't think we can do quick fixes and have them be anything but just sort of something we can crow about. I think we have to take the long view. At the same time, I think we can do some short-term things like media, like some glitzy sorts of parades and things like that. But that's not the real deal. The real deal is the relationships and the outreach.

CHAIRMAN PENDLETON. Let me give you one number. I read recently where 42 percent of local government expenditures go to wages. If that is the case, it looks like somebody has to work at what you want to work at. What are we paying people to do? And it comes to my mind whether or not there is a need to rethink or recast what our public service delivery system is. Maybe we are delivering to the public an outdated set of services.

DR. NICKENS. The question is to which public.

CHAIRMAN PENDLETON. To which public. But the public you're talking about, for some time there's a denial, if you will—there are some nice cars

and some bad cars, and there are bad houses and then there are a few good houses. But in terms of how we deliver public services to communities, what I hear you saying is that maybe there is a need to rethink what services we need to deliver to make a community effective and to make it believe in the government that is allegedly supposed to service it.

I want to throw it out as a matter for thought, not that we should go back and try to redo everything that cities do.

Commissioner Ramirez.

COMMISSIONER RAMIREZ. Did I understand correctly, Dr. Nickens, that the Congress allocated as a line item $1.5 million?

DR. NICKENS. Yes.

COMMISSIONER RAMIREZ. It seems to me that $1.5 million within the context of the amount of money that the Federal Government is spending on AIDS is a little bit like the relationship between the amount of time that this Commission is spending talking to people other than people like yourself, and that it is a very small tail trying to wag the biggest part of a very large dog.

Can you tell us what you think would be a sum of money that would cause there not to be a discriminatory allocation in the resources needed to fight this disease?

DR. NICKENS. Well, there is more than one thing I want to say in response to that.

First of all, the Office of Minority Health is really designed as a coordinating and advocacy and also an office that does some pilot programs, so we are not seen as sort of one of the major operating units. That is kind of how we were designed.

There are major other programs going on in other parts of the system. Centers for Disease Control, I think, is spending $20 million in fiscal year '88 that will go to State and local governments to then in turn give to minority organizations.

COMMISSIONER RAMIREZ. Is that a line item for minorities?

DR. NICKENS. Well, it's written in their budget documents that way. I don't know if Congress actually wrote it that way, but in their budgets it's listed that way.

Also, I think they're giving $8 million to national minority organizations as well. So there is more money going.

The other thing is that I think we can get too dazzled by dollars. We have to not only spend money—and that is very important—but we also have to spend it well. And I think the other issue is how programs are designed. I think some of what you're hearing from the testimony is that these programs can easily be designed badly, and it's not so easy to design them well. So you can, in the stereotypical way, throw money at it.

So I am very concerned not only about how much money is allocated, but also how we spend it. So we work very hard in the system to try to

make sure that the money we get is spent very well. I don't mean we, the Office of Minority Health, but the system, the Department.

CHAIRMAN PENDLETON. I just want to caution my colleagues that we have to evacuate at 6 o'clock. So ask your questions, and maybe we can get answers to everybody's questions.

COMMISSIONER RAMIREZ. I want to ask Ms. Rosales Arriola one particular question. You have talked about immigrants. We have also heard testimony that the preponderance of Hispanic AIDS and seropositive individuals, AIDS infected—I have difficulty with the terminology—are IV drug users.

Do you have any information as to the proportion of AIDS-infected individuals who are recent immigrants versus second-generation, low-income Hispanics?

MS. ARRIOLA. I don't have any official information. I'll tell you what my gut instinct would be, that that is a generational issue, that you're not going to see it in the first wave of an immigrant group in the first generation.

COMMISSIONER RAMIREZ. So it is one that—

MS. ARRIOLA. Drug abuse is a reflection of problems within a community most likely related to unemployment, poverty, and—why not go to the euphoria of a drug if all you are faced with is life conditions that are miserable. I mean, you're not going to find that, I think, in the first generation. So it would be an inconsistency, I think, on the part of the government to be promoting testing of immigrants if you are going to accept the definition of people who are at risk. The focus is wrong.

COMMISSIONER RAMIREZ. I just want to say I really appreciate the panel, particularly because they have verified my contention that if we heard from more people who are on the firing line and who are affected by civil rights policies, we might get a better understanding of what we are supposed to be doing.

Thank you.

CHAIRMAN PENDLETON. Thank you.

Commissioner Destro.

COMMISSIONER DESTRO. Just one question, and it again underscores the value of all your testimony. That is, I was captivated by all three of your comments about the need to give information in a culturally meaningful way. And one of the primary institutions in many of these communities for giving this kind of information appears to be churches, and one of the difficulties that I see in looking at other cases is that at the same time as there is an overt move on the part of the government to bring churches into the distribution of information circle, if you will, there is a negative response on the part of civil libertarians to keep churches out. And probably the best example of that that I know of in recent years was the big litigation over the foster care in New York City and the churches being involved in that.

How would you suggest that that problem can be solved, that either you have the churches and they do it meaningfully, or you don't and you lose a big resource? One of the litigators in the case told me, "We never really thought the church would react the way it did, and we were all kind of taken by surprise." How do you deal with that, one of the more effective social institutions being somewhat pushed out of the process?

MS. ARRIOLA. I would agree that it's a very delicate balance to strike, but how you get in to define what is a religious influence, let's say, community group, and whether or not religious values are going into educating someone or simply influencing the education, for example, of a foster child is not going to be easily as discernible.

The issue has to be one of decentralizing the way we are funding AIDS education throughout this country. If a local support group emerged from concern by members of a community church, and those members of the community church, if they know they have access to funding, form their own organization, their religious attitudes or religious values that may be influencing their concern to deal with the problem within the community is not relevant. It is only relevant when the attitudes are being used to somehow discriminate, for example—you are referring to the *Wilder* case, I think, in New York City—

COMMISSIONER DESTRO. Yes.

MS. ARRIOLA. —and there the problem was one of government funding going directly to perpetuate racial segregation or discrimination on the basis of religious—it basically turned into religious favoritism.

We're not talking about that here. We're talking about people who may be influenced by simply their moral values to take care of sick, poor, dying people. And certainly government doesn't have a right to say, "Okay, we want to fund the church groups." We want to fund the local community groups that are in touch with those people.

COMMISSIONER DESTRO. Would you exclude the church groups from them, though? Would you say that church groups by definition should not be eligible for funding?

MS. ARRIOLA. Probably from a civil rights, civil libertarian concern, you wouldn't want to have government and religion together operating hand in hand, no, you wouldn't, as a facial matter.

COMMISSIONER DESTRO. Dr. Nickens, you were shaking your head the other way.

DR. NICKENS. Well, I'm not a lawyer so I can't tell you about how the legal niceties can be arranged, but the fact is the churches are powerful institutions, and if we don't manage to use them in some way we are missing an opportunity. I think it's that simple. How you arrange that, I think, is a strategic issue, but there is no question that the ideal goal is to have churches using their role as powerful community institutions, not

using their role as theological organs to influence people's behavior and values.

Ms. RUMSEY. I was just going to say we do a lot of work with the churches, and I think it depends really on the denomination as to what the response is. I would just say one of the biggest fights that is going on in the church right now is the clash between: Is this a moral issue or is this a health issue for them?

We work with a lot of priests who are in the closet, bisexual at risk. So clearly if the black community looks to the ministry as setting an example, you can't talk about the damnation and evils of homosexuality on Sunday and be doing the at-risk behavior on Monday. It doesn't work like that. So when they normally would be aggressive and standing up and raising hell over it, they are basically very quiet on this issue. And I think they really are trying to work around it.

So if we look at clearly Pentecostal-type religions, what we try to do is make them understand that if you're born again, many times people are born again from many of these behaviors that put them at risk before they became born again, and how can they work around it. So we try to tell them to set up like a multimessage, that there's nothing wrong in telling people to say no or setting a certain tone, but clearly realize there are other people who already are at risk, and therefore what is the responsibility.

We see in the Jewish faith that what they do many times is handle this on an individual basis, where couples will come in to the rabbi and sit down and consult with him of whatever that particular matter is, and they go one by one.

Unfortunately, the black churches are just now starting to wrestle with this. I think they clearly understand they are going to have to do something. But like everything else, it's just taking them time to make that decision.

And in the Catholic church, of course, the fight is over the use of the condom. Unfortunately, it doesn't help the Hispanic woman who is at risk.

Therefore, I think our responsibility is to work with the clergy and to give them some kind of middle ground that they can both feel comfortable with, that they don't feel that they've compromised their position from their perspective, but from a health perspective we feel we are also allowing some kind of protection for that couple.

CHAIRMAN PENDLETON. Before we go to Commissioner Berry, let me ask you a question. What experience do you have with bars, beauty shops, and barber shops?

Ms. RUMSEY. What would you like to know about them?

CHAIRMAN PENDLETON. In terms of how did you get things done. My own experience in another life of mine was that I could get a lot more done through those kinds of contacts as opposed to going to what we would think would be traditional organizations, because there is some leadership

in each one of those places, and a lot of things transact in both those places. So I would think that would be a means of how you would begin to pass out culturally sensitive information.

MS. RUMSEY. I think that's an excellent example of how the community can take on that responsibility, that you don't need an MPH in order to educate. Our model for the outreach program is that each one can teach one. And you're right, because in the beauty shop everybody is coming through there, and what we try to do is make a better educated community.

So why I say to you, "Why did you ask that?" is because we do go to the communities, and we do ask them to display literature, which many of them will do, and posters and such, and give them the hot line cards, and many times they will call back based on that. And that's just as good as hiring someone with a master's who has to have a map almost to get into the community, and doesn't know anything about the groups they're working with, let alone speak the language.

CHAIRMAN PENDLETON. I understand.

Commissioner Berry.

COMMISSIONER BERRY. I'll be very fast. First of all, I'd like to know—and you don't have to answer this; I just wish you'd put it in the record or send it to me, Dr. Nickens and Ms. Rumsey in particular—how much radio do you use for the educational process? And if you know, Ms. Arriola, even though you're in the AG's office.

I know in the black community it's very important in terms of getting information to people. And I know it works, because it works politically in campaigns and things like that, so I don't see why it wouldn't work in this situation. And how much activity do you fund, Dr. Nickens, to grassroots organizations and the like—when I say "you," I mean HHS, not just your office—in terms of radio outreach activities, and so on, to the minority community on AIDS?

But the question I have is on clean needles and decriminalization. I have been struck all day, and in your testimony particularly, Ms. Rumsey, about the impact of the drug culture on this whole problem. And in the absence of being able to stop drugs from coming into the community, which we haven't figured out how to do yet, would you be in favor of support—all three of you—of clean needle and syringe programs, or even decriminalization as a way of trying to reduce the incidence of transmission in the crack culture that you describe and all the rest.

What is your view on that, Ms. Rumsey, and anyone else?

MS. RUMSEY. What I have to say is officially the department of Dr. Joseph is right now working on a program, but they will probably be setting up a pilot program to distribute needles maybe under some controlled setting.

Just generally, though, I think the way the program is set up—this is just my personal opinion—it's like too little too late. Clearly if we talked to people like Dr. Benny Primm, who runs ARTC in Brooklyn, he already has areas that are 80 percent infected males, and clearly you're going to see that same ratio almost in the female population.

Commissioner Berry. So it's too late?

MS. RUMSEY. I think right now, unless there's a massive effort, and clearly once you start talking massive effort you have everybody jumping up raising hell over it, you know, "You're encouraging drug use," that it really is not going to make that much of a difference.

I know I do a lot of work with the IV drug population, and it's not that they don't want to use needles; it's not that they don't understand how to use them or they won't wash them out, but really there's just a lot of other issues that I think will impede some of those populations from really making an impact that we could see, because the other part of that program is that people still want to have a result almost immediately. And how can you have a result immediately when you have such high infection rates in some of these populations? You may not see that result for 5 years, and people don't set up a program like that.

CHAIRMAN PENDLETON. You mean long incubation rates, too.

MS. RUMSEY. Yes.

Commissioner Berry. Do you folks agree with that?

DR. NICKENS. I have a couple of different things to say. One of them is that I think in New York you do have very high seropositivity rates among intravenous addicts. That is not true in many other cities. There are many cities in the country, cities like Cleveland and Akron and places like that that have very high rates of intravenous drug abuse but fairly low rate of seropositivity right now—and San Antonio. There are lots of them.

So that's one point. So I don't think it's too late everywhere.

I think the needle exchange issue is very complicated, and I think one of the things that's scary about it is there are lots of wrong ways to do it and probably not too many right ways to do it. What you don't want to do is put new incentives in the system for gaming and for drug abuse and so forth and disincentives for treatment. So it's a very complex issue.

The current feeling, I think, is maybe we need to try an experiment, maybe we need to try it in a controlled way to see what happens. But I think that has to be real carefully designed.

The decriminalization issue—you meant drugs in general? Again, I think it's the same kind of issue. It's so fraught. If you look at England, they have not had a stunning success with their program. Then the question is: Everywhere you draw a legal rim around an activity, outside of that you're going to get criminal behavior. So do you cast your net so wide that everything is okay and freely available, in which case you may have a society that scares us all to death. Do you have an age cutoff for

availability of drugs? Do you allow 14-year-olds to walk in and buy crack at a drug store with a prescription?

This is really tough stuff. So as a concept I think the recent debate with Schmoke and others is interesting in the sense that it raises the issue and it should be debated openly, but I would hate to see anyone move very quickly on it. I think that's the danger, that we move precipitously before we've thought out all the implications.

Commissioner Berry. So study, study, study would be okay.

DR. NICKENS. Well, I'm not a really study, study, study person.

Commissioner Berry. I'm not being critical.

DR. NICKENS. No, but it is often a critical remark, and appropriately so, by the way. But I think in this case, once you do these things you can't go backwards so easily as we saw with prohibition and so forth.

That's what really worries me, that if we move precipitously in response to this emergency, we may create more problems than we solve.

MS. ARRIOLA. I think we do have enough information right now. There are enough agencies, whether State, local, or Federal, that can identify where the sources of the problem are. For example, the clean needle issue, in terms of the Hispanic community, is much more an East Coast problem. It is not viewed that way on the West Coast, where in terms of the Hispanic population, what they need is more education about how to cut across those values and attitudes, especially the issues of sexuality. Because bisexual lifestyle is something that is very common in these communities, because of these very strong attitudes. We have to recognize that. We are not getting to these people. We are not getting to the men and the women.

And I want to restate something that Sunny said earlier. Stop this emphasis only on the woman. In terms of Hispanic men, there has got to be greater emphasis on his role, his participation in high-risk behavior, that putting on a condom isn't going to necessarily make him less of a macho man.

There isn't enough education. We are really talking about education. Clean needles was a good idea a couple of years back. But the rate of infection shows that you have got to now deal with not spreading that virus any further. And you do that with culturally appropriate education.

CHAIRMAN PENDLETON. One last statement from Commissioner Ramirez.

COMMISSIONER RAMIREZ. I was going to ask Dr. Nickens if he could work with our staff to provide us some maps that show distribution by race and ethnicity and by high-risk behavior, distribution across the country. Because I think that gives us a sense of the nature of the problem, and I'd like to see that.

DR. NICKENS. To the extent we have it, we certainly can try to work with you on that.

COMMISSIONER RAMIREZ. Gender also.

DR. NICKENS. Right.

CHAIRMAN PENDLETON. We did very well.

I thank the Commissioners, thank all the panelists today. I thank the staff.

These hearings are recessed until tomorrow morning at 9 o'clock. You're welcome to come back tomorrow morning if you are in town and hear some more of this.

[At 6:10 p.m., the consultation/hearing was recessed, to reconvene at 9:00 a.m., Tuesday, May 17, 1988.]

Morning Session, May 17, 1988

CHAIRMAN PENDLETON. Could we have the first panel up, please: Mr. Smith, Mr. Silverstein, Ms. Hunter, Mr. McDonald, Dr. Heaton, and Mr. Carvin.

Would you please stand, ladies and gentlemen, and be sworn? I hate to rush you but we are on a tight time schedule, and Mr. Smith has to go back to his place in the sky.

[Laughter.]

[George Smith, Robert Silverstein, Nan Hunter, Bruce McDonald, and Robert Heaton, M.D., were sworn.]

CHAIRMAN PENDLETON. Mr. Smith, you have to leave us, so we will take you first, ask what questions we can from staff, and then we'll move on to the rest of the panel.

I will say, Panel, you will not have to sit here the entire time this morning. We will have to take a little break, at least to allow our recorder a chance to crack her knuckles and relax just a little bit.

Mr. Smith, if you could take about 8 minutes or so and tell us what you have to tell us, and then we can ask you some questions.

Panel V: AIDS and 504

TESTIMONY OF GEORGE SMITH, STAFF ASSISTANT TO U.S. SENATOR GORDON HUMPHREY, COAUTHOR OF THE HUMPHREY-HARKIN AMENDMENT

MR. SMITH. Good, I'll try to do that.

First of all, very quickly, Chairman Pendleton, we had a little computer crash over at the Senate Judiciary Committee yesterday, but I was able to run off a couple of copies of the prepared statement, which I would like to submit for the record. I won't go into it in my remarks now, but there is a prepared statement.

CHAIRMAN PENDLETON. Thank you.

I'd like to say that I thought when you worked people over there 60 to 80 hours a week and pay them for 40, you wouldn't have that problem.

[Laughter.]

MR. SMITH. Let me just get going real quick here.

I appreciate the opportunity to share what insights I have on what has been referred to as the "Contagious Disease" amendment to the Civil Rights Restoration Act, which was just passed last January.

The gist of this amendment was that it changed the application of the Rehabilitation Act to persons with contagious diseases in the employment context. The amendment represented a compromise, which was largely worked out on the floor of the Senate and off the floor of the Senate during the debate of the Grove City Civil Rights Restoration Act, between Senator Gordon Humphrey of New Hampshire, for whom I work, and Senator Tom Harkin of Iowa, along with several other interested Senators.

Let me stress at the outset, before I go into the details of my remarks, that it is not strictly accurate to look upon this as an AIDS amendment. I think in the long term this amendment to the Rehabilitation Act may well have more impact on other contagious diseases where the transmissibility vectors are more clear than it will have on AIDS where they are less clear.

Having said that, let me go a little bit into the background of the amendment.

As you all know, the Federal Rehabilitation Act prohibits discrimination on the basis of handicap in federally assisted programs and activities, as well as by Federal contractors. The core of the Rehabilitation Act is to prohibit invalid, improper, unjustified discrimination against genuinely handicapped persons, and I think it's fair to say when the act was passed the focus was upon such traditional handicaps as blind persons, deaf persons, and wheelchair-bound persons. Although there was no explicit limitation to that effect, most people recognize that was the genuine thrust.

And certainly, as pointed out by Justice Rehnquist in his dissenting opinion in the *Arline* decision, Congress did not contemplate when it passed the Rehabilitation Act that it was going to get into the business of regulating contagious diseases, which raised issues entirely different than the traditional handicaps involving persons in wheelchairs, blind persons, etc.

To move along quickly, obviously an important background factor in the action Congress took in the Grove City decision was the March 1987 decision in the *Arline* case. I expect that most of the Commissioners may be generally familiar with that. I will just briefly state that the *Arline* case involved a school teacher who had tuberculosis. She was suffering recurrent tuberculosis which is, of course, a contagious disease. She was experiencing some recurrence of the disease. And the question placed before the court was whether a contagious disease, such as tuberculosis, constituted of the individual who had it an individual with handicaps for purposes of the Rehabilitation Act.

This was the central issue of the *Arline* decision, whether contagious diseases should be treated as handicaps under the Rehabilitation Act.

The Supreme Court decided yes—I believe the vote was 6 to 2—and I think some of the observations made by Justice Brennan in writing the *Arline* opinion are among the things that caused some of the concern that led some of us to seek legislative change in this area, which I think created the concern regarding the treatment of contagious diseases, not just AIDS but including AIDS, under the Rehabilitation Act.

One of the things Justice Brennan said in the *Arline* decision was: "We do not agree with petitioners that in defining a handicapped individual under Section 504 of the Rehabilitation Act the contagious effects of a disease can be meaningfully distinguished from the disease's physical effects on a claimant."

Justice Brennan went on to say, "It would be unfair to allow an employer to seize upon the distinction between the effects of a disease on others and the effects of a disease on the patient, and use that distinction to justify discriminatory treatment."

Finally he went on to say, "Allowing discrimination based on the contagious effects of a physical impairment would be inconsistent with the basic purpose of Section 504."

So the gist of what Justice Brennan was saying in the *Arline* decision was that it was irrelevant, probably even improper and a pretext, for employers to consider the contagious aspect of a disease in making employment decisions with respect to people who have contagious diseases. He seemed to be implying that this was an improper and irrelevant factor in determining whether a person was an individual with handicaps.

And he also seemed to imply it didn't apply. I think the *Arline* decision made it quite clear that because an individual who has a contagious disease, whether it be tuberculosis or any number of other contagious diseases, the employer would be required under the *Arline* decision, even if that disease constituted a risk or threat to others—Justice Brennan referred to the risks involved. He nonetheless said the employers would have to grapple with this in the context of trying to accommodate or cage the disease in the employment context.

The *Arline* decision caused enormous concern in some circles regarding whether the Rehabilitation Act was being asked to do more than it was capable of doing. Of course, a traditional handicap, although it handicaps the person who has it, is not a threat to anyone else, with the possible exception that there are certain handicap situations where it may be a safety risk, not a health risk. But in the case of contagious diseases, there is a risk to other people in the employment context, not only coworkers but the people who the employee serves and deals with.

So there was considerable concern following the *Arline* decision that perhaps the Supreme Court had gone too far and was asking employers to do too much.

Given the limited time, I will try to move very quickly through this. Some of the precursors of what occurred on the floor of the Senate was that Senator Armstrong from Colorado introduced a bill in the Senate which called for a provision which would have made persons with contagious disease outside the Rehabilitation Act altogether, unlike the amendment that we finally came to, which was simply limited to the employment context.

Congressman Bill Dannemeyer of California, who many recognize as a leading figure expressing concerns on AIDS issues, introduced a bill in the House which, curiously enough, turned out to be very, very close in language to what we came up with in the Harkin-Humphrey amendment on the floor of the Senate.

But at any rate, it was clear before we came to the floor on the Grove City bill that there was considerable concern that *Arline* had taken the Rehabilitation Act too far, and we had to try and cut it back to the areas where it was originally intended, and to prevent employers from having to deal with sensitive and dangerous health decisions involving contagion that they shouldn't have to deal with.

In the committee markup of the Grove City Act, Senator Humphrey offered his first attempt at an amendment to try to resolve and correct the law in this area. The amendment he offered in committee was somewhat broader than that which we worked out in compromise on the floor. The committee amendment was not limited to the employment context. It was limited to any coverage of the Rehabilitation Act. It is difficult to say whether it was broader or simply different than the bill we came up with on the floor, in that the committee amendment spoke in terms of "where the contagious disease presents a risk to the health or safety of others." On the floor we ended up using "direct threat to the health or safety of others."

But to make a long story short, there was enormous sensitivity and a certain amount of fear in dealing with this issue because it is so sensitive. And Senator Humphrey's amendment was defeated very badly in committee. We received only two votes supporting it—Senator Thurmond and Senator Humphrey.

With that, the Senator was still determined to try to do something to improve the law in this area, but he recognized that the Armstrong bill and the approach he had tried in committee probably could not get the kind of support at this time. So we went to the floor of the Senate on the Civil Rights Restoration Act, with the hopes of getting a more narrow amendment adopted.

The amendment that Senator Humphrey originally brought to the floor was somewhat different than the Humphrey-Harkin compromise amendment. I won't go into the details, but again the Humphrey amendment spoke in terms of risks, rather than direct threat.

When we circulated the amendment we were contacted, to our pleasant surprise, by representatives of other Senators, I believe including Senator Harkin's staff, indicating to our surprise that perhaps we were not as far away from each other as some might think in crafting an amendment to deal with the problem.

To make a long story short, I mentioned this to Senator Humphrey, and he encouraged me to work with Senator Harkin's representative, Senator Kennedy's, and some others, and an attempt was made to compromise an amendment between what the forces represented by Senator Harkin and Senator Humphrey wanted.

I think there was one primary distinction between the two approaches, and I think it's quite important—and I think it's been the source of much of the post-passage debate over what this amendment really means.

The Humphrey amendment—our approach was to change the basic threshold definition of "individual with handicaps." In other words, you don't even get into the Rehabilitation Act if a person is not an individual with handicaps. So our language would have had the term "individual with handicaps." Again, this was never discussed on the Senate floor, but this was kind of among the discussion.

The proponents of a more narrow approach suggested language whereby we would not change the definition of "individual with handicap"; we would simply carve out an exemption from the term "otherwise qualified individual with handicap." Had we done that, a person with a contagious disease, which is a direct threat to others, would still be an individual with handicaps, and would be fully covered by the act.

Our side would not accept the proposal to have this carve-out apply only to "otherwise qualified." We insisted it apply to the threshold definition of "individual with handicaps."

As a result, the amendment now reads—I don't have it directly in front of me, but it essentially reads that a person who has a currently contagious disease which presents a direct threat to the health or safety of others, or which would prevent the person from being able to do the job in question, does not constitute an individual with handicaps for purposes of the employment discrimination provisions of the Rehabilitation Act.

So I think we are going to confront a difficulty here in that the plain language of the statute seems to be at variance somewhat with some of the post-passage interpretations of the act. There have been statements in the press and subsequent insertions in the *Congressional Record,* indicating that this amendment does nothing to change existing law, that it has no effect on the *Arline* decision, and it essentially is just a codification of what we had before. I would stress that Senator Humphrey would not have moved forward with this amendment were that the case.

I think the best way to get a handle on how this amendment changes the law is to read the statements from Justice Brennan's opinion in the *Arline* decision, the ones I quoted earlier in my testimony. And there is no way you can reconcile those statements with the language of amended section 7(8) of the Rehabilitation Act.

In other words, Justice Brennan says, "It would be unfair to allow an employer to seize upon the distinction between the effects of a disease on others and the effects of a disease on the patient and use that distinction to justify discriminatory treatment."

He said, "We do not agree with petitioners that in defining a handicapped individual under Section 504, the contagious effects of a disease can be meaningfully distinguished from the disease's physical effects on a claimant."

Well, Congress has now done that. In other words, they are not saying you can discriminate on the basis of contagious disease. What they are saying is the effects of the condition on others must be determined to determine whether the individual is an individual with handicaps in the first place.

I don't know whether I've gone over my time. I just want to wrap up by stating—I know this is a conference on AIDS and the law. I think, as I indicated before, the effect of this amendment may be less significant under the current state of the medical art with respect to AIDS than it is with other diseases, for the simple fact that the term "direct threat" is key.

I think, again, the language is good in one way, in that if the state of the art of medical science regarding the transmissibility of AIDS determines in the future that situations that we don't now envisage may involve transmissibility, there may be considerable situations where this amendment could apply to AIDS.

Under the current state of the art, I would think this amendment would have very limited application to that. And I guess the best way to gain a handle on that is to say there are really two things that are critical: One, what is the evidence on transmissibility? And, two: What is the nature of a particular job, and what kind of intimate contact does that involve?

I would simply, by example, suggest the kind of case where we may have courts using this amendment in an AIDS-type situation. There is some evidence—I don't know whether it's conclusive; I'm not a medical doctor—suggesting that other than sex and needles, AIDS may be transmissible through the exchange of blood outside the sexual or needle contacts. If this is the case, there would certainly be many fields in the medical profession, such as a dental technician, where there is a lot of exchange of blood, a surgeon, surgical nurses, situations where people actually deal with blood of other people's bodies.

I think a court, under certain circumstances, may well find that under those circumstances the disease may present a direct threat to the health and safety of others. I don't know.

But in terms of the broad variety of jobs that don't involve any intimate physical contact, where there is no likelihood of blood being exchanged, I think it would be quite unlikely that this amendment would have much effect on the AIDS situation under the current state of the medical art.

That concludes my summary. Thanks for the opportunity.

CHAIRMAN PENDLETON. I'm sure that we'll have some questions and Mr. Silverstein would like to respond in kind.

Mr. Silverstein, I understand from counsel we'll allow you a little bit more time but we kind of constrained Mr. Smith's time because of time constraints.

The Chair would like to change the thought for just a minute to indicate to people that it's interesting that sometimes we tend to forget, but today is the anniversary of *Brown* v. *Board,* 1954, on May 17.

For those of us who have some sense of whence we came in the black, this is the same day, about 10 years later, that the famous sociologist who wrote "Black Bourgeoisie," Franklin Frazier, died. I just note that for the record, and perhaps we might want to talk about it later on.

Mr. Silverstein.

TESTIMONY OF ROBERT SILVERSTEIN, STAFF ASSISTANT TO U.S. SENATOR TOM HARKIN, COAUTHOR OF THE HUMPHREY-HARKIN AMENDMENT

MR. SILVERSTEIN. Thank you. My name is Bob Silverstein. I am the staff director of the Senate Subcommittee on the Handicapped. The chairman of the subcommittee is Tom Harkin from Iowa.

I'd like to start by also looking at the *Arline* decision and just very quickly walking through that decision, because that's essential in understanding the context of the Harkin-Humphrey amendment and what transpired in Congress.

There are two steps in any 504 case that one must go through in analyzing whether or not you have been discriminated. First you have to determine if you're handicapped; second, you have to determine if you are otherwise qualified.

In the context of contagious diseases, what this means is that if you have a contagious disease, as a result of *Arline,* you are handicapped. That means one thing and one thing only. That means you can go into court and make your case, make out a prima facie case that you are otherwise qualified, meaning that getting to the step of handicapped only gets you into court and gives you the opportunity to present facts and look at what medical judgment has to say and have the case based on facts and medical

judgment. But you have to make out a prima facie case that you are otherwise qualified.

What that means for a person with a contagious disease is: Do you pose a significant risk of communicating an infectious disease to others? For example, if you do, and there is no reasonable accommodation that could prevent that transmissal, you lose, because you are not otherwise qualified.

Again, handicapped contagious disease gets you into court, but you have to show that, notwithstanding a reasonable accommodation, you do not pose a significant health or safety risk to others. You have to make out a prima facie case to that effect.

If you can't, if the facts show, based on facts and sound medical judgment, that that isn't the case, you lose. You lose in the employment context; you lose in any other context.

The *Arline* decision is supported by every public health official or organization that I am aware of. The American Medical Association, the American Nurses Association, the American Public Health Association, seven States, all issued briefs in the *Arline* decision. And what those briefs said is that construing 504 to include those with contagious diseases will complement rather than complicate State efforts to enforce public health laws. In other words, the public health officials thought that if we say that you're covered by 504, it's going to help their efforts to address the problem of AIDS, not hurt it.

This was adopted by the Supreme Court in footnote 15.

Now, let's go again to the Civil Rights Restoration Act with that in mind.

As George said, Senator Humphrey did introduce an amendment to the full committee. It was defeated 2 to 14. That amendment would have excluded persons with AIDS basically from coverage as handicapped persons under 504. People who voted against it included the chairman of the committee, Senator Kennedy; Senator Harkin, the chairman of the subcommittee; Senator Weicker, the ranking Republican member of the subcommittee with jurisdiction; Senator Hatch, Senator Quayle, Senator Cochran, Senator Stafford.

The committee report states on page 28: "The amendment represents a complete retreat from the principles for which Section 504 stands."

Now, let's go to the floor in terms of the compromise amendment. The Senators who were involved were Senator Humphrey, Senator Harkin, Senator Kennedy, who also was the chief sponsor of the Civil Rights Restoration Act; Senator Weicker, who was the chief Republican sponsor of the Restoration Act; Senator Hatch was involved as well, and to a lesser extent Senator Cranston, who is known as the father of 504.

Now, let's go to the language for a moment of the amendment and the important colloquy that accompanied that amendment. So we're not

talking in the abstract; we're talking exactly in the words of what happened and the colloquy that accompanied the language.

Let me start out with a summary statement in terms of my position.

In my opinion this amendment clarifies—it does not modify; it clarifies—how section 504 of the Rehabilitation Act of '73 applies to individuals with contagious diseases and infections. The amendment is consistent with the Supreme Court decision in *Arline,* and the amendment does not change or modify the substantive standards of section 504.

This fact, this conclusion, is evident from reading the statement of purpose that preceded the amendment, the language of the amendment itself, and the colloquy that followed the amendment.

The statement of purpose expressly says—and I quote: "Purpose: To provide a clarification for otherwise qualified individuals with handicaps in the employment context."

I would note we intentionally did not state that the purpose of the amendment was to change or modify. The word used was "clarify." The language of the amendment also reflects this intent, and George has already quoted from that language.

This language was purposely patterned after and it is virtually identical to language that was used in 1978 with respect to drug addicts and alcoholics. At that time many employers had fears about 504 and what they had to do vis-a-vis alcoholics and drug addicts. The legislative history of the '78 amendments makes it crystal clear that Congress understood that the "otherwise qualified" standard for 504 already ensured that employers would not have to worry, because if those folks posed a direct threat to health or safety and there was no reasonable accommodation, they too could be fired. That was the law of the land prior to the amendment.

But in order to allay fears, Congress in '78 chose to include language. And the legislative history accompanying the '78 amendments—every word of it—makes that crystal clear.

This was expressly said and stated in the colloquy that accompanied the language:

> The amendment is designed to serve the same purpose as what happened in '78. The objective of the amendment is expressly stated in the statute the current standards of 504 so as to reassure employers that they are not required to hire or retain individuals with contagious diseases or infections who pose a direct threat to the health or safety of others and cannot perform the job.
>
> The basic manner in which an individual with a contagious disease or infection can present a direct threat to the health or safety of others is when the individual poses a significant risk of transmitting the contagious disease or infection to other individuals.

The Supreme Court in *Arline* explicitly recognized this necessary limitation—and that's what it is, a limitation and protections of 504, and this amendment is clearly consistent with that standard.

Again we stated in the colloquy expressly:

> The amendment does nothing to change the requirements in the regulations regarding the provision of reasonable accommodations to a person with handicaps, as such provision applies to persons with contagious diseases. Thus, for example, if a reasonable accommodation would eliminate the existence of a direct threat to the health or safety of others or eliminate an individual's inability to perform the essential functions of the job, the individual is qualified to remain.

Finally, we stated in the colloquy:

> The two-step process for Section 504 applies in cases involving individuals with contagious disease or infections. That is, if a court must first determine whether an individual is protected under the traditional three-part definition of handicapped

—which is you have a physical or mental impairment, you have a history of, or you are regarded as having an impairment—

> the courts must then make an individualized determination as to whether the individual is otherwise qualified to hold a particular position at issue in the case.

Now, as I said, let me try to amplify a little bit the language that was used in '78. I have a quote from Senator Williams who was chairman of the full committee back in '78. October 14, 1978, page S-37-510: "Again, the amendment in this regard simply makes explicit what prior interpreters of the Act, including those of the Attorney General and the Secretary of Health, Education, and Welfare, have found."

In other words, it is just consistent with current law. There are three or four quotes, and I will be glad to submit them all for the record.

Senator Cranston, who is the father of 504, was instrumental in getting this amendment adopted on the Senate side. What is critical is that the House back in '78 had passed an amendment which excluded all drug addicts and alcoholics from coverage, and the Senate said, "No way; that doesn't make any sense. We want to have the current law which makes sense, a two-step notion—handicapped and otherwise qualified apply."

And that's what that language means. The Supreme Court in the *Arline* decision expressly adopts that in footnote 14 and the accompanying text.

Senator Cranston introduced a statement in the record, following the amendment, which goes through the whole history of the '78 amendments, and at a subsequent date—I have already asked for permission from General Counsel—I will submit all that for the record, the full statement.

CHAIRMAN PENDLETON. Fine.

MR. SILVERSTEIN. HEW, at that point in '81, had a policy manual on 504. Let me quote what it says: "While the amendment"—the '78

amendment dealing with drug addicts and alcoholics—"clarifies the position of Congress, it does not make any substantive change to the regulation. Where an individual's addiction does not interfere with his ability to perform, with reasonable accommodation, the essential functions of a job, a denial of employment is discriminatory."

The American Law Division of the Library of Congress—I don't know if those on the panel are aware that Congress has a research arm that is called the Congressional Research Service. In that is the American Law Division. Frequently they do objective analyses of documents for everybody—Democrats, Republicans, conservatives—everybody. They did an analysis of the '78 amendments in a document called, "American Law Division Analysis of the '78 Amendments, Proposed Amendment to the Definition of Handicapped Persons Regarding Alcoholics and Drug Addicts." The document concludes that the '78 amendments codify current law. That is the two-step process and does not change anything.

CHAIRMAN PENDLETON. Mr. Silverstein, if you will for a moment, I understand we're going to run out of Mr. Smith's time. Is that correct or not correct?

MR. SMITH. At some point I'm going to have to go back. We have a 10 o'clock hearing on the FBI.

CHAIRMAN PENDLETON. I want to give him time to finish, but we need to begin to ask some questions for the record from Counsel. I don't want him to run away before we have the questions asked.

MR. SILVERSTEIN. Five more minutes?

CHAIRMAN PENDLETON. If you would just bear with us, we want to get this part. We're not going to exclude you at all.

Go right ahead.

MR. SILVERSTEIN. Let me go quickly to other expressions of congressional intent with respect to this amendment.

There are at least 20, 25 statements in the *Congressional Record*, if not more, on this amendment. I will go through a number of those, but I can say categorically that I have not seen a single statement in the record that says that there is any impact whatsoever on the obligation to provide reasonable accommodation.

Senator Kennedy, Senator Weicker, Senator Cranston, Senator Harkin, Senator Inouye, Senator Kerry, Senator Simon, Senator Dole, Senator DeConcini, Senator Bingaman have all expressly said that this amendment is consistent with current law, it's consistent with the *Arline* decision, it's consistent with the standards of 504, including the obligation to provide reasonable accommodation.

Senator Hatch and Senator Symms, who both voted against the Restoration Act, have expressly said in their statement that the reasonable accommodation provision applies, and that was one of the concerns that they had.

On the House side we have statements from Chairman Hawkins, who is chairman of the Education and Labor Committee which has jurisdiction over the Restoration Act; Congressman Edwards, who is chairman of the Judiciary Subcommittee with jurisdiction over the act; Congressman Jeffords, who is the ranking minority member of the Education and Labor Committee; Congressman Coehlo, the Majority Whip; Congressman Waxman, the chairman of the Subcommittee on Health and the Environment; Congressman Frank, the chairman of the Subcommittee on Administrative Law and Government Relations; Congressman Weiss, the chairman of the Government Operations Committee with oversight jurisdiction over 504; Chairman Owens, chairman of the Subcommittee on Select Education with jurisdiction over 504—all saying the same thing.

And let me just quickly quote from Congressman Jeffords, a ranking Republican member, because he captures the essence of many of the statements that appear in the *Congressional Record*—and I quote:

> During Senate consideration of the bill, a third clarifying amendment was added to the bill. With regard to persons with contagious diseases or infections, the Harkin-Humphrey amendment places within the terms of the Rehab Act the "otherwise qualified" standard, now set forth in the regulations and case law. In brief, the Harkin-Humphrey amendment adopts the approach and standards of the Supreme Court in the *Arline* decision. It provides that persons with contagious diseases and infections remain protected in their jobs under the Rehab Act if they do not pose a direct threat to the health or safety of others. This determination would require a case-by-case analysis based on reasonable medical judgments. In other words, there would have to be a determination that there is a significant risk of transmission of the disease or infection to others in the workplace, a risk which could not be eliminated by reasonable accommodation.

The American Law Division not only made an analysis of the Rehab, the '78 amendments, alcoholics and drug addicts, they made an explicit analysis of the Harkin-Humphrey amendment. Let me quote from page 20 of that document: "Thus, this colloquy language, like the statutory language, would support the argument that the amendment restates existing law."

Not only do we have the objective American Law Division of the Congressional Research Service, we also have a statement from Deputy Assistant Attorney General at the U.S. Department of Justice, Civil Rights Division, Mark Disler. He states in a letter that was sent to the Senate right before the override vote—and I quote: "As a consequence, more sectors of American society will be burdened with the need to attempt to accommodate contagious persons—employees, students, members, participants, customers, including those with AIDS."

And I'm running out of time.

CHAIRMAN PENDLETON. I'm not so sure you ran out of time.

MR. SILVERSTEIN. Well, George says he's got to go.

MR. SMITH. I wondered if I could have 1 minute.

CHAIRMAN PENDLETON. Do you want to debate this?

MR. SMITH. No, I thought I could in less than 1 minute say something.

CHAIRMAN PENDLETON. Less than 1 minute, and then we'll go to a couple of questions from Counsel.

MR. SMITH. I would simply say, as you will note, almost everything Mr. Silverstein states comes from the post-passage statements. People put a spin on a statute. I would simply stress that Congress votes on statutory language, not on *Congressional Record* statements, not on post-passage spins. I would suggest the answer to this question lies in the statutory language and it's not consistent with these post-passage statements.

That's all I have to say.

MR. SILVERSTEIN. And I would suggest that it lies in the language with the statute, as clarified by the colloquy, and you have to understand where that language came from. It just didn't come out of the blue. It is modeled expressly on something that happened in '78.

CHAIRMAN PENDLETON. Interesting.

Counsel, do you have a couple of questions?

MR. BALCH. Yes, actually four questions, but let me begin, if I may, with No. 4, because that's the reasonable accommodation question that you gentlemen have been debating. And summarizing Written Question No. 4, which will be placed in the record here: If a particular individual's currently contagious disease or infection would constitute a direct threat to the health or safety of others, under Humphrey-Harkin must an employer accord that individual reasonable accommodation?

[The complete Question No. 4 is as follows:]

"The fourth question on interpreting Humphrey-Harkin: As the Supreme Court emphasized in *Arline*, under 504 there are two steps in determining whether an individual is entitled to redress. The first is to determine the threshold question whether the plaintiff is a 'handicapped individual' within the meaning of 504. The second is to determine whether the plaintiff is 'otherwise qualified.'

"In *Arline* the Court held that 'A person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified . . . if reasonable accommodation will not eliminate that risk.' The Court also said that as part of reasonable accommodation, 'Although they are not required to find another job for an employee who is not qualified for the job he or she was doing, [employers] cannot deny an employee alternative employment opportunities reasonably available under the employer's existing policies.'

"In short, under *Arline,* the determination about significant risk comes in step two, not step one, and that step two determination includes a consideration of reasonable accommodation.

"But the Humphrey-Harkin amendment provides that one who poses a direct threat is not an 'individual with handicaps,' which on its face appears to make the direct threat determination part of step one—which might mean that if there's a direct threat you don't even get to step two and there is no need to consider reasonable accommodation. The colloquy says both that Humphrey-Harkin 'does nothing to change the current laws regarding reasonable accommodation as it applies to individuals with handicaps' and that 'the two-step process in Section 504 applies in the situation under which it was first determined that a person was handicapped and then it is determined that a person is otherwise qualified.'

"So which is it? Assume that an individual does pose the 'direct threat'—must the employer accord that individual 'reasonable accommodation,' including perhaps another job, or not?"

MR. BALCH. Mr. Smith, do you want to address that directly?

MR. SMITH. Yes, I think it's clear from what we both just said, I think we probably have differing interpretations on that. Here is why I think the language makes it clear that the answer to that is not—

CHAIRMAN PENDLETON. The answer is not what?

MR. SMITH. It does not require accommodation. In other words, what it means is, if you are not an individual with handicaps, the act doesn't apply to you. And under this thing, if you're not an individual with handicaps, because of the contagious disease condition, it doesn't apply to you under the employment section. It does apply with respect to the other.

First of all, it's a threshold definition. Section 7(8) is the definition of whether you are an individual with handicaps. If you're an individual with handicaps, you don't get into the act.

I think the colloquy even underscores this. In part of the colloquy, Senator Humphrey or Senator Harkin—I don't know who came first—agreed that isn't it true that the two-step test still applies. First you determine if you're an individual with handicap, and then you determine whether you are otherwise qualified. If you don't pass the first step, individual with handicap, none of the act is triggered.

And again I must stress that language that would have been different from what we adopted was proposed in the discussion. In other words, they proposed merely to amend the "otherwise qualified" language of the statute, not the threshold definition.

Let me add one other quick point.

Since the definition, the exclusionary language, involves whether a person is a direct threat and whether he is qualified to do the job, the application of that language will be quite similar—quite similar to an

otherwise qualified disposition. So the actual effect, regardless of which way we go on your question, may not be as different as you might think.

MR. BALCH. That's an important question, isn't it? Because under, for example, *Arline,* do both of you agree that the employer must provide another job, if it's a standard approach, to make available other jobs? I'm referring to the footnote that you have before you in the excerpt from *Arline,* footnote 19.

I take it it's a key question whether, under Humphrey-Harkin, reasonable accommodation is required, as opposed to under *Arline,* I take it, you both would agree it clearly is required.

MR. SMITH. I think "reasonable accommodation" is the wrong term to apply to Humphrey-Harkin. You may disagree. I think you do have to engage in this careful analysis to see whether the person comes under the statute. But if you can conscientiously determine he is a direct threat or can't do the job, then you don't get to the accommodation situation.

MR. BALCH. Let me turn to Written Question No. 1.

MR. SILVERSTEIN. Do you want me to reply, or are you going to ask him all of them?

MR. BALCH. Just because he has to leave, and we'll certainly give you the opportunity afterwards.

Summarizing Written Question No. 1, which will be put in the record at this point: In your view, is it the intent or effect of the Humphrey-Harkin amendment to settle an issue left open in *Arline* by establishing that asymptomatic contagious individuals who pose no direct threat and can perform their jobs are covered by sections 503 and 504 of the Rehabilitation Act?

[The complete Question No. 1 is as follows:]

"First, *Arline* explicitly said the Court reserved judgment on whether asymptomatic carriers of a contagious disease are 'handicapped' for the purpose of 504. Some argue that seropositive individuals who have neither full-blown AIDS nor ARC fall in that category. The Humphrey-Harkin amendment to the Grove City bill states that 'an individual who has a currently contagious disease or infection' but poses a direct threat or can't perform the duties of the job is not included in those covered by sections 503 and 504. It has been suggested by some that this implies that someone with a 'currently contagious disease' who does not pose a direct threat and is able to perform the duties of the job is covered by 503 and 504. Thus the argument is that Humphrey-Harkin settles what was left open in *Arline* by establishing that asymptomatic contagious individuals are covered. The question is: In your view is this the intent or effect of the Humphrey-Harkin amendment?"

MR. SMITH. I don't think we focused on that. It seems to me if the person has no symptoms—in other words, there is nothing visibly wrong

with him. I'm not a doctor. When you say "asymptomatic" do you mean someone who is merely a carrier?

MR. BALCH. I believe that would be the interpretation, yes.

MR. SMITH. Again, we didn't purport to resolve that issue. That goes to such difficult questions as to the risk of transmissibility and the circumstances in which it arises. So I don't think we've pretended to be able to resolve that kind of a question.

MR. BALCH. And, of course, we'll ask Mr. Silverstein after you have to depart.

Summarizing Written Question No. 2, which should be put in the record at this point: In your view, is it the intent or effect of Humphrey-Harkin to govern or provide guidance in areas other than employment as a Congressional Research Service Study suggests might be the case?

[The complete Question No. 2 is as follows:]

"The second issue is this: On its face the Humphrey-Harkin amendment deals only with employment, as did the 1978 alcoholism and drug addiction amendments on which it was at least partially modeled. A study by the Congressional Research Service notes, however, that it has been argued that the 1978 amendments apply in areas other than employment which are also covered by section 504, such as education, and suggests that possibly Humphrey-Harkin should similarly provide guidance for the courts in interpreting 504 in fields other than employment. The question is: In your view, is it the intent or effect of Humphrey-Harkin to govern or provide guidance in areas other than employment?"

MR. SMITH. I think what is fair to say on that—again, I'm a great believer in the plain language of statutes. So by the terms of the statute, of the amendment, it applies only to the employment context. However, I would think the principles are quite similar, and it certainly is intended to provide guidance. But it plainly does not govern them because it applies only to the employment context.

MR. BALCH. Summarizing Written Question No. 3, which will be placed in the record at this point: Is there any difference between the *Arline* standard which is "a significant risk of communicating an infectious disease," which disqualifies an individual from 504 protection under *Arline,* and the "direct threat to the health or safety of other individuals" standard that disqualifies an individual under Humphrey-Harkin? And if there is a difference, what is it?

[The complete Question No. 3 is as follows:]

"The third issue: Under *Arline,* 'A person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified for his or her job if reasonable accommodation will not eliminate that risk.' Under Humphrey-Harkin you are not covered if you are 'an individual who has a currently contagious disease or infection and who, by reason of such disease or infection, would constitute a direct

threat to the health or safety of other individuals.' Is it the intent or effect of Humphrey-Harkin to change the *Arline* standard and, if so, how? Is there a difference between 'significant risk of communicating an infectious disease' and 'a direct threat to the health or safety of other individuals'? If so, what is it?"

MR. SMITH. I haven't really thought in great detail about that. I maybe want to think that one over. The "direct threat" language—I think one way to look at the importance of the "direct threat" language is to contrast it with a situation where there is no physical threat, there is only the perceived threat related to hysteria.

I think the intent there—and again this was something the Senators did not discuss—I think by "direct threat" we meant something that was not imaginary, that was not purely speculative, but had some basis in physical situations, as opposed to something that was purely imaginary. And I think that's the focus of "direct threat."

"Direct threat," I don't believe—and there are some comments on this from Senator Wilson—I don't think the Senators purported to say what degree of medical evidence you must have to establish that there is a direct threat. As long as it's something that a trier of fact can find, that an employer could reasonably consider is a risk, could be considered a direct threat.

Frankly, the Senators did not go into that in great detail. I think the direct threat mainly separates something that is actual and based on some kind of scientific or medical evidence, as opposed to something that is based purely on hysteria or misperceptions. That's what we mean by "direct threat," I think.

MR. BALCH. I now want to give Mr. Silverstein an opportunity to respond to the same questions. Of course, Mr. Smith, you are welcome to stay as long as you feel you can.

MR. SMITH. Thank you, sir.

MR. BALCH. Mr. Silverstein, just taking those same questions and in that order, the first written question, which was, as you'll recall—

CHAIRMAN PENDLETON. Just a minute. I'm sure other members at the table might want to ask you some questions later, so you might want to be available for a phone call or something.

MR. SMITH. I'd be glad to.

CHAIRMAN PENDLETON. Go ahead, Mr. Balch.

MR. BALCH. Restating the first question, Mr. Silverstein: In your view, is it the intent or effect of the Humphrey-Harkin amendment to settle the issue left open in *Arline* by establishing that asymptomatic contagious individuals who pose no direct threat and can perform their jobs are covered by sections 503 and 504 of the Rehabilitation Act, something which on its face at least *Arline* reserved decision about?

MR. SILVERSTEIN. In my opinion, persons who are seropositive have always been covered by any or all of the three prongs of the current definition of "handicapped persons" set out in section 7(8) of the Rehabilitation Act. There are three prongs:

The first is you have a physical or mental impairment which substantially limits major life activity.

The second prong is that you have a history of such an impairment.

And the third prong is you are regarded by others as having such an impairment.

In my opinion, as I said, seropositive persons have always been covered by those three prongs of the test. Lower courts, such as Local 1812, support my interpretation.

Although the Supreme Court did not address this issue directly because the case did not involve a person who was seropositive as set out, as you know, in footnote 7, the decision itself does address the broad issue through extensive dicta, and those dicta deal with the question of the illegality under section 504 of discriminating against a person on the basis of irrational fears, mythologies, and misperceptions regarding the person as having a physical or mental impairment that limits a major life activity.

Based on the dicta in *Arline*, it is clear to me that a person who is seropositive would be covered.

The language used, to get to your question directly, in the Harkin-Humphrey amendment is clearly consistent with that interpretation. The phrase used is "a disease or infection."

Now, I also agree with the Reagan administration's decision or interpretation as enunciated in the OPM guidelines on AIDS in the workplace, when they say that we must bar discrimination in the workplace against persons who are seropositive.

MR. BALCH. Would it be accurate, then, to characterize your position as saying that under *Arline*, properly interpreted, and existing law, properly interpreted, seropositive individuals are covered, and Humphrey-Harkin is not inconsistent with that?

MR. SILVERSTEIN. That's right.

MR. BALCH. But Humphrey-Harkin does not itself, in your view, address or attempt to—

MR. SILVERSTEIN. It addresses it by making sure that this language is consistent with current law and the *Arline* decision by expressly including the phrase "disease or infection."

MR. BALCH. I understand.

Going to Question No. 2—

CHAIRMAN PENDLETON. Excuse me. How many more questions do you have, Counsel?

MR. BALCH. I was just going to give him the opportunity to respond to the two Mr. Smith had responded to.

CHAIRMAN PENDLETON. Okay; fine.

MR. BALCH. The question is: Is it the intent or effect of Humphrey-Harkin to govern or provide guidance in areas other than employment?

MR. SILVERSTEIN. Not the intent of the Harkin-Humphrey amendment. You see, the Harkin-Humphrey amendment is just simply a restatement of current law, so current law is applicable not only in the employment context but it's applicable in every other context as well.

In other words, the two-step notion applies. Handicap gets you into court, but then you have to show and make a prima facie case that you are otherwise qualified. If you can't, the other side rebuts it, you lose.

MR. BALCH. And on the third question, I take it, since you believe there is no difference between Humphrey-Harkin and *Arline*, you don't see any difference between the significant risk standard in *Arline* and the direct threat standard in Humphrey-Harkin?

MR. SILVERSTEIN. That is correct. And that statement was made expressly in the record on two occasions—one in a letter from Senator Harkin to Chairman Edwards and Chairman Hawkins, and a second in a colloquy between Senator Harkin, Senator Weicker, and Senator Kennedy.

The fourth question was reasonable accommodation.

MR. BALCH. Yes. I'm sorry.

MR. SILVERSTEIN. As I have said before, everybody, starting from the colloquy, everybody who has made a statement on this subject has said the same thing—everybody. And that includes all the key actors in the House and the Senate. It includes the American Law Division making an independent analysis. It includes the Justice Department.

CHAIRMAN PENDLETON. At this point, let's take a quick break. Mr. Carvin is here. Then we'll go to the rest of the panelists, if you don't mind.

COMMISSIONER RAMIREZ. But Mr. Silverstein will remain?

MR. SILVERSTEIN. I will be able to remain for about another 45 minutes, yes. But if people are going to make other statements—however you want to proceed. I can stay a little bit longer for questions.

CHAIRMAN PENDLETON. Why don't we just not take a break, and maybe there are some questions.

COMMISSIONER RAMIREZ. The question that stands out—I can appreciate the need to create statutory language in response to the Humphrey amendment—

MR. SILVERSTEIN. There is no Humphrey amendment. It was a Harkin amendment. He's a sponsor.

COMMISSIONER RAMIREZ. The Humphrey amendment was proposed and it was defeated.

MR. SILVERSTEIN. In committee.

COMMISSIONER RAMIREZ. In committee.

MR. SILVERSTEIN. Correct.

COMMISSIONER RAMIREZ. The gist of that, as I understand it, is that the Humphrey amendment was based on the notion of risk—the basic difference at this point between the Humphrey and the Humphrey-Harkin amendment is the language of direct threat versus the language of risk.

MR. SILVERSTEIN. No. The major difference was that the amendment that was defeated soundly 2 to 14 in committee would be an exclusion for all persons with contagious—they're not covered by 504.

COMMISSIONER RAMIREZ. Okay.

MR. SILVERSTEIN. The Harkin-Humphrey amendment is, again, a reiteration of the standard of "otherwise qualified" that is in current law.

COMMISSIONER RAMIREZ. And that is an interesting question. If in fact it is a reiteration of what exists, why was it necessary to have it?

MR. SILVERSTEIN. For the precise reason set out in Point 1 in the colloquy, and for the precise same reason that we did something in '78 with respect to alcoholics and drug addicts. There were misperceptions, there were fears, there was uncertainty as to what this meant.

Can I just briefly take 2 minutes? Senator Harkin, page S.1739, March 2, 1988, *Congressional Record,* deals exactly with your question.

The day the Supreme Court handed down its decision, Chairman Harkin was concerned—there were newspaper articles, and the newspaper articles said, "People with AIDS covered by 504." And that's all they said in the headlines. He on that day put a statement in the *Congressional Record* explaining what it did do and what it didn't do, that two-pronged test. If you're not otherwise qualified, you lose. He said, "As I anticipated, after the press accounts of the decision, my staff on the subcommittee which I chair was inundated with requests for clarifications."

He felt this amendment would allay fears by clarifying current law, and that is exactly what happened in '78 with respect to alcoholics and drug addicts. If you look at Senator Cannon's statement, Senator William's statement, the key chairmen of the appropriate committees, that's what they wanted to do—allay fears. And that is Point 1 in the colloquy that accompanied the Harkin-Humphrey amendment.

COMMISSIONER RAMIREZ. Do you want to break?

CHAIRMAN PENDLETON. Commissioner Berry has a question she wants to ask on the same topic.

COMMISSIONER RAMIREZ. If I can have just a minute.

CHAIRMAN PENDLETON. Do you want to take some of her time?

COMMISSIONER RAMIREZ. Sure; she takes mine all the time, so I'll take hers.

[Laughter.]

We have heard a lot of testimony about transmissibility. I believe the most credible testimony that we have heard indicates that transmissibility can be clearly defined at this point, the issue of transmissibility. But assuming that a case went into court—and some of the courts we know are

not always informed by the same kind of level of expertise that we have had here—do you see that the transmissibility question could be up for grabs in the courts all over again?

MR. SILVERSTEIN. As a result of either *Arline* or this amendment?

COMMISSIONER RAMIREZ. Yes.

MR. SILVERSTEIN. No. Again, given that this is just consistent with *Arline*, the standards set out in *Arline*—I've got the slip opinion, page 13—are going to apply. The Supreme Court has said, "We agree with the AMA that inquiries should include findings of fact based on reasonable medical judgments, given the state of medical knowledge about the nature of the risk, how it is transmitted, the duration of the risk, how long the carrier is infected, the severity of the risk, and the probability that the disease will be transmitted and will cause varying degrees of harm."

And I think that the courts, consistent with the Harkin-Humphrey amendment, will be following the dictates of the Supreme Court.

COMMISSIONER RAMIREZ. Do you believe that a Federal agency in enforcing this legislation would have any option but to use the criteria or the standards or the knowledge base around transmissibility that is the position of the NIH and the CDC?

MR. SILVERSTEIN. No, I would think, based on this decision and the Harkin-Humphrey Amendment, that they would be guided by statements and criteria set out by public health officials, the Centers for Disease Control.

COMMISSIONER RAMIREZ. Okay, I will yield to my colleague if she has any time left.

CHAIRMAN PENDLETON. She doesn't have any time left.

COMMISSIONER BERRY. Just a fast one, and this will be all. I just want to make sure I understand, Mr. Silverstein. Are you saying under Harkin-Humphrey—I started to say Humphrey-Hawkins—are people who are HIV positive covered by 504 or not?

MR. SILVERSTEIN. Again, in response to that question, my answer is under current law they are. My interpretation of the dicta of *Arline* is that they are. Under court decisions handed down by lower courts they are, and this amendment is consistent with those interpretations.

COMMISSIONER BERRY. And the only other thing is about reasonable accommodation, which Mr. Smith—oh, he left and someone else is there now, Mr. Carvin. It was Mr. Smith who answered the question about reasonable accommodation.

How do you tell what accommodation is reasonable? And also, is reasonable accommodation in your view an absolutely critical component of antidiscrimination law for handicapped persons? In other words, could we do without it?

MR. SILVERSTEIN. There is no provision in 504, in the overall rubric, that in my opinion is more important than the reasonable accommodation

provision. Some folks in *Alexander* v. *Choate,* which was a Supreme Court case handed down several years ago—one of the arguments was that only intentional discrimination is covered. The Supreme Court said no way could that possibly be the case, and they rejected that. And the reason is in part because of the reasonable accommodation provision. Without it, people who are mobility-impaired would have no right to physical access. People who are deaf who might need a TTY or TTD instead of using a regular phone would be denied the opportunity to have a job. Blind folks who needed simple modifications—I could go on and on and on.

If we are going to have handicapped persons in the regular classrooms, we may have to make certain modifications. There may be a requirement that you have to write everything. Well, somebody who doesn't have arms or has restricted use of his arms might not be able to do it. They may have to use a computer. They may have to have a band attached to their head and have a pointer.

These are all reasonable accommodations. It's an essential component of 504. And my boss, Senator Harkin, and Senator Weicker and Senator Kennedy under no circumstances would have sat down and permitted any amendment that would in any way address the essential element of 504. And that point also is set out in a colloquy between Senator Harkin, Senator Weicker, and Senator Kennedy.

COMMISSIONER BERRY. And so that applies, in your view, even in the HIV positive or AIDS context?

MR. SILVERSTEIN. Obviously it applies in all contexts, and that is why the second point in the colloquy makes that explicit.

COMMISSIONER BERRY. Okay.

MR. SILVERSTEIN. Now, one last point. You say it's not in the language. Well, look at 504 and you tell me where reasonable accommodation is in 504. It doesn't exist. It is the underpinnings of 504. The term that's in 504 is "otherwise qualified, no discrimination." But it's not there because it's the essence of 504. You can't have 504 without reasonable accommodation.

COMMISSIONER BERRY. Thank you, Mr. Chairman.

CHAIRMAN PENDLETON. Just let me ask a question here.

You say that people who are HIV positive are covered; right?

MR. SILVERSTEIN. Currently they are.

CHAIRMAN PENDLETON. How is that determined? If people are asymptomatic, what do you do about asymptomatic people? Does someone go out and take a test? And we heard in testimony even yesterday that there is a fear that if you take the test, you're going to be discriminated against in the process of employment and other things. So how can we just categorically say that HIV-positive people are covered when they may be asymptomatic?

MR. SILVERSTEIN. What I said is that there are three prongs of the definition. The first prong is the physical and mental impairment which

substantially limits a major life activity. The second prong is you have a history of impairment.

CHAIRMAN PENDLETON. I understand that.

MR. SILVERSTEIN. Well, I'm saying under each of those there is a possibility that you can be considered a handicapped person.

COMMISSIONER BUCKLEY. What if there is no major or life-threatening activity?

CHAIRMAN PENDLETON. If there is no major life-threatening activity and the person is asymptomatic—there's no impairment except that he's seropositive; right? So how can a person that has no impairment be considered to be handicapped?

MR. SILVERSTEIN. Two ways. One physical or mental impairment of a major life activity is certainly the activity of procreation.

CHAIRMAN PENDLETON. But if you don't have any impairment to your activity—

MR. SILVERSTEIN. One, if someone is seropositive, they will be substantially limited in the major life activity of procreation. Furthermore, they might have—

CHAIRMAN PENDLETON. Say that again.

COMMISSIONER DESTRO. They can't have sex to the same degree—

CHAIRMAN PENDLETON. No, he's saying they can't make babies.

MR. SILVERSTEIN. They are limited in their ability to do that—not that they can't make babies. No, that's not what I said. It is not they can't; they are substantially limited, that is correct.

COMMISSIONER DESTRO. They are substantially limited.

COMMISSIONER BUCKLEY. They can have sex.

COMMISSIONER DESTRO. But the term is "substantial limitation." That's what he's referring to.

MR. SILVERSTEIN. You have three prongs. You also have a second prong. The second prong is a history, and the third prong is regarded as having a physical and mental impairment.

If somebody regards you, even though you don't pose a health or safety risk to others but they regard you as such, like they did with people with epilepsy and cancer and mental retardation in the past—and there's three pages of this in the *Arline* decision—if you regard it as, you are clearly covered. And that's what the courts have said.

CHAIRMAN PENDLETON. I'm not so sure I got my answer, but I'm going to go to something else for the sake of time.

Can we go to footnote 7 in the *Arline* opinion? They really don't talk about HIV positive. They talk about AIDS in footnote 7—

MR. SILVERSTEIN. Correct.

CHAIRMAN PENDLETON. —as being the impairment. But there is no reference to HIV positive as being impaired; is that correct?

MR. SILVERSTEIN. That's correct.

CHAIRMAN PENDLETON. Now, square that with the last thing we talked about just now, about whether or not you are HIV positive. Are you saying what the court is not saying?

MR. SILVERSTEIN. What I said before, and I'll say it again, is that my interpretation of the *Arline* decision is that, clearly, footnote 7 does not address this issue because that issue was not before the court.

CHAIRMAN PENDLETON. Okay.

MR. SILVERSTEIN. However, there's dicta—I'm going to the slip opinion, page 4 to 5 of the slip opinion, and pages 9 through 11 of the slip opinion, primarily footnote 10, which all address the first and third prong of the test. And I said the dicta in the *Arline* decision, in my opinion, support that.

Here are some of the statements:

"The definition of handicapped"—I'm reading from the *Arline* decision—"reflected Congress' concern with protecting handicapped against discrimination stemming not only from simple prejudice but from archaic attitudes, laws, and from the fact that the American people are simply unfamiliar and insensitive to the difficulties. To combat the effects of erroneous but nevertheless prevalent perceptions about the handicapped, Congress included this last definition."

Then if you'll look on pages 9 through 11, you've got statement after statement after statement about the impact of perceptions regarded as the third prong of the test.

CHAIRMAN PENDLETON. Just one more question.

Ms. Arline was found to have tuberculosis in 1977. 1977 was the first time she was found to have tuberculosis.

You're shaking your head?

MS. HUNTER. She had been hospitalized for tuberculosis earlier in her life.

MR. HOWARD. '57.

CHAIRMAN PENDLETON. '57; right?

MR. HOWARD. And she tested positive in '77.

CHAIRMAN PENDLETON. So she tested positive in '77.

COMMISSIONER BUCKLEY. Once you're positive, you're positive for life.

CHAIRMAN PENDLETON. Okay. Did she pose a direct threat to the class in '77, under the direct threat of Harkin-Humphrey?

MR. SILVERSTEIN. I'll answer your question directly. The fourth part of the *Arline* decision says, "The remaining question is whether Arline is otherwise qualified for the job."

And then they say, "The District Court must make an individualized inquiry, to make appropriate way for legitimate concerns," et cetera.

My answer to you is I'm not going to answer it. That's what a district court should be doing, based on facts, medical judgment, the full panoply of information.

CHAIRMAN PENDLETON. All right, we have just a couple more questions. We have to give time for the other panelists. We're going to run out of time with Mr. Silverstein here, and we don't want to do that.

COMMISSIONER DESTRO. I'd certainly like the other panelists to address it, because I know others address it in their papers. But maybe you could tell us with respect to whether or not there were any discussions as to who bears the ultimate burden of proof of proving that they are otherwise qualified. You made the comment that the individual has to make the prima facie case. I assume if we are doing the usual back-and-forth in an employment discrimination case, it's the plaintiff that bears the ultimate burden of proof of showing that they are qualified as opposed to the employer showing that they are not qualified.

MR. SILVERSTEIN. We do not address it at all in the Harkin-Humphrey, but again it is consistent with current law, Harkin-Humphrey, and under current law the interpretation of that issue that I personally believe in is set out in *Jassony* v. *U.S. Postal Service,* 755 Fed. 2d, 1244, at footnote 5. And basically that's a summary of the *Pushkin* case, which is one of the seminal cases on this issue, and basically what that says is that the plaintiff must make out a prima facie case that, (a) handicap, (b) otherwise qualified, and then the burden persuasion shifts to the employer and the employer must rebut that. And that would apply in this situation.

So to take this situation, the plaintiff or the individual discriminated against would have to make out a prima facie case in terms of the information that is set out.

However, also, which is clear in the Justice Department interpretations, is that the burden with respect to undue hardship, the burden is always on the employer for sure.

CHAIRMAN PENDLETON. The Chair is getting a little bit interested now. I just want to have Commissioner Berry ask one more question, because I think we are being unfair to our other panelists who probably want some of this discussion here, and we're taking a lot of time here.

Commissioner Berry, do you want to ask one more question?

COMMISSIONER BERRY. The district court in Orlando on remand, if they were to, after taking factual testimony and evidence, decide that she was not otherwise qualified at this time; in your view would that erode the effect of Harkin-Humphrey or the *Arline* case, or would that be consistent with the standards in the case?

MR. SILVERSTEIN. It would be consistent with. What we are trying to say is each individual, each person, is treated as a human being, entitled to individualized determinations based on facts and medical judgment, not based on hysteria.

COMMISSIONER BERRY. I just asked you that because I said that yesterday and I wanted to make sure I was right. Or at least you agreed with me.

CHAIRMAN PENDLETON. We want to take a break, and we'll come back and give the other panelists a chance to make their presentations.

Mr. Silverstein, can you stay a little longer?

MR. SILVERSTEIN. I can stay a little longer, yes.

[Recess.]

CHAIRMAN PENDLETON. May we reconvene, please.

I must say that this, in a sense, is getting to the meat of why we are here. Yesterday, in spite of all the discussion and the interest by various people and various groups who presumed we were duplicating some other commission's work, that is not the case at all. But I think we are clear today that yesterday provided an underpinning for the kinds of material we are hearing today, and allow us to understand it and to get into some meaningful discussions about discrimination against people who are either HIV positive or ARC or AIDS or contagious diseases, period.

At this point I'd like to thank the staff for arranging it this way so we can move right along with the more important issues having some underpinning so it cannot be said that we wind up with sloppy work or having a sloppy hearing. But I am really satisfied with where we are right now.

Ms. Hunter, do you want to go next? Is that all right with you? We are trying to take 8-to-10 minute statements from everyone, and then we can have a chance to have Counsel questions for the record, and then we will have a chance to have Commissioner questions.

I must say this panel did, as compared to other panels, gave us rather voluminous documents and statements which I enjoyed reading, and provided me with background to understand the issue and to be able to ask some questions today.

Without any further ado, we will have Ms. Nan Hunter from the American Civil Liberties Union in New York give us a summary of her statement.

Ms. Hunter, thank you for coming.

TESTIMONY OF NAN HUNTER, AMERICAN CIVIL LIBERTIES UNION, NEW YORK

MS. HUNTER. Thank you. Mr. Chairman and members of the Commission, thank you for inviting me.

I'm going to focus in my oral testimony before the Commission today on three major points—three major points, frankly, that I believe exist essentially as consensus points that I believe this Commission should redirect its focus to. I would urge this Commission that the failure to consider these points as the major areas of focus in its examination of the issues of AIDS and discrimination would render this entire process, frankly, rather futile and irrelevant.

These are the three points:

The first is that I would urge this Commission to do as we in the American Civil Liberties Union have done, and to begin with an examination of what is in the interest and the broad interest of public health in this area. As Mr. Silverstein alluded, and as I review in my written testimony, public health leaders have overwhelmingly developed a consensus that antidiscrimination laws and the vigorous enforcement of those laws are essential, not just for legal reasons but for public health reasons.

The American Medical Association has come to that conclusion, the American Public Health Association has come to that conclusion, the Centers for Disease Control at the February 1987 conference that it held on the issues of testing came to that conclusion, the Association of State and Territorial Health Officials has come to that conclusion, and the National Academy of Sciences has come to that conclusion.

If there can be such a thing as a point of consensus among the leading scientific experts in our nation as to the importance of the enforcement of antidiscrimination laws, then we have it. It is too late in the day to pretend otherwise.

In reviewing what the relevance of that consensus is for legal interpretation, both the organization which I represent, the ACLU, and the American Bar Association have relied heavily on the development of that consensus in explaining the policy reasons underlying the need for strong enforcement of antidiscrimination laws.

Those reasons are outlined in my written testimony, and I'm sure have been and will be outlined by the representatives of those organizations that this Commission hears from, if it does hear from those organizations on this issue.

Secondly, with regard to the existence of Federal law in this area, I would point out to you a couple of things as to that.

First, this Commission has now spent the better part of the morning dealing with the very particular issues that arose in the Civil Rights Restoration Act. I would urge the Commission not to overlook one overall statement made by Mr. Smith, the representative of Senator Humphrey, that it is quite unlikely, in his words, that the amendment about which the testimony was heard will have an effect on AIDS cases. That is to say that Mr. Smith by that statement, I think, substantially agreed with the position taken by Mr. Silverstein, and with the position taken consistently throughout the legislative history of this amendment, that is, that although we may have interesting discussions about the fine points of reasonable accommodation, we come back to the fact that with regard to AIDS cases and conditions relevant to AIDS, that is, the range of HIV-infection conditions, this amendment leaves the law in its previous state.

That was the testimony of Mr. Smith as well as Mr. Silverstein. And I'll be happy to go over with the Commission in question-and-answer some of the details that were discussed there.

But the second point I want to make is that section 504 has always and continues to accommodate very comfortably the situation of AIDS. It's very unfortunate to make reference, I think, to the phrase "traditional handicaps," for two reasons:

First is that if the Civil Rights Restoration Act does one thing very clearly, it makes clear that Congress intends to cover persons with a contagious disease or infection in those situations in which the definition specifically includes them.

Secondly, throughout the history of the court's application of section 504, indeed there have been any number of situations in which the courts have had to deal precisely with the question of whether the individual's employment or the individual's participation in a program posed any threat to the health or safety of other persons.

Two examples from United States Courts of Appeals which come immediately to mind are situations involving a school bus driver who was hearing-impaired and a machinery operator who had the condition of epilepsy.

Obviously in the case of the school bus driver, to focus on that, which was a case in the third circuit, the issue was whether the individual's handicap, in that case a hearing impairment, posed a threat to that individual's ability to do his job safely. That was, in fact, the sole issue in the case.

Under the "otherwise qualified" analysis, as embodied in the statutory framework of section 504, as interpreted in regulations which now have become in essence codified in section 504 dealing with reasonable accommodation, the courts have dealt with that issue, that is, the issue of whether a handicap poses a threat to other persons, and have dealt with it repeatedly.

AIDS may in some situations pose that same issue. It is not a new issue. It is not a new departure under the statutory standards of section 504.

The third major element that I would like to discuss just briefly is the question of what this Commission should be focusing on. A part of the public health consensus to which I referred earlier is that the law as it now exists is not sufficient, in the sense that it is not sufficiently broad to protect those joint concerns, that is, the joint concerns of protection of civil rights and of the effectuation of public health efforts.

The Federal law, as you may be aware, does not cover, for the most part, employees in the private sector. It does not cover, for the most part, the private sector with regard to housing, public accommodation, or transportation. It covers only those persons in the private sector who are employed by or involved with entities which receive Federal funding.

The problem with section 504 is not that the framework of the statute in its analysis of "otherwise qualified" and its incorporation into that framework of the situation of AIDS, which as Mr. Smith, I reiterate, agreed the new amendment would be quite unlikely to have any effect on—the problem is not that that framework is inadequate, because it is and has been. The problem is that the coverage of 504 is inadequate.

State laws that would perhaps otherwise cover individuals not covered by the scope of 504 may not exist at all. Some States don't have them at all. State laws may not cover AIDS because their definition is different from section 504.

State laws may not cover also the private sector. Some State handicap discrimination laws cover only individuals employed by the State. State handicap laws may not cover at all issues such as housing, such as public accommodations, such as transportation.

We are left, therefore, with an irrational system of legal protection and analysis in terms of AIDS-related discrimination in this country. We are left with a system in which an individual who is employed by an entity, which is covered under 504 because it receives Federal funding, is protected from discrimination under the standards of 504, as amended, while an individual who may, or may not for that matter, be infected with the AIDS virus but may be perceived to be or, as in some cases that we in the ACLU have seen, simply may be somebody who volunteers his or her time in a community organization dealing with AIDS, may be fired. And if the individual's employer does not receive Federal funding, and if that individual lives in a State where the State handicap law either does not exist or for some reason does not cover that entity, then that individual has no legal protection whatsoever.

Two individuals who live side by side, who may be brother and sister, who in any other respect may be similarly situated—one may be fired without any recourse; the other may not be fired, would be protected under the statute because of the currently irrational system of coverage.

That is the issue that I urge this Commission to turn its focus to and to address in its final report. That is the issue that the public health authorities in this country have singled out as being a problem in the law which undercuts public health issues. And that is the issue that I would respectfully suggest is the proper focus of a United States Civil Rights Commission.

Thank you.

CHAIRMAN PENDLETON. Thank you, Ms. Hunter.

Mr. McDonald.

TESTIMONY OF BRUCE MCDONALD, ESQ., ROBBINS & LARAMIE, WASHINGTON, D.C.

MR. MCDONALD. Thank you, Mr. Chairman, and members of the Commission. My name is Bruce McDonald, and I'm with the law firm of Robbins & Laramie. We are here today representing a rather illusory client that we are just describing as employers.

First what I'd like to do is say a word about education because I think education applies to the employment situation as well. A colleague of mine, who knew that I was coming to give testimony today, said, "Bruce, tell the Commissioners, please, we support education, but be careful what you say to people."

I said, "What do you mean?"

He said, well, he had a 6-year-old daughter, and she came home from school, and he said, "What did you learn today, honey?"

And she said, "Well, we learned about AIDS today."

And he said, "Oh, really? What did you learn about AIDS?"

And she said, "Avoid intersections and buy condominiums."

[Laughter.]

So it's important exactly what you're going to tell people.

As far as the employer's perspective on this question is concerned, it makes me think of the commercial where you have King Kong coming up the Trans-America Tower in San Francisco and creating mass havoc and destruction and devastation, and then the woman in the white dress at the top floor comes up and steps on his finger and says, "Hey, you big galoot, who's going to pay for this? Who's going to pay for this?"

That's the question that is really at issue: Where is the money going to come from to finance the health care for basically an entire population of individuals who are going to become very ill? And the advent of drugs, which is going to prolong their life and perhaps sustain life indefinitely, is going to increase the cost. And from an employer's standpoint, he's got to be concerned about the cost of financing the health care for this population of individuals.

And I think to suggest that most employers, who are in a white collar situation, have a serious concern about transmissibility or transmission in the workplace is perhaps not to give employers sufficient credit. I mean, people are not really worried about catching AIDS from the drinking fountain—at least I do believe that, and I will continue to believe it, and I think most employers believe it.

On the other hand, you are looking at health care financing costs, even in 1991, of $10 to $20 billion, and nobody tells you what to expect in 1992. Doesn't it seem strange that the numbers keep doubling until 1991, and then nobody tells you what's going to happen in 1992? Does it keep doubling?

If so, the private health care insurance system in this country is not going to be adequate to finance this disaster. And as a result, I think the first thing that the Civil Rights Commission needs to be concerned about is to prevent the conditions that give rise to civil rights conflicts in the workplace. And that means getting money to finance the health care for these people, rather than imposing a wholesale financial burden on employers under the rubric of a civil rights statute for the care of these people.

At the moment there is a very real possibility that a person who is terminated from his employment or who is unsuccessful in gaining employment will not be able to obtain insurance benefits that are necessary for his care. I'm talking about HIV-positive individuals.

That creates an enormous incentive for a person who is HIV positive to fight like heck and assert every civil rights protection he possibly can in order to protect his employment interest.

At the same time, there is a financial reason for the employer to resist those efforts because, basically speaking, a person with a positive HIV test result has a poor medical prognosis at this time. So the conditions are there for a conflict between the civil rights interests of employees and the financial interest of employers. And as long as the conditions for that conflict exist, then there is going to be a civil rights crisis.

Now, as to what exactly is a civil rights crisis, we need to compare the term against the phrase "public health." There's an interesting word called "verbigeration" that Webster defines as the rote repetition of stereotype phrases, and you will hear that frequently in the AIDS debate, because you have people pretty much lined up on one side talking a lot about civil rights and another group who's lined up pretty much on the other side talking about public health.

So what really is the difference between these camps, if you will? I have thought of an illustration that might help to clarify it.

Imagine applying the principle of reductio ad absurdum. Take the absurd extreme of the situation, the extreme that nobody would ever recommend, and compare it to the extreme on the other side.

All right. The public health extreme, the kind of extreme measures that the most radical public health advocate could possibly espouse would be mandatory compulsory testing for all individuals, complete disclosure, identification, stigmatization. In fact, if the public health principles in that sense could be carried out to their extreme, you might even have somebody recommending a visible identification of an AIDS carrier, or as people keep talking about isolation, quarantine, and that kind of thing.

Those are the unacceptable extremes on the one end of public health, and they are basically extreme examples of what you might call disclosure, because disclosure is a public health principle. If all of a sudden tomorrow morning every person in the country with HIV infection turned bright

purple, there would be a very stultifying effect on the rate of transmission in the country, because people who weren't infected would look at a bright purple person and say, "I'm not going to have sex with that person."

That's the extreme on the public health disclosure side.

Take the other extreme, the civil rights extreme. You would have absolute confidentiality of AIDS and AIDS-related conditions, a statutory entitlement to complete secrecy of all test results, no requirement of testing whatsoever, no disclosure, and absolutely no—no permissible discrimination on an employer's part. And I use "discrimination" in the sense of making decisions, because every time you make a decision you discriminate.

Well, I think it's fair to say that the country is a lot closer to the one extreme than it is to the other. I am not in any sense recommending that we go to a radical shift towards a more aggressive public health policy, but I do think we need a more aggressive public health policy.

I respect Nan and her viewpoints enormously, and I am privileged to be here with her. But I totally disagree about the consensus, the supposed consensus. I gather there is a consensus on some points, but there is a very serious disagreement about whether we ought to be pursuing a more aggressive public health policy.

Now, those remarks have been very general, and I guess I felt I didn't really need to go over any of the arcane points of section 504 since they got so much attention previously. But maybe there are just a couple of points on it that we could say.

The issue under 504 is who has the burden of proof. The issue is not whether asymptomatic HIV carriers are handicapped. They are handicapped; all right?

Now, when the Supreme Court made a decision to include contagious disease sufferers among the group of handicapped persons, that was when the fundamental choice was made. If you are going to define an AIDS victim as handicapped, then you've got to define an HIV victim as handicapped. Otherwise people will have an incentive to take adverse measures against the HIV carrier before he becomes impaired, "Let's find out if he's got HIV so we can get him out of the workplace now before he develops an impairment and becomes handicapped."

That creates a scenario in which civil rights conflicts arise, and that is exactly what you don't want to have happening.

So as far as I'm concerned, people with HIV infection are handicapped. The question is: Who has the burden of proof to establish whether the person is otherwise qualified for the job?

The last thing I heard Mr. Silverstein say was that the employer always has the burden of proof to rebut the presumption in terms of the reasonable accommodation issue.

Well, it gets very difficult talking about these technical and academic points, because every time you get to the place where you think you're on firm ground, you find there is another stepping stone that you need to jump to in the statutory and regulatory definition.

But the question definitely has to do with the burden of proof. The Supreme Court did not discuss it in *Arline,* and there are a number of civil rights cases, including handicap cases, that talk about a shifting burden of proof. So that once the individual makes out a prima facie case showing that he's handicapped, the burden shifts back to the employer.

It's our thesis, it's my thesis on behalf of the so-called employer, that this burden of proof in the case of a contagious disease cannot and should not be applied to the employer because to do so would transform the civil rights statute into a health care financing statute and a public health statute by making it impossible for employers to make good-faith decisions based on considerations of health and safety in the workplace.

CHAIRMAN PENDLETON. Thank you, Mr. McDonald.

Dr. Heaton.

TESTIMONY OF ROBERT HEATON, M.D., DEPARTMENT OF PSYCHIATRY, UNIVERSITY OF CALIFORNIA AT SAN DIEGO

DR. HEATON. I'm a neuropsychologist and a relatively recent addition to a team of researchers at the University of California at San Diego who is studying the neuropsychiatric effects of HIV. The research team is headed by Dr. Igor Grant, who is currently out of the country on sabbatical and unable to participate in your hearings.

It is well-documented now that clinically obvious, fairly gross neurocognitive impairment is common in the late stages of HIV infection. The deficits typically include slowing of information processing, inattention, conceptual and problem-solving impairment, learning and memory difficulties, apathy and reduction in drive, often in association with motor slowness and clumsiness.

Although secondary factors such as opportunistic infections and cancer of the brain are present in a minority of cases, there is now general agreement that AIDS-related dementia is primarily due to direct effects of HIV on the brain. The prevalence of dementia in patients with AIDS and AIDS-related complex, or ARC, may be as high as 50 to 70 percent, and in some cases prominent CNS involvement occurs before the appearance of systemic infections or the involvement of other organ systems.

In the last few years there have been a number of clinical reports and some research data suggesting that milder neurocognitive impairment may occur in the early stages of HIV infection, before the onset of severe immunosuppression and physical symptoms of illness.

One of the few studies of this phenomenon that has been published to date was conducted by Dr. Grant and his colleagues at UCSD. Although

this project was completed before my arrival, I am familiar with the methods used and the findings. I will describe these briefly, and will discuss the significance and limitations of the findings. Also I will be happy to answer any questions you may have. It should be mentioned at the outset that this was a relatively small-scale pilot study, primarily intended to help guide future research efforts.

The study sample consisted of 55 gay males. Forty-four of these were infected with the AIDS virus, and 11 were HIV seronegative controls who had comparable ages and educational backgrounds. Of the 44 seropositive subjects, 15 had AIDS, 16 had ARC, and 13 did not meet clinical or laboratory criteria for the AIDS or ARC diagnoses. This latter group was not seriously immunosuppressed and was essentially asymptomatic in terms of physical indications of disease.

A 2-hour neuropsychological test battery was given. This battery yielded nine major test measures, reflecting adequacy of logical analysis and new concept formation, sequencing efficiency, attention and speed of information processing, and verbal and nonverbal learning and delayed recall.

Subjects were classified as neuropsychologically impaired if they showed at least mild impairment on any of the nine major test measures, or if they showed very mild impairment on at least two measures. The test score cutoffs used here had been developed in previous studies of brain-damaged and normal subjects.

Using this criterion of abnormality, 87 percent of the AIDS patients were found to be neuropsychologically impaired, 54 percent of the ARC patients were impaired, and 44 percent of the HIV-positive asymptomatic subjects were impaired, as compared to only 9 percent of the HIV-negative controls.

Three tests were most responsible for those group differences. First was the category test of new concept formation, which is from the extensively validated Halstead-Reitan Battery, and is the most sensitive test in that battery to brain damage, generally considered.

The other relatively sensitive tests in the Grant study measure efficiency of verbal learning and concentration and speed of information processing.

For 23 of the 28 AIDS and ARC patients, magnetic resonance imaging scans were available to investigate the possibility of morphologic brain abnormalities. The MR scans were read by a neuroradiologist who was blind as to the subjects' group assignments and neuropsychological status.

Abnormalities were detected in the scans of 69 percent of the AIDS patients and 50 percent of the ARC patients. In 74 percent of the cases there was agreement between the neuropsychological tests and MR scans regarding the presence or absence of brain abnormality.

Now, this study suggests a correlation between stage of HIV infection and the prevalence of mild neurocognitive impairment. Also, 44 percent of

otherwise asymptomatic cases showed some evidence of mental impairment. However, in my opinion, it would be a mistake to draw firm conclusions or to make inferences regarding public policy from such data as these.

As I noted before, this was a small pilot study that was conducted to help guide future research efforts. As such, it has some significant limitations. The subject samples were small and their representativeness of AIDS, ARC, and HIV asymptomatic individuals, generally considered, is uncertain.

A history of previous alcohol and/or drug abuse was reported by many people in all four subject groups. Although there was no obvious correlation between such reports and prevalence of neuropsychological impairment, the possibility cannot be ruled out that some of the impairment noted was due to lifestyle factors or other factors not directly related to HIV.

While the test battery was designed to tap a variety of important abilities that can be affected by brain disorders, this too has some limitations. It was relatively brief, taking 2 hours as compared to 6 to 7 hours for a comprehensive neuropsychological assessment. Each of the tests is known to be sensitive to brain disorders, but the sensitivity and specificity of the tests, in aggregate, has not been studied before.

For example, many of the tests in the Grant study came from a well-known standardized procedure called the expanded Halstead-Reitan Battery. Summary scores from that battery have been extensively validated for detecting presence or absence of brain disorders, and for predicting important aspects of patients' everyday functioning. This claim cannot be made of the method used to establish neuropsychological abnormality in the Grant study.

These comments are not intended to be criticisms, but only to point out the preliminary nature of the Grant et al. findings. Larger-scale longitudinal research is needed to clarify the incidence, the progression, and the clinical importance of neuropsychological impairment in successive stages of HIV infection. Such research is currently in progress at UCSD, with Dr. Grant as the principal investigator, as well as in other institutions.

Unfortunately, our ongoing research has not progressed to the stage where any formal results are available to present to you. However, based on my clinical ratings of the data that are being collected, I can give you some preliminary observations.

First, perhaps 15 to 20 percent of HIV-positive asymptomatic subjects have mild neuropsychological impairment. The severity and range of these deficits would not qualify for the clinical diagnosis of dementia. However, I do believe that they are clinically significant, in that they are at a level that definitely suggests some impaired brain function. Also, my clinical criteria for mild definite impairment are more stringent than those used in

the pilot study. These cases all have more than one deficit, such as mild conceptual impairment, learning and memory impairment, poor concentration, or reduced speed of information processing, and motor deficits, which could affect the patients' performances in certain demanding jobs.

On the other hand, this level of impairment is not common in HIV-positive individuals who are otherwise asymptomatic, and at this point it would be premature to conclude that the deficits are definitely secondary to HIV. The needed data have not been analyzed to enable a correlation between neuropsychological status and MR scan abnormalities and the presence of HIV in the cerebrospinal fluid, for example, in HIV-positive asymptomatic individuals.

Many more controls and AIDS and ARC patients are also needed to make baseline comparisons, and longitudinal assessments are needed to determine whether the mild deficits seen in the minority of HIV-positive asymptomatic individuals are progressive. All these studies are being done, but the results are not yet available.

I will add here that there are some spotty, borderline, or very mild deficits in a higher percentage of subjects being studied, but at present the etiology and clinical significance of these are even less clear.

Based upon the currently available research and my own clinical observations, I think it would be unjustified to exclude HIV-positive asymptomatic individuals from even sensitive occupations, or to engage in any widespread neuropsychological screening of such individuals, unless they have also shown some indication of performance decrement or unreliability, for whatever reason, on the job.

In the latter instance, neuropsychological testing might be obtained just as it often is in cases of possible brain dysfunction that does not involve HIV. Again, most HIV-positive asymptomatic individuals are neuropsychologically normal, and it is not yet certain that the mild deficits shown in a minority of such individuals are secondary to HIV.

To make an analogy, we know that, in general, advanced age tends to be associated with reduced neuropsychological abilities. Many people over the age of 60, for example, would be considered mildly "impaired" in their conceptual, problem-solving, and new learning abilities, if norms for younger adults were applied to their performances. Other older persons do not show evidence of age-related decline in neurocognitive function, and we are not sure why some do and others don't.

In any event, one would not normally exclude any older person from a job or propose widespread testing of older persons who have no reason other than age to suspect reduced capabilities.

CHAIRMAN PENDLETON. Thank you.

Mr. Carvin.

TESTIMONY OF MICHAEL A. CARVIN, DEPUTY ASSISTANT ATTORNEY GENERAL FOR THE OFFICE OF LEGAL COUNSEL, U.S. DEPARTMENT OF JUSTICE

MR. CARVIN. Thank you, Mr. Chairman.

I am pleased to appear today to discuss with you an issue that is obviously complicated and controversial and very important. I guess the first point I make is that, unfortunately, not all of the complications as a legal matter have been eliminated by either the *Arline* opinion or the Harkin-Humphrey amendment.

I guess the other thing I should emphasize at the outset is that, perhaps unlike some of the other speakers here, I don't have any firm views on the legal questions. The Department has not come to any conclusions as to the status of AIDS people or people with an AIDS-related complex in the wake of *Arline* or in the employment context in the wake of Harkin-Humphrey. We are examining those issues currently. I suspect over the summer the Office of Legal Counsel will be providing further guidance on the 504 question. As you know, also OPM has issued some guidance for Federal personnel matters.

What I'd like to do is just briefly review what our analysis was in the June 1986 opinion which opined on the protection of AIDS carriers under 504, and discuss the manner in which both subsequent legislative action and the *Arline* opinion affected our analysis, and what questions remain in the wake of those developments.

The basic premise of our June 1986 opinion was that while people who suffered from the disabling effects of the AIDS disease were indeed covered by 504, and while discrimination based on those disabling effects was prohibited under the statute, that contagiousness alone was not a handicap within the meaning of the statute, so that discrimination based on fear of contagion, discrimination against an asymptomatic carrier of AIDS was not prohibited by 504.

Our basic analysis was that "handicapped individual" in the statute, the definition of that phrase used as its touchstone physical impairment. If you were regarded as having a physical impairment, if you had a record of having a physical impairment, or if you indeed had a physical impairment, then you were a handicapped individual.

But we felt that once you lost that nexus to an actual inherent limitation on your ability to substantially participate in major life activities, that that was not justified by the statute, the notion being—for example, Mr. Silverstein commented before that in the wake of *Arline*, it might be possible to say that an asymptomatic carrier of AIDS was handicapped because he could not participate in sexual activities as fully as he had prior to contracting the disease.

The problem with that argument is that that means that any time society at large or a segment of society avoids a person for any reason, wholly

unrelated to an actual disability such as a respiratory disease or being in a wheelchair, then that person comes within the coverage of 504. I call this the Richard Nixon argument. Richard Nixon under this definition is a handicapped individual because people avoid him for political and other reasons, and thus his major life activities are substantially limited.

What the example, I think, illustrates is that turns 504 into a general nondiscrimination statute, that any time a person is shunned by society they become handicapped. The argument was that you've really got to tie it to some kind of physical condition. Otherwise ugly people, people with poor hygiene, et cetera, who are generally unpopular because of a condition that is related to their physical appearance but does not impose any inherent limitations on them, or is not regarded as imposing any inherent limitations on them, becomes a handicap and thus becomes protected by 504.

Now, we extended this analysis. So that was with respect to asymptomatic carriers. We felt they were not covered at all by the statute.

Then you got the question of a person who is indeed covered, like Ms. Arline clearly was, because she had a respiratory illness related to her tuberculosis. The question there becomes, if she is a handicapped individual: Is discrimination on the basis of the contagious effects of her disease rather than the disability caused by her disease, the respiratory problem—is that prohibited under 504?

So you've got two questions: Is contagiousness alone a handicap? And if you are a handicapped individual, can someone discriminate against you on the basis of contagiousness?

I think it's quite clear that the Supreme Court resolved the latter question in a way different than we did. It said, "We're not going to draw distinctions. If you've got a disease that both renders you physically impaired and is contagious, and an employer discriminates against you on the basis of that disease, we are not going to draw a distinction between the disabling effects of the disease and the contagious effects of the disease."

So to that extent, clearly the OLC's June 1986 opinion needs to be reevaluated and modified.

The other question, though, whether a person who is not physically impaired at all, where he is able to transmit a disease but has suffered no adverse effects himself from the disease—whether that person is covered was clearly left unresolved by the Supreme Court in footnote 7 of the *Arline* opinion. They said they would leave that until another day, the asymptomatic carrier question.

So to sum up, after *Arline*, I think the major question is whether, outside the employment context, are asymptomatic carriers of AIDS or other diseases protected by 504.

The other principal question that seems to me to be left in the wake of the Harkin-Humphrey legislation is that in the employment context,

obviously the Harkin-Humphrey amendment says if you have a currently contagious disease and you're not a direct threat and you're not capable of performing the job, then you're not handicapped.

As I say, all my views here are preliminary and tentative and don't represent the Department. I will say, though, that it certainly is reasonable to infer from that negative statement that somebody who has a currently contagious disease but is not a direct threat, and is capable of performing the job, would be a handicapped individual within the Harkin-Humphrey amendment, would be protected by 504.

But having resolved that negative pregnant question, there is still an additional ambiguity, which would be—I guess the easiest way of putting it is: When do you analyze the "direct threat" and "capable of performing the job" questions? Do you do it before the employer is engaged in any reasonable accommodation, or do you do it after the employer is engaged in a reasonable accommodation?

If a person, say, is a direct threat, without any accommodation by the employer, but the employer could take steps to eliminate that threat, is the person entitled to the job? Is the handicapped individual entitled to the job?

The reason for the ambiguity on this question, as probably was discussed this morning, Harkin-Humphrey amended the definition of "handicapped individual." And as also was noted, generally there's a two-step process under 504. First you ask: Is the person handicapped? Are they entitled to any protection under 504? Or are they excluded from the scope of the statute entirely?

Then you get into questions about, "Well, notwithstanding the handicap, is he qualified?" Well, if he is not qualified on his own, say, would he be qualified if the employer engaged in some kind of reasonable accommodation?

So I suppose under what we call the literal reading of the Harkin-Humphrey amendment, since the amendment went to the definition of who was within the scope of the statute and didn't deal with the question of who was otherwise qualified and didn't mention reasonable accommodation, one straightforward reading of the statutory language would be to say this person—you ask the questions about direct threat and capable of performing the job. If the answers to those are negative, one of those is negative, then he's outside the statute and the employer's obligation ends right there.

That would be the statutory language, as I'm sure has been discussed at length this morning. There is legislative history which is to the contrary which talks about reasonable accommodation.

The normal rules under 504, of course, is that you look to reasonable accommodation; you don't just ask the question whether the person is

handicapped. Harkin-Humphrey kind of melded those concepts so it would be fair to look at both of those issues in conjunction.

And I suspect as well, since this amendment was based in large part on the 1978 amendments concerning alcoholics and drug addicts, that the legislative material surrounding that issue might well provide further guidance as well as to how this question is resolved.

So in my mind, those are really the two major questions that remain today, these arcane legal questions, which is: One, outside of employment, are asymptomatic carriers covered? And, number two, in the employment context, does the employer have an obligation to reasonably accommodate contagious individuals?

As the discussion has revealed before, there are obviously a number of other issues going to: Who is otherwise qualified? What is an individual's inquiry into these questions? Can you look at a class of persons? What constitutes reasonable accommodation? Is a threat to the individual himself enough? Where does the burden of proof lie?

I suspect that we will be treating with all of those questions as well in our opinion and we'll certainly be happy to share our thinking with you when we have arrived at a conclusion.

Thank you.

CHAIRMAN PENDLETON. Thank you, Mr. Carvin.

Counsel.

MR. HOWARD. Thank you, Mr. Chairman. Mr. Fumento has just two questions for Dr. Heaton, and then Mr. Balch will address his questions to the other panelists.

MR. FUMENTO. I will try to be brief.

First of all, how quickly do symptoms of severe dementia arise? What I'm getting at is, often we can use a physical to screen people in critical positions, but physicals are usually yearly. Will these symptoms arise over a long period of time, or can they come on in a short period?

DR. HEATON. Here, of course, we are talking about people in the later stages of HIV infection. Dementia happens then, not early on. So these are people who have clear evidence of physical illness. Were you thinking otherwise?

MR. FUMENTO. Well, I was thinking asymptomatics.

DR. HEATON. In terms of asymptomatics, the answer is that we don't know. They are mild deficits. In order to answer that question, they need to be followed over time. The only studies that have been conducted and published so far look at them in a single point in time, and they see a certain prevalence of mild impairment. The question is: When did that occur, and is it changing? And, if so, how rapidly? That is the focus on the ongoing research now.

COMMISSIONER DESTRO. Could I ask a question?

MR. FUMENTO. Sure.

COMMISSIONER DESTRO. Doctor, I thought I heard you say that dementia shows up in late stages. I've read some articles which indicate that dementia may show up as the first indication of late-stage AIDS. Is that true?

DR. HEATON. It may show up as the first physical indication of late-stage AIDS, but it's in people who are immunosuppressed.

MR. FUMENTO. Then you made a statement that you believed that it was enough to wait until there was some overt sign of a problem before pulling someone from a job. The problem is in some areas—

DR. HEATON. Before evaluating the situation further is what I suggested.

MR. FUMENTO. The problem is there are some situations—airline pilots or air traffic controllers—where as soon as that thing comes up, it could come up in a critical situation. Can you envision a job-specific dementia test that can be applied, say, to airline pilots or air traffic controllers or anybody suffering from HIV or another disease such as hypertension that may cause dementia?

DR. HEATON. I think in any kind of job situation that is that sensitive, there needs to be periodic evaluations of performance, and I think that type of evaluation does exist certainly in the airline industry. And it is specific to the jobs that the people are trying to perform.

So I think, like in the case of an airline pilot, if a person flunks his simulator testing, then the question is why, and then they may send that person for neuropsychological testing to see if there is any basic change in his abilities that can account for the difficulty he is showing. But I would not recommend at this point that there be any widespread application of neuropsychological tests to HIV-positive asymptomatic people. I think the current evidence just doesn't support that.

MR. FUMENTO. Thank you, Doctor.

CHAIRMAN PENDLETON. Mr. Balch.

MR. BALCH. Ms. Hunter, are you aware of any evidence of individuals being regarded as having AIDS and being discriminated against on that basis simply because they are or are perceived as being gay?

MS. HUNTER. Your question sort of goes through several twists and turns.

The issues that arise with regard to section 504 have dealt with individuals who are regarded as having AIDS or regarded as being seropositive. Those individuals and those cases have fallen very squarely within the terms of a situation in which an individual is identified, correctly or incorrectly, or is regarded as being or suspected of being seropositive.

Perhaps you could elaborate for me what the basis for your question is.

MR. BALCH. Well, I guess what I'm wondering is: Are you aware in your experience of situations in which individuals, because they are gay,

without further evidence or basis, are suspected of and treated as though they had AIDS?

MS. HUNTER. There are certainly situations in which gay men have been singled out for adverse treatment, and that adverse treatment has related to fears or stereotypes regarding the AIDS epidemic. It is certainly true, for example, that the lack of laws protecting against discrimination, against sexual orientation—the absence of that law has been used as a pretext, if you will, for discrimination based on AIDS and based on seropositivity. And that is the reason that a number of public health leaders have called for the enactment of statutes prohibiting discrimination based on sexual orientation.

I think as the epidemiology of this disease broadens, if you will, we will find increasingly not only gay men but other minorities in the population will be subjected to discriminatory action, based in whole or in part upon perceptions that they have AIDS or that they are infected with the AIDS virus or they are perceived to be so.

MR. BALCH. Might I ask, if it is convenient, if you are able during the 30-day period that the record is open, if you could submit any of the incidents or episodes you referred to, that would be very helpful to the Commission.

Mr. McDonald—

MS. HUNTER. Excuse me. If I might, I'd like to comment because I happen to have the advantage of having with me the consensus statement on neuropsychological aspects of HIV infection, to supplement Dr. Heaton's testimony.

As he pointed out, very appropriately so, the data that have been published so far do not form the basis for any policy recommendations in that area. But the Commission, I think, should be aware, as perhaps it is not, that there was a 4-day consultation in March of this year convened in Geneva by the World Health Organization specifically to examine currently available data on the neuropsychological effects of HIV infection, with particular regard to asymptomatic HIV-infected persons. This consultation involved 48 experts from 17 countries, representing a number of disciplines.

There was a consensus statement which emerged from that consultation, which is very brief:

> At present there is no evidence for an increase of clinically significant neurological or neuropsychological abnormalities in CDC Group 2 or Group 3 HIV-1 seropositive, i.e., otherwise asymptomatic individuals, as compared to HIV-1 seronegative controls. Therefore, there is no justification for HIV-1 serologic screening as a strategy for detecting such functional impairment in asymptomatic persons.

This, I think, is along the lines of some of the comments Dr. Heaton just made in response to Mr. Fumento. But I think the record should be augmented in that regard, and if the Commission considers anything with

regard to that particular question, I believe the record would be deficient if it does not consider this brief statement of the World Health Organization, which as I understand it is being augmented now by a very complete review by the World Health Organization on that specific question.

MR. BALCH. If you could submit that for the record, we certainly would appreciate that.

MS. HUNTER. I'd be happy to.

MR. BALCH. Turning to Mr. McDonald, when you argue that the employee, rather than the employer, should bear the burden of proof, are you talking about the burden of persuasion or also the burden of going forward with the evidence?

MR. MCDONALD. Well, the burden of persuasion is usually considered to be a more significant and outcome-determinative burden, and that is the burden that I believe an employee or individual should sustain under section 504.

MR. BALCH. So you are not arguing that the employer should have the burden of going forward with the evidence?

MR. MCDONALD. I believe that the employer should not be charged with the ultimate burden of persuasion in this kind of situation. If the employer has a burden to simply show a rationale of some kind—I don't think that's a serious problem. I really don't believe that most employers, and certainly not the imaginary employer that I represent, is going to take that kind of discriminatory action for absolutely no reason.

MR. BALCH. Looking toward that, how do you respond to the argument that says isn't it more reasonable to require the employer, who is saying, "You are fired because you're a threat to the health of fellow employees" to demonstrate the threat on which he or she is relying exists?

MR. MCDONALD. Well, I think if there is a situation where there is no conceivable rationale for the employer's concern, that's the kind of situation where the employee is likely to have sustained his burden of proof, like the case in the ninth circuit where the court of appeals reversed the district court which had refused to grant the preliminary injunction to a school teacher. The evidence was overwhelming that the school teacher did not pose a threat of contagion in the classroom. And that's the kind of situation where the employee is likely to have sustained his burden of proof.

MR. BALCH. Mr. Carvin, does the Justice Department have a position on the burden-of-proof issue?

MR. CARVIN. Not that I'm aware of, and again that would be something that we'll probably look at. All I can say is Title VII analogue obviously is that the plaintiff has the burden of persuasion throughout, although there is a shifting burden of production on subsidiary questions. Normal rules of civil litigation is that the plaintiff bears the ultimate burden of persuasion,

and that the Supreme Court has not spoken directly to this question. How much guidance that provides you in this context, I really can't speak to.

MR. BALCH. Ms. Hunter, what do you think of Mr. McDonald's burden-of-proof argument?

MS. HUNTER. I think Mr. McDonald's argument is incorrect. The courts have interpreted quite authoritatively, I think, the burden of proof, specifically in the section 504 context. The plaintiff in section 504, as indeed in other employment discrimination contexts, as indeed generally in civil litigation, has the burden to make a prima facie case. It seems to me that, specifically with regard to this issue, that is to say AIDS, and some of the discussion that has gone on here this morning, the plaintiff has to come forward with a prima facie case involving the elements of the statutory standard, including the Harkin-Humphrey amendment.

A prima facie case, I believe, would be met quite aptly in this situation by an assertion which could be substantiated by any number of things, including, for example, the official position of the United States Government as reflected in the Centers for Disease Control guidelines, that persons with AIDS or infected with the AIDS virus do not pose any risk to the health or safety of others in the normal workplace environment.

Once that prima facie case is met—and I think it would be extraordinarily easy to meet it in the context of AIDS—and I presume that this Commission is focusing on the context of AIDS—once that prima facie case is met, then the employer has the obligation under the law to come forward to demonstrate, to try to demonstrate, that either the individual was not hired or fired because of something other than the person's handicap, which is seldom an issue in AIDS cases but might be, or that the person is not otherwise qualified for the position in question.

If the employer presents evidence sufficient to meet that aspect of what Mr. Carvin described as a shifting burden, then the plaintiff has the opportunity to rebut that by showing that he or she is otherwise qualified.

It is quite clear in the section 504 context that the language of the regulations make it explicit that the burden to show reasonable accommodation is with the employer in the context of employment, or with the recipient of Federal funds in other situations.

I might add that the only situation that Mr. Smith, who testified earlier, alluded to, in which he thought that the amendment would have—the example that he gave in terms of discussing reasonable accommodation was the situation of health care workers. Again, one could simply refer to the Centers for Disease Control guidelines on that. Reasonable accommodation presumably would not include what is a normal workplace standard operating procedure for health care institutions which are infection control procedures.

MR. BALCH. Let me just follow up on that for a moment, if I may. You mentioned a number of times in this what you've just said, and also in your

prepared testimony, that a significant risk doesn't really exist in a normal workplace setting. You mentioned one context in which there might be an abnormal workplace setting where it would exist. What would you regard—

MS. HUNTER. What are you referring to there—an abnormal situation in which it would exist?

MR. BALCH. Which circumstances would you regard—you take the position, as I understand it, that a significant risk related to AIDS does not exist in, quote, "the normal workplace setting," if that is correct.

MS. HUNTER. That is my position, and it is the position of the Centers for Disease Control. I'm not aware of any organization that takes a different position.

MR. BALCH. My question is essentially in what abnormal workplace settings does it exist?

MS. HUNTER. None to my knowledge that would be covered by the requirements of section 504. Again, there I would refer you to the Centers for Disease Control and their guidelines for the workplace, and further to the recent advisory letter of the Occupational Safety and Health Administration, specifically with regard to infection control procedures in a number of health care settings.

Those documents taken together, I think, establish—abundantly so—as the official position of the United States Government, that adherence to standard infection control procedures in health care institutional settings essentially eliminate not only the risk of HIV transmission but the much more serious risk of hepatitis virus transmission which, as you may know, is a virus which is much more easily transmissible, because of the nature of the virus, than is the human immunodeficiency virus.

And I would refer you there again to the official statement of OSHA, which in its preliminary part refers to the very serious problem of infection control procedures as they pertain to hepatitis virus transmission.

MR. BALCH. I guess I was intrigued because in the original typescript of the prepared testimony that you submitted you said, "Under this test"—the significant risk test—"because of the medical facts as to transmission of the AIDS virus, a significant risk that persons with AIDS or the AIDS virus will endanger their coworkers cannot be found."

And the "cannot be found" was crossed out, and in handwriting it said "does not exist in a normal workplace setting." And I was wondering if that had, in fact, been made a distinction that you had intended to make?

MS. HUNTER. The editing of this document is not—I can't see from this, for example, what follows on the next page. But there is no distinction between "cannot be found" and "does not exist in a normal workplace setting," except to the extent that the clarification refers to employment. I think the phraseology makes clear that it's a reference to employment. Obviously, there is a risk of transmission of the AIDS virus in the world,

but that risk does not exist in a normal workplace setting. I think that's pretty self-evident.

MR. BALCH. Mr. McDonald, do you have a comment on that?

MR. MCDONALD. I have a catalogue here of some of the abnormal work situations where there is a risk of blood-borne disease transmission.

May I say that hepatitis can be transmitted in a particular situation. So can the AIDS virus—maybe not as easily, but you've got documented history of hepatitis transmission in a particular situation. That establishes, as far as I am concerned, a possibility of HIV transmission.

Here are some of the abnormal work situations where blood-borne disease transmission has been documented:

> Hospitals generally, including specifically anesthesia personnel, dermatologists, hemodialysis workers, laboratory workers, occupational health care personnel, pediatric health care workers, and other occupations, including prison workers and correctional officers, police, dentists, dental hygienists, emergency workers, hazardous waste management workers, mortuary and funeral service employees, special education personnel, and persons in facilities for the mentally handicapped as well as teachers generally.

Now, we may not have documented HIV transmission in any of those situations. Does that mean there is no risk because it hasn't been documented yet? And is that the kind of evidence that you're going to exclude or consider?

MS. HUNTER. Excuse me. May I respond to that?

CHAIRMAN PENDLETON. Briefly. Go ahead.

MS. HUNTER. With all respect for Mr. McDonald and certainly for his full right to express his views, it seems to me here that he is not in fact qualified to express views with regard to transmissibility. I believe this Commission heard yesterday from Dr. Fauci on the issue of transmissibility, and I would hope that the record would be clear as to what the relative weight of that testimony is.

And I must say again, with all personal regard for Mr. McDonald and his full right to express his views, I found that it was extremely troubling to me that he testified with his characterization of public health views. Again, I would note that the largest public health association in the world is the American Public Health Association, and I find it unfortunate that they are not testifying here with regard to the public health consensus.

And lastly, with regard to the group on whose behalf Mr. Mcdonald does state he is testifying, and that is, as I believe you put it, the imaginary employer.

There have been a number of organizations, specifically of employers, to develop policies with regard to AIDS. I think it is unfortunate that they are not here testifying, and I would hope that the record is not influenced by the absence, again, of the weight of American employers because I

believe that, indeed, a fair-minded inquiry into what has happened in that regard is that the largest employers in our nation have responded actually quite well and have determined that AIDS and AIDS viral infection should be treated as other disabilities.

I think, in other words, that there is a serious problem here with the record before this Commission on these issues, and I would urge the Commission to not venture into those areas without substantially augmenting the record on those points.

CHAIRMAN PENDLETON. Just let me say, Ms. Hunter, I understand your admonition but I don't take it in a negative way. Let me say to you that the record being established here is not the only record that we have. So to assume that whatever someone says here becomes the record I think is not fair to my colleagues here. We have done more reading and more things that would comprise the record for this hearing. To assume that we just hear from one person—you or Mr. McDonald—and that is the record, that one outweighs the other or the like, is not the case at all.

I think it's clear, with any kind of hearing we would have, there would not be that serious defect in the record as you indicate just because we've heard the view of someone. I would assume that maybe Mr. McDonald could make the same accusation, if you want to call it an accusation—make the same statement. I'm not so sure he's speaking for himself, that he's speaking about what he might have researched at some point. Maybe he wants to clear that up himself. I'm not putting words into his mouth.

COMMISSIONER BERRY. Mr. Chairman, may I intervene, please?

I think there is a substantial difference between complaining about listening to somebody's testimony and complaining that a person is testifying to matters about which they lack expertise.

CHAIRMAN PENDLETON. I would agree.

COMMISSIONER BERRY. Now, we may hear from people—and we do all the time—who have no expertise. Some of them confess that they don't have any on the record.

But it does seem to me that it is not unfair for someone to call attention to the fact that someone is testifying about something in an area where they are not expert, and to express their wish and hope, since they may not be fully aware that we will know that that person—

CHAIRMAN PENDLETON. I was just trying to respond to the fact, to relieve Ms. Hunter's concern that we are not just going to hear it and assume that that's the evidence we would have to use in making a recommendation, but there are other documents we would look at, certainly, that would allay her fears.

COMMISSIONER GUESS. Mr. Chairman.

CHAIRMAN PENDLETON. Yes, sir.

COMMISSIONER GUESS. On this point I'd like to raise a question very briefly. Mr. McDonald indicated at the start of his testimony that he was

here representing a loose confederation of employers. Who do you represent in this matter, Mr. McDonald?

MR. McDONALD. Well, I'm responding to the invitation of the Commission to present viewpoints on behalf of employers generally. I'm not here representing any particular employer. These are my viewpoints.

COMMISSIONER GUESS. These are strictly your viewpoints, and you don't represent any client who has a vested interest in the matters before the Commission?

MR. McDONALD. Actually, Mr. Guess, the clients that my law firm represents tend to be more biotechnology and technologically related companies.

COMMISSIONER GUESS. Let me ask you a more specific question, Mr. McDonald. Are these billable hours?

MR. McDONALD. No.

COMMISSIONER GUESS. No one has an interest in you being here today?

MR. McDONALD. No, in fact I'm knee-deep in buffalo chips right now.

COMMISSIONER GUESS. Could you give me a definition of buffalo chips? I'm from Tennessee.

[Laughter.]

MR. McDONALD. It's an absence of billable hours. When I go for as long as I have without billing hours, as I did preparing this testimony, I get knee-deep in—

COMMISSIONER GUESS. So none of your clients have an interest in this testimony?

MR. McDONALD. That is essentially true, yes.

COMMISSIONER GUESS. So you're just here because this is a personal interest of yours?

MR. McDONALD. That's true.

CHAIRMAN PENDLETON. It's the same as we heard testimony yesterday from people who came on their own. Mrs. Arriola came on her own yesterday and did not represent the Attorney General's Office of New York at all.

MR. McDONALD. Could I take 30 seconds to elaborate?

About a year ago I was doing a project with the D.C. Bar putting together a panel on which Nan and other esteemed representatives served. And in trying to publicize that program so that we could fill up the auditorium that year, I went down to Atlanta to attend this conference that the CDC held in February of '87. It was at that conference that I became convinced that there was a very serious imbalance developing between what the so-called consensus among the public health officials was and what I thought was a reasonable estimation of the public health situation. I thought the majority of people who were discussing the problem at that time were just dead-bang wrong about some of the things.

I am certainly not a medical expert, but just responding for 1 second to what Nan said, all I said was that a hepatitis B transmission risk has been described in the medical literature. And you don't have to believe me. I cited the medical testimony. And if it passes by the same route that hepatitis B passes, I just submit that the issue needs to be examined further.

CHAIRMAN PENDLETON. The colloquy is noted, but can we go on now with questions?

Are you through, Counsel?

MR. BALCH. Yes.

CHAIRMAN PENDLETON. Commissioner Buckley has questions.

COMMISSIONER BUCKLEY. This is a hypothetical question. I need it to make sure that I understand. And this is addressed first to Mr. Silverstein, then Ms. Hunter, then Mr. Carvin, and Mr. McDonald, and Dr. Heaton I'd like to have come in on.

Let's say there's a 25- to-35-year-old white male, and the employer believed him to be gay so he has been fired. After being fired he takes the test and he finds that he is seropositive. Does he come under the 504 protection or the Humphrey-Harkin amendment in your interpretation?

MR. SILVERSTEIN. Again, let me understand the facts. A 25-year-old white male who is gay—

COMMISSIONER BUCKLEY. No, the employer believes that he is. The employer made that assumption that the white male—

CHAIRMAN PENDLETON. Stereotyping.

COMMISSIONER BUCKLEY. Yes, stereotyping. The white male did not tell anybody or any of his employers that he is or is not or any visible activities or anything in the workplace.

MR. SILVERSTEIN. And then he's fired?

COMMISSIONER BUCKLEY. And he has been fired.

CHAIRMAN PENDLETON. Excuse me just a second, before you ask that. This goes to the "regarded as" language in the 504.

MR. SILVERSTEIN. What I would like to do is answer your question through statements by Senator Kennedy, the floor manager of the bill. He addressed this directly, if you will bear with me in terms of finding it.

CHAIRMAN PENDLETON. As you are finding that, just let me pose this on the same point that my colleague has raised.

If 504 applies, do we now confer upon all homosexuals the right to be covered under 504?

MR. CARVIN. To supplement the facts here, the employer at the time he fired him had no idea as to whether he tested—

COMMISSIONER BUCKLEY. —seropositive or not; right. The individual himself didn't, either. But after the employer said, "You're gay and I think you might have AIDS," or something like that. Then he said, "Okay, I'm going to check it out."

COMMISSIONER BERRY. How many more bells and whistles are you going to put on the hypothetical?

MR. SILVERSTEIN. I found it.

COMMISSIONER BERRY. How tall is he? It started out rather simply.

COMMISSIONER DESTRO. But these aren't really hypotheticals.

CHAIRMAN PENDLETON. This is true.

MR. SILVERSTEIN. "Neither Title IX nor any of the other statutes amended by S-557 has ever been interpreted by the courts to provide protection on the basis of sexual preference. None of the regulations have ever so provided and nothing in this bill creates any such protection. Homosexual groups recognize this lack of protection in seeking new legislation specifically prohibiting discrimination on the basis of personal sexual preference. Does this bill create any rights for homosexuals under section 504?"—which is your question.

"Answer: No, this bill does not preclude an entity from discriminating against an individual solely on the basis of the fact that the individual is homosexual. Thus, if an entity's religious practices require it to take disciplinary action against any individual who is homosexual and it takes such action solely because of that person's homosexuality, nothing in section 504 would offer protection to such an individual."

COMMISSIONER BUCKLEY. But now that the person knows he is seropositive, can he go to the courts now and say, "I am seropositive but I was fired. He thought I was gay, and because the CDC is reporting 79 percent of the AIDS patients are gay, he fired me because he thought I had AIDS."

So can he now go to the courts?

MR. SILVERSTEIN. He can go to court. The issue of whether or not he will win or not is up to the trier of fact.

COMMISSIONER BUCKLEY. So your opinion would be he does qualify as a handicapped person?

MR. SILVERSTEIN. He could make a case and have the case determined on the facts, but not based on homosexuality, based on the fact that he is regarded as being a handicapped person.

COMMISSIONER BERRY. Mr. Silverstein, the way you stated it, for somebody who is not a lawyer they may not understand, and with all due respect I don't think my colleague did. When you said he can go to court and make a case, one might infer from that, if one is not a lawyer, that you mean there is some legal basis in the Harkin amendment or, despite what Senator Kennedy said, for sexual preference to be a basis, or that the HIV test was automatically a basis for him retroactively claiming that that was why he was fired.

If I understand you, you mean that, of course, anyone can go to court and make a claim. Whether you get thrown out or not or whether you win

depends on whether you can prove that at the time the employer fired you he did it as a matter of fact because he thought you had—

MR. SILVERSTEIN. He was regarded as having a physical or mental impairment.

COMMISSIONER BERRY. Right. So he doesn't mean, if I understand you correctly, that there is a legal claim under—

MR. SILVERSTEIN. It's a question of fact for the trier of fact. But there is a possible theory, and the possible theory is that in fact the individual was regarded by the employer as having AIDS.

CHAIRMAN PENDLETON. Are you also saying in this case—

MR. SILVERSTEIN. But clearly not based on homosexuality or sexual preference—clearly not.

CHAIRMAN PENDLETON. From the section you read, that would not wind up codifying, if you will, homosexual men as—

MR. SILVERSTEIN. As I said, under none of the civil rights statutes. Senator Harkin on the floor made the same statement, the last sentence of which was, "no ifs, ands, or buts."

COMMISSIONER BUCKLEY. So he does not come under 504?

MR. SILVERSTEIN. Not based on sexual preference or homosexuality. That is not a handicapping condition, and you're not protected by Title IX or Title VII.

COMMISSIONER BUCKLEY. Even if the employer fired him because he said, "Well, you probably have AIDS, too."

MR. SILVERSTEIN. No, I didn't say that. In other words, if you say you've got AIDS and you are regarded as having a physical or mental impairment, you've got potential basis for a lawsuit, that you were fired because you were regarded or you actually have a physical or mental impairment.

MR. CARVIN. Can I ask a question? What if it had a discriminatory impact on AIDS victims and no homosexual policy would clearly disproportionately affect people with AIDS. Would you say there is a disparate impact theory under *Alexander* v. *Choate* under 504? You referred to that case before and I just didn't know the answer.

COMMISSIONER BERRY. That expands the hypothetical—since we're going to have a colloquy here—by including not only this instance that my colleague was discussing but numerous other instances that may have arisen—that's what you do in a disparate impact—that may have arisen on a similar set of facts, which raises a presumption that the employer fired these people for that reason. That's a different hypothetical.

MR. CARVIN. As I understand Title VII law, an individual plaintiff can bring—

COMMISSIONER BERRY. We're talking about 504.

MR. CARVIN. That's really my question, whether the Title VII model would work here. An individual plaintiff in a Title VII case can proceed

under either a disparate treatment or disparate impact theory. So what if they made the claim that firing a homosexual is your policy as a disparate impact on AIDS victims?

MS. HUNTER. Let me see if I can try to untangle this, because I think the hypothetical now is really quite tangled. Your original hypothetical, as I understand it, that Mr. Silverstein responded to, was a question of firing based solely on sexual orientation.

COMMISSIONER BUCKLEY. I said—

MS. HUNTER. Let me go through this, because you have changed your hypothetical, and that's one of the problems in this colloquy.

I think there is no question that section 504 does not cover firings or adverse actions based solely on orientation or sexual preference. I don't think there is any question about that.

Now, one of the questions I might add that gets lost in all this pertains to public sector employers. That does not mean that there is no legal protection from being fired based on sexual orientation. A governmental entity which fires an individual based on sexual orientation would be subject to suit under constitutional standards. There are civil service regulations, in fact, which protect individuals from being fired or adversely affected in their jobs because of sexual orientation.

So it would be incorrect for the Commission to conclude, for example, or to write that there are no legal protections against firing or adverse action based on sexual orientation. However, it is correct that section 504 does not provide statutory protection or coverage from firing or adverse action based solely on sexual orientation.

You then changed your hypothetical and inserted into it the idea that the employer perceived the individual or thought the individual had AIDS or somehow was affected by AIDS. If you change the hypothetical in that way, the sexual orientation becomes completely irrelevant. The question under section 504 is whether the individual is regarded as having that impairment or having an impairment, in this case the impairment of seropositivity or whatever.

With regard to the twist from Mr. Carvin, there is nothing in the case law, to my knowledge, that deals with that kind of yet once-removed issue of disparate impact. Where you're talking about disparate impact, it's almost in essence to me like a kind of—in a sense double hearsay in the way that it is constructed. The issue, I think, is completely unsettled and unaddressed in the law.

One of the issues that would seem to me would be a primary problem there, if one were addressing it in terms of sexual orientation, would be the fact that, by the epidemiology of AIDS, you would have to talk inherently only about male homosexuals. So that would seem to me to introduce a question as to whether that sort of theory would have any validity at all.

But with regard to the hypothetical that I treat as being sort of properly before us, that is, the hypothetical from the Commissioner, the issue, I think, is quite clear, as Mr. Silverstein said, that sexual orientation would not be considered a handicap under section 504, so that firing solely on the basis of sexual orientation would not be actionable under section 504.

CHAIRMAN PENDLETON. Do you have another question?

COMMISSIONER BUCKLEY. No.

CHAIRMAN PENDLETON. Just let me ask one question of the panel in general.

COMMISSIONER BERRY. I have some questions, too.

CHAIRMAN PENDLETON. Okay.

This might just go to a part of what you said. In your discussion you were saying that present laws are not sufficient enough, and there needs to be consideration by this Commission to expand coverage to the private sector, and so forth. You also indicated to us, as some others have, that there is a consensus among health care professionals, for lack of some other term—that is, the American Medical Association as well as in the legal profession some of the employers that you mentioned—that we need to expand.

What are we expanding? What public health laws now discriminate against people with AIDS?

MS. HUNTER. I'm not talking about public health laws that discriminate against people with AIDS. That's not the point.

If I could answer your question, which is what are we expanding—the answer to that question quite simply is the scope and coverage of discrimination laws based on handicap, that is, laws prohibiting discrimination based on handicap. Laws that prohibit discrimination based on handicap are unlike laws that prohibit discrimination based on race or gender or national origin or religion in that they don't extend into the private sector in the same way that Title VII, for example, does.

So when I say "extend the law," what I mean is to extend the concept of laws prohibiting discrimination based on handicap in the same way and to the same extent that Title VII now covers employees in the private sector.

CHAIRMAN PENDLETON. That's kind of a general statement. I wanted to get on the record something a little bit more specific.

MR. SILVERSTEIN. Could I add a brief comment?

CHAIRMAN PENDLETON. Go ahead.

MR. SILVERSTEIN. The National Council on the Handicapped, which is established pursuant to the Rehab Act, the same Act that we have, 504, with 12 commissioners, I believe, all of whom are Reagan appointees, has submitted a draft bill to the Congress for extending civil rights protections beyond 504 coverage, to deal with private sector employment, public accommodations, et cetera. It's called the Americans with Disabilities Act,

which was introduced 2 weeks ago Thursday, I believe, on both the House and Senate side.

CHAIRMAN PENDLETON. If I could just continue a second more. What is the responsibility on the part of individuals who are at risk or put themselves at risk either to be HIV positive and ultimately have full-blown AIDS—what is their responsibility in helping to reduce this epidemic? And do we believe that civil rights laws will help to reduce the epidemic, or do we just make people comfortable in their own behavior mechanisms?

As we look at the numbers, whether they increase or whether they go down or not, we don't know in 1991 or 1992, as we heard yesterday in terms of transmission, what the universe will be of full-blown AIDS.

That being the case, what do civil rights laws do in that respect? Do they interrupt the transmission? Do they help to control the disease?

I can understand people being protected, but what is the obligation on the part of—I'm going to coin a word here—the infectee?

MS. HUNTER. Let me respond, if I could, to that.

First, civil rights laws do help control the epidemic.

CHAIRMAN PENDLETON. Tell me how.

MR. SILVERSTEIN. Can I quote from you from footnote 15 from the *Arline* decision, which deals directly with this issue?

CHAIRMAN PENDLETON. Ms. Hunter, we'll go back to you.

MR. SILVERSTEIN. Is that okay?

MS. HUNTER. I yield my time to my colleague from the Senate, Mr. Silverstein.

MR. SILVERSTEIN. "Indeed, because the Act requires employers to respond rationally to those handicapped by a contagious disease, the Act will assist local health officials by helping remove an important obstacle to preventing the spread of infectious diseases: the individual's reluctance to report his or her condition. It is not surprising, then, that in their brief as amicus in support of respondent, the States of California, Maryland, Michigan, Minnesota, New Jersey, New York, and Wisconsin conclude that 'inclusion of communicable diseases within the ambit of 504 does not reorder the priorities of state regulatory agencies, and would not alter the balance between state and federal agencies.'"

And they go on to talk about the importance, as part of the civil rights statute, from the point of view of public health officials, of having protections.

CHAIRMAN PENDLETON. Mr. Silverstein, we heard some excellent testimony from people who were in the street yesterday, and particularly from Ms. Rumsey.

Now, people out there who are at risk don't believe in the government, and many people who are at risk are minority people. I think she painted quite a scenario about why minority people do not believe in the government, and they don't believe in a lot of civil rights laws, either.

If you're telling me that civil rights laws are going to help interrupt and control—and I understand what you're reading there, but I'm not going to buy it. Because unless you can tell me that somebody is going to go to a street corner and tell some junkies or some pushers, "Hold it; this is going to be a problem; you ought to correct your behavior; these bad things happen to people," we're not going to interrupt anything, not only because of what that does to people but because of the economy or economics involved with it.

So I'm not quite comfortable with the answer that I find in what you're reading versus what we're going to do with the people who are at risk.

I think, as my colleague here is also saying, we're going to wind up—white men can escape a lot of this because they can go into the woodwork at some point, but black men in terms of these numbers and Hispanic men and black women who have a problem are going to wind up being severely stereotyped, which was a part of my colleague's question here. It's a matter of stereotyping, which is the word I used; she didn't use it, but I think that was implied in her question.

And I hear what everybody is saying, but I don't find out what we're going to do with civil rights laws to interrupt these individual behavior patterns. I think people should not be discriminated against. But when we talk about this disease, we are trying to interrupt and control and prevent the transmission.

Now, if you can tell me how this law is going to do that or how the Harkin-Humphrey is going to help in this process, I just want to know that.

MR. SILVERSTEIN. All the public health officials that testified before Senator Kennedy's committee were almost unanimous in their feeling that the answer is in part through nondiscrimination provisions—in part; there are other parts—and the other parts include education, counseling, et cetera. And it is a totality of direction, of concerns, of strategies that are going to address the issue. Education, training, research, and nondiscrimination—and there are others, but that has to be part and parcel of this country's attack on the issue.

CHAIRMAN PENDLETON. We heard yesterday from the gentleman from Long Beach, and we heard a little bit from Ms. Rumsey, that now that people believe the numbers are going down, safe sex isn't being practiced anymore by a lot of bisexual men and homosexual men—that it's not being practiced anymore, and we don't know when we're going to have these numbers elevating again.

So I guess maybe I'm asking for too much, and I'll back off of it, but I'm saying to you, from one who understands a little bit about what goes on in communities, I'm not quite so intrigued.

MS. HUNTER. I'd like to respond to the Chairman's questions at this point, if I could.

First, I would point out that the reason why civil rights laws are important has been documented by any number of commissioners and professional medical associations that have examined this question. I would refer the Chairman to just one example, which is the Association of State and Territorial Health Officers. These are the public health officials of the United States. That is, they are the State public health commissioners, the State public health directors, as well as their territorial analogues in the U.S. territories. That organization has, as part of its official policy on AIDS, stated that the absence of antidiscrimination laws or sufficient antidiscrimination laws is undermining their efforts.

That is as close to a statement from public health directors across this nation that they need antidiscrimination laws as could ever be had. And I think the rationale is actually quite clear. The AIDS public health efforts require individuals in essence to come forward for treatment, to come forward for counseling. And what happens to those individuals, if they cooperate in public health efforts, is essentially that they suffer medically unjustified discrimination. In other words, a situation has been set up in which, if one cooperates in public health efforts, one does not gain from it; one suffers from it.

So obviously there is an extraordinary need, as an auxiliary part of the public health campaign, to enforce and to strengthen those antidiscrimination laws.

I would hope this Commission would consult that organization and that documentation.

CHAIRMAN PENDLETON. That's the problem with that. Let me give not a hypothetical but a real case. I used to run a Model Cities program. One of the projects was community-based treatment for narcotics. We had a kick pad and the whole bit.

Researchers from an unnamed school would come into San Diego to be able to set up some kind of mechanism to find out whether the treatments worked or not. And as soon as the addicts found out that their name was going to go into the computer or that their number was going into the computer, they backed away and did not come for treatment—or did not come for the research.

My point is that I understand what is written and what people assume, but I am prepared to tell you that there is another universe out there that doesn't believe any of this. And I'm just trying to let you know that I don't know what civil rights protections are going to do, because they aren't going to believe that there is a sincerity on the part of government. And I would hate to see civil rights laws being used to attempt to attract them into complying or, as my colleague would say, to disclosing or what have you. I'm not so sure that's really going to happen. At some point we've got to take what is being discussed by Mr. Silverstein and Mr. Smith and in

some way apply that to the universe that people we're talking about don't know anything about these kinds of discussions.

MS. HUNTER. I would like to thank you, Mr. Chairman, because you have actually just presented a very strong and compelling argument for the need for access to testing on an anonymous basis. The example you just gave from your own experience is corroborated across the country by examples that have occurred in HIV testing and counseling centers, in which the strongest possible incentive to urging people to come forward is to provide that testing and that counseling are on an anonymous basis. And you are quite right that if it is done on an anonymous basis, a number of the civil rights issues and the possibility of discrimination is not present.

So I urge you to remember that when you're—

CHAIRMAN PENDLETON. All I want to say to you is I like what you're saying but I'm not so sure that's the answer.

COMMISSIONER BERRY. Mr. Chairman, could I ask a question?

CHAIRMAN PENDLETON. Just one question, Commissioner Berry. I need just a little bit of time. I have one question of you.

COMMISSIONER DESTRO. I wanted to follow one up, Commissioner Berry, on the same direction.

COMMISSIONER BERRY. I'll wait; I'll wait.

CHAIRMAN PENDLETON. I just want to ask one question with a very brief answer.

Do you believe employers in your representation of this nebulous group out here or undefined group—do you believe they are going to be required to file an affirmative action plan to seek out people who are HIV positive or otherwise?

MR. SILVERSTEIN. No, I don't think so.

COMMISSIONER DESTRO. Could I follow up? I just wanted to follow up the anonymous testing question. I didn't get a chance to do this yesterday, but after we had our telephone conference with Mr. Rideau from the Angola State Prison down in Louisiana, I picked up the telephone to talk to him about a couple of other questions.

He addressed the anonymity question, and this is one I'd like any of you to deal with, because we are really dealing with—part of it is the antidiscrimination provisions which assume a certain amount of disclosure. And I'm willing to concede that those are necessary in order to foster disclosure, to a certain extent.

The problem, though—and this was pointed out very clearly in the prison context by him, and he asked me to put this in the record for him—is that in the prison context, even if the prison officials know that a certain person is HIV positive, he says that is compartmentalized information in the prison. He says the prison hospital and the prison medical records are isolated, at least in his prison, in a separate place, so nobody really knows exactly who is seropositive and who isn't.

He says that assuming that nobody knows the status actually in the prison population—either the guards or the other prisoners—you really have no knowledge to protect yourself against irresponsible behavior by the people who are seropositive.

His argument was that at least the guards, who keep an eye on everybody and what they're doing—and he says they have a rather extensive network of snitches who will tell the guards what's going on—they should at least know, to be able to keep an eye on the general population of the prison to protect them from irresponsible behavior.

So I guess that reduces itself to the question that, assuming you do have some protection for the civil rights of people who are HIV positive, you also then have a concomitant obligation on the part of the person who tests seropositive to disclose to the employer—do you have a disclosure obligation, or should you have a disclosure obligation so the employer can, (a) take the reasonable steps, and (b) protect other people in the workplace from behaviors that might not be appropriate in the workplace setting.

MS. HUNTER. I find your implicit analogy between prisons and workplaces to be rather interesting.

COMMISSIONER DESTRO. I wasn't trying to draw that analogy, but some people might draw it, I suppose.

MS. HUNTER. Given that there is no transmissibility problem, as I think has been settled at this point in the medical literature, then there is no reason for an employee to disclose to an employer his or her status.

COMMISSIONER DESTRO. Well, there are the insurance things, but I'll save those, because all I wanted to do was talk about the nexus between disclosure and protection. It seems to me you can't get the protection without a certain amount—well, you can have the perception problem, but if you certainly want to have the accommodation you've got to disclose. Isn't that true?

MS. HUNTER. Well, you're mixing apples and oranges there, because now you're talking about reasonable accommodation, suggesting that the individual is being adversely affected in some way, being fired or being not promoted or whatever.

The original question, as I understood it, dealt with risk of transmission. Because there is not a risk of transmission, you simply don't have a disclosure protection nexus.

COMMISSIONER DESTRO. Going back to the question of assuming that people do carry out their civil rights obligations under 504—and most of the material I've seen with respect to corporations is that they do try and accommodate disabled people in their workplace; some people don't but many of them do; they have a good corporate responsibility—the question then becomes: Those individuals who may be seropositive or may have some kind of problems with AIDS may go forward to their employer and request accommodation because of those kinds of things, and employers

may well want to ask, for purposes of protecting—there are other factors. There are more cases involving sexual harassment in the workplace. Employers have an obligation to keep an eye on things that nobody ever thought, before Meritor Savings Bank, that they had an obligation to keep an eye on. And one of those is the possibility of sexual activity and sexual harassment in the workplace, and that may well present a situation where there is a risk of transmission in the usual workplace.

MS. HUNTER. I think that is simply far too remote to ever justify any kind of requirement of disclosure from employees to the employer.

COMMISSIONER DESTRO. That's all I wanted to ask about.

Go ahead.

COMMISSIONER BERRY. I have several questions but I'll be fast.

First of all I'd like to ask Mr. Carvin whether the Justice Department has given any policy guidance at all to the agencies on how to enforce these laws since the *Arline* case was decided. Have you done anything since the 1986 policy guidance that you referred to, or the Civil Rights Division in its responsibility to coordinate civil rights enforcement throughout the government? Is there some later policy guidance somewhere around?

MR. CARVIN. The Office of Legal Counsel has not provided any kind of sweeping guidance on these questions. It has come up in sort of an ad hoc context in individual litigation, and all we've done in that context is really advised the Civil Division, which represents Federal agencies that have confronted this problem. For example, there was a question with respect to Foreign Service officers in the State Department, and maybe the Peace Corps as well, where they were testing people before they went abroad for AIDS. But other than that kind of litigation, specific advice, no. We plan on doing that in the near future.

COMMISSIONER BERRY. And the Civil Rights Division hasn't done that, either, given any kind of policy guidance?

MR. CARVIN. Other than the sort of ad hoc thing, none that I'm aware of, no.

COMMISSIONER BERRY. Could you make specific inquiry when you go back to the Justice Department as to whether there has been any later policy guidance since the 1986 memo that you referred to when you were talking about the infections—the one you discussed?

MR. CARVIN. Sure.

COMMISSIONER BERRY. To the agencies. I don't mean just within the Justice Department but to the agencies throughout the Federal Government, about how to modify their enforcement, either since *Arline* or any time since then, and just confirm or deny or find out what the case is and let us know for the record?

MR. CARVIN. Sure. I can answer conclusively right now for the Office of Legal Counsel the answer is no.

COMMISSIONER BERRY. I know that, but I'm asking you to check, since you're the only person here from the Justice Department, to check throughout the Department.

MR. CARVIN. Okay.

COMMISSIONER BERRY. The other thing is when the Chairman mentioned the part about minorities, Hispanics, and black males and females and the impact of AIDS, I think what he was referring to—we had a little colloquy—and Commissioner Buckley—about the data from CDC, which shows the increase in cases among black males, females, and Hispanics. While the public attention is focused largely on gay-bashing and talking about male homosexuals, that that isn't where the numbers seem to be going, and that there is a potential for race discrimination as well as handicap discrimination, and we would hope—and I'll ask you, Mr. Silverstein: Is there any possibility for the people on the Hill who have responsibility in these areas, at least staff to staff, to talk about these relationships, and what kind of enforcement strategies are going to be required, because these are going to be the issues. We all know that there is a high degree of discrimination, or has been, against racial and ethnic minorities anyway in the employment area, and to make it even worse—so there might be some coordination or some thinking about this problem that might be necessary.

That isn't really a question.

And has the ACLU given any consideration to this problem that I just described, Ms. Hunter?

MS. HUNTER. Yes, Commissioner, we have. In our testimony before the President's AIDS Commission, in fact, we recommended very strongly that that Commission conduct, as part of its purview of the civil rights issues of AIDS, two things: One is the issue that I alluded to before, which was the lack of protection in the employment discrimination field based on sexual orientation.

The other, which we specifically addressed and asked the Commission to address, was the inadequacy of remedies based on race discrimination, and indeed the very real factual reality, I would say, that racial minority persons and low-income persons in this society suffer very much from inadequate, less competent, I think, health care provisions. This, too, is going to be a major issue that we see developing in the context of the AIDS crisis.

As I'm sure this Commission is aware, there are Federal statutes on the books that deal, for example, specifically with race discrimination in the context of employment. So that particular recommendation would not be appropriate. However, we felt it was appropriate to direct that Commission's attention, and this Commission's attention as well, to the issues of racial discrimination and income discrimination, not only in employment but additionally in the context of the provision of health care and the

medical treatment that is going to hit urban communities very, very hard in the context of the AIDS epidemic.

COMMISSIONER BERRY. I meant that, but also, Mr. Silverstein and Ms. Hunter, I also meant stereotyping of people, that if you think the high-risk groups consist of black males and black women and Hispanics, just as people stereotype male homosexuals and say, "We don't want to hire them; they might have AIDS" or whatever, that if you're going to reduce your risk of getting such people and having to insure them, as Mr. McDonald worries about for his hypothetical or imaginary employer, you might decide yet another reason not to hire the person.

So we have to consider those issues, I would think, increasingly as we go along.

The other thing is there were a number of questions about State laws. I was out in the State of Washington last week and they were telling me about their State law when I said we were having these hearings. They said all they did was listen to testimony from medical experts, and then to pass a law which didn't discriminate against people who had AIDS or HIV for any unjustified discrimination, consistent with what the medical people told them.

It's not clear in my mind—do most States have laws like that for people working in private employment?

MS. HUNTER. It's very much a mixed bag. The majority of States have some kind of law prohibiting discrimination based on handicap. And most of the States that have any law at all deal with employment discrimination. That's the most frequently covered kind of discrimination.

However, a number of those States either don't cover AIDS because the definitions in the law differ from the Federal statute that we have been discussing, or some of those laws don't cover any private sector employees at all. They only cover the employees of the State government, or perhaps the State and local governments.

In addition, there are a minority of States that have any handicap discrimination laws at all that deal with nonemployment areas, such as, for example, housing.

COMMISSIONER BERRY. So that's the argument for strong Federal laws, the absence of—

MS. HUNTER. There is an absence of Federal law in any of those areas, and there is a very compelling need for it in all of them.

COMMISSIONER BERRY. Let me ask one other question, and then I have one for Mr. McDonald and I'll be finished.

Have any of the States had laws long enough for us to find out whether any bad things happen to people because they were enforcing them—I mean any public health bad things that happen to folk because they had laws that prohibited discrimination for medically unjustified reasons against people who are HIV positive or had AIDS?

MS. HUNTER. No, quite the contrary. In the States, in fact, where there is the largest concentration of reported cases of AIDS, there have been rulings from State officials, human rights agencies, and in some cases State courts, that persons with AIDS and related conditions are covered by the State handicap discrimination laws, at least insofar as those State laws exist in terms of what their coverage may be at all. There has not been, to my knowledge, any response from a public health official in any of those areas to indicate that the rulings under the State civil rights statutes have had any adverse effect at all on public health efforts in those places.

COMMISSIONER BERRY. Mr. McDonald, I read your paper with great interest and listened to the discussion, but at the end I was left not knowing what you want to have done. I knew what you didn't want to have done. You didn't want the financial responsibility to be a burden on the employer. I understood that. You wanted the burden of proof to be placed on the person who was claiming they were otherwise qualified. I understand all of that.

What I want to know is: What do you think is the appropriate response to protecting the rights of people, individuals who may be HIV positive or may at some point be—at the same time that the rights of the employer are protected, do you want public money spent for the insurance to insure the risks? Or what is it you want done?

MR. McDONALD. In the conclusion of the written presentation I tried to state clearly that employers have no need or desire—particularly they have no desire—to assume a militant posture in this debate. The *Arline* decision, as it was rendered, represents a perfectly adequate framework within which to resolve these disputes. The comments I made about burden of proof really are not terribly radical. The statement I made about hepatitis B transmission seemed to provoke an inappropriate degree of excitement, I thought.

I think that public money is needed to prevent an exacerbation of the tensions between employers and employees, that we need to be devoting more resources to it on a Federal level. I think that on a Federal level we need a lot more money and a lot more attention to the problem. But I don't agree that the Federal imposition of antidiscrimination standards into all aspects of employer and employee situations is appropriate.

CHAIRMAN PENDLETON. Just one second. I want to ask to put one question on the record, if you will. This is for Ms. Hunter.

Are you aware of a recent study, at least earlier this year, in the *AMA Journal* which stated that a group of homosexual and bisexual men being voluntarily tested, over 12 percent said they would not inform on their primary partners if they proved to be seropositive, and 25 percent would not inform their nonprimary partners.

Do you still believe that voluntary testing is the way to go, or do we do something else?

Ms. Hunter. Well, first of all, that's a non sequitur, if I might say so. It doesn't really speak to involuntary testing at all. Mandatory testing, involuntary testing, as far as I know, has not been recommended by anybody. I am aware of the study that you referred to. It's a study that, if I recall correctly, was a survey administered to people prior, in fact, to counseling about their test results and the implications of the test results. There are extraordinarily compelling data which have emerged from the New York Blood Center, which employs a counseling process for individuals who get tested, and which has had a 100 percent success rate in counseling individuals with regard to informing their partners.

I'm curious as to why you bring that up, because I frankly can't imagine the relevancy with regard to section 504.

Chairman Pendleton. Well, I think it's clear—I just wanted to find out more about the testing. You brought up the relevancy of my question in terms of whether or not—you said I made a good case for anonymous testing. I would assume I got the privilege of asking you a question about whether or not you thought voluntary testing was appropriate or not.

Ms. Hunter. Well, we could have another 3½ hours on voluntary testing.

Chairman Pendleton. I'm sure we could.

Ms. Hunter. I'd be happy to stay and talk about it.

Chairman Pendleton. I'd be glad to.

Mr. McDonald.

Mr. McDonald. May I add two points. One is that the preoccupation with gay rights and the relation of that subject to the AIDS dispute is something we are going to look back on in 10 years and be very sorry about because it has obscured the issues and created a political nightmare in trying to deal with it.

Chairman Pendleton. Thank you.

Mr. McDonald. Secondly, the brutal truth is that disclosure as a general proposition is a public health principle, and confidentiality as a general proposition is a civil rights principle. And there is a conflict between these principles. It doesn't mean that one needs to be abandoned or laid to waste at the expense of the other. It simply means that the character of the rights involved needs to be fully understood.

Chairman Pendleton. Ms. Ramirez.

Commissioner Ramirez. Thank you, Mr. Chairman.

I have enjoyed the legal discussion this morning, but I would like to infuse into the discussion some basic frontline facts about what is happening to people who are dealing with this problem in communities across this country. We did have compelling testimony yesterday from nonlawyers who were talking to us about the fact that AIDS is a disease that is visited upon families, and that the consequences of the disease have

legal and quality-of-life consequences for families, whether the other members of the families are infected or not.

And it seems to me that, as Ms. Hunter has stated, it is the obligation of the Civil Rights Commission to determine whether our laws are adequate to protect citizens in a just manner in terms of any irrational discrimination.

I am particularly compelled to bring this up in the light of Mr. Carvin's statement that the earlier definition of coverage under section 504—and I am not a lawyer so I won't be held accountable for the fine points, but as I understood it, your earlier interpretation of these issues further restricted coverage of protection of 504 to individuals who were now symptomatic rather than asymptomatic.

Let me leave that there for a moment and go on with my statement.

In preparation for these hearings, I had my assistant meet with six individuals in my State who are on the front line of dealing with the needs of people confronting this. I just want to share with you three findings.

One is that a hot line in my State received in one weekend 11 calls reporting lost jobs related to AIDS hysteria or actual AIDS cases; that women of husbands who have AIDS are losing their jobs, all of their family money, and insurance, and are being ousted from their homes because of the relationship to this disease.

And there is an expression of concern about the need for money or legal services to advise the families as they exhaust their resources on such issues as the need to file bankruptcies and wills and attempts to protect the future of their children involved in these cases.

It seems to me if we are going to be evaluating the adequacy of laws to promote justice for people involved with this disease that one of the things we ought to start doing is measuring the incidence of discriminatory practices against people who are associated with the disease, whether directly, as IV—I can never get those terms straight; I am also not a doctor—as carriers of the disease, or people who are associated with the disease, either because of lifestyle, family relationships, or now we look at the issue of race and ethnicity.

Clearly, the Chairman has made an argument for this Commission to be concerned about programmatic as well as legal considerations in dealing with discrimination. I am very pleased to see him do that. But I am wondering whether, in the Justice Department, in the Congress, or in the nonprofit organizations, you have any information that there is any kind of tracking of the incidence of discrimination visited upon individuals related to the existence of AIDS, number one, whether it's in employment, housing, or any other area.

And, number two, I would like to hear from you from the perspective of the Justice Department, the Congress, and the ACLU, whether you believe that 504 and other existing laws are adequate to deal with this more expanded level of discriminatory practices associated with the disease—

and I won't even go so far as to ask you to comment on the adequacy of laws on the basis of race, gender, and sexual orientation.

If you understand my question, number one, is anybody looking at the extent and nature of discrimination? And, number two, are the laws adequate to protect people from that form of discrimination?

MR. SILVERSTEIN. With respect to the first question, Senator Harkin, as Chairman of the Subcommittee on the Handicapped, has announced that we will start hearings on the Americans with Disabilities Act this summer. One of the things we are going to try to do is, in fact, what you are describing, but not only with respect to persons with AIDS but people with epilepsy and diabetics and people who are mentally retarded and mobility-impaired.

We have to start that process of documentation in terms of the nature, extent, and severity of the problem. And, yes, we are in the process now of developing the mechanisms for doing that.

With respect to the second question, there is pending legislation just in the AIDS area dealing with nondiscrimination. But, again, the issue is not only persons with AIDS. It's persons with epilepsy and mental retardation and diabetes and cancer, et cetera, and we have to be looking with respect to all disabilities in terms of the full range of life functions in which discrimination can occur. And that is, again, what Congress is now in the process of doing. A vehicle that is being used will be the American Disabilities Act, which I described before, that was developed by the National Council on the Handicapped.

COMMISSIONER RAMIREZ. Mr. Carvin.

MR. CARVIN. Well, I think both questions have been addressed. As to the reported cases of discrimination, I suppose we have a rough handle in terms of those people who have reported complaints to Federal agencies or brought litigation themselves. What we don't have, so far as I know, is any handle of what proportion of the real problem that might be, whether it's the tip of the iceberg or what percentage of reported cases, how close a correlation that is to what actually goes on.

On the second question, I think this legislation is something that the administration has looked at, a kind of legislation like this in terms of extending, at least in the employment arena, 504's protections. This came up, I think, actually in the Carter administration, where there was a movement to add handicap discrimination to Title VII, and at that time the Justice Department didn't think it was a good idea since discrimination on the basis of handicap is different in degree and kind in some ways than race and ethnicity and gender. They didn't want to confuse the two models, on issues like reasonable accommodation and that sort of thing. Whether or not that is still the approach that is most appropriate, I think they're continuing to look at, and I just don't know at this point.

MS. HUNTER. With regard to the nonprofit sector, or at least our experience at the ACLU—first I would just encourage you to continue your focus and your concern with regard to what this Commission looks at. In fact, there is a remarkable absence of any kind of tracking of incidents of discrimination. Now, at the ACLU we publish a docket of AIDS cases, so we do in fact have an ongoing docket which tracks all of the cases relating to AIDS discrimination brought in Federal or State court, or at least all the ones we are aware of. However, those cases are truly, I can tell you, only the tip of the iceberg.

There are only two entities that I am aware of that do any systematic tracking at all of the number of AIDS-related discrimination complaints. The much more extensive one is the New York City Commission on Human Rights which, as part of that city agency, has an AIDS discrimination unit, and for the last several years they have published data as to the number of AIDS-related discrimination complaints they have received in the areas that are covered by that statute in New York City. To my knowledge, that is the best and most complete tracking system. And that covers, of course, only New York City.

The city of San Francisco also has a somewhat comparable unit, I believe, and they also publish some data.

Other than that, to my knowledge, there is no data.

With regard to your second question which is, in essence: If your concern is how to solve the civil rights problems or do justice in the context of AIDS, what do you have to look at? I think the things that have been alluded to this morning are the areas to focus on. The fact that even in the very basic area of employment, there are millions of Americans that are completely uncovered by any kind of protection from medically unjustified discrimination, and indeed even those individuals who are lucky enough to work for an entity that is covered by 504, that individual may be, and probably is, completely unprotected from, for example, being evicted from her or his apartment for medically unjustified reasons, and of course having the entire family evicted.

So those kinds of gaps in the coverage of statutes translate into the very kinds of life stories that I think your office has uncovered in terms of your own research.

CHAIRMAN PENDLETON. There are a couple of questions from my colleague, Mr. Destro. We want to take a short break. We are running into the next panel. It is now a quarter of one. Our next panel starts at 1:15. Those of you who have to leave have to leave, I understand. We want to try to give our reporter a break and have some break for ourselves.

Mr. Destro, go right ahead.

COMMISSIONER DESTRO. I have two questions, and one goes to insurance. It would be very useful to take up where Mr. Carvin's statement

left off, which is the notion that discrimination on the basis of handicap in some quarters is considered different in both degree and in kind.

In reading the Supreme Court's opinion in the Cleveland, Texas case, the court explicitly refused to deal with handicap or disability as a suspect classification because it felt that there were some rational reasons why you might treat disabled people a little different, which are related to the whole basis of the policy.

And what I would like to focus on is two separate points. The first is insurance, and the second one is treatment.

Ms. Hunter, have you run into any cases at the ACLU with respect to denial of medical treatment on the basis of AIDS?

MS. HUNTER. Yes.

COMMISSIONER DESTRO. Could you tell us about those for the record.

MS. HUNTER. There are a number of such cases around the country, and we have been personally involved in situations in which individuals have been, or were at least at one point, refused treatment in a hospital, refused access to a nursing home. There are cases, I believe, now being litigated in New York, I think by the entity I just referred to. The New York City Commission on Human Rights has before it cases involving persons being refused treatment by a dentist. It has cases before it of individuals being refused treatment in a hospital setting.

I think, quite frankly, the incidents of refusal of medical treatment have been, unfortunately, fairly widespread.

COMMISSIONER DESTRO. Would it be your position that section 504 applies to refusal of medical treatment in an institution which is covered by section 504?

MS. HUNTER. Yes.

COMMISSIONER DESTRO. Mr. McDonald.

MR. MCDONALD. Section 504 does not require an employer's group health insurance plan to cover any particular handicap. The fact that a condition or disease is a handicap does not mean that insurance plans have to cover all handicaps. And it is not a point that I have tried to emphasize because I don't want people to get the idea that I'm advocating that employers should drop AIDS as a condition that's covered in their group health insurance plans. But the Rehabilitation Act does not require it to be covered. And this is another reason why I think the approach taken by the Commission and the Congress and the courts towards an extensive application of the Rehabilitation Act should be done with some circumspection.

COMMISSIONER DESTRO. That gets into the question of: To what degree does the employer owe coverage? Does the ACLU have a position on, for example—can you discriminate in benefit? If Congress does—and I think they should—extend the law to cover private employers engaged in commerce to protect handicapped people—should discrimination in

benefits, given the additional need for handicapped people for benefits—should that be considered and balanced as Congress debates that issue? Because that is certainly going to come up, and it's related to the insurance issues.

MS. HUNTER. Again, I think there is something of apples and oranges getting mixed here in terms of the question. The coverage under the handicap discrimination law refers or should cover, I think, terms and conditions and benefits of employment, construed as it is normally construed in employment law.

The issue of insurance coverage raises a whole host of other subsidiary questions. As I'm sure you are aware, there are several jurisdictions that have taken the step of, for example, prohibiting AIDS-related testing, or HIV antibody testing anyway, as a precondition to insurance.

As a point of fact—and, again, I would urge the Commission to not go into this very complicated and complex area on the basis of what is going to necessarily be an extremely brief colloquy here at the very tail end of this hearing. But group health insurance policies across the country have not, as a matter of policy or as a matter of any professed need on the part of the insurers, eliminated coverage of AIDS or AIDS-related conditions from their scope. That is, I think, an important precondition or an important fact to be kept in mind.

COMMISSIONER DESTRO. I understand that. What I'm asking, I think, is a more general question with respect to the relationship of who bears the burden of the handicapped. We're talking handicapped generally now, in terms of insurance as a benefit of employment. It is certain to come up, and I certainly want to have the benefit of your thinking as I consider going up and maybe volunteering to testify in favor of such a bill as has been put in. That balance is going to have to be struck, and to what extent does the handicapped person and his or her resources—are they going to be expected to bear the cost of whatever accommodations they need, and to what extent does the employer have to bear the cost? And that is the crux of the insurance debate. It is also part of the crux of the nondiscrimination on the basis of AIDS debate.

MS. HUNTER. Well, it's actually not. You left out an important element there, it seems to me. That is, the other option for allocating that cost is a more general societywide option for allocating that cost.

COMMISSIONER DESTRO. I agree that that's an option, but in terms of seeing it as purely a part of the employment relationship, the question is who bears the burden in that context. And Congress has done that in terms of some of the costs of unemployment. They said, "We're not going to have any costs borne by the government. We'll just shift all the costs to the private sector."

Somebody is going to bear the cost. The question is: How do you allocate it in terms of the employment relationship? I agree the public

financing is always an option, and usually is the option of last resort. But it is one of the implicit things that people are discussing whenever they talk about benefits and disabled people.

Ms. HUNTER. That's right. And certainly the question about how the inevitable health care costs are allocated and how those are shared are very important policy questions. I mean, I would only say very briefly and in a very, very general response to that that my position would be that those costs should be shared—should be allocated out through the society, as indeed decisions have been made with regard to certain other handicaps, and increasingly, I think, with regard to catastrophic illnesses generally, and that one should not expect individuals and families to bear the full costs of that event.

CHAIRMAN PENDLETON. I would just say between you and me, Ms. Hunter, there might be a disagreement in that respect. I don't happen to think we can continue to say that society should bear the burden for one's behavior in many respects. It goes back to my point earlier about whether or not one is going to control one's own behavior in this respect, and how we make that the linchpin of how we eradicate this disease as opposed to distributing costs, whatever one wants to do. And I think those are probably two different positions on this matter, but I respect yours.

With that, thank you for coming. It was a great panel and it was a long morning. You're welcome back, those of you who'd like, for this afternoon.

[Recess.]

Afternoon Session, May 17, 1988

CHAIRMAN PENDLETON. The Chair wants to note for the record his own disappointment that the press decided to, in a sense, play games with the Commission's hearing. All the cameras and press were here yesterday and reported on yesterday's hearing and the ACT UP group tended to walk out, and that got lots of television news last night and this morning.

What the Chairman is concerned about is that now that we get down to the meat today of our statutory responsibility, that we have no press and no protesters, protesters from the sense that at least they understand where we are today, which was part of their comments yesterday that we shouldn't be discussing transmissibility; we should be discussing and talking about civil rights.

Well, we are. But as I said this morning, we were attempting yesterday to get some underpinning to understand the extent of the disease that we are dealing with, or the epidemic or the pandemic with which we are dealing.

So I just note that for the record, and maybe one of my colleagues or both of my colleagues might want to respond so the Chair does not wind

up by himself. Although he is used to being in that position, I do not mind other comments.

COMMISSIONER DESTRO. Mr. Chairman, I would like to respond for the record, although it's not a response; it's really more of an amplification of your comment.

I got a call last week from a Mr. Osborne from ACT UP, and I was under the impression then, which was confirmed yesterday, that there would indeed be a demonstration. It was pretty much of the same genre of demonstrations that have been seen on this issue before.

As you pointed out for the record yesterday, there are really a couple of issues here, and we can see it from the comments of the demonstrators, that the important facet of all of this is that the demonstrators were interested in a different aspect of the problem than we were discussing yesterday; that their clear interest, as Mr. Osborne pointed out to me on the telephone last week, is not so much the kinds of discrimination issues that we are dealing with here today, but with their perception that the government is not doing enough fast enough to help current victims of AIDS. And that is why they held up their watches yesterday. The time is running out for people who currently have AIDS.

They would have preferred us, as we looked at this thing, to look into FDA procedures for new drugs, to look only at the testimony of AIDS victims in trying to establish the parameters of the problem.

I was asked on the telephone, and yesterday by another reporter, as to why we might be taking testimony from a person involved in the real estate industry. And my answer to him, and my answer to Mr. Osborne on the telephone, was that the perception of the buyer is only one part of the sale equation, that the seller is probably better advised of the degree of fear in the marketplace than the buyer is. Individual buyers can respond to individual situations, but the sellers will have a much better impression of how persuasive the problem is in the marketplace.

And it just underscores what I consider to be one of the most unfortunate aspects of most of this debate, which is the focus purely on present victims of AIDS. That's an important focus but it's not the only one.

Commissioner Ramirez pointed out a totally unspoken part of all of this today, which is the impact of discriminatory activity on the family members of AIDS victims. The people from ACT UP were not at all interested in that aspect of it.

So in any event, I consider it to be unfortunate as well.

I should also point out that we did not get enough testimony—it's hard to get it because people are afraid to admit it, but I made a mistake in not asking Dr. Allen yesterday on the record why they were having trouble getting more than four hospitals to respond to the CDC's questionnaires. And the response is that the hospitals are afraid.

So there is a considerable amount of fear out there; there is a considerable amount of inconsistent activity and inconsistent arguments. And as long as we are very careful as we go through this, I think we will find the more pointed and clear we can make our own recommendations and findings, we will have all the publicity than we know how to handle.

CHAIRMAN PENDLETON. Thank you, Mr. Destro.

Ms. Buckley, do you have a comment?

COMMISSIONER BUCKLEY. The only thing is to again concur with what both of you have said, and that is that yesterday we did have the medical aspects of the disease discussed. We did have to do that before we could really understand what AIDS is all about. And from that point, then, we can go into the civil rights issues with a lot better perspective of what we are dealing with.

It is unfortunate that we don't have more people here to listen to the testimony that is being presented, but it is important that we stress that individuals who have AIDS today and individuals who will have AIDS in 10 or 20 years—we need to be aware of some of the problems that they may deal with. And the stereotyping that does occur in the community when you go to seek employment or when you go to register your children in school or to buy a house—the stereotyping will be done. Whether you're a white male homosexual or you're a black female, you will meet some problems.

The idea here is: Are the laws that are on the books now capable of dealing with the discrimination they may face 5 or 10 years from now, and will they be able to have the health care that they will need. When 50 percent of the females that have AIDS right now are black females, and when 50 percent of the children under 5 years old that have AIDS right now are black children, then it becomes a serious concern.

The Hispanic community and other minorities may be affected, and we need to deal with it in the context of whether there will be racial and ethnic discrimination for these groups in the future.

Unfortunately, again, if we could have more people involved in this issue now, we could prepare for what 1992 may offer. And hopefully the discussion begins here and we will be able to monitor the situation better.

COMMISSIONER DESTRO. If I may just add to that, that's one of the more frustrating things about the media attitude. They were not here for the last panel, when Ms. Arriola and Ms. Rumsey and Dr. Nickens were here. But that is really a critically important issue, and I think many white Americans would be absolutely amazed. Their only perception of AIDS as genocide may well be the KGB's disinformation campaign. They don't have any sense, I don't think, that many minorities on the street, so to speak, perceive there is a genocidal aspect to this, and I think they would be shocked. And that is an important component of control efforts, people's perceptions of what the controllers are up to. That is news, too,

but somehow that gets lost in the concern about what is apparently the issue of the day.

CHAIRMAN PENDLETON. Finally, I just want to say that we are in a, perhaps, great ideological war, if you will, about where we are with civil rights in this Commission. But it seems like it is not a balanced war. We are both using the same weapon, which is the press, and this Commission doesn't get enough of it in the right places.

Mr. Goldman, thank you for bearing with our afternoon opening kinds of statements. The Chair believes it was important to put that on the record as one begins to look at the record in 1992 or some other time.

We are glad to have you here, Mr. Goldman, and we would like for you to summarize whatever testimony you have, because we have something from you for the record. We'll take a little time with you, and then ask you a few questions.

TESTIMONY OF DONALD S. GOLDMAN, ESQ., REPRESENTING THE HEMOPHILIAC FOUNDATION

MR. GOLDMAN. Thank you very much.

I'd like to just introduce myself. My name is Donald S. Goldman. I'm the immediate past president of the National Hemophilia Foundation. I'm an attorney in West Orange, New Jersey. I have hemophilia. I was president of the National Hemophilia Foundation during the period of time from 1984 through 1986 and was chairman of the board for 2 years prior thereto. As a result, I have been intimately involved with the activities of the National Hemophilia Foundation during the critical years, and I continue to be a member of the board of the foundation.

First of all, just to make sure everybody understands what hemophilia is, hemophilia is a congenital blood disorder involving people who lack a certain protein in the clotting of their blood, which is commonly called clotting factor, which results in prolonged bleeding. Contrary to the common myths, people with hemophilia do not bleed profusely from open cuts or wounds or anything else. The bleeding that is involved is primarily internal.

Persons with hemophilia are the largest users of blood and blood products of any group in this entire country and in the world. And as a result, I'd suggest that persons with hemophilia are our nation's early warning system, our NORAD system, if you want to call it that, in terms of our nation's blood supply. If there is something wrong with the Nation's blood supply, persons with hemophilia will be affected before the general population will. We serve that function not exactly willingly but we serve it nonetheless.

As a result, in fact, in 1982 when the first cases of AIDS among persons with hemophilia began to be detected, it was the first sign and symbol that scientists were able to determine that perhaps AIDS was not behavior-

oriented, that rather in fact it was caused by some kind of disease, because previous thereto most theories involving the origin and transmission of AIDS had to do strictly with behavior and had to do with drugs and ingestion of drugs and certain kinds of activities, whereas once persons with hemophilia in geographic disparate places across the country began to get AIDS, then it became clearer to many of us that it was clear there was a transmissible agent and that it was being transmitted in the blood supply.

The National Hemophilia Foundation has been probably the leading proponent of safety in the blood supply. We are the only people around, I think, who represent consumers of blood and blood product as opposed to organizations representing those who collect it, distribute it, and not to diminish their concern about issues of safety because they have them also, but we represent, if you want to call it that, the difference between chicken and eggs. The difference is those who are interested and those who are involved, and the difference is one is interested, namely the chicken, and the pig is involved, and we are involved in blood because we receive it.

With that introduction, let me say a few items, and I will cover them very briefly and respond to questions.

The National Hemophilia Foundation believes that it is important from a public health perspective, in dealing with the issue of civil rights that you have here, that persons with AIDS or HIV infection be protected from risks of discrimination, but for a different reason than some people have articulated here.

First of all, we see no logical distinction between persons with AIDS and persons with hemophilia or persons with cerebral palsy or persons with epilepsy or anything else, and there is to us no logical distinction between them in terms of the ultimate issues of discrimination. That is to say, if your goal is to eliminate discrimination, it ought to eliminate discrimination against all those who are disabled and handicapped.

We certainly support the recent legislation which has been introduced by Senators Weicker and Harkin that I think was mentioned earlier, which would extend the 504 protections to essentially Title VII type protections. We believe that is appropriate and necessary—not on issues of public health but on issues of dealing with the most vulnerable people in our population, the disabled, allowing them to expand their opportunities and thereby benefit the country as a whole, which is at the present time, as a result of discrimination against the handicapped, not having the full benefit of those who are disabled and handicapped.

However, from a public health perspective, there is a different issue. From a public health perspective, we believe that increased voluntary risk-reduction counseling for those at higher risks with AIDS ought to be done. There ought to be more counseling. There ought to be more HIV testing.

And it is important from a civil rights perspective to remove barriers to those items.

Barriers are money. It costs money to do HIV testing and counseling. And particularly our experience in the hemophilia population is that it is a little bit easier perhaps—and maybe somebody will say what I'm about to say may be somewhat prejudiced against gays—but I think it is somewhat easier to argue and give people counseling and tell people to avoid sex when they're talking about homosexual sex than it is to say in the context of a married couple to tell them to avoid sex when they're sleeping in the same bed together in a way that is socially sanctioned and socially approved.

It is easy to say use condoms all the time, but it is more difficult to say use condoms to a married couple who are lying in bed together and wake up at 3 o'clock in the morning with a great deal of love for each other, and don't want to get up and they're too tired to get up and go to the bathroom to get the condom or even a night table.

We all know those things in a very practical way, and believe me it is very, very difficult to deal with those kinds of issues on what we call a normal heterosexual, socially-encouraged sexual basis, and we have to remove barriers. We have to make it chic to do HIV testing and risk-reduction counseling. We have to apply the same techniques that we are now using for seeking women to have mammographies, for men to have proctological examinations, and women to have PAP smears, and people to be tested for diabetes, and have their blood pressure tested, and everything else. It is that kind of thing that we need.

But what kind of system would you have if you encourage people to have blood pressure testing, and then tell people, "By the way, if your blood pressure is high you're going to get fired from your job."

It doesn't work. So it is in the narrow context of promoting good public health policy and removing barriers—and there is a multiplicity of barriers. There are barriers of confidentiality; there are barriers of education; there are barriers that there's a lack of an effective treatment. That's a barrier to testing.

The removal of any single one of these barriers is not going to solve the problem. Collectively the removal of all of them or as many as we possibly can will be of great assistance in solving the problem.

So it is in that context that we would urge that there be appropriate laws prohibiting discrimination against those with AIDS or HIV infection. And let me make it clear—one of the counsel asked a question before: Are there any examples of people who are discriminated against based upon merely the fact that they are suspected of having AIDS? I can tell you numerous persons with hemophilia.

One I was involved with myself where a 6-year-old child was told that he couldn't use the drinking fountain in the classroom because he had

hemophilia, unless he went out and at his own expense got himself HIV tested and it proved negative.

Those are the kinds of things that we face in our communities. We face in our communities breaches of confidentiality, where a well-meaning public health officer in a Midwest State announced publicly that their voluntary testing program was a marvelous success. Only three people who came forward to the program tested positive, and one of them was a person with hemophilia and two of them were gay.

What he didn't realize was in that community there was only one adult with hemophilia. What happened was the guy's wife got fired; he didn't get fired. His wife got fired, as a result of which he lost his health insurance, as a result of which he couldn't pay for the clotting factor, which is terribly expensive, which he needed to treat his hemophilia.

So we need protections against confidentiality, against breaches of it. We need protections against discrimination. We need more money to provide the kinds of intensive therapies. And really in our judgment, in a heterosexual context, it requires a tremendous amount of counseling, labor-intensive counseling, in order to achieve behavior changes that are required. We need education. We need treatment so that we can give an answer to those who are willing to put them through this process and give them a hope out at the other end. With those kinds of things there may in fact be some help and some solution.

Let me tell you what we don't need. What we don't need are things that in fact work the other way.

What we don't need are the bombings of homes of people like the Rays that I'm sure you read about, whose children were in a school in Arcadia, Florida, and whose house was bombed.

We don't need court decisions, like the district court decision in a case in California, which was subsequently reversed by the ninth circuit that was referred to earlier, in which the trial court quoted the wife of the mayor's fear of AIDS as being evidence of the rationality of such a fear.

We don't need opinions like the June 1986 advisory from the Justice Department arguing that discrimination against people with AIDS and HIV infection is perfectly legal and justifiable.

What we need are the kinds of things that I was talking about—and not because they are designed to help the civil rights issues involved. And the moment that we have a vaccine, that we have methods that we don't need to encourage that kind of testing and counseling—and that's not our only method available of reducing the transmission of AIDS—from a public health point of view, those laws against discrimination need not exist. As far as I'm concerned, they are temporary measures for a public health purpose, at least in that context. The broader measure, of course, would be one that would deal with protections for all those that are handicapped.

If anybody has any further questions on specific issues, I will be more than happy to respond.

CHAIRMAN PENDLETON. Let me first indicate for the record that you would have been on yesterday were it not for plane difficulties, and I'm sure you would have added to the discussion yesterday morning with the panel we had with respect to public health issues. I'm glad that you're here today.

What I'd like to do is perhaps abbreviate the questioning period considerably, and if we have some questions we'd like to submit those to you in writing, unless counsel has some special questions he wants to ask. If not, we'll just move on for the sake of time—not for the lack of interest, but for collecting the information we'd like to collect.

Go right ahead.

MR. FUMENTO. We, in fact, sent almost all of our questions ahead of time to save time, so they were already covered, but we do have one question.

Mr. Goldman, could you tell us—first of all, could you distinguish between Type A and Type B hemophiliacs and the extent to which both groups have been infected with HIV?

MR. GOLDMAN. There are numerous types of hemophilia. The major one is what is called classical hemophilia Type A, and that has to do with a deficiency of something called Factor VIII. It's just a numerical scheme. There is another thing sometimes called hemophilia B, or Christmas' disease, which is Factor IX hemophilia, which is a different protein. There is a third type of hemophilia called Von Willebrand's disease, which affects men and women equally and is not the traditional sex-linked recessive pattern of hereditary transmission that affects both men and women that involves an absence of something called Von Willebrand's factor. And there are other factored deficiencies that are even more rare.

Because they receive different blood products, and the processing has apparently affected the transmission of the virus, most studies indicate that about somewhere between half to 90 percent of those with hemophilia A are infected with HIV virus, whereas a lesser percentage, probably somewhere in the area between a third and two-thirds of those with Factor IX, and it depends on how much blood products they used and when and with what frequency.

MR. FUMENTO. Thank you.

CHAIRMAN PENDLETON. Mr. Destro, do you have a question?

COMMISSIONER DESTRO. Yes, just one, actually.

Yesterday several of the witnesses referred to the fear that the government would maintain lists of people who come up seropositive. That was identified more or less as a gay fear, that they would have lists of gay people.

Can you tell us whether or not the foundation has similar feelings with respect to the potential for keeping of lists or discrimination against hemophiliacs as hemophiliacs, if there were to be some kind of routine testing?

MR. GOLDMAN. I think I can tell you that persons with hemophilia fear such things, and I can give you a good example of it.

There was a hospital in a major urban city that decided what it wanted to do was put a list of all of those who were HIV positive up on the emergency room wall so the emergency room staff could know who it was. Well, this list on the wall was virtually accessible to the entire world if you passed by it.

COMMISSIONER DESTRO. Is that employees? I assume it's employees. Who?

MR. GOLDMAN. Patients who had gone through the program and had been tested.

COMMISSIONER DESTRO. So if they came in again, everybody would know.

MR. GOLDMAN. If they came in again. And anybody who went to the emergency room of this hospital could find out who in the community was HIV positive. And there was tremendous fear. And what patients with hemophilia were doing—by the way, the way they got on that list was because they were participating in something called the Mosely study, which is a major nationwide study of blood-transmitted diseases which has been going on for years in centers across the country. What the patients did was say they wanted to pull themselves out of the study, and they were going to try to seek to have the university's Federal funding for the study reduced because the confidentiality required by the research project wasn't being respected. So the answer is that fear and concern is not one that is limited to gays.

COMMISSIONER DESTRO. And is the assumption out there to the same degree, that if you have hemophilia you have AIDS?

MR. GOLDMAN. I think the answer to that is yes, but I think there is something else going on, and I think because of the way persons with hemophilia in fact have gotten the disease as opposed to the way gay people have gotten it, I think people have been more able to suppress their anxieties in dealing with persons with hemophilia and have been more charitable and kind, and we're dealing largely with children and not adults, and there are a lot more sympathies. The occasions are clearly reduced although the occasion I just cited to you before of the school child, those occasions clearly exist.

COMMISSIONER DESTRO. Thank you.

COMMISSIONER BUCKLEY. For the record, I don't have the testimony here in front of me—

MR. GOLDMAN. I don't have any written testimony.

COMMISSIONER BUCKLEY. But you submitted something in writing. No?

MR. GOLDMAN. No.

COMMISSIONER BUCKLEY. Then it must be from the transcript.

Could you tell us the incidence of full-blown AIDS in hemophiliacs? Do you have a percentage of the population that has full-blown AIDS?

MR. GOLDMAN. First of all, you have to understand that the definition has recently changed, and they keep on changing the definition. I think the latest number is somewhere in the area of about 650—about there. If we assume, for the sake of argument, that probably somewhere between 7,500 and 10,000 persons with hemophilia have been infected by the virus, you can make your own calculations.

I would point out, however, that because of the recent availabilities of treatment processes to treat clotting factor, there is no longer any risk of the transmission of AIDS through blood and blood products. One consequence of that, that has to do with some other areas that are involved, is that as a result of those treatment processes, the cost of clotting factor, which was already costing somewhere between $6,000 and $10,000 per year for every person with hemophilia, has been multiplied somewhere five-to eight-fold, so the cost is now, because of these new improved processes, somewhere in the area of $50,000 to $80,000 a year. And, frankly, nobody knows who is going to pay for it.

COMMISSIONER BUCKLEY. What I was trying to establish for the record was, number one, that the incidence of full-blown AIDS in hemophiliacs was not as high as, say, in other populations.

MR. GOLDMAN. That appears to be true, and that is a subject of interest and research.

COMMISSIONER BUCKLEY. And the other, then, would be if the blood is now cleaner to where the threat of new transmissions would not be as high, then the incidence of AIDS in the hemophilia population should go down.

MR. GOLDMAN. But the fact of the matter is that it has remained constant. That is to say, if you work it out and you look at it, there are approximately 50 new cases of AIDS among persons with hemophilia every quarter. It's been going up at the rate of about 200 cases per year. Yet, we know that because of the new methods of treatment, that the new infections stopped somewhere in the area between 1983 and 1985. So from that pool of who was infected back in 1985, which we estimate to be somewhere in the area of between 7,500 and 10,000, approximately 200 new cases are still occurring every year, year by year, without any diminishment, and without any reduction as time goes on.

COMMISSIONER BUCKLEY. But that would be from the incubation period being so long.

MR. GOLDMAN. That's correct.

COMMISSIONER BUCKLEY. But once that is factored out of this—say in 1992 it's factored out—then you should see that the new hemophiliacs that would be discovered then would not be showing it at all.

MR. GOLDMAN. That's correct.

COMMISSIONER BUCKLEY. They would be new to the group, and they would not be getting the tainted blood—

MR. GOLDMAN. That is correct.

COMMISSIONER BUCKLEY. —which is their only source of access to the AIDS virus.

MR. GOLDMAN. That's correct.

COMMISSIONER DESTRO. Are there any statistics on spouses of hemophiliacs?

MR. GOLDMAN. Yes, there are. And there are high rates of infection among spouses of persons with hemophilia.

CHAIRMAN PENDLETON. I just want to make a point, not so much ask a question.

I raised some questions yesterday about the public costs of treating AIDS, and a lot of discussion about cost had to deal with treating those in the homosexual community. When you add the cost of treatment that you just mentioned, $50,000 to $80,000, plus $10,000 for AZT, then we're not talking just about the cost to the IV drug-abuser community and the homosexual-bisexual male community.

We are also talking about tremendous costs for people who are hemophiliacs; is that correct?

MR. GOLDMAN. Absolutely. But don't forget, the cost for that is not a treatment for AIDS. The cost of that is, in fact, a preventative.

CHAIRMAN PENDLETON. Thank you for the correction, but I'm trying to say it's not a treatment, but there is a public cost in the management, if you want to talk about the prevention and control of this disease; is that correct?

MR. GOLDMAN. Absolutely.

CHAIRMAN PENDLETON. Counsel.

MR. HOWARD. Following up on Commissioner Destro's last point about infection rate among spouses, could you tell us what that rate of infection is?

MR. GOLDMAN. That depends. We have very small sample studies. There are relatively few studying it carefully, but the latest study that I saw was somewhere near 10 to 20 percent. There are presently, I believe, 19 cases in the country of sexual transmission with families with hemophilia. There are 17 cases of wives who have gotten—and these are cases of AIDS, by the way. There are 17 cases of wives of persons with hemophilia, and two cases of husbands of persons with hemophilia, because with Von Willebrand's disease it also affects women, so it can go

that way also, although it is relatively rare. The numbers are less but it can go both ways.

I hope that effectively destroys whatever silly people are running around saying, that normal sexual conduct doesn't transmit AIDS and whatever Masters and Johnson may be preaching this week. That's silly.

The problem that we're having and we're finding is that merely knowing HIV status does not in all cases stop people from doing it the way we'd like them to do. And in many cases it's done with knowledge on both sides. You have to understand that the marriage and the marriage relationship is a very, very special relationship. In fact, one of the studies indicated, for example, that among young families with hemophilia, there is an increased pregnancy rate. And what is going on is a World War II syndrome. But you can't have sexual intercourse trying to achieve pregnancy and use a condom at the same time. Nobody has yet figured out a way to do it.

CHAIRMAN PENDLETON. It has happened.

MR. GOLDMAN. Not effectively.

COMMISSIONER BUCKLEY. Five percent.

MR. GOLDMAN. Those kinds of things—and it takes a tremendous amount of counseling in that kind of caring and loving and complex interpersonal relationship that involves a husband and a wife. And studies have previously been done on the transmission of other venereal diseases, which have shown equally often dismal results with expedient and simple methods of counseling. Spouses want to be part of what's with their spouse. There is even a sympathy syndrome of saying, "If my husband has AIDS, I ought to get it, too."

CHAIRMAN PENDLETON. Do you have another question, Counsel, and brief answer?

MR. HOWARD. I can ask him later.

CHAIRMAN PENDLETON. Mr. Goldman, thank you very much.

MR. GOLDMAN. I'd like to indicate if there are any further questions that any of you have, either as a Commission, or informally if you'd like to, you all have my telephone number and my address. I'd be more than happy to respond either on a formal or informal basis, whichever is your wish.

CHAIRMAN PENDLETON. Thank you for coming.

We next have a panel on housing discrimination—Holly Ladd and Thomas Lynch.

Mr. Goldman, would you stand just a minute for me, please? I didn't swear you in. I do that often.

MR. GOLDMAN. As a member of the bar, anytime I appear before a body, I consider myself sworn in anyway.

[Donald S. Goldman, Holly Ladd, and Thomas J. Lynch were sworn.]

CHAIRMAN PENDLETON. Do you want to flip a coin, you two guys?

I am reminded my vernacular here for the Commission is not right. You two persons, would you care to flip a coin?

Ms. Ladd, you are first on the list. We're trying to do about 8 minutes or so here of the summary of your testimony and a few questions from Commissioners this time.

Panel VI: Housing Discrimination

TESTIMONY OF HOLLY LADD, FORMER GENERAL COUNSEL, BOSTON FAIR HOUSING COMMISSION

Ms. LADD. Let me introduce myself for the record. My name is Holly Ladd. I'm an attorney and member of the bar from the Commonwealth of Massachusetts. I currently serve as the Deputy Director of the Boston AIDS Consortium. I had served previously for 3½ years as the general counsel for the Boston Fair Housing Commission.

In addition, in terms of rounding out my knowledge of HIV infection, let me add that I have served as a member of the Board of Directors to the Fenway Community Health Center in the city of Boston for over 5 years, a health center which has been involved in HIV infection since we first began to see it as an issue in Boston. Therefore, I am aware of many of the medical and social issues relative to HIV infection from that vantage point as well.

Since you have my testimony in writing, and since we are pressed for time, let me just review with you some brief points and then allow you to ask questions on those issues you'd like me to elaborate on.

First of all, as we know, the relevant areas of law that we are discussing this afternoon are Section 504 and how it applies to the area of housing. We are also, I am sure, going to touch upon Title VIII and, by extension, local and State laws which cover the area of fair housing.

As you know, Title VIII currently does not cover disability, although there are amendments pending before Congress on that issue.

While there are no regulations from HUD as to how to implement 504 in the area of housing, Section 504 is administered by HUD, and HUD does have procedures to receive complaints and complete investigations on discrimination in housing by federally subsidized housing providers, including public housing agencies and specifically with regard to the provision of public housing in terms of the physical structures or the provision of subsidies through Section 8 or through local programs that are further subsidized by Federal money in that regard.

There are, obviously, gaps. As the panel this morning pointed out to you, when you're talking about Federal regulation of federally subsidized or federally funded programs, as with the area of employment, 504 would be limited to those situations where you're talking about housing that has some Federal nexus. Most of the housing in this country is not that type of housing. Most of the housing in this country is privately owned.

For that reason, we have to look to State and local statutes and ordinances which provide protection. And I have included for you as an appendix to my paper a list—one was supplied by HUD—of those substantially equivalent State and local jurisdictions that have fair housing ordinances or statutes and indicate for you those which include handicapped or disability among their protections.

Also included for you is a second appendix, Appendix B, which lists State and local agencies which have coverage for disability so you can get a sense of the variety of language which is used, not at all exclusive. I'm sure there has been much work since a year ago when I put those documents together.

As was stated this morning, the incredible patchwork of protections for people with disabilities leaves a lot of us in the area of fair housing guessing as to which law is applicable for any particular situation. Since we do not have regulations under 504, and since there has been very limited case law in the area of housing discrimination with regard to disability, those of us on the State and local level which do have disability protections are often forced to look at sister legislation to Title VIII, or sister applications of Section 504, particularly in the area of employment, for guidance as to how to apply definitions and how to work ourselves through the maze of determining a proper analysis for any given situation.

So we will be looking, those of us in the area of fair housing, to how the courts will continue to discuss the issues raised in *Arline* and continue to discuss the issues raised in the Harkin-Humphrey amendment as guidance for the development of fair housing law.

There is not a large body of case law reported, particularly in the area of AIDS and housing discrimination, one, because this is obviously for all of us a fairly new area of the law and, two, because there is a general underreporting, I believe, of fair housing violations in this country. And that is being repeated, of course, in the area of HIV infection.

I have tried to provide for you some anecdotal information. What we are beginning to see, as this Commission has alluded to this afternoon in its opening comments, is that HIV infection as it moves through communities which are not necessarily identified by their sexual orientation but through communities of color particularly, that traditional and institutional barriers to access to equal housing are being compounded by fear of HIV. I only, once again, have anecdotal data from conversations with members of the Haitian community in the city of Boston who feel a great exposure to discrimination at this point, both in the area of housing and in the area of employment and other public accommodations.

I think when we're talking about housing more than employment, we are talking about families. We are talking about where people who live with each other are going to continue to live, and we are talking about

how a decision by a particular landlord impacts an entire unit of folks, all folks living in the house.

I was particularly compelled in that regard by testimony from New York in a compilation of cases which they provided to me, where women with children—where the woman and the child were both infected—would find themselves constructively evicted by the landlords in those situations. Particularly heartrending, of course, is the story included in the packet, where a woman was debating whether or not to go into the hospital to get necessary treatment because she was afraid that while she was in the hospital the landlord would continue to harass the Red Cross worker who would be taking care of her child in her absence and would continue to shut off the hot water and the electricity.

Stories abound from New York in situations where people have reported that while they are sick, and while the landlord knows they are sick, they are turning off utilities in an attempt to evict people from their apartments.

If we have any question as to whether or not we need protection from discrimination in the area of housing, particularly in the area of evictions from rental housing, on the issue of AIDS, we must consider the need for people to know, frankly, where they are going to go to die. We are talking about people who are ill. We are talking about people who may have lost their jobs. We are talking about people who are living by receiving public benefits, by and large, including housing benefits. We are talking about people who are faced with having to make incredible decisions in their lives. And the last one that I would want to see anybody have to face is whether or not they are going to have a roof over their heads that particular night. Because if we're talking about watching people die quickly, the lack of housing is going to increase that.

That is an experience we are seeing right now in the city of Boston among the homeless population, and the particular increase of late of HIV infection among the homeless population who are being served out of Boston City Hospital.

There are new issues emerging in the area of HIV infection and housing which will be drawing our attention over the next year. I am happy to report the happy resolution of one issue in the city of Boston, and that is the provision of care for people who need hospice services. While that might be perceived as a public accommodation, it does come under some State and local ordinances with regard to zoning questions, and whether or not group homes are protected, particularly group homes for people with handicaps or other disabilities, mental disabilities.

There is some case law on point to that, and hopefully the Cleburne Living Center will provide us some guidance, the Supreme Court case on that. I won't get into that since obviously you have access to a copy of that.

In Boston we were able to successfully go to a neighborhood which felt itself impacted greatly by a lot of other kinds of institutions and say, "We need a hospice for people with AIDS." And that community, after some very careful discussion by medical providers and researchers, understood that it was of no threat to them and welcomed that hospice to their community. We, in fact, were at a groundbreaking ceremony 2 weeks ago that was well-attended by people in the community.

That leads me to the last point I want to make which I neglected in my haste to get through my comments. I have quoted for you the Montefiore study. I do want to go back to the Montefiore study.

The other new emerging issue I want to touch upon, which I know Mr. Lynch is going to speak about, is the whole notion of the duty to warn, and the role of the realtor in advising potential buyers of property that the property had previously been occupied by a person with HIV infection.

We have in California a statute which specifically says the realtor does not have a duty to warn. We have an advisory opinion from the realty association in Texas saying that a relator does have a duty to warn.

I think the answer to the duty to warn brings me back to the Montefiore study. At a Montefiore hospital they conducted a study of household members, 101 household members of people with full-blown AIDS. That study included people who had lived with a person with AIDS from anywhere from 3 to 48 months, the life of the study.

What they determined in that study was that, with the exception of people who engaged in sexual practices who they excluded initially from the study, the household members of a person with AIDS were at no risk for transmission—zero risk for transmission. There was one transmission among the household members who did not have their own risk factor and therefore were not included in that number of 101. That was a 5-year-old girl, and there is sufficient evidence to conclude that she may have acquired HIV infection perinatally.

Since that time there have been over 11 studies of household members and boarding school chums, roommates, and their exposure to HIV infection and the rate of contagion. Over 700 individuals were included in those studies, and there has been no transmission among any of those individuals who did not have their own risk factor. That information, as I said, is included for you in my written testimony.

COMMISSIONER DESTRO. May I just ask briefly how long have those people been followed? Have any of the people in the Montefiore study been followed since that time?

MS. LADD. My understanding from Dr. Friedlander is that they have been followed and there has been no change on that. The 11 studies—I don't have each of the studies. I can go through them. We are talking about things that have been conducted in the last 2 years, so obviously we don't have a long list.

But as you know, HIV infection in terms of testing—and you can assume there's been testing—is 6 weeks, approximately, from the date of infection to the date that you have seropositivity. So if they are not seropositive after the first 6 weeks and they are tested again—this was a scientific study out of Montefiore—we can assume they're not going to, 2 years from now, provide us with any data that we don't already have.

So that brings me back to the duty-to-warn question. If we know that the rate of contagion is zero among household members sharing everything from drinking glasses to toothbrushes and toilets, it is therefore not reasonable, in the reasonable person standard that we have all learned to abide by, for a person to have a fear of acquiring AIDS by moving into an apartment or a residence that has previously been occupied by a person with AIDS.

Now, whether or not it's reasonable, I know, does not control human behavior. But whether or not it should control the real estate industry is the question that is before us. And I believe reasonable behavior and a reasonable person standard should control the real estate industry, and indeed should control the courts in reviewing claims made by people who feel that their property is less valuable once they've found out that it had been occupied by a person with AIDS.

Throughout our history property valuation has always been a major issue. My house is worth what it is today because the Orange Line, one of the major transportation routes in the city of Boston, public transportation, opened up across the street, and I have a shiny new station, so I benefit from that.

I think that other times in our history people have looked at the value of a property based upon what neighborhood it is in and who else is living there. Because my neighborhood is predominantly Hispanic, maybe my property is not worth what it should be. And that's a discriminatory factor.

Because my house might have been occupied by a person who died in that house of cancer, which in fact is true, maybe my house is not as valuable as the house next door, but that's an irrational basis.

Maybe my house was occupied by a person who is black, and somebody has some sort of stereotype that a person who is black smells differently than a person who is white and, believe me, I've heard it working at the Fair Housing Commission. That does not mean that the house is of any less value.

And we must begin to provide, because of our role as leaders in this country, the rational basis for people to be making decisions.

Also as leaders in this country, we have to be providing the kind of information that you are collecting here today and yesterday and tomorrow to people who are in the business of providing services, and I hope that when we discuss 504 in housing, as I mentioned in my paper, we're discussing how to get that information out to people who are

providing housing, how to make sure that managers of public housing know what the risk factors are so they can deal with their management staff and they can deal with tenants as they begin to find that people who live in their buildings are infected with HIV.

CHAIRMAN PENDLETON. Thank you, Ms. Ladd.

Mr. Lynch.

TESTIMONY OF THOMAS J. LYNCH, VICE PRESIDENT, BEGG, INC. REALTORS, WASHINGTON, D.C.

MR. LYNCH. Good afternoon. Let me introduce myself first of all. My name is Thomas J. Lynch. I am a real estate broker and have been practicing as such for some 20 years in the Washington metropolitan area. In my former life I was a biologist with strong concentration in areas of human medicine, genetics, immunology, virology, and bacteriology.

I have been involved in the issue of AIDS for nearly 2 1/2 years as a result of an invitation from the Institute of Pathology at Walter Reed Hospital to participate in a forum discussing the legal and medical and other worldly issues associated with AIDS, and as such have worked on the problem, in a sense rolling back some time and some years, looking at research in areas that were perhaps much more familiar to me and much more of the moment some years ago. But it's like riding a bicycle. Once you learn how, there is really no problem picking up basically where you've left off.

I've got a concern here with respect to the role of the realtor in fair housing and the AIDS epidemic as we view it today. I think it was interesting that one of the Commissioners remarked in his opening remarks—I think it was Mr. Destro—that someone had called him on the phone and said, "Why in heaven's name are you having a real estate broker testify at a hearing on civil rights basically and AIDS?"

I raised that question myself 2 years ago when I made my first public statements to a group of doctors and lawyers at Walter Reed Hospital, and most of the people in the audience more or less said, "Well, why? We are somewhat curious ourselves."

And I said, "First of all, let me tell you that we are in a very, very interesting world today in the sense that what happens tonight, our time tonight, tomorrow, or yesterday, and so on and so forth in the stock markets in Japan and in Germany and in Switzerland and in England is going to have an impact immediately on what happens in the economic world here in the United States. So no sector and no aspect of American life, frankly, is going to go untouched by the AIDS epidemic that some people have referred to as the bubonic plague of our time and our century."

Everybody is touched by the housing issue. You have to live somewhere. I don't care whether you buy it. To own it or rent it, you have to

deal with the housing issue. Unfortunately, an awful lot of people in this country are faced with a housing issue where there are very few and limited choices, and we have a group of homeless people that have to be dealt with as well with respect to the question of AIDS.

But basically the real estate industry, and residential real estate in particular, makes up about 25 percent of the gross national product of this country. We are talking about a multibillion dollar business. In 1940, 33 percent of American families owned their own homes, and 67 percent rented. In the 1980 census, those numbers were juxtaposed and we had 67 percent owning and 33 percent renting.

What does this have to do with anything? Well, basically we are talking about a large portion of the gross national product. We are also talking about a large portion of the hard assets owned by people in this country. And AIDS definitely is going to have an impact on that and an impact on the realtor.

Under Title VIII, the sweeping fair housing law of 1968, the burden is on the realtor, not an individual. If you read Title VIII and how it is structured, you'll see that basically the exemptions cover people that own one or two properties, that live in their own property. The net is out there for the realtors, for the professional practitioners. And in terms of a piece of legislation, that makes a great deal of sense because you're going to get much better compliance if you go after the people who do somewhere between 85 and 90 percent of the real estate transactions in this country.

So it is an issue for real estate brokers. The burden of the fair housing falls on the realtor.

Then we have the question of the law of agency, the law to protect the interests of one's client. Typically speaking, if a realtor is offering a property for sale or for rent, he is working in the best interests of the owner of that property and, as such, has an obligation to do everything he or she can to protect those interests, financial and otherwise.

However, there is a contrast to the law of agency, as we know it. That comes to us from the various and sundry real estate laws from the commissions around the country that say we have to extend the obligation of notice and the law of agency to third parties. In other words, buyers have to be aware of material facts that conceivably affect the value of a property—the usefulness, the utility, whatever, of a piece of property.

There's a large question of arguing whether or not the knowledge that an occupant is a victim of AIDS or a previous occupant died as a result of AIDS, whether or not as a material fact it is going to affect the value of the property. I think the medical evidence that you listened to the other day certainly attests to the fact that there probably is very, very little, if any, real problem of communication of the disease from the property itself. A property can be cleaned. If there was the presence of AIDS there, it can be properly cleaned.

However, a big concern to the seller of the property, and a big concern to the buyer of the property, is any stigma that may well be attached to that property. We have cases where there have been heinous crimes committed in properties, and those properties were very, very difficult to sell. There is a clear line of a devaluation of the property as a result of stigma attached.

The previous witness mentioned that this is all very unreasonable, but as an observer of human nature and one who has worked closely with the public for many years, I have some real problems, because I think the public is going to react in an unreasonable fashion until they are absolutely convinced, through education and other means, that the danger isn't there. And, frankly, when one has the choice to choose property A, where they would have knowledge of AIDS being a factor or someone being sick with AIDS in that property, they will choose another property.

This has been a matter of personal experience where buyers have asked questions, and we say we have no knowledge—and we actually did not have any knowledge—of a situation, and buyers have volunteered and prospective renters have volunteered that if, in fact, that was the case, they didn't want anything to do with that particular piece of property.

So there is a potential for economic impact on owners and would-be owners. Because one of the things you have to consider now more than you did years ago—our parents bought a home. They said, "We'll leave it in a pine box." We buy homes; we move around. We're thinking about what we're going to sell it for when we're making a decision to buy. Is it a good investment? And that is a real serious consideration, and it will have economic impact.

The National Association of Realtors has been sort of dancing around this issue, but they said if you are asked a direct question and you have direct information, then you—"you" meaning the realtor—are probably safer to disclose.

In California, as a result of a case whereby an attorney purchased a home—she suspected that the individuals, one of whom had pneumonia and another one who eventually died of hepatitis, had AIDS. She had one child who had a very, very low immunotolerance. She wanted out of that contract. She in fact did get out of that contract. She received most of her money back, including some money from the Home Insurance Company that actually entered in and supplied some of the reimbursement in that particular case. That case in Berkeley is the one that led to the California no-disclosure situation.

Texas, as has already been mentioned, has taken the other tack. Here locally the local associations have more or less avoided the issue. There are a number of brokers around the country that have been questioned on this, and they say there's really nothing to worry about; there's a cure around the corner.

I think anybody who has spent a lot of time studying what's going on with AIDS would realize there is not a cure around the corner. That is certainly my perception, and that's been 2 1/2 years of study, and very, very intensely, and very, very hard. I think that's sort of the head-in-the-sand routine and we have to be somewhat careful about that.

The economic impact. One study out of Palo Alto said we're talking somewhere in the neighborhood of a 15-fold cost due to AIDS between 1985 and 1991.

COMMISSIONER DESTRO. Cost of what?

MR. LYNCH. Well, it's a group of costs. There's the cost of medical care, the related research and education programs, and the staggering cost of loss of productivity. And you're talking about going from 1985—one of the projections is from $4.9 billion total to $66.4 billion currently.

CHAIRMAN PENDLETON. Could you give us the source of those totals?

MR. LYNCH. Yes. The source of these totals—this is the Palo Alto Medical Foundation Research Institute. I'd be very happy to supply you with this information.

There was another study that was done—

COMMISSIONER DESTRO. These aren't studies related to the particular impact on real estate, are they?

MR. LYNCH. Yes, this is a tie-in to real estate, because what you're talking about—these figures were the basis of a projection by the real estate arm of Deloitte, Haskins & Sells, that the real estate industry stood to lose, in 1987, a billion dollars as a result of AIDS due to loss of rents, loss of productivity, tenant disenchantment, loss of jobs, the potential of companies moving out of areas where there is a high incidence of AIDS.

We know that there are a few top cities in the country. I am not so happy to report that Washington is number five, is in the top five cities in the country with AIDS cases. So for someone who is a practitioner of real estate in this area, it comes home very, very quickly.

But those costs, the cost to the employer in terms of insurance, are expected to go up fourfold by 1991. People who have been surveyed feel that employers should be responsible for the treatment, not the government. This is a problem for the employer, and it reflects on real estate in terms of commercial real estate, and also the residential real estate.

I think it gets down to the question of who should bear the cost. If it's going to cost as much—and I've heard the numbers and I don't disagree with those numbers, the cost of maintaining individuals—$10,000 a year for AZT and so on and so forth, that we're talking about questions of medical care from the cities. We have people who lose their funds, their assets, who have to rely upon public health facilities. You're talking about whether or not the Federal Government is going to supply additional funds.

The District of Columbia got over $500,000 for AZT treatment of individuals in the past year. How much is the District, how much is any particular city going to have to rely on its own resources? Its resources are taxes, and the taxes come from real estate.

Typically, over 60 percent of the income to a municipality comes from real estate taxes, ad valorem taxes, and in order to support the problems of AIDS, those real estate taxes are going to have to go up, and the increase in real estate taxes tends to depress the value of the real estate.

So in the long run, I don't think it's any great surprise that the burden of the cost is going to be spread over the population. The people of the United States are going to pay. Some are going to pay sooner than others, if there is an impact in their area of a high concentration of AIDS cases due to lost of productivity, loss of jobs, loss of work centers, and a devaluation of real estate.

These are some of the problems as I perceive them, and I would certainly entertain your questions.

We are on the horns of a dilemma from the real estate industry, on the business of notice. We are also on the horns of a dilemma when someone says, "What impact do you suppose this is going to have on my investment decision?" And those are questions that we face, some of which are general real estate issues and some are very much fair housing, and certainly whether we're disclosing or not disclosing, we're going to impact on the civil rights of individuals, be they buyers or sellers.

CHAIRMAN PENDLETON. Ms. Ladd, I just want to ask you a question.

I guess your statement about patchwork of protections triggers off a thought by Commissioner Allen.

COMMISSIONER RAMIREZ. About what?

CHAIRMAN PENDLETON. She mentioned patchwork of protections for people. I assume you meant civil rights protections, did you not?

MS. LADD. Yes.

CHAIRMAN PENDLETON. Commissioner Allen for some time has toyed—he hasn't toyed; he has been serious in thinking about a uniform code of protections for people, that every time we have one of these conditions we don't have to come up with a new set of protections with its own bureaucracy and its own cost for managing that protection.

Do you think that would help in the case of where we are, down to the discrete area of 504 and housing and so forth? Or do we need to have separate bureaucracies to handle this patchwork of protections?

MS. LADD. In looking at the history of civil rights legislation, what we have understood is that different people need our attention at different points in time. And that is as much a factor of what we learn as a society as anything else. When we are learning that people with disabilities need protection, we can go back and change the Federal law that is there as a baseline.

Now, traditionally through the history of civil rights legislation we have allowed States and localities to provide further protections for people, given their own needs in their own communities and their own politics, frankly, than the Federal Government would supply.

I don't know whether a uniform code is what we need at this point, but we need to continue the same kind of growth that we have had as a community and as a nation in discussing the issues of civil rights and protection. And as we learn that we do not need to be afraid of people in wheelchairs, we begin to understand that we don't have to exclude them from our social networks, and we do not have to exclude them from housing, nor do we have to exclude them from employment.

And it is that kind of reduction of fear which has led us to the point we are at now with the amendments to Title VIII on the whole issue of disability. You add in a whole new area of disability that people hadn't thought about 5 years ago, and the issue of fear comes back up.

So to answer your question, no, I don't particularly at this point in time think we need a uniform code. I do think that we need to be open to growth.

CHAIRMAN PENDLETON. Not that we need, but I'm asking if you think it could work.

Ms. Hunter said this morning, for example, she believed 504 always covered AIDS. Because we have this AIDS epidemic, we don't need to do anything else because 504 still covers it.

MS. LADD. I think if the code covers the people who deserve to be protected in this country which, frankly, is everyone, then a uniform code would work. I think a code which doesn't include everyone would not work.

CHAIRMAN PENDLETON. I thought that was the Constitution, but that's okay.

MS. LADD. Well, that's what I'm agreeing with you on.

CHAIRMAN PENDLETON. On the other hand, Mr. Lynch, I'd like to ask you a question. As one who is sort of interested in the real estate market, I guess what we have been hearing for some time, not just on this issue but other issues about civil rights protections, is that employers and people who provide goods and services, if you will, are really bad and mean people; that is, they are greedy and they're insensitive to the needs of others, and therefore we need to have these kinds of statutory protections, if you will, that keep them from being insensitive or being greedy and profit-motivated.

I was interested in your discussion about from whence profits come. I wish we could have gone a little longer with it but that's not a topic of this discussion. But in order to be able to accommodate, in order to be able to have money in or from the market, it has to circulate. In order for it to circulate, somebody has got to put it in.

Now, I think you make a good point. If public service costs come from property tax, except for sales taxes in cities and maybe some other ad valorem taxes in some places, then what we are talking about in order to be able to raise the kind of revenues to do the kinds of things that Ms. Ladd is talking about in localities, there's got to be some way that the two points you have can get together so there is the kind of care that I think needs to be provided. At the same time, those who take risk in the marketplace, it looks like right now they're taking more risks than just with their capital. I mean they risk an idea and they could get wiped out very quickly if there isn't a kind of return on their money to do the kinds of things that have to be done.

Do you have any response to that?

MR. LYNCH. Well, I am not exactly sure what you're driving at in the sense that I think it is possible to be profitable and to be caring.

CHAIRMAN PENDLETON. I'm sorry.

MR. LYNCH. I said I think it is possible to be profitable and to be caring. If you really want to address the issue—I was making the point that one of the drawbacks, one of the potential drawbacks with the real estate industry would be if we have to come up with the dollars, if we have to come up with the dollars to meet the problem—and we're going to have to come up with the dollars to meet the problem one way or another—the greatest source of revenue for the individual municipalities, which are tasked for the care of the individuals within their borders—the single greatest source of income is the ad valorem property tax. And high taxes have a deleterious impact on property values.

CHAIRMAN PENDLETON. Or people buying property, period.

MR. LYNCH. There's no question about that. It becomes a question of choices. That is a very, very strong issue. People make that decision all the time. One of the most common questions that we are asked when people come from out of town to the Washington metropolitan area, they say, "Tell me about the relative tax situations from this community to that community, this county to that county, because I'm here to explore my options."

CHAIRMAN PENDLETON. One of my friends comes up with the theory of positive fiscal residual, and he says what that means in terms of towns is that if you make the poorer communities or the less-chance communities or the low-income communities look as good in terms of public facilities and the like as the high-income community—the high-income community assumes that their property taxes are being used to supplement what might be paid in the lower taxing area, and therefore they leave the community and go someplace else. Has that been your experience at all?

MR. LYNCH. Well, people do make decisions to move on the basis of taxes. I've heard that raised as an issue, that they feel that their tax monies aren't doing that much for them. But I think basically the bottom line,

when people make tax decisions, is how much tax are they actually going to have to pay, the real estate tax being one of those components.

Ms. LADD. If I could jump in at this point, I don't know what the housing market is in D.C. I can only assume that it's somewhat similar to the housing market in Boston. I also don't know what the housing market is in Texas. And given the economy in Texas, I assume it's somewhat different than the housing market in Boston.

CHAIRMAN PENDLETON. Believe me, the market in Texas is substantially different from most other places in the world.

Ms. LADD. I was putting it mildly.

But if, for instance, in the city of Boston, without further discussion, we allowed realtors this duty to warn without control, and we allowed landlords the right to consider their future property values and their ability to resell in an incredibly tight housing market, we would see landlords in the city of Boston refusing to rent to Haitians, refusing to rent to Hispanics, and refusing to rent to blacks, and continuing to refuse to rent to gay people, based upon the incredible numbers of the increase in HIV infection among the minority population of the city of Boston over the last 6 months, and the anticipated increase.

We would find the whole issue of this morning's discussion on drug abuse and people who have rehabilitated themselves from drug abuse and alcohol abuse revisited in the housing market in the city of Boston because of the incredible increase in the HIV infection rates among IV drug users in the city of Boston. And we would find women and children on the streets because of the landlord's fear that they wouldn't be able to rent the property again or they wouldn't be able to sell the property, just in case one of those people who are perceived to be in a high-risk group might come down with AIDS infection.

I think what you do in a city with a tight housing market is exacerbate those continuing institutional forms of discrimination that we are experiencing already.

CHAIRMAN PENDLETON. I would submit that part of what you say is true because of these new conditions, but that was the same thing said about Harlem. Harlem wasn't always black. But because the landlord could get more money out of renting his house to more than one family, he made a profit. So it isn't just that they're going to move away. In other words, if somebody can pay the rent, sometimes they don't care, because there are other problems associated with that; I agree with you.

Ms. LADD. There is a range of problems. AIDS is only one of many problems.

CHAIRMAN PENDLETON. Oh, I agree with you.

Ms. LADD. It tends to magnify all of them.

CHAIRMAN PENDLETON. There's a different situation from when Harlem started as compared to now.

MS. LADD. That's right.

CHAIRMAN PENDLETON. My final question is this: On the 20th of April, Congressman Frank added some language to H.R. 1158 of the Fair Housing Amendment. He stated this: "Nothing in the subsection shall require a dwelling to be made available to any individual whose tenancy would constitute a direct threat to the health or safety of other individuals."

It was adopted 22 to 13.

Do either one of you want to comment on that?

MS. LADD. This reflects the discussion that we had this morning about the Harkin-Humphrey amendment, and it tracks that language specifically with regard to the issue of direct threat. It is certainly acceptable to a fair housing advocate, and I believe that since we've discussed the risk of transmissibility and you have the Montefiore study cited in your report, you could refer back to that to conclude that this language would amply protect both future tenants in apartments, cotenants in apartments, and landlords, and future buyers.

CHAIRMAN PENDLETON. Mr. Lynch.

MR. LYNCH. I have one comment. The landlords have an obligation to maintain safe premises, and I think there are provisions in the fair housing in many places to take care of that. These are old requirements, and so on and so forth.

However, I'd like to also say something about the business of disclosure, and another little insight into the situation vis-a-vis the real estate industry.

The question of allowing realtors to disclose without control—I don't think it's a quid pro quo that you're going to have fair housing violations. There's a fair housing statute in the Nation and there are fair housing statutes in various States and local municipalities. There are strictures on the books and remedies for people who violate those fair housing statutes.

One thing I think has to be considered with respect to the question of disclosure for the real estate broker. Contrary to some isolated cases here, especially in the Washington area and some large cities, most real estate companies are small mom and pop operations. And one of the greatest concerns that a real estate company has is the cost of litigation, even when you're right, because anyone can go to the courts of this country with the most spurious of accusations and you still have to defend yourself. And the cause, in terms of the real estate practitioner, is that, "I don't want to leave myself open, and if I disclose I am possibly leaving myself open in terms of my seller. If I don't disclose, I'm leaving myself open in terms of the buyer or the renter."

This is where the problem really is, and this is why a lot of brokers—and I think a lot more will come down in favor of disclosure when asked. I don't think it's something people have to stand on the street corner and announce, but it's a question of whether or not, when someone is asked a

direct question and you have knowledge and you can answer that question in the affirmative, not to answer that as far as I'm concerned is a dereliction of one's duty.

CHAIRMAN PENDLETON. Commissioner Berry has a question, and then counsel has a question, and then we'll move to the next panel.

COMMISSIONER BERRY. I only wanted to say that I think the whole discussion has taken place without any context. Ms. Ladd tried to talk a little bit about context but not very much. If someone listened to the conversation here, they would not know that there is housing discrimination running rampant already in the United States—racial discrimination, attested to and verified, and even attested to by the President himself who says the fair housing law doesn't have any teeth and he wants one that does. The Department of Housing and Urban Development tells us about millions of complaints of discrimination on the basis of race. There are testers who go around—and this has been upheld by the Supreme Court. And right here in the District of Columbia we have evidence of substantial discrimination on the basis of race in rental housing, apartments, and the like.

So this discussion was like, "We've got this AIDS issue now, and what are we going to do about discrimination on the basis of that?"

What we're talking about is: What do you do to keep from compounding the already existing problem of rampant discrimination, which is the major unsolved civil rights problem, even more serious, in my opinion. It's one of the most traditional problems. And it's not that anyone is tarring, as it were, real estate brokers. I've sat through so many hearings for longer than I care to remember, being on this Commission, about housing, and brokers come and people who own real estate operations, and they always tell us that they are not discriminating and they are not bad people—I believe that—and that all they're doing is reflecting what their clientele wants, and until we can change the people we can't expect them to be different because they're just trying to make a buck. So I understand that argument.

And I assume that people in the real estate business no more nor less have a tendency to discriminate than other people. I assume that without arguing.

But what we are really talking about is: How do you keep the problem from being compounded? We've had evidence and we've discussed earlier today about how Hispanics and blacks, males and females, are increasingly the populations that are identified as having HIV positives, and the next wave of AIDS people, and talked about the employment situation and how the racial discrimination that already exists will be compounded by them stereotyped, blacks in general and Hispanics in general, as being carriers.

How are we going to keep in the housing area from having the already serious problem of discrimination from being compounded by adding yet again the idea that these people may also have AIDS?

And, Mr. Lynch, if I understood you correctly, you talked about how people want to know this information when they want to buy houses, or whatever, like who owned the property and so on, because they are trying to make decisions based on where they're going to invest their money. And I understood what you were saying to mean that people are probably going to discriminate anyway until we educate them out of it.

But does that mean we are not supposed to have as strong laws and policies as we can to try to stop them? Or should we just assume that until some day we can educate everybody to stop discriminating, there isn't much we can do about this? And why isn't it sufficient to let the real estate industry do the same thing we ask of everyone else on this issue, to follow the best medical judgment about what is justified in dealing with people, whether they have AIDS or whether they have HIV positives or whatever. And if there is not a material fact about transmission related to the sale of some property, why do you have to disclose that to someone when you know yourself, based on what you've said here, that that might discourage them from wanting to buy it?

So why can't you just follow what the medical experts tell you is correct in the area of transmission and use that as your guide as you go along? I don't mean you personally, but I mean the real estate industry.

Mr. Lynch. I would say the bulk of the real estate industry probably knows very little about AIDS, and they're a good reflection of what the situation is with respect to the population in general. I'm very much in favor of education, and I think education is the solution.

But I'll tell you something, education is painfully slow. I have been an educator as well as a real estate practitioner for more than 30 years. Twenty-five years or so ago I served on a committee in Onondaga County, New York—the city of Syracuse is in Onondaga County—of health professionals and health educators, and we were brought together in a crisis situation because we had to educate the teenage population so we could make a dent in teenage pregnancies.

Well, 25 years later the problem is bigger than it was before we started all those programs back then. So some of these problems are just going to go away painfully slow.

I think education is the issue, but at the same time I think an individual, who is faced with making a decision as to whether or not I disclose something that I know—giving out information and making judgments are two different things. I think the judgment lies in the hands of the person who asks the question.

Now, there are certain things by law that we are not to disclose in terms of fair housing, which you are very familiar with and I'm very familiar with. But this issue has not been dealt with in terms of AIDS, and AIDS because of the fact that it can kill you—and it kills all of its victims—is a very, very nerve-racking situation. Otherwise there wouldn't be as many

hearings on the impact of AIDS on this, that, and the other thing on a day-to-day basis. You can't open the newspaper any day without reading a major article on AIDS. In today's article in the Health Section of the *Washington Post,* the next big wave is the adolescents. There we go with the young people, and some rather scary numbers in terms of the statistics that they showed in today's paper. And they are the ones that to me have the greatest problem, because when you're under 35 you're immortal. You can do anything. It's never going to happen to you.

Ms. LADD. If I could just add a comment.

CHAIRMAN PENDLETON. Yes, quickly, please.

Ms. LADD. I share your frustration with the focus of the panel. I have been doing fair housing law for quite some time and was told to speak specifically about 504 and AIDS and tried to sneak in a few other things. The issue of compounding has been something that I have been dealing with directly for the last year.

Within the city of Boston, and indeed within the State of Massachusetts, the largest increases in cases and 50 percent of the city's caseload are single minority women, heads of household on Section 8, because both the State of Massachusetts and the city of Boston do provide protection for people who are receiving public benefits.

When you add the potential of HIV infection into that category, it is going to go through the roof in terms of compounding social and economic issues and our ability to respond to it. We are already having difficulty responding to the Section 8 issue, and education alone is not enough. Our landlords know on Section 8, and it's not enough.

So I thank you for giving us a context and assure you it wasn't my intention to exclude it.

CHAIRMAN PENDLETON. Commissioner Berry is right.

COMMISSIONER DESTRO. Let me ask Commissioner Berry a question. Basically, as I understand your question—I just want to make sure I understand it. I think you are saying why can't the real estate industry just take the position that it's irrelevant, and rather than have their associations say, "We think you ought to disclose," why can't they say, "Based on the medical testimony that we have, this is irrelevant, and we'll fight it; and if we go to court, then as an association we'll take the position that this is medically and therefore materially irrelevant."

COMMISSIONER BERRY. That's right, and, "We'll win," because the whole Public Health Service, CDC, everybody else, all the latest information says—we know this medically—that casual transmission, or whatever it's called, isn't possible, and that in fact buying and selling houses will not be influenced—this is not a material fact. Then why should the real estate industry disclose to people something which they already know by their own testimony will discourage some people from buying

and selling houses when it's not a material fact. That's a part I just don't understand.

COMMISSIONER DESTRO. With that clarification, why do you think the real estate associations in places like Texas are taking a completely opposite point of view.

CHAIRMAN PENDLETON. They do not have any money in Texas and they're trying to sell the units.

COMMISSIONER DESTRO. What I mean though is that they can sell the units—

CHAIRMAN PENDLETON. There's a profit motive to this, Bob. I want you to understand that you're right.

COMMISSIONER BERRY. Why tell somebody something, which you have all the evidence behind you to show is irrelevant, when you have already concluded that that irrelevancy will make someone who is irrational by your judgment, because you said people who are not educated, make a judgment, and they're using as a basis something which is irrelevant.

COMMISSIONER DESTRO. This is an important question. The leadership of the industry has decided to lead, but in Texas they've marched off in the wrong direction. And one might assume they might want to march off in the correct direction. Is there any evidence other than in California that people are going to be going off in the other direction?

MS. LADD. Let me just state it's not the State of Texas.

COMMISSIONER DESTRO. I understand. It's the real estate industry.

MS. LADD. And there will be legislation, as I understand, being filed in the State of Texas to correct that situation.

CHAIRMAN PENDLETON. I think the conversation here is that there is a petition from this body that the real estate industry could be a fantastic education mechanism in the process of disseminating information that this isn't a relevant factor, and, "Let's get on with it." As many people as the industry comes in contact with, it does seem to me that's an appropriate way to go, and they could do the country a great service and get back to the fact that they can market the product at some point.

We have to stop because we have two more panels, and it is now 3:00 o'clock, and we took Mr. Goldman this afternoon. The chair is going to have to put his foot down and say we have to stop and go to the next panel, please.

Thank you.

MS. LADD. Thank you very much for the opportunity.

CHAIRMAN PENDLETON. Our next panel is a panel on testing, and we have Dr. Burke and Dr. Dawson.

Dr. Dawson has given us some information here that we hope we can read at some point, sir. Nonetheless, we'd like for you, if you possibly can, to give us some summary of testing from your perspective. We think we have some understanding—a little bit of it, anyway.

Who wants to go first?

[Donald Burke and John Dawson were sworn.]

Panel VII: Government Testing

TESTIMONY OF DONALD BURKE, M.D., WALTER REED ARMY HOSPITAL, WASHINGTON, D.C.

CHAIRMAN PENDLETON. Dr. Burke, go right ahead.

DR. BURKE. I did distribute some written testimony. I assume you have all just received it.

COMMISSIONER BUCKLEY. No, we've read it.

DR. BURKE. What I do want to emphasize is that there are a number of misconceptions about HIV testing. We have experience now with doing HIV tests in the military for 2 years, almost 2½ years now, and collectively in the Department of Defense we have tested somewhere on the order of 6 or 7 million individuals.

I would like to run through some of the more common misconceptions about HIV testing so that I can refute some of these misconceptions.

The first misconception is that false positive test results are common.

We have actually measured the false positive rate in the Army testing program, and we have found that we make an incorrect false positive call one out of every 135,000 individuals who is tested. Although that is a low rate, we think we can do better, and we have recently made some modifications so we believe our false positive rate now is on the order of one out of every quarter-million or one out of every half-million individuals. So from our perspective the issue of false positives is not a major concern.

The second misconception is that HIV screening is not cost-effective.

We pay approximately $4.00 per individual tested. For applicants to military service nationwide, about one out of every 600 individuals is positive. That comes out to be about $2,500 per case detected nationwide. For those areas with the highest prevalences, the costs are about $300 per case detected.

Another misconception, number three, is that the logistical problems of setting up a program are insurmountable.

We received the direction to start our program on the 30th of August 1985, and we were fully operational testing 60,000 people per month 6 weeks later. Admittedly, we did have an infrastructure for doing that, but it is possible to set up a program, large scale, and do it well quickly.

Misconception No. 4: Suicides are commonplace when widescale testing is implemented.

I have reviewed the situation reports from all of the approximately 3,000 persons found to be infected among the applicants for military service, and

there is yet to be a recorded suicide among all of those individuals who have been notified of their positive status.

Misconception No. 5: Pretest counseling is too expensive so that to render programs prohibitively expensive.

In most of our programs, since we deal with relatively low-prevalence populations, our pretest counseling consists of distribution of written materials. We do not do intensive pretest counseling. We reserve our counseling intensively for individuals who are positive. We feel it is much more important to make sure that those people understand the disease than it is to spend a lot of time and money on people who don't have the infection.

Misconception No. 6 is that because there is no cure for HIV, testing is useless.

HIV-infected persons are directly benefitted by the knowledge of their infected status. First, they can be assured of prompt diagnosis and effective therapy of opportunistic infections.

Second, those who know their infected status may be able to slow the progression to AIDS by careful attention to diet, fitness, and avoidance of other infectious diseases.

Third—and this I consider very important to the individual—HIV-infected persons can avoid the guilt and pain of having unwittingly transmitted a fatal infection to their lover or spouse.

And then the last misconception, No. 7, is that widescale screening for HIV will drive the epidemic underground.

To date there have been about 75,000 persons found to be infected through alternative test site programs. This represents about 5 percent of the total of the persons who are infected in the United States; that is, about 5 percent of the 1.5 million infected Americans. As a direct consequence of our national failure to encourage widescale routine testing, the epidemic is already underground. It has never come above ground.

I reject the fatalistic attitude that effective routine HIV testing is beyond the capability of U.S. public health agencies. The means are in hand today to establish an accurate diagnosis in each and every case of HIV. We as a society must abandon the "strategy of preferred ignorance." We can no longer systematically deny the rights and benefits of a painful but critically important knowledge to the 1 to 1.5 million members of our society who carry a fatal infectious disease.

I believe that routine testing for HIV, with voluntary exclusion of those who actively decide not to be tested, can be a powerful public health tool in controlling the epidemic. Infected persons detected in routine screening programs should be the focus of intensive yet compassionate counseling to insure that they fully understand the fatal and communicable nature of the virus infection that they carry.

Thank you. That is my prepared testimony.

CHAIRMAN PENDLETON. Colonel Burke, thank you for the succinctness and the brevity of your testimony.

DR. BURKE. And the accuracy, sir.

CHAIRMAN PENDLETON. I'm glad you said it. If I had said it was accurate, someone would have questioned my qualifications to be an expert witness here today. It's not that we don't have expert witnesses. I sometimes wonder if we have expert listeners.

Dr. Dawson.

TESTIMONY OF JOHN DAWSON, M.D., AMERICAN MEDICAL ASSOCIATION

DR. DAWSON. Thank you, Mr. Chairman and members of the Commission. My name is John Dawson. I am a general surgeon from Seattle, and a trustee of the American Medical Association.

In June of 1987, the American Medical Association House of Delegates adopted an interim report on the prevention and control of AIDS. I believe this is in your hands as the report designated YY. This report included 17 recommendations on such issues as testing, education, confidentiality, and antidiscrimination. We are pleased to provide you with those copies, and hope you will have time amid the materials you have to peruse it.

In developing the recommendations contained in our report, we have sought to balance two separate, sometimes competing, concerns. First, the person who is afflicted with the disease needs compassionate treatment. Those who have the disease and those who have been infected with the virus should not be subjected to irrational discrimination based on fear, prejudice, or stereotype.

Second, and of critical importance, the uninfected must be protected. Those individuals who are not infected with the AIDS virus must have every opportunity to avoid transmission of the disease to them. In our opinion, while providing a judicious balance, AMA policy provides protections for both populations based upon the current state of medical and scientific knowledge.

Clearly, one of the most important subjects addressed in our report was that of testing for the HIV antibody. We concluded with the recommendations that:

First, voluntary testing should be available to all.

Second, testing should be mandatory for blood, organ, and tissue donors, immigrants to the United States, military personnel, and prison inmates.

Routine but voluntary testing should be provided at sexually transmitted disease clinics, at drug abuse clinics, to pregnant women in high-risk areas, early on, and to certain individuals seeking family planning services.

Essential to any testing program is appropriate counseling on ways to reduce the risk of infection, on responsible behavior for those who are

infected, on strategies for coping with the infection, on the necessity for notifying sexual partners and other contacts regarding possible infection.

Informed consent should be knowingly and willfully given prior to testing.

We believe that all of our testing recommendations fit with the main purposes of testing; that is, to identify infected individuals for treatment and protection of third parties, to offer education and counseling aimed at modifying high-risk behavior, to obtain epidemiological information, and to protect the Nation's blood, organ, and tissue supply.

The question often arises as to why the AMA has not endorsed widespread mandatory testing outside of the categories I have listed. Mandatory testing has been proposed for those seeking marriage licenses or for hospital admissions, for example. We believe that health care resources would be better focused elsewhere in the battle against HIV.

Mandatory testing of low-incidence populations would divert finite testing and counseling resources from high-risk individuals who volunteer for testing because they have reason to believe they are infected. In addition, the estimated cost for uncovering one valid case of infection within a very low incidence population would be high.

These reasons hold true for mandatory testing for HIV as a premarital screen. Heterosexual spread appears limited to those who are heterosexual partners of high-risk persons. It has been estimated that heterosexually acquired infection accounts for .021 percent of military applicants and .006 percent for blood donors.

These rates suggest that at the present time it would not be cost-efficient to conduct premarital screening. Both Illinois and Louisiana enacted compulsory premarital testing, and in both States there has been strong support for repeal of the legislation.

But will voluntary testing work? We believe that voluntary testing is working already. One indication is that in many areas the capacity for testing and counseling cannot meet the demand.

The greatest threat to the success of voluntary testing and counseling is that individuals will resist learning their serologic status if safeguards for maintaining confidentiality and protection against discrimination are not assured. It is for this reason that the AMA has made these recommendations:

One, reporting of positive results of HIV testing to public health officials should be anonymous or, if carefully implemented with strict protections for confidentiality, with identifying information.

Two, laws must be adopted to encourage as much uniformity as possible in protecting the identity of HIV-infected individuals, except where the public health requires otherwise.

Three, antidiscrimination laws must be clarified or amended to cover those who test positive for the antibodies to the AIDS virus.

Discrimination inhibits the control of AIDS by discouraging voluntary testing. It also has the destructive effect of removing those who are otherwise productive members of society from the work force or otherwise denying them involvement in fundamental aspects of normal life.

The AMA has taken a strong stand on discrimination and we have backed this up in the courts. In several recent cases the AMA has filed amicus briefs supporting an interpretation of existing constitutional, Federal, and State law to encompass individuals with contagious disease in general and AIDS or HIV infection in particular. Copies of our briefs in these cases have been made available to members of the Commission.

In conclusion, the AMA concurs with the U.S. Surgeon General that, "Voluntary testing, easily accessible to all with appropriate counseling and with safeguards to ensure confidentiality, is good public health practice."

Individuals who know their HIV antibody status can take appropriate precautions to prevent infection of themselves if they are seronegative or to prevent transmission to others if they are seropositive. Mandatory testing, however, should be applied only to the limited categories that we have identified.

Thank you.

CHAIRMAN PENDLETON. Let me just try something here. We heard yesterday—both of you were not here, but we heard testimony to the effect that the male homosexual lobby has been so powerful in this country as to suppress the initiation of sound public health policies for communicable diseases, and that the reason why we talk about voluntary testing and sort of pass this off is because of that strong male lobby pressure.

Do you sense that at all, Dr. Dawson or Dr. Burke?

DR. DAWSON. I do not.

CHAIRMAN PENDLETON. In the Army you don't have that kind of problem, I'm sure. But have you sensed that within the AMA? Has the AMA made any statement about that?

DR. DAWSON. No. I do not feel it has suppressed voluntary testing. In fact, in the San Francisco area, there has been a lot of voluntary testing though it's been done anonymously.

CHAIRMAN PENDLETON. I'm just saying we heard that testimony yesterday that strong pressure has caused public health officials—I think Dr. Pence and Dr. Monteith and someone else indicated that there was strong pressure, political pressure primarily, on legislatures as well as on public health agencies, which has reduced the effectiveness of adequate or traditional public health procedures for dealing with communicable diseases. And I think we want to hear on the record how you feel about that.

DR. DAWSON. Well, in trying to be concise, I'd say I have not sensed those pressures. There is no group that is anymore involved with the HIV

positivity concern, and they are as concerned as anyone could be to have education, information, appropriate treatment, research, but I have not sensed a desire to push it underground. They are definitely antidiscriminatory in their desires.

CHAIRMAN PENDLETON. Dr. Burke.

DR. BURKE. I think it is fair to say that we have not been perhaps as aggressive as we might be in use of the one tool that is open to us technologically to deal with this epidemic, and that tool is the detection of individuals who are infected, with the antibody test. As best as I can tell, about 75,000 or 85,000 persons in the United States know that they are infected. That is, the number of positives that have been found through the alternative test site testing programs.

Best estimates are that there are 1 to 1.5 million people in America who are infected. Therefore, I would say that probably no more than 5 or 10 percent of all of the persons in the United States who are infected with the virus know or suspect that they are infected with this virus.

I am afraid I would have to disagree with my colleague from the AMA who says that these programs are successful. I do not believe that 5 to 10 percent is an evidence of success.

Another way of looking at it is that many of the groups that are severely involved in this epidemic, particularly the urban black population, are not the individuals who are going to find that they are tested. If there is any one group that is very aware of the disease, it is the gay population in the United States, the male homosexuals, and by and large that is the majority of the people who are going to determine if they are infected or not.

But my guess is it is a very small percentage of individuals in the urban areas who are aware of their infected status. These are often men who used intravenous drugs, who are married or who have a partner who they live with in a marriagelike relationship, who may infect heterosexually that spouse, and they have no idea that they are infected.

I think there is an epidemic that is going on in many of the cities in the United States today. There is good evidence that perhaps as many as 1, 2, or 3 percent of the adults in many of the counties of those cities are infected with a fatal communicable disease and have no knowledge whatsoever of the fact they are infected with a fatal communicable disease that they can transmit to the persons they care about the most.

I do not consider this a success from a public health point of view. I think that we, as a society, should encourage testing on a routine basis, that is, to make it available at every encounter with the health profession. I think in situations where there is a high prevalence of infection, routine hospital admission testing makes sense. In places where the prevalence is low, it does not make sense, but in places where 1, 2, or 3 percent of the population are infected, it can be very cost-effective in containing this epidemic.

CHAIRMAN PENDLETON. Dr. Dawson, go right ahead.

DR. DAWSON. If I may, Mr. Chairman, I don't think we disagree on the desirability of much wider testing. There may be a difference relative to whether or not it's mandatory or voluntary. I would like to point out that Dr. Burke's experience and his extrapolations are, from a parenthetical phrase he used, "We have a unique infrastructure." And that is true in the military. It's a little difficult to extrapolate to the population at large.

We have as much a desire—I think there's no disagreement—that we identify as many of the people as we can in the United States who have HIV. There is no disagreement on the enormity of this epidemic.

The question on testing always brings up who, when, and how often. That is with regard to whether you're looking at a prison population or not. But there is a difference between what has happened in San Francisco in the homosexual gay community and in the Middle Atlantic States where you have a much higher incidence of the IV drug abuser. You have a difference in an attitude of responsibility. Some are insured. They have gone in San Francisco more to monogamous relationships, better controlled sexual procedures. When you come to Iowa and the Midwest, you find that they abandoned their prison testing because they found zero seropositivity in 800 inmates. You come into the Middle Atlantic, the New Jersey area and you find a high incidence.

We need to find and come together in some way to encourage people that the answers to this epidemic are information and education, and that the one tool we do have now is testing. It needs to be applied in a manner that does not arouse fear, drive people underground, but allows the kind of counseling and control that will allow us to actually be positive in contributing to the situation.

CHAIRMAN PENDLETON. I would just suggest a couple of things to you. We heard yesterday afternoon—and I'm sorry there weren't more people to hear the last panel yesterday—Dr. Nickens from the Office of Minority Health in the Public Health Service, Sunny Rumsey from New York who is running some community-based activities, and Ms. Arriola from the New York State Attorney General's—who talked to us about some community kinds of activities or things that are going on in communities.

I would just submit to you that we probably need to give you their addresses. I think at some point you could correspond with these people and perhaps visit the environment as they deal with this very critical issue. You would find it quite informative.

Let me just pose something to you that I had kind of put together yesterday. Yesterday morning on the public health panel we had Dr. Pence and Dr. Menitove. Dr. Menitove was representing the American Association of Blood Banks. He agreed that in the past 1½ years the Red Cross has reported 2,500 cases of HIV-infected blood in the system. Upon tracing, it was discovered that 90 percent knew that they were in high-risk

groups, which means that 2,250 HIV carriers knew that they stood a good chance of contributing infected blood to the supply, despite the battery of tests—of course, in California there are all kinds of devices—this is supposed to talk about anonymity and so forth. They could have voluntarily kept that bad blood out of the system but chose to do otherwise.

Now, if you take that entire body of HIV-identified carriers and subtract out the number of hemophiliacs and the infants and those likely to be accepted by a blood clinic in the first place, then one may fairly suppose that conservatively the 5 percent you talked about, Dr. Burke, or more, of the HIV-infected people behave irresponsibly.

Now, this does not assume that it is any greater degree of irresponsibility than in the general public, but the 5 percent you could probably agree would cause a major health problem in America.

I guess my problem with voluntary testing is this problem, plus the fact that as long as government is in it, and as long as people in communities—IV drug users, gay and bisexual men, and prostitutes—know this, they aren't going to be on anybody's registry for fear of the computer tape.

Now, somewhere in this process we talk about civil rights. We also talk about the civil rights of the people who are not infected. And somewhere in here, when we talk about voluntary testing, I have some problem with that, and whether or not there are people who continue to act irresponsibly, for whatever reason that might be.

How do we handle that 5 percent that Dr. Burke talked about?

I'm not trying to put the weight on your back but I'm just trying to get on the record some information. Both of you can answer, if you'd like to, or respond.

DR. DAWSON. Could I ask a question first? You mentioned that 90 percent knew that they were in a high-risk group, or did they know they were HIV positive?

CHAIRMAN PENDLETON. HIV positive—

DR. DAWSON. They knew they were HIV positive?

CHAIRMAN PENDLETON. No, sorry, high-risk group.

DR. DAWSON. They knew they were in a high-risk group.

CHAIRMAN PENDLETON. Yes, but didn't test themselves, and they gave the blood.

DR. DAWSON. And when they gave the blood, they then found out they were HIV positive.

Well, we have seen the mandatory testing that has been imposed, as I alluded to—in fact, I mentioned it specifically—in Louisiana and Illinois when they get a marriage license. They found, first of all, that people fled to adjacent States.

It is difficult to change people's behavior—

CHAIRMAN PENDLETON.. That's the point I was trying to make.

DR. DAWSON. —with anything other than education and information that seeps into their inner being. You have the administrative problems that go with trying to bureaucratically handle mandatory testing. How often are you going to test? What is the cost for doing it?

CHAIRMAN PENDLETON. $100 a test or more?

DR. DAWSON. Well, Colonel Burke says $4.00 for the Army, but I don't know if that included the followup Western Blots or not, but in Illinois for the marriage testing it ranged between $35 and $300.

COMMISSIONER DESTRO. Is that per test or per case?

DR. DAWSON. Per test. They went to get married and they paid $35 up to $300 to be tested.

CHAIRMAN PENDLETON. This means that they voluntarily paid $300 to be tested.

DR. DAWSON. Well, you don't get a marriage license in Illinois.

CHAIRMAN PENDLETON. But I'm saying the person who is to be tested voluntarily pays the $300; is that right? The government is not paying $300, is it?

DR. DAWSON. You mean now, on voluntary testing?

CHAIRMAN PENDLETON. You pay $300 to get the marriage license.

DR. DAWSON. Yes, that's what they were paying in those States, so they went to Indiana, Wisconsin, Iowa, or someplace else.

DR. BURKE. Let me point out, when you get up to the $300 range, somebody is making a lot of money on that.

DR. DAWSON. That's true.

DR. BURKE. The actual testing cost of actually administering the test and doing confirmatory assays, Western Blot, and in fact two other confirmatory assays when necessary, is $4.00 per specimen. In fact, it's less than that. The point is if any agency is serious about making routine tests available on a wide scale, it can be done with the economy of scale. If you set up a system in which each individual must go to a physician who in turn must find a laboratory, who in turn must find someone else to do the confirmatory test, it costs $35 to $300. If you set up an inefficient system, you have a costly system.

CHAIRMAN PENDLETON. So is public health responsible for that kind of protocol; right?

DR. BURKE. What disturbs me is that the system in Illinois is not a system which is geared toward economy of scale right now. If the system were established, it could be done for $4 to $8 per individual. But it is not established there.

DR. DAWSON. They did some 50,000 tests, so there was a moderate number of tests. They just were not in a system that would be like an Army system.

But you also have the problem that the method by which you pick your laboratories, Dr. Burke, you have excluded certain laboratories. Whether

or not we have enough laboratories in the country that can do the kind of quality you've got, that would be of interest, I think.

DR. BURKE. Let me address that. I have spent a good part of the last 2 years of my professional life specifically on that point. I recognize that good quality testing was an essential feature of any testing program. So I and a few of my colleagues have invested substantial time and effort to make sure that the tests are highly accurate.

I wish that the other public health agencies that are charged with epidemic control would spend equal amount of time and attention to the quality of testing that was done in the United States today. There is still not a system in place nationally to insure the laboratories that are doing HIV testing do it with an extremely high level of proficiency.

Again, if this were approached systematically with the goal of achieving routine testing on scale, it could be done. These are surmountable. These are technical issues which can be done if there is any commitment. And the problem as I see it is the lack of commitment so far.

CHAIRMAN PENDLETON. I have just one last question.

I live in San Diego. There is a big service population in San Diego—not so much Army but Marines and Navy. The Public Health Department has had big trouble trying to close down gay bathhouses. And I looked at that and said, "If they want to do that, that's up to them," until I read one little part in about a four-series article that really alarmed me. And what the reporter indicated was that men in gay bathhouses could have between 11 and 50 encounters with different or the same individuals each time they went.

Now, it does seem to me that in the public health interest there could have been some speedier consideration to closing down bathhouses, but that didn't really happen until late in this epidemic.

Then we get to the matter of whether or not we get to the civil rights of people being able to run the houses versus their own behavior versus the public health and that delicate balance between societal protections and individual protections.

What should be done about the gay bathhouses?

DR. DAWSON. Well, the gay bathhouse is just a symptom of the lifestyle of individuals who were indiscriminate in their sexual practices, homosexual males.

CHAIRMAN PENDLETON. But not just homosexual males.

DR. DAWSON. And bisexual males.

CHAIRMAN PENDLETON. I forgot to make this point. Many men who went said they were bisexual. And just to add to the point, bisexual men, I think, are probably a bigger problem to us than the homosexual men who want to go to be tested, because the bisexual men are the ones, if you will, who stay in the closet much longer, especially if they're married.

DR. DAWSON. With regard to the bathhouse particularly, I happened to be talking to the health reporter from San Francisco right after the correlation between the bathhouses and the activity and the spread of AIDS in San Francisco came out, and I think as you know they have been shut down. It is not because they were shut down that the lifestyle changed among the homosexuals or heterosexuals. It's because they became aware of the significance of this epidemic and became monogamous or celibate in most respects. There are those smaller percentages that are irresponsible and continue to spread it.

But I don't think you can find any mechanism bureaucratically to control all of the people who are going to be irrational in their behavior. And I come back that the final answer is going to be education and information and an understanding seeping into the inner being of the people of this country as to what causes this disease. I don't think you can go into mandatory testing of everybody in this country—I don't think you can go to anything other than an encouragement of voluntary testing, with the mandatory testing where we have recommended it, and with some changes as we gain new information.

We still have a window in the testing that we do now, and until we get to where we have widespread use of the radio immunoassays to get the code of the protein that's on the virus itself so we eliminate that window, even with wide testing now we have a problem. But I don't think we need to focus on the test as the answer to the HIV alone. It is an important tool, but we don't want to drive people underground. We want to make it so they come into the system so that they can be counseled and that they don't transmit it through their sexual practices with wife or lover and innocent children by having the wife get it.

CHAIRMAN PENDLETON. I'm sorry; I've taken too much time already. I have some more questions but I'm going to defer to my colleague on my left.

COMMISSIONER BUCKLEY. I just want to clear up something for the record, and this will be for Dr. Burke.

In your Misconception No. 1 where you say "false positive test," the test you have reference to is—?

DR. BURKE. Where we make the diagnosis of HIV on the bottom line.

COMMISSIONER BUCKLEY. ELISA?

DR. BURKE. This is with the ELISA, followed by Western Blot, and, in fact, we are very careful. Before a person is called definitely infected with HIV, we require that a second separate blood sample be obtained from the individual and that that one is positive also.

COMMISSIONER BUCKLEY. So then in reality, before you make the seropositive statement, you do two ELISAs and a Western?

DR. BURKE. We do two ELISAs followed by a Western Blot, and then go back to the individual and get a completely new blood sample and do two ELISAs and a Western Blot on that.

COMMISSIONER BUCKLEY. And the cost on this is still $4?

DR. BURKE. When you average it out, because only about one out of every thousand individuals in our program is infected, so the cost of the second test is really fairly trivial compared to the cost of the screening itself. And when you fold that in, it still comes out to about $4.

COMMISSIONER BUCKLEY. Another question. I don't know if I have a current definition or not, but I've got the August 14, 1987, CDC definition for AIDS surveillance. In that one they list, if the laboratory tests were not performed or gave inconclusive results, and then they list 12 diseases that would be used to diagnose the AIDS.

Now, would you know or would you have an explanation as to why they are saying you have inconclusive results from the tests? Would it be the laboratory problem you addressed a little while ago? Why would you have to rely on all these 12 other diseases?

DR. BURKE. I share your puzzlement as to the case definition of AIDS. My own perspective on this is that the issue here is not AIDS. AIDS is just the end-stage manifestations of a very long infection with HIV. What we are interested in here, and what our public health should be focusing on, is HIV, not AIDS.

One of the ways of thinking about this—it's like an astronomer who is looking through a telescope at a super nova that is exploding. He knows that he's looking at light that originated 5 or 10 years ago.

Similarly, when we look at AIDS cases that are occurring today, these are the exploding epidemic that occurred 5 to 10 years ago. As long as we continue to focus on AIDS, we will be 5 or 10 years behind the curve.

So we must change our attention to HIV. We must set a climate where we diagnose HIV in every instance that it occurs. Otherwise we are doomed to failure in our efforts to control this disease.

COMMISSIONER BUCKLEY. I agree with you.

Now, another thing. The CDC puts out statistics, and the source on this is Paul Symms, January 5 through 8, Institute in New York—he gave a speech and he used some statistics, and he is using September 1987 statistics on HIV-positive cases for 1,000 inspections. And he says this is on civilian applicants for military service. His figures are a lot higher than the figures you are giving us. And your figures are higher than what Dr. Fauci gave us yesterday.

Is this because you are including different services, or is this because of again the tests and reliability of them? Would you know?

DR. BURKE. I'm not sure what populations he is dealing with there. The tests themselves, I think when they are applied through our military

programs, are very accurate. And I don't think we are talking about variations in the test itself.

What we find is if we look, say, in the North Central United States among civilian applicants for military service, only about one out of every 10,000 is infected. It's a fairly rare infection in the North Central States.

If we look in Queens or if we look in Brooklyn, then we find that 1 to 2 percent of the applicants—one out of every 50—is infected.

So it depends on where you are looking, and I think that may account for most of the difference in the statistics that you are referring to, that if you choose your populations according to different geographic locations, there is marked differences.

COMMISSIONER BUCKLEY. If you look at the CDC statistics that are given out—and this would be the May 1988 report that shows you the number of cases of AIDS, ending May of 87, and then May of 1988—and if you look at it, it looks like the disease was more concentrated in the East, and now it's moving to the West. The number one State in '87 was New York. The number one State in '88 is California.

In your testing of civilian applicants, are you seeing this movement also where it's going from one part of the country to another—the actual detection of AIDS?

DR. BURKE. As we discussed a minute ago, those statistics on AIDS are telling us what happened to the epidemic in 1978 or 1979. Those are infections that occurred 5 to 10 years ago. AIDS cases today are infections that occurred 5 to 10 years ago. So I can't judge what happened 5 to 10 years ago because we weren't testing 5 to 10 years ago.

But we have not seen any marked changes in the distribution, in the geography of HIV in the United States just over the 1 year.

California is relatively high; New York down to New Jersey, Washington, D.C., Baltimore—all high areas. And it really has not changed dramatically in the 2 1/2 years we have been testing.

COMMISSIONER BUCKLEY. We have Dr. Redfield's statement, which I assume is also your statement.

DR. BURKE. We share many similar attitudes.

COMMISSIONER BUCKLEY. In that statement, the emphasis there is the movement. The statistics that we are getting right now from CDC, the homosexual community is the one that was really impacted. But you're telling us to be alarmed at the future, and some of the discussion we have had today has been 1992, and 1997 is the year you choose.

DR. BURKE. Right.

COMMISSIONER BUCKLEY. For both of you, then, when you're talking about voluntary testing and we're talking about IV users and the increase of the incidence in AIDS of IV users—and I suspect it will increase in the next couple of years—how are you going to be able to affect their behavior to where they really understand how serious it is and how important it is,

that even if you are an IV user you have to go get voluntary testing to detect for this? Would they be afraid they would be picked up for using the drugs and then would not go? How can you suggest voluntary testing in light of the fact that most of the people that really need it are going to be a population that is involved in a criminal act to begin with? Could you help me on that one?

DR. BURKE. One of the things that you're raising is the assumption that HIV antibody positivity is a marker for illicit behavior, or at least unusual behavior in our current social climates. And we particularly face that in the military. That is, we have screening programs in the military, and we have made the decision—and I think it was a very foresighted and courageous decision on the part of our military leaders—to say that HIV is not grounds for any adverse administrative action. It is not prima facie evidence of any illicit behavior.

And I think that is a very rational position. This is a medical condition. It's an epidemic that we have to deal with and we don't need to get it totally confused with other issues of drug abuse or homosexuality or promiscuous heterosexual activity. The issue is to deal with it primarily medically, to intervene appropriately medically. And when you do that, when you make that mental association, I think you can deal with it effectively on an individual-by-individual basis.

DR. DAWSON. I might add just one comment relative to the IV drug abusers who are HIV positive. Most of those have been identified in prison populations, not because they came in for voluntary testing. They were tested as part of the prison routine.

COMMISSIONER BUCKLEY. In the female population you have 54 percent of the females who have been identified or IV users—the CDC figures for May '88 have, of the females that have been identified that have AIDS, 54 percent of these were IV drug abuse individuals. Are you saying these would be from the prison population? Most of these would be from the prison population?

DR. DAWSON. I think where you have them identified, it is not very frequent that they would come in for routine testing just because they are curious. If they are involved in the combination of IV drug abuse and prostitution, it's because they have been picked up and incarcerated somewhere and then tested that this information is obtained.

We don't know the extent of it among those who have not been detained or incarcerated.

COMMISSIONER BUCKLEY. Would you suspect that this would be even less than the tip of the iceberg then?

DR. DAWSON. I think you can extrapolate. If you knew how many IV drug abusers there were in the country—I have some figures also from CDC that are not far off from that. They explain, as you have already had here, the extent to which this disease, HIV, is prevalent among the

minorities, that blacks compose 12 percent of the population and yet they have 25 percent of the AIDS cases, and so forth.

And the IV drug abusers are the group now which we are really concerned about because of the linkage between IV drug abuse, prostitution, the extension into the heterosexual population, and the impact that that clearly will have. The difficulty in controlling it, even getting them in for testing, whether you had a voluntary or mandatory program—

COMMISSIONER BUCKLEY. Would your voluntary testing be anonymous?

DR. DAWSON. Well, yes. Voluntary testing anonymous, and then reported according to whatever the health department laws are, but in an attempt to epidemiologically identify the extent of the disease, because we are still guessing that it's 1.5 million in the United States.

COMMISSIONER BUCKLEY. In the Masters and Johnson review in *Newsweek*, they talk about how they did testing, and they did anonymous testing, but they found out the people who were tested didn't call in to find out their results.

Do you think that will continue to happen? What they said in their report—they had a study; they did anonymous voluntary testing, and a lot of those people didn't want to know.

DR. DAWSON. To totally control everybody who tests out positive, you'd have a police state and you wouldn't want that. So you have to depend in the final analysis on the dissemination of information and education, and the fact that testing is a tool to help ameliorate a disease that affects everybody. And somehow that has to come into the public's perception—

COMMISSIONER BUCKLEY. It's to help them.

DR. DAWSON. To help them, yes.

COMMISSIONER BUCKLEY. Because in this case they didn't want to know if they needed help, and they preferred not to know. And it's like that didn't help anything. To have them tested didn't help them. They should have cared enough about themselves to want to do something.

CHAIRMAN PENDLETON. As we go to Commissioner Destro, I just want to say it is unclear—I am not proposing mandatory testing in my line of questioning. I'm just trying to get on the record what happens in the two situations. But that discussion should not presume that this Commissioner is looking toward mandatory testing at all.

COMMISSIONER RAMIREZ. I wanted to ask Dr. Burke how frequently you test people in the military.

DR. BURKE. We test all applicants for military service, and that is done as part of the routine medical examination in which they also get their full physical examination. If a person is found to be positive, that is a medical exclusion from entering.

Once a person is on active duty—we went through the entire active force between 1986 and 1987, and our current policy now is to see to it that

everyone is tested at least on a 2-yearly basis, every other year. That policy will be continually reviewed, and depending on the findings—we have already gone through the force once. We are now just starting to go through the second time. And it depends on what incidence of new infections that we find that will guide our decision as to whether or not we will continue to do this on a regular basis.

COMMISSIONER RAMIREZ. Dr. Dawson, for the record, could you describe for us as briefly as possible the process and the involvement of practitioners at different levels that led to the AMA policy statement which you read?

Secondly, can you describe for us, as briefly as you can again, and maybe supply for the record, the activities of the AMA of any critical issue that you believe the AMA itself may be dealing with in terms of the education of its own membership in being providers of basic information and education.

DR. DAWSON. The AMA task force on AIDS is basically our Board of Trustees, approximately 15 people. We deal with this at our Board of Trustees meetings, which meets about five times a year. We present interim and annual reports—that's twice a year—to our House of Delegates, which is the policymaking body of the AMA.

It is the House of Delegates who finally, after getting the Board of Trustees' report, had reference committee hearings on each of these aspects fully debated, with input from the entire federation for the House of Delegates, which represents all of the State medical associations and most of the specialty societies in the United States, including representatives from the Armed Forces, and Surgeon General Koop is a delegate to the AMA. So we get input from all over the country from all physicians. And it is our basic theory that the physician should be the source of information.

So we have published books and pamphlets. The *Journal of the American Medical Association* has many articles on this. We are trying to become the educators of the public through the physicians.

That's about as concisely as I can put it, in the interests of time. If you'd like to have something else answered, I'd be glad to.

COMMISSIONER RAMIREZ. I just wondered whether you had a specific strategic outreach program to practitioners in particular areas—we heard a lot about AIDS being visited upon young families, poor families in particular—whether you had any kind of a targeted strategic program.

DR. DAWSON. Well, other than through our publications, which are significant and extensive, and by encouraging and heightening the awareness of the physician—they needed to be educated before we could educate the public—we're doing that.

We also have an adolescent health care program, which is really just now getting under way. And our concern in that area is the 900,000

teenage prostitutes on the street, two-thirds of them girls and one-third boys—the population that will be the source of carrying it into the future if we can't put a handle on it.

We are trying to disseminate information and knowledge and the magnitude of the problem so the physicians can become the educators of the public. But we're not targeting San Francisco doctors or Mid-Atlantic doctors in that way.

CHAIRMAN PENDLETON. Mr. Destro, you have a couple questions?

COMMISSIONER DESTRO. I'd like to get a little clarification for the record, if I could. We have been hearing various terms thrown around, and I'd like to get both of your impressions on the terminology.

Most of us understand the difference between voluntary and mandatory testing. But one term that seems to elude definition is: What does everybody mean by routine testing?

Dr. Dawson, would you address that?

DR. DAWSON. Yes. We recommend, as was mentioned in there—and I think you have it in front of you—for specific areas, sexually transmitted disease clinics, we recommend that—

CHAIRMAN PENDLETON. Are those the old VD clinics?

DR. DAWSON. Yes, the old VD clinic.

CHAIRMAN PENDLETON. I just wanted to make sure of the terminology.

DR. BURKE. Let the record show STD equals VD.

DR. DAWSON. That's right. I think we all understand.

We recommend that that be done as a routine basis, but preceded by the counseling, and we say, "This is something that is smart and wise."

Incidentally, they have noted in San Francisco that the rate of gonorrhea has gone down remarkably among the gay population. We recommend routine but voluntary testing in that area, at drug abuse clinics.

COMMISSIONER DESTRO. Let me interrupt there for a minute, though. When I go to the hospital, the doctor determines which tests I get. They don't ask me, "Do you want to have this test or that test?" and I just assume whatever the doctor determines is that which is routine.

So when you say "routine voluntary," that is immediately where the ambiguity, at least in my mind, arises.

DR. DAWSON. Voluntary implies the use of informed consent.

COMMISSIONER DESTRO. Okay.

DR. DAWSON. That's what the voluntary really means. And when a patient of mine comes in the hospital and I suspect there may be some reason, because of high-risk indications that there may be an HIV positivity, I don't order it along with the test for hepatitis B or other things. I am not allowed to do that, really. I have to get his informed consent or her informed consent before I can order that.

COMMISSIONER DESTRO. Why? As a doctor, why do you have to get informed consent?

DR. DAWSON. There are laws in some States.

COMMISSIONER DESTRO. In Washington State, are there?

DR. DAWSON. Not now, but we in our hospital have a staff policy.

CHAIRMAN PENDLETON. You have a staff protocol?

DR. DAWSON. Yes. I know of a situation in a Midwestern State where a doctor was doing just as you said, getting it on every patient that came in, and if they were positive, cancelling the surgery that was to be done.

CHAIRMAN PENDLETON. Do you do that? Do you cancel surgery if you get them? Never mind.

DR. DAWSON. I do surgery and I do surgery on HIV-positive patients. But I don't get a test on all patients without informed consent. I only get tests on informed consent.

COMMISSIONER BUCKLEY. Do you ask for it on your surgery patients? Do you suggest it?

DR. DAWSON. No, not routinely; no, I do not.

We have a fair HIV positivity in the Seattle area. It's not as heavy as in San Francisco. But I don't get it on all of my surgery patients. In fact, I get it only on those that I think are in high-risk groups.

COMMISSIONER DESTRO. Let me just make sure I understand the definition, then, because I think this is a critical difference. "Voluntary" is basically informed consent of the patient; "routine" is the discretionary determination about whether the physician determines that it's a necessary test and it's not up to the patient. When you put "voluntary" and "routine" together, you have merged the two.

DR. DAWSON. Voluntary routine testing at a sexually transmitted disease clinic is going to be patient-specific and the information is going to be there. There can be voluntary testing at anonymous centers. If I think someone should be tested and they say they don't want to be tested, I can direct them to an anonymous testing center in our city where they are given a number, and there is no record on a computer tape.

COMMISSIONER DESTRO. I don't want to confuse the two things because I think they are getting confused. I see Dr. Burke has been kind of champing at the bit, so let me let him respond.

DR. BURKE. I think I basically agree in the terminology that Dr. Dawson offered, that is, "voluntary" implies a consent process, and usually when we say "consent process" it means signed consent rather than just oral consent. That is the standard in many jurisdictions in the United States today.

I think most practitioners of medicine prefer to practice medicine in a climate with their patient where they do make decisions, and they make decisions all the time. There are hundreds of tests and therapeutic decisions that are made with patients in which we do not insist on signed informed consent for all of those interactions. And I don't know of any physician who doesn't look forward to the day where we can practice medicine

regarding HIV in the same way we practice medicine with all other diseases. That is an objective which the medical profession really would like to see happen some day.

The problem is we can't do that as a medical profession. I can do that in the military. I can get tests on patients who are in the hospital who are active duty without having to get any informed consent. But for practitioners in the United States today, it's like if you were going to get a chest X-ray, to get a person advised of the fact that, you know, "If you get a chest X-ray you may find a little nodule and you may have to have chest surgery and you may have cancer and terrible things may happen to your life, and you may get a divorce because your wife can't stand you anymore," and get that all written down on a piece of paper—that could happen. Yet, we make a special case for HIV to do all of those things.

I understand there are concerns, and there are legitimate concerns about the issues of discrimination. There are legitimate concerns about the misuse of that information. But these are transitory. I see us within a few years—3 or 4 years—I hope this is all behind us, and that we practice medicine the way we are used to dealing with patients, in an atmosphere of respect and trust that is mutual. And I assume that's what the AMA looks forward to happening over the next few years, too.

DR. DAWSON. I agree.

COMMISSIONER DESTRO. If I can go back to the situation at your hospital, you said you had a staff protocol that indicated before you could do the testing for HIV you should have informed consent. What was the rationale behind establishing that protocol?

DR. DAWSON. Well, there's a recognition that there's a lot of fear and concern, and that the implications of a positive test are so massive in the environment in which it has to be lived out today that it could have horrendous implications in a patient's life if they turned out to have a positive. It becomes very difficult to keep that information confidential in a hospital record.

If you ordered as you order a blood test and it comes back through the computers, it can be picked off by anybody; it can be looked at by anyone. Then you have a situation where it becomes known rather quickly that an individual is HIV positive, and then all of the things that come with that.

COMMISSIONER DESTRO. Does that go to the issue of security of the computer system or the relevance of the information to the treatment decision? Because especially as it goes to the AMA's decision to recommend routine but voluntary testing at an STD clinic, it seems to me if somebody goes into an STD clinic what they want to know is whether or not they have any STDs, and if you don't do routinely the whole workup on STDs you haven't really given them an STD workup if you've left out one of them or leave it up to them—

CHAIRMAN PENDLETON. You're speaking about HIV, you mean.

DR. DAWSON. Not including HIV in the workup.

COMMISSIONER DESTRO. Assuming HIV is an STD, then you have basically said, "We'll test you for everything except this one thing, which is going to be up to you."

DR. DAWSON. What we have said—and the AMA in the report YY says in high-risk areas a staff may indeed invoke a mandatory testing policy. It is not that we are against mandatory testing. We want to see it used in the appropriate area. We have outlined the ones we think are appropriate, and that is changing every 6 months.

I would hope, as Dr. Burke has said, that we reach a point where it's just recognized that this is something we need to know and it will become routine in the VD or STD clinics that you'd include HIV testing.

Our concern now is if it were done routinely, you may find empty waiting rooms in the STD clinics, because of what happens to patients when they get a positive HIV today. It's not like having positive gonorrhea.

CHAIRMAN PENDLETON. I'm agreeing with you. That's why I want to ask one other question here. You don't need informed consent to do hepatitis B testing; right?

DR. DAWSON. That's right, we don't.

CHAIRMAN PENDLETON. And that's communicable, but that is not STD so you don't have to worry about that in terms of its public implications. Is that what you're saying?

DR. DAWSON. The personal implications to the individual.

CHAIRMAN PENDLETON. They are not as great with hepatitis B as they are with HIV.

DR. DAWSON. That's right.

CHAIRMAN PENDLETON. Therefore, there may or may not have been a fear in how you do this, but there was a social conscience on the part of the AMA, if you will, to say, "We're not going to do this in a routine way; we're going to test HIV"—I lost myself.

DR. DAWSON. We encourage the testing. We want the testing to be done. We don't want to drive the people in the environment in which a positive result frightens so many people—we don't want to drive them away. We don't want the STD clinics to be sitting there and not having any patients coming in.

COMMISSIONER DESTRO. Basically, as I understand it, the judgment has been made—again we flip back and forth between the term "mandatory" and "routine." But it seems to me you are never really going to reach the level at which the general public perceives that the medical community is just as worried about the person who doesn't have it but who may be exposed as the medical community is concerned about the person who may have it and doesn't want to know about it. The perception is that the equities all balance in favor of the impact on the person who may be HIV

positive and not necessarily on spouses or sex partners. And that is the perception I have been picking up from people that I've talked to.

DR. DAWSON. I think that is a misperception in our desire. What we are trying to do is make it so that the patients who are HIV positive are identified and the patients who are HIV negative are protected. And the balancing on when you do the testing—I hope it gets to the point where, as Dr. Burke said, I can test for HIV when I suspect or am suspicious and want to use it as a routine part, without having to get written informed consent.

But the concern in the environment today is that if the patient is not informed, you are liable to drive them underground. They will not be tested. They won't come in. So how do we protect the HIV negatives if we don't ever get at the HIV positives?

COMMISSIONER DESTRO. Dr. Burke.

DR. BURKE. I agree with your position. I think all of those concerns are very legitimate on the part of physicians who must care for patients. But the question is how did we get to this position where we have a perfectly good diagnostic test with accuracy which is unparalleled in the history of medicine, where we are as a society afraid to apply it to a devastating disease. It just doesn't make sense.

I think there are two historical routes for that. One of them is that there is this concern that HIV is casually transmitted, that you can get AIDS from your next door neighbor or that somebody can get it from their coworker, and how do we get around that? Well, I think we've made a start in our general education campaign so that people understand that it is not casually transmitted.

The second one is that somehow HIV is a unique marker of homosexuality or drug abuse, two conditions which in many parts of our society are thought to be illicit behavior, that they're frowned upon.

I think those are the two. But we know that HIV can be transmitted heterosexually, as well as homosexually or through drug abuse. It is not a unique marker of any of the conditions commonly openly criticized in our society. And we need to spend more time on that general education as well.

What I'm trying to say is there are these two misconceptions, so we have to spend a lot of time and effort in our public health education campaign, not only on methods for decreasing transmission, but on clearing up these two misconceptions so we can set the right climate so doctors can practice medicine the way we have always practiced medicine.

COMMISSIONER DESTRO. Then let me ask you: Do either of you know the extent to which insurance companies are routinely testing applicants and what kind of figures we're getting out of that?

DR. DAWSON. I know they are routinely testing, but I don't have any numbers.

COMMISSIONER DESTRO. Is there any access to those numbers, to your knowledge?

DR. DAWSON. The Health Insurance Association of America may have those numbers; they may not.

What I know is one of my sons—he and his wife just had a baby, and they would not give him more insurance until he was tested for HIV just routinely.

CHAIRMAN PENDLETON. Let me say I happened to have been riding on a plane one day with an insurance executive from Texas who was an executive for four insurance companies. And he said that they have in a sense instructed their agents in a rather stereotypical way—that is, males who were hairdressers or actors or bartenders or interior decorators—to be tested.

Now, if they turn out HIV positive, they will ask the applicant does he want the results given to his physician. And if the applicant says no, they don't transmit it.

Then I asked him, "Pretty soon you will have a registry or profile and will soon develop an actuarial table on certain men, and you started this by stereotyping, but then you'll have a computer run there of all these people by name that test seropositive, and that is dangerous."

And that bothers me.

COMMISSIONER DESTRO. The other question is: Is there any indication that coroners are doing routine testing during autopsies to see what kind of incidence—they obviously are not going to hurt anybody's civil rights in that context—to get a sense of what people are dying from. Is there any indication of that?

COMMISSIONER BUCKLEY. It's a stigma to the family.

CHAIRMAN PENDLETON. It's the same stereotype, Bob.

COMMISSIONER BUCKLEY. It's a stigma to the family.

DR. DAWSON. Again, I have no data on that, except there is legitimate concern on the part of coroners and on anyone who is doing autopsies. The same for people who do any other invasive procedures.

CHAIRMAN PENDLETON. You don't go to the morgue at Walter Reed, do you, and check on things?

DR. BURKE. I haven't for a while, but I do that fairly often on patients who expire, yes.

COMMISSIONER DESTRO. I had heard in a number of instances where doctors were getting—is there any such thing as a test that you can buy that you could just do yourself?

CHAIRMAN PENDLETON. It's not a pregnancy, Bob.

COMMISSIONER DESTRO. I understood such tests were going to be shortly available, and that doctors might decide just to do these tests on the fly for their own information.

CHAIRMAN PENDLETON. For $500 a head?

DR. BURKE. Actually, the technology has moved along very well, and there are now a number of companies that are almost ready to take to the FDA application stage a test just like that, that are home test procedures. Actually, there have been applications in California already for marketing of that kind of test.

My own view on that is that the technology is still a little premature and that we need to have a second backup, that those persons who are found to be positive should have that confirmed somehow. But it's not quite ready.

DR. DAWSON. A followup on that is I can't think of anything more devastating than to come home at the end of work and find a letter in the mail telling you you've got a fatal disease. There should be counseling.

CHAIRMAN PENDLETON. They used to call it a draft notice.

[Laughter.]

DR. DAWSON. You got a chance to live with the draft.

COMMISSIONER DESTRO. Would that lead the AMA, though, to oppose FDA certification of home tests? Because I've seen some letters from the FDA indicating that FDA may have a problem in certifying home tests for precisely that reason.

DR. DAWSON. I don't think that's a reason not to do it. We are in favor of widespread testing to identify this disease. It's just to be aware that this is one of the side effects that needs to be dealt with.

CHAIRMAN PENDLETON. We have one last question from Ms. Prado.

MS. PRADO. You mentioned contact tracing in your statement YY, and I was looking through it because we have an interest in contact tracing, how you see it in the context of your position on testing. I really couldn't discern where or how you see contact tracing being used.

Can you clarify for me your position on that?

DR. DAWSON. Well, it is vague at this point in time and it does need to be clarified more. And we have recognized that, for example, in Colorado, they have had rather aggressive contact tracing, and in some areas it's virtually forbidden by law you can't really follow up on some of this.

MS. PRADO. What area is that in?

DR. DAWSON. Well, you can't disclose information in some areas, even to notifying a spouse. It is difficult to trace things through contacts if you are not allowed to mention that someone is positive.

MS. PRADO. What has the Colorado experience been?

DR. DAWSON. I can't give you the numbers on Colorado, but—

MS. PRADO. Can you provide this for the record?

DR. DAWSON. —I can get the Colorado experience update for you, both a summary of what their rules are and how it's worked. I know they are the most aggressive on contact tracing in the country.

CHAIRMAN PENDLETON. Gentlemen, as we conclude, I just want to mention this. My colleague, Commissioner Buckley, has some good information here. I'd like to add into the record the *AIDS Weekly*

Surveillance Report from the Centers for Disease Control of May 2 gives us some indication as to how the disease is being followed.

But even more interesting here is a booklet, a supplement, Volume 36, No. 1–S, from the Centers for Disease Control, October 14, 1987, and it is their morbidity and mortality weekly report.

There is a listing of indicator diseases here. I guess the part that alarmed us says, "Without laboratory evidence regarding HIV infection"—we have a whole list of indicators here that indicate that AIDS, if it was, diagnosed by the definitive methods below, means you have AIDS but you could test HIV negative, inconclusive.

I guess my point is that when we say testing for AIDS, the question becomes: For what are we testing? And it's not just one test for one indicator. There are a whole series of deficiencies. Is that correct, Doctor?

DR. BURKE. No.

CHAIRMAN PENDLETON. What are we testing for?

DR. BURKE. When we test, we do not test for AIDS. We test for infection with HIV, the virus.

CHAIRMAN PENDLETON. That's what I wanted in the record.

DR. BURKE. I think this is an extremely important point. When we talk about AIDS, AIDS is just when you get infected with something else, when you've already had HIV for a long time and it has wrecked your immune system. So all of these other conditions are just indirect markers. Frankly, I don't like that definition of AIDS. I think it's not a very good definition. I think we are not interested in AIDS. We are interested in people with HIV infection who have wrecked immune systems.

CHAIRMAN PENDLETON. I wasn't challenging that. I was just trying to say I wanted it in the record but I wanted to be able to ask—you have already answered the question I wanted to ask you.

DR. BURKE. I'm glad to get it in the record for you, sir.

CHAIRMAN PENDLETON. Because that's important to understand. You can't get that unless you have something else. So we're talking about people who are seropositive, not so much people that have full-blown AIDS.

DR. BURKE. That's correct.

COMMISSIONER DESTRO. But you're interested in people who have HIV, whether or not their immune systems are wrecked.

DR. BURKE. That's the whole point. If we wait until the people are ill, those are people that became infected 5 or 10 years ago, and they have been continuing to transmit the infection for 5 or 10 years. So if we just focus on AIDS, the whole effort is doomed to failure—absolutely. And we need to change our whole psychology in dealing with this disease.

CHAIRMAN PENDLETON. We have one more question from Commissioner Buckley.

COMMISSIONER BUCKLEY. I don't know if you can answer this for me or not, but in looking at Dr. Fauci's slides yesterday, can you tell me is AZT specific for the transcriptase involved in HIV, or can we not make it that specific? Is it specific for that particular transcriptase, do you know? I'm concerned about what effect it would have on the other body cells.

DR. BURKE. It is very specific for that enzyme compared to cellular enzymes. But like any other drug, if you give it in a high enough concentration, it can influence other host enzymes, and particularly some of the other DNA polymerases. And in fact some of the toxicities that are run into when you give somebody AZT in high dose for a long time are due to effects on other hosts' cellular enzymes.

COMMISSIONER BUCKLEY. Thank you.

CHAIRMAN PENDLETON. We'll take a 10-minute break and give our recorder a break, and then go to the next panel.

Thank you very much, gentlemen.

[Recess.]

CHAIRMAN PENDLETON. Our final panel for the day involves seropositive children in school.

We have Dr. Allan Morrison, Jr., M.D., from Arlington Hospital.

DR. MORRISON. Actually from Fairfax Hospital, but that's okay.

CHAIRMAN PENDLETON. What's the difference? Is it a big difference?

DR. MORRISON. A huge difference.

CHAIRMAN PENDLETON. And Steve Weitzman, Esq., from the Americans for a Sound AIDS Policy in Fairfax.

Would you gentlemen please stand and be sworn in.

[Allan Morrison, Jr. and Steve Weitzman were sworn.]

Panel VIII: Seropositive Children in Schools

TESTIMONY OF STEVE WEITZMAN, ESQ., AMERICANS FOR A SOUND AIDS POLICY, FAIRFAX, VIRGINIA

CHAIRMAN PENDLETON. Who wants to go first?

DR. MORRISON. I have no prepared statement.

CHAIRMAN PENDLETON. You can still go first. It doesn't matter. Do you want to go first?

Mr. Weitzman, go right ahead.

MR. WEITZMAN. I did not intend, nor will I, read this lengthy statement. I do want to make one change in there. There was some mistyping on the numbers of children identified as 13 and under. You have the MMWR statistics.

CHAIRMAN PENDLETON. Which page?

MR. WEITZMAN. It's on page 3. There are approximately 950 cases of children under 13 years old with ARC or AIDS, of which 500 have died. The projections are that there are 10 to 30 times as many children who are

HIV positive, but those are projections and we don't have hard data, and then the projects depend on who you talk to.

CHAIRMAN PENDLETON. Page 3?

MR. WEITZMAN. If I may start and give you the central focus of this paper, my concerns, as your concerns, are civil rights concerns. I think in the area of civil rights this AIDS issue is rather unique. It is not simply a situation between an employer and an employee, as it has been for the most part in discrimination—a child and the school. There are other children. There are third parties who will be affected by the decision. So that considerations here can be distinguished from considerations in the normal Title VII discrimination case. That's one thing. You've got to focus on the effect on that third party and that third party's rights, and I address that.

The other thing is I believe the commotion that has arisen in the schools revolving around AIDS has been problems of formulation of public policy and teaching that policy to ordinary people.

At the end of my paper, I address the District 27 case, which is Queens, New York. This is after the judge rendered an opinion stating that the child or children should be allowed in the school. The judge goes on with a very strange thing for a judge, and that's to issue his own commentary. He said, "From the outset it was clear that the respondents operated with a notion that they knew"—that's the government officials—"what was best and would make all necessary decisions for everyone's good. Believing this, they acted in an imperious way, accepted little by way of inquiry, and no criticism."

Let me skip to page 26—well, let me go on.

The above statement by a court is an unusual criticism of the executive branch, in this case New York City. As the court makes clear, city officials acting within the bounds of the law does not mean that the officials were without fault when they, as public officials, are responsible for much of the controversy over AIDS policy while their job is to limit or eliminate that controversy.

In criticizing the position taken on confidentiality, which I'll talk about in terms of privacy issues, which banned even a school from knowing it had an infected child, as missing the spirit of the law, the court pointed out that in our system of government, where officials govern at the consent of the individual, decisionmaking needs to be open. The public has a right to know. Where is Ralph Nader?

The court next attacked the claim that confidentiality was necessary to prevent panic, saying that excuse was not supported by any evidence. Indeed, the exercise of constitutional rights to protect cannot be classed as panic. That's the third parties concerned about their children.

"In the ultimate, the conduct of the petitioners"—which is the Queens' parents—"and their constituents disprove the mistaken notion of the respondents that the people cannot be trusted with the information they

need to know and make reasonable judgments. Instead of educating and inspiring confidence and trust of the public, respondents left them frustrated and hostile in the face of such an emotionally charged issue. It is these public officials that unwittingly let loose the forces of anxiety and fear. In a democracy, unanimity is never expected. However, open forthright conduct by public officials should avoid much of the distress and acrimony which surrounds this litigation."

Now, I'm not advocating that the names of the children should be disclosed or identified in any way. That part of the data can be left out. But in formulation of public policy—this is Judge Harold Heiman in New York City—it is quite amazing for a judge to make this kind of observation. But it is at the core of the problems which are addressed everywhere.

On medical—and we have our medical science, our medical judgment. That is the process by which we can make a decision on a public health basis. This is a public health issue. We have information in terms of the science on what we have observed from the epidemiology. We have information from the science to the extent that we have been able to examine the behavior of this virus. We then have medical judgment. And medical judgment is supposed to be advisory. It's okay.

Now, given this information, do we have a red or blue litmus test? The answer is no. Do we have an opinion? Yes, we have an opinion, that it is very unlikely, it is almost impossible, to define transmission by the vectors that have been discussed in the school environment. There's a very limited risk.

The next step in the process should be the government, the representative of the public, assessing that process, assessing that risk and its willingness to take or not take that level of risk. There are guidelines that can't be totally irrational or arbitrary, motivated by some other purpose.

But the policymaking belongs to the generalist. He makes the final decision. He has all his advisors. We are not a government that has turned over policymaking at the ultimate to the experts. The experts advise; they serve staff functions in every line of government. But it is the chief executive officer's assigned official, who may or may not be a scientist but he's got a different role—he's addressing the whole area of risk. Now, he may have guidance from a legislature, or he may have authority to set law as to what is or is not an acceptable risk.

That is one of the things that I do not find being isolated in the process so that people can see that it isn't somebody who knows it all who is making the decision for me and my child. The democratic process is at work. We're using the best available information to arrive at the correct result.

My feeling is that if more process—and I'll talk about where I think process needs some improvement in this democracy theory of mine, although it's been around for a long time—it is to open up so people can

view. And let me direct that. The confrontations in the school systems that we have seen have involved situations where school boards made a determination without any general guidance from their State health authorities, or the general guidance was prepared, as in the Patterson case in New Jersey, without the Administrative Procedure Act.

Now, I don't advocate the Administrative Procedure Act as something that is going to solve all problems. But I think the administrative procedure of 503 rulemaking notice and comment is at minimum a due process right, a substantive due process right in this country, that you should have an opportunity to participate, to present questions, and that even the silliest and most stupid question would be answered, not turned away.

And I think that in New Jersey the judge threw out the State policy which copied the CDC and said, no, you had to follow the Administrative Procedure Act in New Jersey, which is much like the Administrative Procedure Act of the United States.

So for overall guidance, we need this policy, this law, this statement of the acceptable risk, or guidance to follow up as the risk progresses, if the child deteriorates or doesn't deteriorate. It is totally part of the process, and that's got to be implemented everywhere. On hindsight we can now be perfect. I would implore all States and all school systems to get that kind of policy.

The next question comes up about the individual decision on an individual child. I think that clearly school systems have to have some kind of notification somewhere that they have an HIV child situation and that they act accordingly in terms of not only the views of others but the child, to make sure that the child is being properly attended to by the public health authorities or their own physician—things of concern for the child.

I think much of the discussion which relates to transmission has become a stalking-horse in a sense—you know, something we're past. The things I'm most concerned with are the health of the child as the child deteriorates; and when they get or possibly can get other diseases which may be transmittable to other children, I think the confidentiality has to be absolutely protected. I think there are a whole series of questions on which there is banter back and forth, and I only add to it, as to why there should be disclosure to the school itself, which I think the school should know and should be able to be part of that decisionmaking and supervision process of the child—questions of whether the teacher should know, the nurse should know.

I understand but I am not at this point weighing in, as Dr. Dawson pointed out that the AMA apparently did—you know, they came up with the science and they looked at the social concerns and made a decision. I think the social concerns you can make as public policymakers against that, but I think the school needs to know and, like I said, other people need to know to protect that child, whatever special precautions—you know, the

child has to have his medicine—and be on notice to really do their jobs, because they are for 6 or 9 hours, depending on the setting, the substitute parent, and they have that responsibility just like a parent.

In many situations, knowledge of a seropositive child comes as a consequence because many doctors are recommending that the children not be given vaccines with live viruses in some situations, so the child may have to skip a vaccination and that might be noted.

I find it insidious and dangerous when you're surprised when somebody finds out that that child has it and it can cause public pandemonium. I would much rather see an orderly process that says, "Oh, we know about it; we're taking care of it; we're doing everything responsibly and everyone is okay. There is no danger to your children, and this child is protected."

I may be accused of thinking of a utopian situation, but I don't think that's at all probable.

I think this has to be routine. It is not something special; it's usual; it's an orderly process.

Now, part of the frustration, as I mentioned, is what happens after a school decides that that child presents no problem, it is not going to be any problem to any other child, and that they are properly being medically attended to. Suppose somebody should disagree?

I think in this process we are not like those other discrimination laws. There is a third party or third parties involved.

I question whether they should not be allowed to obtain medical records, anonymous—everything taken out as to names—so they can go and get a second opinion from somebody in infectious disease that they know if they don't understand this whole thing, and that they are attended to. I think the process of educating parents cannot stop with one school board meeting one night. Hopefully the public policy process has gotten a lot of this aired. But I don't think we can give up in this area on people who still may not understand.

Certainly we can't exhaust all resources because of one person. But this is a difficult area to understand, even though all of us with graduate degrees in this area—there are lots of doctors that don't understand it, that don't have the expertise that Dr. Morrison would have. And they would consult with Dr. Morrison in their own patient situation on how to treat somebody with HIV or AIDS or ARC.

So I don't think that there is anything insidious about the parent going away feeling unanswered. And sometimes doctors who aren't particular experts in the area may get a question, and instead of saying, "I've got to defer that question tonight and get back to you," somebody likes to pop a quick answer and give absolute assurances—we're learning there aren't absolute assurances in this area.

I think there, in terms of responsibility, those parents who still question it should be worked with so they understand why the decision is made, how it is made, and learn a little more about the nature of this disease. It can't harm them, and certainly eventually we will all be networked together on the subject of AIDS, and we'll be communicating to each other back and forth the correct views on the subject of AIDS.

Let me raise an irony on the CDC guidelines. In the *Arline* case, which you discussed this morning, there's a footnote that mentions deference to medical authorities, I think the court's view there in terms of deference, it's deference on the four AMA questions and the answers thereto. Also a fifth question, which I asked Mr. Silverstein about, as to the quality of the data on which the decision is made. I think you have to have a statement that this is absolute data, what kind of data, what's the quality of the data we're dealing with in making that decision.

In a case out in California, the *Thomas* case, which is in the footnote, the CDC guidelines relating to biting, where CDC on two other associations had made a judgment call that said that if a child is aggressive against other children, that child ought to be examined and may not be suitable for an ordinary classroom situation.

The judge in that case challenged the policies for a lack of presentation of the underlying scientific basis for them. But that was a judgment call—it's the best judgment call being made by our authorities—whereas in all the other cases it seems the CDC guidelines are most closely watched.

In the Ray case, the Ray case has an exhaustive order on viewing the children and noting, too, that the children have been given adult responsibilities in terms of their behavior.

So I mention that as an irony. The courts even haven't settled on what medical information or medical judgment we're going to rely on. And in this whole area, the whole global area if you step back, everything is some kind of risk-based analysis. What is the risk? What is the level of risk? When are you at the 5-yard line, the 3-yard line, the 1-yard line? When do you punt? It's all judgment calls.

CHAIRMAN PENDLETON. Could you kind of wrap up for us?

MR. WEITZMAN. Yes, I'm wrapping up on that point. I think the public has to participate in a very open process. I'd love to see the CDC guidelines opened up for comment and question, and then again the public will do the right thing. I'm very confident of that.

CHAIRMAN PENDLETON. Dr. Morrison.

TESTIMONY OF ALLAN MORRISON, JR., M.D., FAIRFAX HOSPITAL

DR. MORRISON. For the record, I am Chairman of Infection Control at Fairfax Hospital and Reston Hospital and in private practice of infectious diseases in the northern Virginia area. Our group recently served as the

medical advisors to the Fairfax County School Board Commission's Special Commission on AIDS Policy and Education in the Schools. So our practice comprises a tremendous burden, increasing burden, and volume load of HIV-infected individuals, and we have been active in the community in that capacity as well.

I think just a couple of straightforward comments will easily summarize my position on this issue.

First and foremost, although we have learned volumes about HIV since the advent of this epidemic in the early '80s, we really have learned very little, if anything, new about its modes of transmission. I think the transmission modes are well-known; they are well-described and they have been exhaustively studied.

I believe that the modes of transmission do not support excluding HIV-positive children from schools. I think the educational process in our country is mandated by law. It is compulsory, and I think the greater good has been served by that position and stance, and I think that HIV seropositivity should not alter that mandate to the Nation.

I think there is no compelling medical, social, or any other type of evidence to support the removal of an HIV-infected child from school a priori simply because of the presence of that infection. I think that a medical review process is an appropriate way to assess cases on an individual basis, but that does not preclude the child from continuing his or her matriculation in that context.

With regard to Mr. Weitzman's comments, he did indicate that it is almost impossible to find cases of transmission that might subscribe to the methods that are speculated about in schools—for instance, biting, kicking, scratching, urination, and the like. I would make a stronger statement and say that there is no evidence, and I know of no cases that have been compellingly produced to support that notion.

With regard to our personal experience in our group in the State of Virginia, we have been educated personally by virtue of the resurrection of the original law regarding contagion and diseases, and what that law tells us in the State of Virginia, in any event, is that removal of children from schools will occur with any infectious disease or condition which may be transmitted by an infectious route.

Well, all of us who are parents would then conclude that schoolrooms would be empty a good portion of the year, colds and sore throats and ear infections being what they are.

The point I am making, though, is that the laws were designed at a time—at least on a State level, and there is some analogy between States, in other words—that those laws were devised at a time when true concerns about tuberculosis and about infections in the preantibiotic era held much more strength in protecting fellow schoolmates from potentially lethal diseases for which there was no therapy.

You might make the same argument about HIV, but again I think we could discuss that on the basis of scientific evidence.

Then, finally, my final comment really, is that I have heard much from concerned parents and citizens about this issue of children who are HIV infected needing to be protected from other children as a justification for removal from the school environment.

Medical science has allowed for the extended survival of children who have a broad range of immune-deficient states, such as leukemia, such as congenital immune-deficient states, lupus, diabetes—a wide variety of immune-deficient states, all clearly immune-deficient states, many of whom are on chemotherapeutications, steroids, and other conditions, whose immunologic defect mimics the potential risk that is seen in the HIV-infected person.

The point I'm making is that unless we are going to view this similarly, and unless we will remove children with any immune-deficient state, I think it is imprudent to single out from the pack the HIV-infected child for special consideration.

With that I will conclude.

CHAIRMAN PENDLETON. Counsel.

MR. FUMENTO. Dr. Morrison, you spoke on the possibility of HIV transmission. Let's assume that the risk of transmission in school is low but that it's not zero. How would you reply to the parent who says he doesn't care how low the risk of transmission is, that so long as it's anything above zero he doesn't think his children should be in class with a seropositive child?

DR. MORRISON. The risk of transmission of HIV in the school environment, I believe, needs to be evaluated in the medical context. If you are saying that you have fear as a parent that an HIV-infected child will have sex with your child or share needles with your child, then I would concur that there is a theoretic risk.

To say that incidental contact with an HIV-infected child poses a risk, I would argue that the medical evidence does not support that claim, and I would dispatch the question.

MR. HOWARD. Dr. Morrison, you made a reference to your favoring the attendance of HIV-positive children in school but that they should be medically screened on a regular basis. Did I hear you say something to that effect?

DR. MORRISON. My comment was that I am in favor of HIV-infected children being followed and evaluated longitudinally by their personal physicians for conditions which might situationally preclude them from matriculating safely. They may be too sick to be in a classroom, just like a child with a severe croup may be too sick to be in school.

I want to make two points clearly. I think the medical evaluation can be ongoing without excluding the child, and that periodic review of a child's

condition might be appropriate, but I would view that as a jurisdictional issue, not as a matter of public policy issue. In other words, the health department, in liaison with a school system, may suggest or urge that medical review could occur, but I would view that as truly something that should be decided at a local jurisdiction and not as a matter of public policy.

MR. FUMENTO. Mr. Weitzman, you covered so much ground in your testimony that I'd like to narrow it down to a few points.

Could you be more definite in your policy proposal? Let me ask a series of short questions.

First of all, should asymptomatic seropositive children be allowed in schools, and under what conditions?

Second, should children with AIDS or ARC be allowed in schools?

Third, who should be informed of that child's seropositive status if he is asymptomatic?

And, finally, do you believe there is a real possibility, however small, of HIV transmission in a school setting?

MR. WEITZMAN. Would you go down them one by one and I'll give you an answer on it?

MR. FUMENTO. Should asymptomatic seropositive children be allowed in schools?

MR. WEITZMAN. I believe the policy of the school should be to be notified—it goes to this—and then reviewed. The child should not be stopped from going in, but I think the review should be noticed when it's discovered, if it's discovered during the school year or before the school year—consultation with the personal physician between the public health authority that works with the school system, so you can get an initial idea of what's there. And then somebody can say, "Well, we think this child should be excluded for such and such," and then a procedure can go in place.

I think I agree with Dr. Morrison. First, presumptively that child is probably going to be allowed to go into school, and the administrative process has got to be shaped to move quickly on that initial decisionmaking level.

MR. FUMENTO. Isn't that already the case, though?

MR. WEITZMAN. I don't know right now how far all school systems have gone to adopt policies properly under their State laws. I suspect they have not gone through proper procedure and proper involvement. We were affected here in Fairfax County in what might probably be a typical situation where all of a sudden somebody finds out during part of the school year that some child is now entering the class who's got HIV, and it's the worst situation they can possibly have.

And then, following that, going through the process of excluding the child—I don't think it was called for in that sense.

MR. FUMENTO. Why would a child ever be excluded?

MR. WEITZMAN. The only time I would envision a child ever being excluded is when there was serious enough illness involved or serious enough deterioration that the child might have become a danger. I think you've got to look at the CDC guidelines, and I would defer that back to the doctors rather than me as to when would there be some justification of keeping the child out of the school environment.

MR. FUMENTO. The child being, if the child is seriously ill, a danger to himself or herself or to other children?

MR. WEITZMAN. That's the case for all children. But the basic thing is a public policy decision on risk-taking, and that needs to be articulated by the person who makes the law for that jurisdiction. And he will be informed of the risks. Then they make the decision based on that information, and then set up a screening procedure for children.

MR. FUMENTO. With a child who has AIDS or ARC everybody knows about it, but presumably most of these children would be asymptomatic. Who should be informed? The nurse of the school? Should the principal be informed? The teacher? Somebody in the school system above the school?

MR. WEITZMAN. If you treat each situation at a different level, I think the school authority, through their public health person, should know. I think that is clearly necessary. The school board is part of policymaking as far as children are being screened for a variety of issues and they carry the responsibility of the school system in toto. I just don't see how you exclude part of our governmental process from at least knowing. You can preserve identity. You can tell them the nature of the facts. I think preserving identity is readily done in these situations.

MR. FUMENTO. So in other words, somebody in such and such a class is seropositive but we're not going to go beyond that?

MR. WEITZMAN. Well, first you have to determine: Is it notification only at the school level? Then you go: Is it notification in the individual classroom? And I think judgment calls have to be made on why does the teacher need to know and why doesn't the teacher need to know? What could a teacher do to help by knowing, and what would the teacher not do by knowing?

That, again, is a public policy choice. But I think that the teacher knowing the child—although everyone says, "Well, you follow the same procedures in cleaning up spills and things like that"—sure. In a 30-child room in New York City, everything is going to be called to a halt every time somebody scratches or there are bloody noses or something like that. The realism of setting priorities for the teacher as to what she is going to worry about or not worry about are not being taken into consideration in a real world sense. If she knows Johnny has a problem and something like that happens, then she is alert to that. But she's got 50 things going on in

her mind. I think she ought to know and she should be cued to react to that situation.

MR. FUMENTO. The only problem might be that if she knows Johnny is seropositive, then there's a good chance that other people are going to find out, and you know what happens then.

MR. WEITZMAN. The awful thing in this is the cutting back that we're doing because of what we are afraid of happening and the stigma. That's a consideration that the society has got to make as a judgment call on that issue up and down.

My thesis is that that has not been made by the government democracy in our system. It's been made by our experts, and you should probably listen to them. I don't agree that we should heed them. I think you've got to make that decision as a public policy decisionmaker of the government, and you'll make the right one. I have no doubts we'll make the right decision—isolated.

MR. FUMENTO. Dr. Morrison, what do you think is the right decision as to who, if anybody, should be notified of an asymptomatic child's seropositive status?

DR. MORRISON. I believe the decision rests first and foremost with the child and the child's physician. That exclusive relationship, which is a medical and a legal relationship, must be kept in the firmest focus, and around that any other policy decision should be made.

I think there is a dangerous precedent when one begins to presuppose that the knowledge of HIV seropositivity in a child will be blithely translated into equal treatment in the classroom, equal treatment on the playground, equal treatment of the parents of that child. And I really believe that the civil rights of that child will be compromised unnecessarily because the basic elemental question is, as Mr. Weitzman clearly delineates, the issue of risk.

As I said, if the child is having sex with another child or is sharing needles with another child or is donating blood through some bizarre ritual with another child—and I suppose in the United States there is room for that happening as well—then those instances translate into real risk, unacceptable risk.

But if you talk about incidental transmission, then I think the risk has yet to ever be proven, and I think that the confidentiality issue is the number one concern of a physician treating just such a group of patients.

So I believe that notification, if it is in the interests of the child, agreed to beforehand by the child if the child is old enough to participate in the process, by the child's parents or legal guardian, and the child's physician—that if those elements have in agreement decided that a notification process should occur, then I think it should. Because the contrapositive issue is that an assumption will be made that if you don't know an individual is HIV positive, then they are not. And I think that is

equally a dangerous assumption for a teacher in a classroom in New York City or any other place in the country.

So with regard to events that occur in a classroom, and the classic scenario is—and we all remember it from our childhood—Johnny punches Billy in the nose. Billy has a bloody nose. Ed, who is an altruistic fellow student, takes a Kleenex to the nose of the child who is bleeding and says, "Come to the school nurse"—then I think what needs to occur in our society is education, and education reduces fear. And education in the classroom, which is still going on right now as we speak, can direct itself towards how to deal with those issues.

The thing I like about that approach specifically is that, in addition to HIV questions, it also deals with other blood-borne-transmission diseases, such as hepatitis B and cytomegalovirus, for instance, which has tremendous morbidity, mortality in the community as well, and is also transmitted by the same route.

So from a hygienic standpoint, I think we enhance dealing with the playground scenario, and I think that the worst-case-scenario fear of the parents of the child can be managed by education in the classroom as well as in the community.

So I do not think, in other words, that notification of the teacher or of the school system should be an automatic event. It should be medically arrived at by the principal parties.

MR. FUMENTO. You're saying when it comes to nosebleeds we treat everybody as if they're seropositive and when it comes to how we treat them as persons we treat everybody as if they're seronegative?

DR. MORRISON. It's a difficult point. The CDC is probably within 2 weeks of modifying universal precautions—and you're all very familiar with the tenets of that proposition. The purpose of modification of those universal precautions is to narrow the scope of concern specifically. Unless the document I have been privy to see in draft form is going to be chopped, urine and feces will be eliminated from the list of risks. Why? Because, again, we find no evidence that those—although you could theoretically culture the virus from those body sites, we find no evidence that that is a true mode of transmission. So education can allow us to modify our level of fear and concern, and by amplifying that education I think the population at large can learn from that and modify their behavior.

I do believe that children should be taught not to get their hands soaked in blood. Yes, I do believe that. But I think it's at least as much from a general hygiene standpoint as from an HIV standpoint. And I have the bias of being involved and responsible for policy in hospitals where blood spills and exposures are a far more morbid event. A needle stick that goes deep into your arm is quite different than a bit of blood on a Kleenex. And we

don't know that transcutaneous blood through the skin is a mode of transmission of this virus. That has not been shown.

MR. FUMENTO. I'm not going to ask any new questions, but I'll give Mr. Weitzman a chance to reply.

MR. WEITZMAN. The question is—can be posed in terms of notification—can something come out of the notification to the benefit of the health of all the children. I don't think it should be idly dismissed, and I don't think there is any legal basis for saying that if there is some health benefit with the notification you don't do it automatically. I think the policymaker then has to make the policy decision, and he has to say, "I'm going to make sure the teachers don't disclose," or takes stern measures in that area, or puts sanctions on confidentiality of the information on the individual—you know, that's the test, whether it is: Do I do routine testing? Do I do mandatory testing? You've got to weigh it. Will it medically help? That's the first question that's got to be on the table. And it will medically help to such and such an extent, a lot or a little, so much.

Then you can go on as a policymaker to weigh the countervailing issues that the child's civil rights are known in the community and things like that, and hopefully the stigma will go away, which has been attached to this disease for most unfortunate reasons.

MR. FUMENTO. Thank you.

CHAIRMAN PENDLETON. Commissioner Destro.

COMMISSIONER DESTRO. I'd like to ask Dr. Morrison: The testimony has focused up to this point on elementary school kids. The trend in high schools of late, and a lot of controversy—in Alexandria and other places, in Boston and other cities—has been with respect to the establishment of school-based clinics for contraception and sexually transmitted diseases.

Now, looking at the high school population, would your analysis change with respect to information about seropositive high school kids if the assumption which underlies school-based contraceptive clinics is that high school kids, by and large, are sexually active or there's a lot of sexual activity going on, which would justify the establishment of a clinic. Wouldn't that also support the knowledge by school authorities that one of the kids may have HIV infection? Because then you really are dealing with risks that there is sexual activity going on, which is a more realistic assumption in a high school.

DR. MORRISON. Well, that is obviously a much more subtle question and I think a much more important question. But I think, again, the transference of medical information to a populace, to a budding sexually active population of high school students regarding appropriate sexual practices, whatever that is defined as being, and regarding appropriate barrier techniques for prevention of pregnancy and other sexually transmitted diseases, would focus obviously on those methods which I

teach my HIV-positive patients to engage in if they decide they are still going to be sexually active.

So I guess I have a model in my own practice for the type of activity you are suggesting.

I do not believe that the knowledge that an individual is HIV positive alters their decision to be or not to be sexually active. At least one cannot suppose that. Certainly in practice it is indeed true, and unfortunately it is true at both ends of the spectrum.

COMMISSIONER DESTRO. Let me stop you right there and make sure the record is clear. What is indeed true? That they do not modify their sexual behavior or what?

DR. MORRISON. I would say the vast majority of people become asexual, at least with regards to intercourse, anal or vaginal intercourse, or sexual interaction that might result in significant transmission behaviors. But there is that small segment that become hypersexual, if you will, who have decided, pedal to the metal, that they are going out and they're going to engage in sexual behaviors that will place potentially a large population at risk.

The point of your question, though, was: Should the knowledge of HIV seropositivity in a teenager alter the efficacy of a sex education program or a teenage pregnancy counseling program or an STD prevention program? And I think the school system, as an educational body, will not prevent, will not alter, nor will the child be altered by a foreknowledge of HIV positivity in the child. That child will still be sexually active if they're going to be sexually active, and I think they will only be benefitted by the knowledge that the school system would provide, because the barrier methods that would be taught or the consciousness raising or the ethical or moral issues that might be addressed might prevent an event.

COMMISSIONER DESTRO. Let me continue with it.

I'm sorry, go ahead.

DR. MORRISON. One other comment. I don't think the providing or withholding of educational material through a school system is going to alter ultimately the decision in the back seat of a car or wherever that that individual is going to be sexually active today.

COMMISSIONER DESTRO. No, don't misunderstand my question, because it really goes to the issue—again I hate to use the analogy that I used this morning with the employment contacts. But most of the studies that I have seen with respect to teenage sexual activity is that teenagers are pretty notoriously unreliable with respect to being effective at effective contraception.

CHAIRMAN PENDLETON. Why are we being so nice about the wording here? Why don't we just talk about it like it is? Just face it. At one time we talked about not having teen child care centers in high schools. Now we have child care centers in high schools, and in Washington, D.C., now

they have room for 40 kids in the junior high schools and they're looking for more room.

Obviously people are being very active. And as the *Wall Street Journal* said, in south central Los Angeles teenage pregnancy for young women is a right of passage. It's not taboo. So we're not kidding anybody about this point about whether or not there are going to be some things going on with teenagers. All of us understand that when the sap starts to run it's very difficult to turn it off. And teenagers are going to be very active in things, and they are very active.

So with that kind of activity, and with the fact that we have a high dropout rate and a high absentee rate in schools, they're not going to school every day, and they might not have gotten that at school. They might have gotten that someplace else. The young kids are doing all kinds of things these days.

I don't want us to be kind with this business about sexually transmitted diseases and this business about barriers. There are not many barriers left at many schools that we talked about in California as well as New York where this problem is extremely prevalent. And I raised the point yesterday: What do we do about teenagers in the correctional institutions? I mean there are a lot of things going on here which can also be called school to some extent. But I submit to you there are not many barriers.

COMMISSIONER DESTRO. Make sure that you don't misunderstand the thrust of this question, though, that like the prison situation where the prisoner we talked to yesterday said the authorities know, and I think school authorities know or tend to know, because people know through the grapevine, who the irresponsible ones are. The kids certainly know who is hanging around with whom and who is sleeping with whom. That is something we knew when we were in high school.

And the question really doesn't go so much to the impact on the person who is HIV seropositive, but it's the potential duty to warn the partner who may be. And that certainly is going to have a negative impact on the person who is HIV seropositive. But if they're having sex with somebody, I don't care whether they're using barrier methods or not, that is something that the other partner has the right to know about, and I think the courts are beginning to enforce that right.

So this is really the question I'm going to, in terms of the potential duty to warn the sex partner in a situation where there is an observed sexual activity by the school authority.

CHAIRMAN PENDLETON. We're going to take about 8 more minutes with this discussion.

COMMISSIONER DESTRO. I'm done after this one.

DR. MORRISON. I am reminded of an event, which I think is analogous in answering. When I was in training in Atlanta, rounding on a young man who has AIDS who was a bartender at a very prominent Peach Street bar,

and who had a bevy of women in his room every night, and he was bisexual. They brought him flowers, and more often than not in rounding in the evening I would find him engaged in sexual activity with these women in bed, and I would routinely drag them into the hallway and ask them if they had any idea what they were doing, and their response was, "I can't get that. I'm not gay."

The point I'm making is I do not believe the specific knowledge of specific seropositivity will alter in any way, as you say, when the sap starts to rise—I don't think it will alter it.

CHAIRMAN PENDLETON. Run, not rise.

[Laughter.]

DR. MORRISON. Run, rise, or flow.

The point is that if education in a broader context is hammered home again and again and again, that is the message. And I think that is the way to approach it, not on specific levels. Because all you will need is one example of a false positive test, one false positive test with a search for partners that ends up all of a sudden saying, "Time out, we made a mistake. This is not a true positive. This was a false positive test," and you'll have a horrendous situation on your hands. And I think that's the worst-case scenario to me.

MR. WEITZMAN. If I could just comment on that to the Civil Rights Commission. I think one of the primary civil rights is the right to life. I don't think there is any dispute about that. I think in the public area there has been a great neglect of a review of the *Jacobson* v. *Massachusetts* decision of 1905 by Justice Harlan. In there he talks about the rights of society versus the rights of the individual, and I think it should be consulted.

In the context of your hearings, do I have a civil right to be informed if you know that you are HIV positive? I think I do. I think it's a civil right, and I think it's a due process right.

COMMISSIONER DESTRO. That's the point I was trying to make with respect to the growing case law about duty to warn with respect to tort cases. The question in my mind boils down to warning in advance or payment afterwards, but with HIV payment afterwards it's too late. You've already been condemned to death with an HIV infection. The concern is really how do you balance those things off.

I agree with Dr. Morrison entirely that the real way you avoid it is just to be careful—not only to be careful, but at least with respect to high school students perhaps not to have sex at all. But that is not something that high school students generally want to hear about.

CHAIRMAN PENDLETON. You know, at one time if you had syphilis or gonorrhea you had a card; you had to carry a card around.

MR. WEITZMAN. I'm not familiar with that.

CHAIRMAN PENDLETON. I remember you had you to carry a card around if you had syphilis. There was a registry.

DR. MORRISON. Right.

CHAIRMAN PENDLETON. But perhaps now you need to be keeping score cards. I mean you give your score card off to somebody and see where you really are, whether you are or are not.

DR. MORRISON. I would hate to see the day when we would have an honor roll and an AIDS roll in schools.

CHAIRMAN PENDLETON. I'll tell you what, it might not be up on the wall, but I'll bet they're there.

COMMISSIONER DESTRO. That lies underneath most of the concern, and it is certainly a valid one. As the prisoners indicated, if the word gets out, people know and people will react. And there really was some ambivalence, even in the prisoner's testimony, with respect to whether they want to know or they ought to know. And I don't think people have really reached a firm conclusion as to which way it is. But I agree with you entirely, that the results could be devastating, but they could be devastating on either side of the equation.

DR. MORRISON. You give a double message to a child who is at a critical point in their sexual development. You say on the one hand, "This person is known to be positive; stay away." On the other hand, the flip side of that is, "If you don't know about this other person, it's okay."

And I think the educational tool is to say, "You make sexual choices, you make sexual decisions, you take sexual responsibility for your acts," and that that has to be placed in the context of Billy begat Freddie who begat Sally who begat Billy and on down the road of all the sexual contacts that have occurred. And to presume that that person has never been in the sexual chain of HIV exposure is an imprudent decision. So the selection process has to be based on an appreciation for the possibility that anyone with whom you sleep has HIV positivity.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I wanted to get back to Mr. Weitzman. I was confused in what you were using as your definition of a child who is either seropositive or has AIDS. What is the definition you use?

MR. WEITZMAN. No, we're talking about seropositive children in school—well, we're talking about both—just has HIV, has no apparent symptoms, has not reached any of the AIDS-related complex stage.

COMMISSIONER BUCKLEY. Are you using the current definition of HIV infection in children under 13 as your guide?

MR. WEITZMAN. Yes, that's the younger children. I have been concerned about the lower grade situation, such as the one we had in Fairfax, a typical kindergarten. And that's where we're going to see more children in the coming years because of the parents who are IV drug abusers.

COMMISSIONER BUCKLEY. Dr. Morrison, do you use that same CDC definition for determining whether the child has AIDS? Do you use that same definition?

DR. MORRISON. Yes.

COMMISSIONER BUCKLEY. Another question: From the statistics that are available from the CDC, most of the children under 12, which are the statistics that are reported for children, are less than 5. They are very young. What would be the progress of the disease in these individuals? We're saying from seropositive—well, from the time they are diagnosed as having AIDS 'til death in minorities it could be 19 weeks to 32 weeks and 2 to 5 years for whites. What would be the prognosis in children from diagnosis of AIDS?

DR. MORRISON. Well, there are several intervals that are important. The time from transmission, from acquisition of virus in an adult until the time of AIDS is usually approximately 5 to 6 years. And then the time to death, from the time of recognition of meeting the case definition of AIDS, ranges from 1 week, 1 day, up to years. Obviously, we are rewriting the book on that with AZT and other helpful modalities.

The point is that the expectation is that the data from which your comments devolve pertain to pre-AZT data, pre other immunomodular data, and I think the life expectancy of the HIV-infected neonate, young child, crank child, or adolescent will be ever-increasing because of a continued lifespan offered by the effective treatment of various drugs.

So I think it is true that the neonate born to an HIV-infected woman whose risk of transmission to the fetus is 30 to 50 percent, that those children will probably not reach an age of 5 to begin public school. I think that's a safe statement.

COMMISSIONER BUCKLEY. The concern I have is: Will we have to modify the curriculum? For example, if I am teaching biology, I no longer do blood typing in my classroom. Now, do we eliminate dissections as well, because the chances that they could injure themselves with the instruments is there. Would we need to be involved in changing the curriculum, then, in modifying some of our curriculum? Since we don't know what the seropositivity level is of our community, would we want to take the risk? Do we need to start thinking along those lines of modifying curriculum to take these points into consideration or not?

DR. MORRISON. If by "curriculum" you mean what is being taught in the schools?

COMMISSIONER BUCKLEY. As far as physical hazards. Contentwise, hopefully there will be some sex education and things like that. But physical activity—gym, PE classes, homemaking classes; the vocational classes where they are involved in the use of tools, other places where they might have any kind of—there are certain standards that you do operate your classroom under, but how much do we reduce those risks in light of

the fact that, let's say, our seropositive students in the classroom will increase?

DR. MORRISON. I think at this time—and I speak personally—I would not alter the curriculum in any fashion. I think the next 5 to 10 years will prove to us the observation that there will be a decreasing number of students in schools who are HIV positive, I believe. And the reason I say that is I think the hemophiliac population, which were the very large cohort originally, will die off, and that those individuals who are born to HIV-infected mothers will not survive a lengthy period of time, and that we will increasingly be looking at the upper and upper age groups where the volitional and responsible teenaged child can be dealt with at a cognitive level and not require alterations in the curriculum. I do not believe that curriculum alterations at preschool or early school training should occur because of fear or because of concern of risk.

COMMISSIONER BUCKLEY. But you don't see that as the high school population—really 12 through 17, 12 through 18—you don't see that we would need to worry about their curriculum at all, either?

DR. MORRISON. Not at this time. If by that you are suggesting that, for instance, a mat burn in gym class or a cut on a football field in playing touch football or a shop class injury or anything of that sort—again, I have to go back to the point, which is if you're not having sex with your classmate and you're not sharing needles with your classmate, I don't believe that there is any risk involved in the HIV seropositive individuals in cross-transmission.

CHAIRMAN PENDLETON. Gentlemen, thank you very much.

These hearings are recessed until tomorrow morning.

[At 5:45 p.m. the hearing was recessed, to reconvene at 9 a.m., Wednesday, May 18, 1988.]

PROCEEDINGS

Morning Session, May 18, 1988

CHAIRMAN PENDLETON. Is the first panel here? Sgt. Wargo, Ms. Foley, Ms. Kelly, Dr. Dawson, and Dr. McKinney.

If you will stand, I will swear you in.

[Sgt. Jerry Wargo, Mary Foley, Kathryn Kelly, John Dawson, M.D., and Rep. Mike McKinney, M.D., were sworn.]

CHAIRMAN PENDLETON. Yesterday the chair noted that it was the anniversary of the *Brown* v. *Board* decision some 24 years ago on May 17. It is interesting that today, May 18, is the anniversary of the *Plessy* v. *Ferguson* decision that may have been overturned by *Brown*. One has some sense of history in these matters to know how far we have come, and that is primarily noted for public information of the audience.

I do need to say again today that I am impressed—I guess markedly impressed—that the media is so absent today as compared to where they were the first day and where they were yesterday. When one reads the account of Ms. Boodman in the *Washington Post* yesterday, one would think that all that happened on Monday was the afternoon protest from the group ACT UP who was identified in the article as gay rights activists.

Just let me say that that has been the recent history of this Commission since, I guess, 1983, that no matter what we try to do in civil rights, in terms of the statutory work, that is seldom if ever recorded in the press.

And I think the witnesses yesterday—and again I want to thank you, Dr. Dawson, for being with us—I think some of you will clearly understand that the exchanges between the Commissioners who are not experts in this matter, as well as the witnesses, did provide an excellent record for the public, as well as an excellent record for us to decide what we want to do, if anything, to recommend public policy initiatives, if you will, to the Congress and to the administration.

I think it's a shame that we see things like, "Impeach the Civil Wrongs Commission," when what we are really trying to get at is some sensible way to balance off the societal interests along with the human interests in this very serious pandemic.

Not to belabor that, I want to say again for the record and for public information how proud I am of our staff. I want all of you who are witnesses to know that this hearing was put together by approximately two people, and in the past we have had between 15 or 16 people putting together a hearing. The travel, the witness interviews, the background papers, all that we could ever do to put this together was handled by one or two people.

And I do want to thank General Counsel and Mr. Fumento for their work, and also the support staff in the General Counsel's office and the support staff of the Commission for doing such a tremendous job in making this hearing, I think, as successful as it is. So when we report to Congress and someone says, "You didn't do what you were supposed to do; we gave you some money and we've cut your budget so many dollars so you can be more effective," I think we were effective on a lot less dollars.

And I want to thank all of you for coming, and again thank the staff for its work.

Today will be another long day, and we will start off this morning with the Health Care Providers Panel.

I should note, Dr. Dawson, you were sworn in yesterday so you shouldn't have had to do that twice. I was sworn in twice up on the Hill in what I sometimes refer to as a political proctoscopy, called a confirmation hearing, and I can understand how you might feel about having to do it again.

We want to take about 8- to 10-minute statements from all of you today, and then turn to counsel for some questions, and then my colleagues for some questions.

This matter of health care providers is an extremely important matter in addressing this pandemic from a public policy perspective.

I'd like to start off with Sergeant Wargo from the Silver Hill Fire Department in Silver Hill, Maryland.

Do they still play baseball in Silver Hill? The Silver Hill Sand and Gravel Company had a baseball team years ago. Do they still do that?

SGT. WARGO. Not that I know.

CHAIRMAN PENDLETON. It was before your time?

SGT. WARGO. Before my time.

CHAIRMAN PENDLETON. It dates me, then.

Go right ahead, Sergeant.

Panel IX: Health Care Providers

TESTIMONY OF SGT. JERRY WARGO, SILVER HILL FIRE DEPARTMENT, SILVER HILL, MARYLAND

SGT. WARGO. My name is Sergeant Jerry Wargo, and I have been a career member of the Prince Georges County Fire Department for 23 years, and I am currently assigned to Engine Company 29, which is the Silver Hill station.

On December 19, 1986, at approximately 7:15 a.m., myself and three firefighters from Engine Company 29 were dispatched on a medical local with Medic 2 and Rescue 3 for an attempted suicide.

Upon arriving on the scene, we were advised by the occupants that they did not call or need the fire department, and the only other person at the house was their son who was asleep in the upstairs bedroom.

I asked the parents if it would be all right if I were to check on their son, and they said fine.

I went to an upstairs bedroom door and opened the door to find a bedroom with blood splattered all over the walls and a large pool of blood on the bed. The parents were shocked to see the scene in their son's room and started screaming for him. There was no answer.

Checking further, we found a locked door in the bathroom. We then forced entry and found a 19-year-old male submerged under water in the bathtub. The water was pure red from the blood loss that he had experienced. Without any thought of harm to ourselves, a firefighter and myself immediately reached into the bathtub and pulled the unconscious patient out of the water and laid him on the bathroom floor.

At the same time, Medic 2 had arrived and started emergency care for the patient who had sliced his arms and wrists with a large sharp knife.

At this time I washed my hands and went back into the bedroom and found a suicide note laying in a pool of blood. The note stated that he loved his mother and father very much and was very sorry for causing them so much grief in their lives. He also stated that he was very, very sorry for being a homosexual.

I then advised the medic crew and firefighters that there was a possibility of the patient having AIDS. [Witness is referring to being infected with the AIDS etiological agent HIV]

His mother then told me that he and his boyfriend had split up a week earlier and that he had run away from home and was going from man to man looking for love and understanding.

Because of this series of events, I advised the medic crew to be sure that the hospital tested this patient for AIDS, which they did.

It must be also noted that just minutes before receiving this call, I had sliced my finger which caused an open wound, and the firefighter who was with me had cut all his fingers while working on the fire truck. Both of us having these open cuts on our hands and reaching into the blood-filled bathtub, and then knowing the patient was a homosexual, gave us great concern for ourselves and our families.

We contacted the Emergency Medical Service's representative of the Prince Georges County Fire Department, who was working closely with the hospital, to notify us as soon as possible of their findings as to whether the patient had AIDS or not.

Three weeks passed before we were notified that, one, the patient was tested for AIDS and, two, due to the law of patient confidentiality they were unable to give us the results.

A second incident occurred in July 1987 at around 2:00 o'clock in the afternoon. Engine Company 29 was dispatched for a personal injury accident involving a ladder truck from Prince Georges County that had run head-on into a small pickup truck. When we arrived on the scene, we found a ladder truck with the pickup truck underneath it.

Rescue Squad 27 from Morningside had already started to pull the vehicle from underneath the ladder truck and there were two victims inside who were both crushed very badly. It took us about a half-hour to get both patients out. One was dead on the scene; the other one was still barely alive. This patient was flown to Prince Georges Hospital where, while treating him in the emergency room, one of the nurses accidentally stuck herself in the hand with a needle while drawing blood. She then asked that this patient be tested for AIDS.

That evening, at approximately 9:00 o'clock, I received a phone call at home asking what I had done on the scene. After telling my supervisor what I had performed on the scene, he then told me that the person in the vehicle had tested positive for AIDS and that I was to get in touch with the county health department as soon as possible.

At this time both myself and the other firefighter are being tested for AIDS. The amount of stress and pressure that has been placed on ourselves and our families is unbelievable. Our lives have changed greatly due to these incidents.

I would like to state that yesterday the Governor of Maryland did sign into law and added AIDS, that if any firefighter, police officer, or paramedic, if we are treating them on the scene, we will be notified of that incident.

I would like to thank the Commission for letting me come down and speak to you today.

CHAIRMAN PENDLETON. Thank you very much.

Ms. Foley.

TESTIMONY OF MARY E. FOLEY, B.S.N., R.N., CHAIRPERSON, CABINET ON ECONOMIC AND GENERAL WELFARE, AMERICAN NURSES ASSOCIATION, SAN FRANCISCO, CALIFORNIA

MS. FOLEY. I appreciate the opportunity to address the Commission, and I am very pleased with the hearings you are having. I think it's excellent that attention is being paid to this issue.

I am a registered nurse in the city of San Francisco. I have been a nurse for 15 years. I'd like to just give a brief history of the policies that nursing has developed on the care of AIDS patients. Nursing has had a very proud history of caring for individuals throughout the world in a series of epidemics—influenza at one time, poliomyelitis, tuberculosis, and syphilis, to name just a few.

The AIDS epidemic came upon us rather suddenly and, as I indicated in the paper I prepared, I have confirmed in some reading that I have in fact taken care of some of the first AIDS patients in the city of San Francisco prior to a knowledge of that particular disease, but certainly it adds some clarity to the types of patients we were caring for in the late 1970s and the early 1980s who had very strange and complex and very life-threatening illnesses.

In the provision of nursing care, there are going to be inevitably risks. There are risks that will exist despite all of the best infection control, despite testing, despite every bit of knowledge. It is an imprecise science. We are working with human beings in very vulnerable environments, and yet it is our duty to care for individuals regardless of diagnosis and without discrimination. I think that is an extremely important aspect of nursing care, that we have a duty to care, that we do not discriminate against individuals.

The American Nurses Association has developed position papers through the Committee on Ethics extending our standards of care, our ethical responsibilities, and clarifying for nurses, who may have questions

about diseases and diagnoses that they are afraid of, that the risks do not exceed our responsibility.

I often make the analogy that if there is a nuclear explosion within the near vicinity of my home, I am a registered nurse, and is it my responsibility to rush into the site of that explosion and try to save people who are definitely not going to survive, and in that act I would therefore not survive. In fact, the risk to me far outweighs my responsibility in that case. I can reject that particular action.

However, now that we know the scientific modes of transmission for human immunodeficiency virus, our responsibility far outweighs the risk. We can control the risk of exposure to a great extent by following the universal infection control procedures.

And the universal infection control guidelines are simple, they are straightforward. They require the use of gloves whenever there is a potential exposure to body fluids. They require that nurses no longer recap needles, or that laboratory workers no longer put a cap back on a needle after an injection has been given or blood been drawn. That is the most frequent incidence of needle sticks, and yet is a very simple behavior that we are retraining individuals in a large population to change old behavior patterns. It certainly reverses what we were taught in nursing school and how many of us have practiced.

It is important to address the fear—and there is fear out there. It is important to address that sense of altruism that many health care workers have. They rush into the scene of an accident, they rush into a patient's room, and without thought for themselves may try to provide assistance. We need to retrain individuals to stop for a moment and think about the safety procedures, the very simple safety procedures that could dramatically minimize their risk to possibly infected body fluids.

What is important is that the infection control procedures and the infection control guidelines will assist us in the care of other infectious agents, hepatitis B being a very important one and one that has been documented to infect over 10,000 health care workers each year, and 200 to 300 of those health care workers may eventually die as a result of that initial infection. That is an extremely high rate of transmission. It has been in existence for years. Very little attention has been paid to hepatitis.

Now with the AIDS epidemic, we are getting a lot more attention paid to blood-borne diseases. We appreciate the attention. We think it is appropriate. The nursing associations have recommended OSHA guidelines, have worked very closely with the Centers for Disease Control. In the State of California we are recommending extension of the California OSHA guidelines to private employers and health care workers in private institutions.

This in and of itself will provide a mode of interruption for health care workers. We do not recommend testing of patients. We do not as a nursing

association recommend testing for the general public. Our rationale is this: The test is imprecise. It only evaluates whether there has been a previous exposure. We know there is a latency period between a positive test result and when that particular exposure occurred. A negative test in and of itself does not guarantee that there is no risk of exposure to health care workers, and therefore workers may be lax or may operate under a false sense of security if they feel a negative test result then relieves them of the responsibility to be careful.

A nurse recently gave me a good analogy. She said, "When I see a 'hazard' sign on the highway, I slow down, and maybe a test result that I could know about would make me slow down."

The opposite of that is, when the conditions are good and the speed limit is 65, many of us go 80. I don't, but many people do. Therefore, we may speed up. We may lose some of our sense of caution, and we may violate the concepts of infection control if we don't feel there is a risk.

Our best behavior in the health care setting and in the general population is to treat all potential body fluids, all body substances, as potentially infectious, and therefore not be wrapped up in policy issues and the controversy about testing.

The reason nurses also do not feel testing is appropriate is that the discrimination that may result from test results being violated, the confidentiality, is dramatic. I have observed individuals, and I was at the hearings with the Ray family that Senator Kennedy had last year where children were expelled from school, the family's home was bombed, and they were denied haircuts, they were denied health care, they were denied religious services, and they were denied housing, all as a result of HIV test results on children.

It is dramatic. It can be extremely, extremely dangerous. Individuals may lose employment. As a result they will lose insurance coverage. They will not be eligible for health care. They may lose housing.

I think the potential for discrimination, until we have very clear antidiscrimination language, which seems to be disappearing from the legislative arena due to the pressures in the Senate and the House—we should not take that responsibility for those potential discriminations.

I was asked particularly to respond to how we'll deal with helping health care workers remain comfortable with the continuing care of individuals. What is very important is education. Education has been the key for us to combat the fear and the prejudice. And, yes, there are nurses and other health care workers who just hold the same prejudices as general society against homosexuals, against IV drug users.

We are educating individuals about modes of transmission, how to care for people, how to identify symptoms, how to counsel, how to interrupt modes of transmission, and how to protect themselves in the health care setting. We are not oblivious to the reality that we need to protect health

care workers. We are a vulnerable group. But what we can do to our best ability is to educate and minimize those risks.

Thank you.

CHAIRMAN PENDLETON. Thank you, Ms. Foley.

Ms. Kelly.

TESTIMONY OF KATHRYN KELLY, ESQ., CROWELL & MORING, WASHINGTON, D.C.

MS. KELLY. My name is Kathryn Kelly. I'm a partner in the law firm of Crowell & Moring here in Washington, D.C., and I understand that I'm the only lawyer here on the panel.

I was asked to outline some of the legal issues which might be involved in a refusal to treat due to HIV infection. Although it may be obvious, I want to emphasize that my remarks go solely to legal parameters and some of the legal issues which might arise, and they do not address ethical or moral obligations.

Any discussion of legal issues in the AIDS arena necessarily involves an understanding of three basic things:

First of all, the law, as most of the Commissioners I'm sure are aware, is a combination of court decisions and statutes that are passed by legislatures. And in this arena it includes administrative regulations which can be promulgated by administrative agencies under either statutes or legislative authority.

Secondly, the law is composed of a combination of State and Federal laws, and thus the law may differ by jurisdiction depending upon where the issue arises.

And, third, lawyers are being faced daily with using traditional legal theories and applying them to the nontraditional problems that sometimes arise in the AIDS area. Therefore, some of the answers to questions about what behavior will be tolerated legally may vary by jurisdiction. And some of the answers may not be clear yet, as the courts are just now beginning to struggle with the application of traditional legal principles to this nontraditional area.

With that as a background, I'd like to look at three different areas of health care provider categories and talk a little bit about the legal issues that would affect each of them.

First of all, physicians. Traditionally, under the common law, private physicians have been able to refuse to treat, or to choose to treat, to put it positively, anyone that they desire. It was considered to be a freedom of contract. They, just like a plumber or anyone else, could choose to contract with certain people to provide services or to choose not to provide services to those people.

However, in recent years, that freedom to contract has been somewhat limited by some doctrines that have arisen in the area of medical

malpractice and other comparable areas. For example, once a physician has undertaken care of someone, he cannot abandon that patient unless he makes certain provisions for someone else to take over the care or treatment of that patient.

Secondly, if a physician is an employee of a health care provider, his employment contract may provide that he is required to treat all patients who present themselves, for example, to a health care facility.

Thirdly, if he is under contract with a health care facility to provide certain services, either that contract or some bylaws which are applicable to physicians who are permitted to practice, for example, in a health care facility, may require that the physicians adhere or comply with all applicable ethical standards.

I think you will probably hear a description of some of the ethical standards that have been recommended by the America Medical Association in this area, and as a result of that there may be an argument that any physician, that is, either by contract or by bylaws, signed up to complying with all applicable ethical standards may be, in fact, precluded from refusal to treat in certain circumstances.

Secondly, let me talk about health care facilities for a few minutes. Again, under the common law and traditionally, private health care facilities were not required to treat all comers. They could choose who they wanted to enter into a treatment contract or treatment relationship with. However, that, too, has been somewhat restricted in recent years, probably even more so than the ability of physicians to choose who they desire to treat.

For example, in the area of emergency room services, the law is very clear that a hospital that runs an emergency room cannot refuse to treat someone in an emergency situation.

Secondly, COBRA, or the Consolidated Omnibus Budget Reconciliation Act of 1985, provides certain limitations on most hospitals having to do with the screening and then transfer of patients again presenting in an emergency situation. There are certain limits on transfer.

And, finally, there is an argument, I think, that the Handicapped Discrimination Act, which I know you have discussed in great detail in another context, would apply to hospitals as grant receivers and as recipients of government grants and programs, and under those circumstances would prohibit those hospitals from discriminating on the basis of HIV infection.

The third area I want to briefly describe is the area of employees of health care providers or laboratories or other emergency care service providers. Employees are in a slightly different position because they frequently are faced with a policy whereby the hospital, their employer or other health care provider, has decided that they will provide service to all comers, including AIDS patients or HIV-infected patients, and yet the

individual employee in an individual circumstance refuses to provide that service.

We are getting over into the area of management and labor relations very quickly, and I am not going to get into that because it's a very complex area. But let me just outline some situations in which an employee may use statutes or legislation to excuse a refusal to treat in an individual circumstance.

First of all, the area of OSHA, or the Occupational Safety and Health Administration. It was referred to a few minutes ago in terms of advocating areas in which OSHA would enforce certain safety standards for health care workers. OSHA has already said that under its general duty clause, that is, its clause that imposes upon employers a general duty to provide a safe workplace, they will follow the Centers for Disease Control guidelines on protection of health care workers.

The OSHA statute also provides that employees may refuse to work and may walk off the job under certain circumstances. That circumstance is an imminent risk of serious bodily harm, coupled with no time to appeal either to the employer or to OSHA itself to discuss the situation and figure out a way around the problem, or to call to the attention of someone the serious bodily harm.

There are some cases that have come up where employees in health care situations have argued that OSHA protected them in certain job refusal situations. Most of these are in the nascent stages. That is, they are lawsuits that have just been filed and have not been decided.

But let me give you an example of one that arose in Indiana where a laboratory technician refused to perform certain tests on blood samples which were marked—I cannot recall whether they were either marked HIV positive or they were marked in some way that indicated that they might be and certain precautions should be taken.

After a series of disciplinary steps, the laboratory technician was finally terminated, and she then applied for unemployment compensation, which was denied on the basis of the fact that she had been terminated for cause. She appealed that denial by arguing that the OSHA protected her, that the general duty clause allowed her to refuse to work under situations where she perceived there to be a serious risk of harm.

In that particular circumstance, the facts of the case ended up showing that the objective standard that OSHA applies showed that there was not an imminent risk of serious bodily harm to her, and that in fact she had what I think the court at least characterized as a religious conviction that she should not be working with HIV-antibody-positive blood, and as a result of that the court denied her use of OSHA as a protection for her refusal to work.

Secondly, many of the labor relations statutes or collective-bargaining agreements may protect employees under certain circumstances where

they refuse to work or where they engage in concerted activity over health and safety issues. Let me give you just another example of a case that has come up. Again, this is an arbitration case, which came up under a collective-bargaining agreement.

In a prison situation, a prison guard refused to engage in pat-down searches of certain prisoners, and after a series of intermediate disciplinary steps he was disciplined for this refusal to engage in a pat-down search.

This case is interesting because the arbitrator looked at his refusal in a so-called subjective standard. That is, they looked to see if the prison guard actually did fear that he might be exposed to AIDS due to a pat-down search. And they found that the prison itself had put out misinformation about HIV contagion.

There was a memorandum from the warden that had been issued at an earlier stage in which the warden had said essentially, "Nobody really knows how this disease is transmitted, so we should be real careful about personal items like combs," which was one of the examples that was used.

Although adequate and correct information was later supplied to the prison by a nurse who came out through the government system and provided training and information both to the prison guards and to the prisoners themselves, the prison guard was acting on that earlier misinformation which came from the warden, and therefore the arbitrator awarded him backpay and reinstated him on the theory that he subjectively feared for his own safety, and although objectively if you looked at it it was not a legitimate fear, subjectively it was a legitimate fear, and it was the employer's own fault, if you will, for providing misinformation.

Finally, there is a group of people that I, for lack of a better term, will call those who are peculiarly susceptible for one reason or another who might choose to refuse to work or to treat HIV patients in certain circumstances. There is a mechanism in most health care provider facilities whereby, either through your private physician or through a physician at the hospital or other health care facility, you can seek exemption from performing certain duties because you are peculiarly susceptible. People who might fall into this category would be pregnant women, persons who are already immune-suppressed for other reasons, or people who are unable to wear protective equipment—for example, someone who is allergic to rubber, latex, or whatever.

Notice, however, that none of these categories are unique to the AIDS area. All of them would arise in other areas of infectious disease or other instances where there might be a group which is particularly susceptible to a certain problem, and all of them require clearance ahead of time, that is, going through some sort of process at the health care provider facility in advance in order to be excused from certain work conditions or to be transferred.

Thank you.

CHAIRMAN PENDLETON. Thank you very much.

Dr. Dawson, you are here once again representing that small body of health providers called doctors.

TESTIMONY OF JOHN DAWSON, M.D., AMERICAN MEDICAL ASSOCIATION

DR. DAWSON. Thank you, Mr. Chairman, and members of the Commission. It is indeed a pleasure to be with you again this morning to specifically address the AIDS and HIV problem as it pertains to the physician's ethical obligations.

Incidentally, I'd far rather be sworn in twice than sworn at once. I appreciate it.

For the record, my name is John H. Dawson, M.D. I am a general surgeon from Seattle, Washington and a member of the AMA Board of Trustees.

Last year the AMA's Council on Ethical and Judicial Affairs issued a very significant report on AIDS. This report, a copy of which is attached to this statement, addressed the question of the physician's ethical obligation toward individuals who are infected with HIV. It is a clear pronouncement: The Council stated that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is infected with HIV.

This report was presented to the American Medical Association's House of Delegates in December. I am pleased to state that our House of Delegates voiced strong support for the report and adopted it.

This ethical standard draws on a historical principle on medical ethics. The tradition of the AMA, since its organization in 1847, is embodied in the following: "When an epidemic prevails, a physician must continue his labors without regard to the risk to his own health."

In the current situation, application of this time-honored principle serves two important purposes. First, it serves to ensure that persons with AIDS and those infected with HIV receive appropriate medical care, even though this may pose some occupational exposure to the physician.

Second, it serves as an example to the general public that the medical community understands the nature of HIV transmission. When physicians behave in a manner that is consistent with the message that HIV cannot be acquired through casual contact, it enhances the credibility of the public health message.

Physicians have, to a large extent, lived up to the ethical ideal and have not refused to treat patients solely because of HIV infection. Of course, there are exceptions. We are asked occasionally how the AMA enforces its ethical principles among physician members. Our answer is that the ethical principles are intended as guides to responsible professional behavior and not as rules of law. The AMA does not maintain the mechanisms for

investigation and enforcement.

What we have done is circulate the ethical principles as widely as possible. We have availed ourselves of every opportunity to testify on this issue before Congress and other bodies. We also have encouraged medical schools to place a greater emphasis on teaching medical ethics and discussing this issue. I am pleased to report that a recent national AMA survey of primary care physicians indicates widespread acceptance of this ethical standard.

Going beyond ethical considerations, the AMA is on record very clearly as supporting the enforcement of existing laws and regulations prohibiting discrimination against the handicapped and applying these laws to individuals infected with HIV.

Let me offer you an example of why it is important for all credible institutions to endorse a reasonable public health approach to AIDS. You recall, and have heard again, of the Ray family of Arcadia, Florida. There the fear of AIDS proved more powerful than law and medicine combined.

This attitude can be overcome only after more of our credible institutions endorse the reasonable public health approach to AIDS.

For our part, we believe the AMA ethical stand on the treatment of patients with HIV infection is clear and unequivocal. The actual behavior of physicians as a whole is something for which the medical profession can be proud. By accepting the small but very real risk of occupational exposure to HIV, we are meeting our obligations to our patients, providing necessary medical care, and benefitting society by example as well.

Thank you, Mr. Chairman.

CHAIRMAN PENDLETON. Thank you very much, Dr. Dawson.

Representative McKinney, welcome.

TESTIMONY OF REP. MIKE McKINNEY, M.D., TEXAS MEDICAL ASSOCIATION

DR. McKINNEY. Thank you, Mr. Chairman. I'm Mike McKinney. I'm a general practitioner in a small town in Texas, also a member of the State legislature and a member of the Texas Legislative Task Force on AIDS. Today I'm representing the Texas Medical Association. I have some written testimony, and I'll just give that to you. What I want to point out is the difference between the TMA polices and the AMA policies.

CHAIRMAN PENDLETON. Which policies?

DR. McKINNEY. Texas Medical Association and the American Medical Association.

CHAIRMAN PENDLETON. I'm glad you are here to talk to us about that.

DR. McKINNEY. They are basically the same. There are some differences, number one, in reporting of cases. We have a State law now that requires reporting of cases of AIDS that meets CDC guidelines by name, sex, and race. We have a requirement to report HIV positivity only by

number, by race, sex, and age—not by name. We also have permission to disclose to the spouse, encourage counseling, but it is not a mandatory followup; it's not a mandatory investigation of the cases.

The main difference comes in the obligation to treat in the guidelines, and most of them are the same. We put a requirement in that, in my view, is stronger than the AMA's, and that is that you not only must treat but if you are not able to treat, if it is not within your realm of competence, or for some other reasons, you must refer—not that you should refer but that you must. The guidelines state:

> A physician shall either accept the responsibility for the care and treatment of a patient with AIDS, HIV, antibodies to HIV, or infection with any other probable causative agent of AIDS, or refer the patient to an appropriate physician who will accept the responsibility for the care and treatment of the patient.

On the surface it would seem that that is merely a change of words, but I would submit that there is a real difference.

Number one, realm of competence. I think everyone would understand that someone who is not competent or not trained in that particular field ought not to be treating it.

There are other instances when they are competent but still ought not to be treating. In fact, the chairman of the AMA Board, Dr. Nelson, even made a statement that said, "In addition to lacking appropriate training or experience, a physician may have a level of fearfulness so great that it would impinge on his or her ability to deliver high quality care." He said in such instances the physician should refer.

We think that is true. There are cases—physicians are human beings, too—where they are simply emotionally not equipped to handle some diseases. I have some colleagues who are not capable of treating people who are dying from cancer, and it has nothing to do with a fear that they're going to catch cancer. It has to do with their emotional makeup. They are simply not emotionally stable enough to treat that. At that point you have a responsibility to see that the patient is taken care of.

And that's what we try to do, is take the emphasis off the physician and put the emphasis back on the patient to see that the patient is taken care of at some point.

If you can deliver the care, you deliver the care; but if you cannot deliver the care, you are required by rule to secure an accepting physician who is capable of delivering that care. If you cannot secure someone who will accept that patient, you've got it, fearfulness and all. Whatever your reason for referring, if you cannot secure an accepting physician, then you are responsible for the care of that patient.

There are some other times, too. You get doctors who get burnout. In our Task Force on AIDS, we have heard a lot of testimony. It turns out that the good, compassionate, feeling doctors, the ones who take their time

with the patient—and that is primarily what we're doing with AIDS patients; in addition to some health care, we are doing some psychiatric health care—those that spend the most time get burnout. And at that point we need to have some way of allowing a physician to limit the number of AIDS patients for which they care or giving them some relief. The current AMA policy would make them treat them.

And it came into a problem with indigent health care, that I can promise you if you have AIDS for very long, you will soon become indigent when it comes to health care.

There is a particular physician in Austin who is a very good doctor, a very compassionate doctor, who started treating a bunch of people with AIDS, and the more he treats the more they like it and the more that come to him, and it's become a problem that he now does an indigent practice that he is essentially not getting reimbursed for. It has created a problem for him. He has not turned any away, and probably won't—he's one of those kinds—but I think he ought to be afforded the opportunity for some relief.

We've got answers for all that. Doctors rush in where fools fear to tread. That's what we do. I think we're going to try to take care of some of that. Instead of being fearful, we are stressing the education in our medical schools. We are increasing ethical teachings, teaching on AIDS. And we are doing continuing medical education, stressing that in Texas. Doctors are just like everybody else. They have certain biases and certain fears, and we are doing our absolute best to do away with those. Education is the key to the whole thing, and we're working on it and we will continue to working on it. And we appreciate your efforts on this.

Thank you.

CHAIRMAN PENDLETON. Thank you very much.

Counsel.

MR. HOWARD. Thank you, Mr. Chairman. I have a few questions for Sgt. Wargo, and then we'll turn to Mr. Fumento.

Sgt. Wargo, if I understand you correctly, you were involved in two cases. In the first case you were not given the information by the hospital on whether the person you had assisted was positive.

SGT. WARGO. That's correct.

MR. HOWARD. And you still have not been given that information?

SGT. WARGO. No.

MR. HOWARD. To your understanding, would the law that was enacted yesterday by the Governor of Maryland apply retroactively to that situation?

SGT. WARGO. Yes. Like the nurse stated here, we were advised to take the test anyhow, whether they have it or not, and it was just to know. But because we didn't have protection on, we were going to take the test anyhow.

In the second incident, there is approximately 20 people who are being tested who were on the scene, and that is police and firefighters.

MR. HOWARD. I'm still not clear on this. In neither case, then, were you able to get the information from the hospital on whether the two victims tested positive?

SGT. WARGO. In the second case we were told, and that was by accident. It was through the nurse who did notify the health department, and the head of the health department took it upon herself to let everyone know.

MR. HOWARD. And now that the law has been enacted by the State of Maryland—I'm still not clear on this—can you go back to the first case you were involved in and find out what the records show?

SGT. WARGO. At this time I'm really not sure.

MR. HOWARD. You mentioned there had been great pressures on your family as a result of the incident. Does that include any kind of discrimination against you or your family because of uncertainty about your HIV status?

SGT. WARGO. Well, they talk about it around the station and at other stations in the county. But basically not. Since we've been tested, it's been almost a year now and the tests have been negative. I guess that is the reason that we haven't really been discriminated or anything.

MR. HOWARD. And how much longer will you continue to be tested?

SGT. WARGO. Our last test is in June.

MR. HOWARD. June of '88?

SGT. WARGO. Of '88.

MR. HOWARD. It is my understanding that the incubation period for the HIV virus can be much longer than that; is that correct?

I could ask Dr. Dawson or Representative McKinney.

DR. MCKINNEY. They don't know. It's probably 3 months; maybe as long as 2 years.

DR. DAWSON. It's documented, I think, out to 14 months which at this point in time is the longest.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. In witnesses we had yesterday, they were saying from exposure to seropositivity it was like 6 weeks.

DR. DAWSON. Most of them turn positive in 6 weeks to 8 weeks.

COMMISSIONER BUCKLEY. They recommend it at 6 weeks from exposure and then 6 months to be sure.

DR. DAWSON. It's been written up within the last 6 months that there are documented cases that have gone out to where it is questioned that it may well be out 14 months in a given case or two. We can't get human experimentation to find out, of course, so you're always extrapolating from information you have.

MR. HOWARD. Sgt. Wargo, if your tests cease in June of '88, what will have been the total period from beginning to end of your testing, or from exposure?

SGT. WARGO. About a year and 3 months.

MR. HOWARD. Representative McKinney, you are also an M.D., of course.

DR. MCKINNEY. Yes.

MR. HOWARD. I'm not sure you mentioned this. Could you tell us how many referrals have taken place in the State of Texas by physicians who did not want to treat HIV positives?

DR. MCKINNEY. Who did not want to?

MR. HOWARD. Yes.

DR. MCKINNEY. None that I know of.

MR. HOWARD. None that you know of.

DR. MCKINNEY. I know there have been referrals from those who are not qualified, who feel like they're not capable of rendering the best care. But as far as I know, none on the basis of fear. The fear is there. But none that I know of.

MR. HOWARD. You also mentioned your work on the Task Force on AIDS in Texas. Is there a transcript from the hearings that you held that you could provide to us?

DR. MCKINNEY. Well, we haven't issued a final report yet. I'll send you a copy of the final report which will probably be August.

MR. HOWARD. Okay.

Mr. Fumento.

MR. FUMENTO. Dr. Dawson, in your hospital when a health care worker suffers a needle stick injury, is the blood of the person from whom the needle stick came—is that tested for hepatitis B and HIV?

DR. DAWSON. No, not normally.

MR. FUMENTO. Ms. Foley, in your hospital?

MS. FOLEY. If it's possible to obtain informed consent of that patient, it is requested of that patient. If they are unable to give informed consent—if they are unconscious or perhaps have expired or they refuse to give consent, we do not test the source patient; we just track the employee. And that's the recommendation. It's really the employee that you need to follow. And the Sergeant illustrated that you do it at the time of exposure to determine baseline, and then you do tests at 6-week, 12-week intervals, 6 months, and a year. So it's not necessary to test the source patient, but if possible it's nice for information.

MR. FUMENTO. But it would, do you agree, probably provide mental relief for those persons who have been stuck, to be able to test that person and find out?

MS. FOLEY. It may help the employee, but on the other hand it may work in the opposite. An exposure to HIV does not necessarily indicate

that the employee will become positive. In fact, there is a very low rate of transmission in HIV infection. It may add to the mental anguish that the employee may experience. The CDC guidelines do say if possible to get informed consent and test the source patient.

DR. DAWSON. I was just going to agree with what Ms. Foley said. You may convey a sense of false security if they test negative because they may be in that window before they become positive. And there is a low incidence of transference. And you had included in your question the hepatitis B. Most of the people in my hospital have had the vaccine for hepatitis B. So even if the patient had it, they presume they are going to be protected from getting hepatitis B.

And as to HIV, it would only be in those who fit into a particular group, the individual surgeon or nurse who has been stuck, where there is a clear indication to them that there may be an HIV positivity. Then they may ask for the informed consent. But in general, we accept our periodic finger sticks, and then just try to use the barrier precautions to prevent it as much as possible.

MR. FUMENTO. Ms. Foley, in your paper I appreciate your having looked into tuberculosis and cytomegalovirus as secondary infections. Do you have any information, though, on toxoplasmosis, which is known to have caused birth defects in pregnant women? Were you able to find out anything on that?

MS. FOLEY. No, I didn't find any additional information. Again, these are illnesses that are showing up in an AIDS population, though those are illnesses that are in existence anyway. TB is on the rise in part because of immigration and the poverty level, I think, of many people in our society. There are AIDS patients that are displaying TB, and also the cytomegalovirus which does exist in other immune-suppressed patients and also in infants. They have shown no greater risk to the nurse than in the general population for the cytomegalovirus. And for both of those diseases, it just recommends the extension of the universal infection control and certain barrier techniques to reduce risk. Toxoplasmosis I did not find any specific information on.

MR. FUMENTO. When you and I toured the inpatient AIDS ward at San Francisco General, there were these bright fluorescent signs on the doors of the AIDS patients' rooms that warn pregnant women to keep out. Have you since found out why they employ those?

MS. FOLEY. There are some institutions that are recommending that pregnant nurses not work with the patients. It's one of those debatable issues. I checked with the Centers for Disease Control and the National Institutes of Health who were both doing the health care worker studies, and neither of them indicated a need for that particular precaution, and in fact reiterated application of the universal infection control.

But I think there is a desire to take all protections possible. I think the attorney indicated that this may be a particularly susceptible population. There may be a desire to be on the safer side for a group, particularly a group who may display extreme emotional reaction. On the other hand, scientifically it does not seem to be justified at this point.

MS. KELLY. Could I just add something to that. I think I would just echo what she is saying, that I don't think there is a lot of scientific backing to say that pregnant women are necessarily a more susceptible group in the AIDS area. Their unborn children are more susceptible in general to certain things, some of those of which are linked to AIDS. I think the things you are seeing are probably a reflection more of the legal and administrative environment than they are of the medical environment.

As I'm sure you are aware, OSHA and a lot of other administrative agencies have put a lot of emphasis on care of the unborn, if you will, and on a worker's inability to waive the rights of their unborn children. I mean, for a nurse to decide on her own behalf to take a certain risk is one thing, but there is a theory that says she can't assume that same risk for her unborn child.

And I think a lot of employers, including health care providers, are sensitive to that and are sensitive to the kinds of charges that they may face 15 or 20 years down the road when that unborn child brings a lawsuit or brings a claim. What you're seeing is a legal sensitivity rather than a medical or scientific sensitivity.

CHAIRMAN PENDLETON. Excuse me a second. In the case of the pregnant health care provider, is it because of the variety of diseases that occur from the breakdown in the immune deficiency system that you might have those signs? There are various kinds of indicators. But it does seem to me that we can get wrapped up in the talk just about AIDS as if it is one syndrome in this whole strand of syndromes.

I would just somehow suggest that that is an education mechanism that needs to be out there because it could be—well, I mentioned yesterday or day before yesterday, it's interesting what could happen to youngsters these days. That is, you could be born with indicators of syndromes about AIDS. You could have a birth defect—spina bifida, esophageal atresia, something like that. And then you could also wind up as a drug addict.

So it does seem like you add those conditions together with the various strands that my colleague and I were just discussing, and you wind up with one serious problem on your hands, I guess from the standpoint of tort as well as from the standpoint of medical treatment.

I only add that in just because I get concerned about the matter of just AIDS itself. It's not just one syndrome we're talking about. We're talking about a whole list of syndromes, and probably some we don't know about at this point.

Ms. KELLY. Absolutely. That's why I was saying I think it was probably a legal sensitivity rather than a medical one. And the flip side of that, of course, is true also. There are lots of risks to pregnant women, if you will, in treating TB or cytomegalovirus, et cetera, that have nothing to do with AIDS patients. It's not just that that's a subcategory of AIDS patients but it's also a subcategory of the patient population in general where it would be equally applicable.

CHAIRMAN PENDLETON. So we're saying that the diseases associated with AIDS, because of the breakdown of the immune system, has impacted upon other kinds of diseases.

COMMISSIONER BUCKLEY. If I may at this point bring this out, as I understand it, the virulence of tuberculosis and cytomegalovirus in AIDS patients is a lot worse than is usual in the population, but the actual infective agent, in this case the tuberculum bacterium or the cytomegalovirus, is not a more virulent strain. It's just that in those patients it is just rampant. But it's not a new virulent strain that has come out in these two diseases. It's just on these particular patients it is just really totally devastating. But it's not a new risk to the health care patient in tuberculosis and in cytomegalovirus.

DR. DAWSON. That is a correct assessment, but it needs to be pointed out, as Ms. Foley did reinforce, that we have a lot of patients in hospitals who are immune-suppressed and have the same kind of virulence. In fact, we see more of them in our hospital, and that's patients who are on intensive chemotherapy, who have their immune system suppressed. Therefore, it also is rampant in some of those.

CHAIRMAN PENDLETON. Let me just raise another point here, if I may. Perhaps in this discussion we have to define what we mean by discrimination. It's a matter of it being illegal discrimination because of race and what have you, but isn't there also a kind of medical discrimination here that you have to make certain kinds of choices about what to do with health care providers or with certain kinds of patients at a certain point, based upon what the consistency is of the virus? That is, if I have to segregate out nurses who are pregnant, there is an assumption that that's because that nurse does not want to treat that patient, and that in a sense is a discrimination against the patient, where as you mentioned, Ms. Kelly, it could be because of other legal factors that might be appropriate.

So when we talk about discrimination we're not just really talking about that which is illegal. We're talking about medical as well as legal discrimination. Am I making that distinction too—

DR. MCKINNEY. You have to discriminate. We discriminate every single day. We just try to do legal discrimination. I discriminate against a different bacteria that gets a different drug. Different people with different diseases—some of them get isolated.

CHAIRMAN PENDLETON. You mean in the treatment of the disease.

DR. MCKINNEY. In treatment of the patient. If they have one particular infection, some of them have to be isolated. They have to be segregated, not only discriminated against but they have to be segregated. You have to do it differently every single day.

CHAIRMAN PENDLETON. Okay. Go right ahead. Go ahead, Mike.

MR. FUMENTO. I'd like to clarify a point of information for the Commissioners. Toxoplasmosis is the disease that if you've ever heard about pregnant women being told to avoid kitty litter boxes, that's the reason they're told to avoid it. It's often carried in the feces of cats.

Ms. Foley, you have spoken of nurses—not today but earlier you spoke of nurses who want to wear everything short of chain mail armor around patients with HIV or patients that they can only suspect as having HIV. Some people might say, "Why don't you err on the side of caution," but what is the down side of dressing up in white chain mail?

MS. FOLEY. The down side of excessive precautions is really a dehumanizing of the care that you can provide to an individual. It is important that we use appropriate barriers when it's appropriate. I wear gloves if I'm touching blood or body fluids. I don't wear gloves to give medications. I don't wear gloves to give a back rub. I don't wear gloves to help someone set up their food tray. I am discriminating in my judgment when there is a potential risk.

We have to be very sensitive as health care providers to all patients. If we are applying universal infection control, then potentially we would be costumed for every single patient that we encounter. It would not only be extremely costly, which I think an institution needs to be vigilant in maintaining a reasonable cost because this equipment is not inexpensive, but it would be very dehumanizing for patient care.

MR. FUMENTO. Dr. Dawson, Dr. Cleary from the Harvard Medical School has stated that a surgeon cuts himself during surgery on average about once every 40 sessions. If he operated four times a week, that would mean on average in 10 weeks he has cut himself once. By definition, when a surgeon cuts himself, he's in the act of cutting somebody else.

Do you think perhaps that's a good reason to test surgeons for HIV and to exclude those from critical positions who prove positive?

DR. DAWSON. I have to make a comment that that's an unusual incidence of cutting oneself.

CHAIRMAN PENDLETON. Do you have any fingers left?

DR. DAWSON. I have cut myself once in my entire surgical career of 30-some years. Needle sticks are different, but cutting oneself is very unusual. And I teach all of my residents relative to how to handle a knife so that that doesn't happen. So I'd have to say I question that an average surgeon cuts himself once every 40 sessions. That's the first thing.

MR. FUMENTO. Maybe the good doctor is talking about himself.

DR. DAWSON. But the question that you have, which pertains to what is a surgeon's responsibility to his patient—because that has come up and is covered in the material you have as to the physician's responsibility to notify patients in the Council on Ethical and Judicial Affairs, AMA Report A, which I think you have—let me tell you that recognizing that the AMA has encouraged increased voluntary testing, I chose to have an HIV test run on myself so I could say I think it's a wise thing to do.

And in our Report A we say:

> A physician who knows that he or she has an infectious disease should not engage in any activity that creates a risk of transmission of the disease to others.
>
> And in the context of the AIDS crisis, the Ethical Judicial Affairs Council reiterated and reaffirmed the AMA's strong belief that AIDS victims and those who are seropositive should not be treated unfairly or suffer from discrimination.
>
> However, in the special context of the provision of medical care, the Council believes that if a risk of transmission of an infectious disease from a physician to a patient exists, disclosure of that risk to patients is not enough. Patients are entitled to expect that their physician will not increase their exposure to the risk of contracting an infectious disease, even minimally. If no risk exists

—that would be, for example, a physician who does just histories and physicals and no invasive procedures—

> disclosure of the physician's medical condition to his or her patients will serve no rational purpose.
>
> If a risk does exist

—as it would in the case of a surgeon who cuts himself—

> the physician should not engage in the activity. The Council recommends that the afflicted physician disclose his or her condition to colleagues who can assist in the individual assessment of whether the physician's medical condition or the proposed activity poses any risk to patients. There may be an occasion when a patient who is fully informed of the physician's condition and the risks that condition presents may choose to continue his or her care with the seropositive physician, and great care must be exercised to assure that true informed consent is obtained.

And that's the position of the American Medical Association.

MR. FUMENTO. Dr. Dawson, what kind of teeth do those rules have?

DR. DAWSON. No legal teeth. We have no mechanism for doing a monitoring or surveying, but there is no question but what the ethical pronouncements of the AMA carry enormous impact. Every ethical physician wants to be ethical. They read, know, and understand most of these guidelines.

It's true that the fear exists that Dr. Representative McKinney expressed, and some of them simply are incapable psychologically or medically from handling AIDS or HIV-positive people.

But all of us refer patients, whether they're HIV or anything else, to establish the best care for the patient that we can. And that often means sending them to someone else, referring them. I know of no patient with AIDS who is without a doctor. I think everyone is being taken care of.

MR. HOWARD. Dr. Dawson, just a followup question. It would seem to me that a hospital would want to test its surgeons for HIV seropositivity just as a way of protecting themselves from liability. Are you aware of any hospitals that test their surgeons?

DR. DAWSON. Not personally. No, I am not aware of any. The inference or suggestion that it would be a good thing I would question. I think our recommended position in Report A is a preferred position, where we heighten the awareness of the physicians of their responsibility to the public and the patients. Again, we come back to the fact that testing is a tool, and we come back to who should be tested and when and how often.

There is a dynamic process, both in the technology of testing and in the management, the treatment of patients who are in the window. We don't really know anything, and it's much better to have an ethical obligation applied than to have a specific mandatory testing at any given random time for those who are taking care of patients. Most of us who do surgery don't bleed into our patients when we're operating. And again, I question that every 40 times you cut yourself.

MS. KELLY. I may be able to add something to that, Mr. Howard. I'm not aware of any hospital that currently has a policy for testing of any of their health care providers, including surgeons, but I am aware of some hospitals that are considering that as a policy.

You may be aware that a consent decree was entered in a case in Cook County in Chicago where a neurosurgeon, who had not been tested by the hospital—that is, he himself knew that he was HIV antibody positive and had disclosed it, and the hospital attempted to put restrictions on his performance of invasive procedures. He filed a lawsuit against the hospital, and a consent decree has been entered. Essentially they came to an agreement, in other words, which the court blessed. So I'm not sure that it is indicative of how any kind of a holding would come out if it were actually a judicially determined decision.

But essentially the agreement they came to was quite similar to the AMA ethical guidelines. That is, there are certain determinations as to which are invasive procedures as to where there would be a risk to the patient, and where there are noninvasive procedures where there would be no risk.

COMMISSIONER DESTRO. Could I just ask a question along that line. I looked into that case and am a bit hazy on some of the facts. As I recall, he

was not in the practice of doing many invasive procedures. He was a radiologist or something, wasn't he? He was at least someone who didn't routinely do anything more than spinal taps, as I recall.

MS. KELLY. I don't remember the facts that clearly, either, but my memory is that the number of procedures from which he ultimately was precluded from doing was relatively small.

COMMISSIONER DESTRO. Right.

DR. DAWSON. I might just add he was a neurologist, not a neurosurgeon.

COMMISSIONER DESTRO. That's right; he was a neurologist.

DR. DAWSON. He did not do invasive procedures, except the ones that you indicated.

CHAIRMAN PENDLETON. Did he cut his finger?

DR. DAWSON. I hope not. I hope he didn't stick it with a needle.

COMMISSIONER DESTRO. Do you know the status of Illinois law with respect to the physician's duty to disclose, if he were, for example, to do an invasive procedure and the patient found out later, without knowing that he was HIV positive? Do you have any sense for what the state of the law in Illinois would have been with respect to duty to disclose?

MS. KELLY. Would you say that again? Assuming that an HIV positive surgeon operates on a patient without disclosing that, and the patient later develops—

COMMISSIONER DESTRO. No, and the patient finds out about it, and says, "That was a part of the informed consent procedure and you didn't tell me and I would not have consented if I had known." Then the question would have been: Is that a battery under Illinois law? Do you have any sense of what Illinois law might say about duty to disclose for medical care personnel in that instance?

MS. KELLY. I don't, but you can bet that the plaintiff would introduce the AMA ethical standards as an indicator of what the standard of care was in terms of informed consent.

DR. DAWSON. I do not know the answer to your question.

COMMISSIONER DESTRO. It seems to me it is certainly the developing trend of the law with respect to sex partners as well, that there are more and more lawsuits that I've seen where people are demanding, either before the fact or after the fact—well, certainly after the fact once they find out something has happened.

MS. KELLY. I think you're right in terms of disclosure. The big difference between a sex partner and a surgeon—a medical care partner, if you will—is the likelihood of infection. That is an enormous difference, and I think that probably is going to tip the balance in terms of any requirement of disclosure because the likelihood, that is, the risk, is so much smaller in one situation that I think it makes them not analogous situations, if you will.

COMMISSIONER DESTRO. When you say "the likelihood," would that be different for a surgeon, for example, than for a neurologist? It seems that way.

Dr. Dawson, what would you think?

DR. DAWSON. When you read Report A fairly carefully, it outlines that whenever there is any risk, this risk, even if it's minimal, needs to be more than disclosed to a patient. You need to refrain—and I'm quite certain if it came to a law, this would be referred to—you need to refrain from that activity. It says if there is any question in the individual's mind—and it need not be a surgeon; it may be someone who does endoscopy or balloon angioplasty insertions by a cardiologist who would not fit generically under the category of surgeon—they should contact their physician. We said, "You must contact your colleagues and find out, get an independent opinion as to whether or not you should be involved in any of this," and in essence putting it into the medical arena, recognizing there are legal implications of whatever we do.

But in the sense of protecting the public, and yet being compassionate toward anyone, be they a doctor or patient who has AIDS, we're saying these are our recommendations. Don't engage in activities, even with minimal risk. It's not enough to disclose.

COMMISSIONER DESTRO. In other words, you have an ethical duty to disclose to protect the public.

DR. DAWSON. Ethical duty.

COMMISSIONER DESTRO. Dr. McKinney.

DR. MCKINNEY. There's a case in Texas of a pediatrician. I would ask in your deliberations to take a look at discrimination. Part of our policy says you must treat a patient who has AIDS. There is not a policy that says you must go to the physician with AIDS. This guy is a pediatrician, and I promise you he was discriminated against—not from a rational fear but from a fear, period.

CHAIRMAN PENDLETON. Counsel has another question.

MR. FUMENTO. Ms. Kelly, to go back a little to the pregnancy issue, are you familiar at all with the Norma Watson case at San Francisco General?

MS. KELLY. No, I'm not, or at least I don't recognize it by that name.

MR. FUMENTO. Ms. Foley, are you familiar with it?

MS. FOLEY. As just being a resident of the Bay Area, yes, I am. We don't represent Norma Watson in her collective bargaining agreement through the California Nurses, but we've certainly watched the case with interest.

She was a nurse at San Francisco General Hospital, had an original case with the city employment regarding some discipline that she was subject to because of refusal to care for AIDS patients, so there was one case relative to that. She has been on medical leave and had some stress-related reimbursement, from what I understand, and now has claimed that an infant that has been born to her is retarded as a result of cytomegalovirus

exposure through the care of patients at San Francisco General Hospital. I understand that that case is still pending.

MR. HOWARD. Sgt. Wargo, just a quick question. Other than the routine testing that you are undergoing for seropositivity, were you forced to adopt any changes in your lifestyle as a result of what happened to you?

SGT. WARGO. Yes.

MR. HOWARD. Could you tell us about that?

SGT. WARGO. Oh, great. Let's see how I can put this. To use protection while having sex.

MR. HOWARD. I wonder if anyone else on the panel who is aware of such changes in lifestyles could provide us with that information. Would anyone else care to comment on this?

CHAIRMAN PENDLETON. I guess there are no takers.

Let me just ask a question of those of you on the panel. Are you aware of the Federal nondiscriminatory requirements under Section 504 of the Rehab Act, all of you?

Do you, Sgt. Wargo? Do you know anything about that at all? Not that you have to, but I was just trying to make a point.

Do you know about what happened in the Grove City legislation as it involves people that provide a direct threat of being contagious? Do you know anything about that, Ms. Foley?

MS. FOLEY. No, I don't.

CHAIRMAN PENDLETON. Dr. McKinney?

DR. MCKINNEY. I just know of it; that's all.

CHAIRMAN PENDLETON. I would presume that most of you work in situations where there is Federal assistance to activities that you are in—not you, of course, Ms. Kelly.

MS. KELLY. I get a lot of assistance from the Federal Government.

CHAIRMAN PENDLETON. I'll bet you do.

I guess the point I'm trying to establish here is that where the law or public policy is adopted, there seems to be a need for an educational process which disseminates this information to you on your policy development activities. I think it is especially true of the ANA, Ms. Foley, in that that would probably have some impact upon collective bargaining agreements and so forth as you begin to negotiate.

I won't belabor that point, but I would just suggest to all of you that there are some nondiscrimination requirements with Federal money that you need to know about as you go about your work, and hopefully people with whom you interact know about these processes.

Dr. Dawson, let me ask you a question. How do you get to be an ethicist? I raised this question in another hearing. I hear all this ethical talk. I'm trying to find out: Are ethicists board-certified or do they just happen? Are they causa sui? How do you get to be one? And how do they get so much power?

DR. DAWSON. Well, I know of no certification for ethicists, and some would think they just ooze into being ethicists.

CHAIRMAN PENDLETON. That's a good explanation.

DR. DAWSON. But certainly by virtue of interest, education, and involvement in the ethics producing standpoint—and there are institutes of ethics—Brookings and Hastings—and there are ethics departments in universities. And there are individuals who take training in this particular field.

There is a point where ethics and religion cross over, and you'll find that many of the ethicists today, and particularly involved in hospitals, are from the Jesuit persuasion, and are involved in helping to set of ethics committees.

But ethics—if I could make it simple in understanding it—is some form of codification of understood morals. As morality changes, so do ethics change to some extent. But for me I have to have some understanding of an operative definition, and I choose that. It's not something I picked out of some dictionary. It's a means of trying to put down specifically in writing the guidelines for what is right.

CHAIRMAN PENDLETON. Then I would presume there are certain biomedical ethics with respect to treatment of HIV-positive people, ARC, and AIDS patients; is that correct?

DR. DAWSON. That is correct.

CHAIRMAN PENDLETON. What are those principles? Does anybody know what those principles are? Are they nondiscriminatory principles in terms of the definition of discrimination in terms of Federal assistance?

DR. DAWSON. Yes, they are indeed nondiscriminatory, and it's included in Report A of the Council on Judicial Affairs.

CHAIRMAN PENDLETON. Let me just ask another question here.

Ms. Foley, in Westchester County, New York, some 39 percent of nurses indicated that if they had to treat AIDS patients on a regular basis they would resign or ask to be transferred. Does that present a rationale for having to have education programs for health care providers to avoid some of the discrimination problems and treatment problems we talk about? What I hear you saying here this morning is that there are people in the health care industry itself who don't know enough about this disease, and as a result that results in fears on both sides, that is, the provider side and the patient side, and therefore we have lots of problems. Is that accurate?

MS. FOLEY. Absolutely accurate, sir. And education is essential for the health care providers. They need to understand what the modes of transmission are and they need to feel safe in their practice with the scientific explanations and also the process explanation of how to take care of patients, and really put it in perspective.

I think the public fear has sometimes driven all of us to respond in some very strange ways because, despite our scientific knowledge and our career as a nurse, we are also just an individual member of society, and we are subject to the news headlines and our friends and our families who express great fears and reservations. We are not immune to that, and therefore our educational goals are extremely important at this point.

We have had a training program in the State of California with the assistance of State funds where we have directly trained 759 health care workers, who then in turn have trained 18,000 health care workers. That is just our first supply of trainers, and it's an admirable program. And it's on the concept that we have to train ourselves.

I also have an obligation to train the janitors that work, the dietary workers, the housekeepers. They are also working in the health care setting and they are exposed to materials. They have sometimes even greater fears than we do because we have professional journals, nurses and physicians have ethical committees, and we have continuing education programs that we go to.

I would suggest that it become mandatory, in fact, because this is a very serious illness and does require a real national response. The most fearful people are often the ones who do not go to the educational programs. There seems to be a self-selection. I've been to a lot of them but I'm not afraid. I'm just concerned and I'm interested in the subject. I have coworkers who are extremely fearful and yet will not go to the programs. Fortunately, many of the hospitals are instituting mandatory programming on the infection control guidelines and are really promoting adherence with those guidelines. So it's coming around.

But you're absolutely right, sir. The education is essential. With education, the health care worker attitude does change. If we did that study a few years ago, the percent would have been much higher than 39 percent, and actually that's an improvement over a period of time. I think we will see that continue to improve over a period of time.

CHAIRMAN PENDLETON. Just a couple more questions.

Sgt. Wargo, have there been any attempts in your department to educate the Silver Hill Fire Department about the transmission?

SGT. WARGO. Well, it's not just the Silver Hill Fire Department. It's the entire Prince Georges County. They have an employees assistance program. What we have that many other departments don't have is fire department management and union working together on the problem, and that is one of our biggest things, that we've had in-service training for all the firefighters and officers of the county.

In the first incident that I was on, it was a mistake on our part, really. We had been trained in it, but to walk into a room and not have your equipment with you—here is someone that is dying, and do you run back to the fire truck to get your rubber gloves, which we didn't have on us. We

just picked the person out. And the medic unit and the people who were working on the patient had all their equipment. Actually it was a mistake on our part.

But the education is there, and it's been given to all personnel of the fire department.

CHAIRMAN PENDLETON. Does anybody feel as though the confidentiality of patient test results and the like, and the inability to disclose that, is discriminatory against people like you, Sgt. Wargo? That is, if you can't find out what it is, does that violate your civil rights?

SGT. WARGO. In my case I feel I should be told. I'm going to a scene to help a person, and in turn I would want them to help me. And in that way I would like to know, yes.

CHAIRMAN PENDLETON. I might just say I read a very disturbing column in the Chicago paper of a person who passed out on the street, cardiac arrest, and a person bent down and gave the patient mouth-to-mouth resuscitation. When the fire department arrived, the paramedic personnel said to the person who gave the mouth-to-mouth, "I notice there's blood on your lips, and this patient has bleeding gums." And the runaround that the person who gave the mouth-to-mouth got in trying to find out whether or not the person had AIDS was just unbelievable. "Go to the health department; if you can't go there, call someplace else," and nobody could disclose.

The end of the story was, "The next time you see somebody on the street dying that way, don't touch him."

I guess my point is that disclosure gets to be as much of a problem as, in a sense, testing. Or is that an accurate assumption?

DR. DAWSON. In that given case that you referred to, whatever happened happened, and the person either had the transference of the virus or he did not, whether or not the victim had it. So the testing of the person who gave the respiratory mouth-to-mouth resuscitation attempts will just need to be tested on a periodic basis to see whether or not he turns positive. The anxiety of running around and trying to find out whether the person had HIV positivity is not as important as being sure that you yourself are negative.

CHAIRMAN PENDLETON. I guess part of the point here is that there was nowhere to go to get an answer about where to go to get tested.

DR. DAWSON. To find out about the victim, or to get tested for themselves?

CHAIRMAN PENDLETON. Is that the way it was, Bill? You gave me that story out of the Chicago paper.

MR. HOWARD. That was the Mike Royko column, yes. The young lady was unable to get the results of the victim's status.

DR. DAWSON. Well, it's more important that he or she be followed.

CHAIRMAN PENDLETON. I guess the point I'm making is that there are people that a lot of things are going to happen to, and unless we understand about confidentiality, the education process, about disclosure as a process, why you do or don't, then that begets fears in people's minds, which certainly begets discrimination in terms of how you treat people or don't treat people. So we do have some corresponding problems here with discrimination that seem to have a rippling effect on this condition.

MS. FOLEY. An important point, though, is that in that case on the street and in the case with the fire department and in the case of even the controlled health care institutions, the exposure is going to occur long before you'll be able to verify whether or not that patient has HIV-positive status or hepatitis status or tuberculosis. In most cases the exposure is over. What we should be looking at is what we need publicly to prevent people from denying care so that if I do see someone prostrate on the street, I don't sit there and debate whether or not I should take that risk, that I act in a humane way, whether I'm a citizen or a health care work.

And then it really is irrelevant whether or not that person was infected. If I've had body fluid exposure, I should just be able to be followed, irrespective of that person's status. What we need to do is forget about knowing or not knowing, testing or not testing, and just track the incidence of the exposure, because we spend an awful lot of time debating confidentiality and debating discrimination. In the meantime we may be denying care, and we may be giving ourselves additional stress.

And I think the doctor is right. You track the person who receives the exposure, and it's really irrelevant if that other individual had already been exposed, whether the test is conducted or not, or that those results are disclosed. Because those results are disclosed, as the sergeant indicated, sometimes in very informal ways. And that chain of information and that breach of confidentiality can have some really serious magnitudes. Even in a hospital setting with confidential medical records, word gets out, and that is a breach of confidentiality that we are very concerned about. It is not essential for me to know the result of a test in order to provide good quality care and protect myself if I follow the right procedures.

CHAIRMAN PENDLETON. This is my final question.

I'm sorry. Do you have something?

DR. MCKINNEY. I disagree. In Texas, first of all, we took care of it 2 years ago. We have specific instances under which it can be disclosed and specific agencies that you contact for the disclosure of the test.

We also have accidental needle prick exposure. We can test without consent for AIDS. If we have a needle stick or a cut and exposure in the hospital, we can test.

CHAIRMAN PENDLETON. Is that involuntary testing?

DR. MCKINNEY. If they don't volunteer, we can do it involuntarily.

CHAIRMAN PENDLETON. How do you feel about that, Ms. Kelly?

Ms. KELLY. Well, it's the law. It would be against the law in a lot of States, but if that's what the Texas statute says—I think the more interesting thing to me is: Do you do followup testing on them then? Obviously, the antibody status at the time of the needle prick isn't preclusive of the person developing it. Then you're tracking two different sets of people.

DR. MCKINNEY. First of all, the law and policy from the hospitals are different. The law says you have a right to test, and if you're an ENT, if you work on an ambulance, you have the right to know.

CHAIRMAN PENDLETON. So he has a right to know?

DR. MCKINNEY. In Texas he could have found out.

CHAIRMAN PENDLETON. Do you want to get a job in Texas?

DR. MCKINNEY. They also don't pay as well in Texas.

SGT. WARGO. They pay pretty well in Prince Georges.

COMMISSIONER DESTRO. Let me ask Ms. Kelly: As a fellow lawyer, I thought that was a great lawyer's answer with respect to the law. But what do you think with respect to the divergence in policy? As a matter of policy, do you think that's a good policy for Texas, or would you prefer to see it the other way? When you said, "Then you'd just be tracking two people," it would seem to me that the person who was pricked with the needle—there would be more assurance if the other person didn't convert, so there would at least be a better sense that somebody else was being followed, that the balance was just struck in a slightly different way. What do you think of that striking of the balance?

Ms. KELLY. Let me answer your question two ways. First of all, let me make the comment that one of the difficulties in the AIDS arena is that the myriad of laws that have been passed—some quickly, you know, years ago when the epidemic first started, some more recently, some well-considered, others not—

DR. MCKINNEY. Ours were well considered.

Ms. KELLY. Yours, I'm sure, were well considered. —some responding to particular pressure groups or interest groups. And part of the problem is that there are actually situations where people are required to disclose and required not to disclose in the same circumstance because of conflicting layers of laws.

So as a bottom line I would say as a lawyer the most important thing is to get some kind of uniformity in terms of public policy, and it is almost more important from a legal point of view—not public policy necessarily but from a legal point of view—to have a public policy that says, "We're going to do it this way, XYZ," than it is to have it be the correct public policy. Because then at least I can advise hospitals in the State of Texas as to what their duties are and what their rights are.

But now to respond to your question as to what do I think the public policy is, I would agree with Ms. Foley that in terms of public policy it's

not really relevant what the test results of the exposed patient—the exposer?—is. And that you get into a situation, and if you're looking at it from either a confidentiality point of view or from a point of view of expending of costs and the cost benefit analysis, if you will, it seems to me much more practical to track the health care worker, the person who was exposed, rather than to have to track the patient or the emergency care victim or whomever who you may not be able to find again to continue to track.

CHAIRMAN PENDLETON. Dr. McKinney, just a final point. Do you believe that the policies that you have balance off the dilemma between ethics and discrimination?

DR. MCKINNEY. Oh, yes. We spent a long time. I debated that issue more than I wanted to last year. It was McAIDS debate they called it after awhile. But we spent a long time trying to decide how to take care of it. What we decided was if you get it you can't treat it. There's treatment but there's no way to cure it.

So we quit looking at trying to find a way to do that. That wasn't our job. But we can treat anxiety. And nobody is acknowledging the fact that if the person exposes you to AIDS or HIV, most likely—I mean the percentage is 99; I hate to give you the wrong percentage but I think it's 99.6 percent, I think—that you're going to test positive. I mean, you can find out. Then we can deal with some other number on what the percentage of the transmission is. But if they test negative, the chances of you having been exposed are very, very, very, very low. And there is something to be said for not having to worry about it. That's where we can avoid discrimination on the street, too.

We have some other policies. You can test them before surgery, if you think there's a risk of exposure. You can require testing before surgery.

We would like for AIDS not to be a political decision. We would like to be able to treat AIDS just like the rest of diseases in America. We cannot because it's contracted primarily by illegal means. In many States it's illegal, and that's the problem.

CHAIRMAN PENDLETON. What is the impact of the immigration law on treatment of people in Texas?

DR. MCKINNEY. The impact on the treatment?

CHAIRMAN PENDLETON. Of AIDS patients.

DR. MCKINNEY. Basically I don't know that it's had any impact on the treatment. They have already been there and we have already been treating them. I don't think it made any difference to us.

COMMISSIONER BUCKLEY. Do you have any results on what part of the immigration bill required the AIDS testing? Do you have any idea what the AIDS results were in that case? A lot of the doctors had to be certified by INS in order to give the tests that were required.

DR. MCKINNEY. Those test results are real hard to get. The results are hard to get. There are specific ways you can get them. The statistics are still being compiled. That will be in a report that we issue probably in August, and I'll see that you get a copy of it. But I don't know that we have that information.

COMMISSIONER BUCKLEY. I have five areas that I'd like to see if you all would give me some information on.

I read Ms. Foley's report and I really liked a lot of the things she said about the nursing profession, and some of what she talks about is the relicensing in some cases of the nursing profession. Now, I know there is some criticism on the licensing of doctors, and they're talking about maybe bringing the doctors back in for—I know you do refresher courses. But for a licensing type of activity would AMA endorse doing that, say—like in teaching we go back and we get certification for new areas that have developed in teaching. Would you advocate that AMA come back and perhaps suggest that we have a refresher course on AIDS where some of this fear and the incompetence that some doctors may feel in treating AIDS patients might be taken care of, and then we could improve the whole health care for the AIDS patients.

DR. DAWSON. We have made no specific statement regarding that, but it needs to be pointed out that licensure is a State activity. New York State now has such that it will require relicensure every 9 years.

Some of the reasons for that would include a requirement that there be certain testing for specific things. We recognize the difficulty in having the disease-of-the-year or disease-of-the-month problem and getting inordinate intrusion by regulatory mechanisms into licensure.

We feel that once a physician is licensed, then he needs to be accountable on peer review, that he needs to be demonstrating that he is competent or she is competent in the field, in however they have managed to narrow their activities or expand their activities, that that competence needs to be surveyed and watched. Licensure, of course, and certification are different things. Certification in general has to do with specialty, certifying competence in a special area. And there is sort of a certification mania going on in which after 3 weeks, 8 weeks, 6 weeks courses you can become certified as being competent in any number of procedures or areas.

So that can give a sense of false security as to the competence of an individual physician. We would prefer that licensure remain the province of the State and that certification remain the province of the specialty groups that would be aware of the importance of communication which, as Ms. Foley said, we have continuing medical education conferences specialtywide, hospital-specific. There is a continuing flow of information. We think what we need to do is have the peer review determine that this is adequate.

COMMISSIONER BUCKLEY. Representative McKinney, would you say that would be true also in Texas since it is a State province?

DR. MCKINNEY. I certainly would want it to remain in the State's control. We don't have mandatory education, but the TMA specifically offers that course. We just got through with our State convention last weekend, and there was a big long course and a big long discussion concerning AIDS and HIV.

The problem is education. We've talked about it all along. We've got to educate the doctors, too. You also have to educate the State legislators, I can tell you from experience. I start with them and then go to the doctors. But I think the State needs to do it, and the State needs to maintain responsibility for its own licensing.

COMMISSIONER BUCKLEY. Because you brought out in your statement that some of the problem in treating the patients with AIDS in Texas was that some doctors had this fear of treating them because maybe they didn't know enough about the disease, and then they might have felt incompetent in treating it. And perhaps education, which has been brought out in quite a few of the professions, could be heightened in your areas.

Mr. Wargo, for the fire department, are you doing any kind of this updating or relicensing or certification?

SGT. WARGO. The amount of training we have now is just unbelievable. It's inservice training in which they make sure that every person in the fire department is trained, and with new updates they're trained again. They have general orders that have come out on how to treat patients, and their education program is excellent.

COMMISSIONER BUCKLEY. For the record more than anything else, Dr. Dawson, does the AMA have a statement on transmissibility? In the discussion so far, we have heard pretty much that not only you but CDC feels the transmissibility of AIDS from health worker to patient is not that much of a concern. You have to be careful when you're performing any kind of invasive treatment of patients, but for the most part you don't see that as a great risk as long as you're careful in your general practice. Do you have a statement on transmissibility from AMA?

DR. DAWSON. We do have a statement on transmissibility. We have one that the Board of Trustees is presenting to our House of Delegates next month in Chicago and will be available if you're still going to have an open docket.

COMMISSIONER BUCKLEY. It's 30 days.

CHAIRMAN PENDLETON. Thirty days at least.

DR. DAWSON. So once that's been through our reference committees and approved by the House, we will see that you get a copy of it.

COMMISSIONER BUCKLEY. Will you share that with other professions as well, perhaps—the nurses and lawyers?

DR. DAWSON. Oh, yes. We have excellent communication with the American Nurses Association on that.

COMMISSIONER BUCKLEY. My biggest concern in this whole issue is the discrimination and treatment issue. I don't know that the American Heart Association has come up with any changes in the CPR or heart-saver courses as a result of the AIDS other than some concern. But as a fireman or as a nurse, if somebody needs help, then how are we sure that you won't discriminate against them and not treat them?

To me, it still seems like a great source of concern. If they come into the hospital and they say, "Well, I'm not going to treat you," or if at some point the doctor says, "I can't handle the disease"—I can understand candidiasis of the esophagus sounds pretty bad, and toxoplasmosis sounds pretty bad. I can see that you could get to a point where you might say, "I need to transfer him to somebody else."

But the issue of whether or not they will be discriminated against and they won't get proper treatment because you don't understand—I don't feel comfortable. I know you said, yes, the physician must take care of the patient. Your ethics statement says that several times. But I still don't feel comfortable, whether because of fear or incompetence, they will be taken care of in a nondiscriminatory fashion.

If you could all kind of give me a sense of what you see from your perspectives for the areas you represent, that this will not happen, that they will be taken care of.

SGT. WARGO. That was one of the concerns that the Prince Georges County Fire Department had also. And there is a strong concern there. Would you, without any type of protection, help somebody?

In our case, the fire department has issued CPR kits to all the firefighters, and they are to carry them in their running coats at all times so that they do have some type of protection.

Then again, if they don't have that protection, I would honestly have to say there would probably be discrimination because of the fear of the disease.

Every day you open the newspaper, that's all you read about. It's somewhere in the newspaper. The fear is great. And when you're working and there's someone that you don't know, personally I think the discrimination would be there.

COMMISSIONER BUCKLEY. Ms. Foley.

MS. FOLEY. Yes, I know in the recertification for the CPR requirements within the hospital, when you go through the recertification or take it new now, they do provide new pieces of equipment. They have airways that are available to any employee who takes the course. And it is a requirement of the hospital that you go through a CPR course on a periodic basis.

COMMISSIONER BUCKLEY. Every year.

Ms. FOLEY. Yes. So this new piece of equipment, this airway that you could carry with you, as the Sergeant is saying, is a protective device so that you can do the mouth-to-mouth with no chance of regurgitation.

Also, in our hospital setting, each patient room is now equipped with disposal bags so that immediate pulmonary resuscitation is possible, that there be no hesitation. Equipment is a very big factor here. It's that barrier technique. And if you can provide the equipment that will satisfy the concerns, and appropriate concerns, by health care workers, then that hesitance will not occur.

I know individuals who are inclined to be the good Samaritan, who would stop on the road, are carrying this equipment with them and are supplying their own vehicles and their own personal affairs with this kind of equipment, because we don't want to stop being helpful to the general public. Therefore, equipment provision and education about that new equipment will very much assist in nondiscrimination.

COMMISSIONER BUCKLEY. Ms. Kelly.

Ms. KELLY. Well, I am not CPR-trained, I am embarrassed to admit. I guess the one comment that I would make along the lines of the equipment issue is that I think you really have two separate questions within your question, and one is: What happens in circumstances where there is appropriate equipment, where you're in a hospital setting, where the worst thing that will happen to the patient is Nurse A is going to get transferred to Shift B and he's going to have Nurse C instead. That is, it becomes in some circumstances a management problem. That is, it may be a problem for the hospital to move people around and they may not want to do that or deal with it, but it is rarely a question of a patient not getting adequate care.

So that's one distinction I would draw. So even if you are dealing with some people with some unreasonable fears—maybe they're people that you're in the process of educating, if you will—you're not talking about a lack of patient care; you're talking about a patient being cared for by someone else and some management problems that may be caused for the hospital administration.

The second part of your question, as I understood it, was what happens when that equipment is not available. Will people be assisted? I think the emergency room situation or the emergency response situation to an automobile accident or whatever by emergency medical technicians is the much more difficult question. But, again, they should be provided with equipment, so they should also have that available to them. Once they have the equipment, then they have the proper means with which to go about their duties despite the fear.

COMMISSIONER BUCKLEY. Could the employee, say in this case a fireman or the nurses, insist, either through legal means or otherwise, that

these kinds of things be available to them so that they would feel safe and they would not have the fear?

MS. KELLY. Absolutely. OSHA has indicated, as I mentioned in my testimony, that they will enforce the Centers for Disease Control guidelines on the protection of health care workers. It is my understanding that they are doing inspections, and that they have fined hospitals for failure to provide some equipment. So they are enforcing them.

I think any employee in a collective-bargaining situation, for example, where they have a right to walk off the job or to refuse to do work under a safety-related reason, would absolutely have the right to refuse to do work or to walk off the job if the appropriate equipment was not provided, and that would, at a minimum, be the equipment provided under the Centers for Disease Control guidelines.

COMMISSIONER BUCKLEY. Like providing rubber gloves for the firemen?

MS. KELLY. Right. Rubber gloves is an interesting example to mention. There have been reports in the press, and I have heard through the grapevine, that some health care providers are having difficulty getting enough rubber gloves, although it turns out upon probing that a lot of that is that they only have a month's supply instead of 3 months' supply. It's not really that somebody going into a room doesn't have gloves.

But it is a problem, and sometimes getting equipment to people, even if we all agree they need it and it's necessary for their job, something falls down in the supply system. And that is certainly the responsibility of the employer or health care provider to make that equipment available. If that health care provider or employer fails to do that, then there is a real problem that arises in terms of liability both to the employee and to the patient for whom the care needs to be provided.

COMMISSIONER BUCKLEY. Dr. Dawson, do you have any comment on it?

DR. DAWSON. Yes. While the techniques and the equipment that Sgt. Wargo and Ms. Foley have alluded to will reduce the concerns, there simply is no way that you can insure nondiscrimination on the part of any individual health care worker toward an HIV-positive patient, assuming they know that they are. You will always find those who, regardless of whether the equipment is available, will rush in, the good Samaritan. You will also find those who have irrational and unreasoned fears, and we haven't been able to eradicate discrimination totally in any area that I am aware of. I don't think you can expect to assure nondiscrimination across the board in this area, either. But certainly it is helpful to reduce the chance of transmission by the techniques and the equipment that have been mentioned.

COMMISSIONER BUCKLEY. I think the concern is really the discrimination where you don't really know that they are either seropositive or have AIDS.

DR. DAWSON. That's right.

COMMISSIONER BUCKLEY. I think that's the concern because that will spread to the general population, will affect them.

DR. DAWSON. There are those who will treat, even with the recognition of the concern, and those who will not.

COMMISSIONER BUCKLEY. Dr. McKinney.

DR. MCKINNEY. I think you've touched on the problem. The problem is not necessarily discrimination against those who are HIV positive, but discrimination against those who are laying on the street bleeding and you don't know. There are going to be people who die simply from a fear. And I can start naming names and giving cases.

But the fear of AIDS is as bad as the AIDS right now, and I think there are people who are being denied care. If we can eventually get to a point where we treat AIDS like we do other diseases, other fatal diseases, then I think we will do a better job of not discriminating.

If you didn't pay attention to somebody doing CPR on someone who is bleeding around the mouth, if you didn't think about it, you're not too bright anyway. If it does go through your mind—and in my definition that's discrimination; if you think about it and you hesitate, you've discriminated for a second. If you don't, then I think you're not very bright anyway.

But we've got rules right now. AMA has rules; we have rules requiring certain ethical behavior. I think you will eventually see a ruling, if somebody denies the care. Number one, tort law makes people pay attention real, real quick, and I think you'll see a case if they deny care on that.

Next I think you'll see them reported—in Texas they'd be reported to the Board of Medical Examiners. We've given them some new tools in the last couple of years, and they will start revoking licenses—on rulings. Then I think you'll see it go from rules, to rulings, to a law, to a written law. It's against the law to discriminate now and people already do it. Once you have it against the rules, I don't know how you make it harder.

COMMISSIONER BUCKLEY. So do you see laws and State laws as a means of dealing with this?

DR. MCKINNEY. Sure, but like I say it's a slow process, and I would say you're probably 4 to 6 years from now, from the State law.

COMMISSIONER BUCKLEY. Thank you very much.

CHAIRMAN PENDLETON. Commissioner Berry, any questions?

COMMISSIONER BERRY. I'd just like to know from Representative McKinney in general, what kinds of rights do people who are HIV positive or who have AIDS, even, have in the State of Texas?

DR. MCKINNEY. The same as everybody else.

COMMISSIONER BERRY. What kinds of rights do they have to privacy?

DR. MCKINNEY. The right to privacy? Exactly the same. You see, that's my point all along. I think they should have exactly the same rights as everyone else. We ought not be going around telling everybody else who's got gonorrhea or diarrhea or anything else. Medical diagnoses ought not to be disclosed, except to people who have a legitimate right to know. Those people have exactly the same rights as people who are HIV negative.

COMMISSIONER BERRY. How much contact tracing do you do in Texas of people who are HIV positive?

DR. MCKINNEY. None, but that doesn't mean we shouldn't. It just means we don't.

COMMISSIONER BERRY. How much weight did your legislature give in these laws that were passed, and the policy, to the CDC guidelines or to what the AMA and all these associations have to say about the issue? How influential is that to people in the legislature in Texas who are responsible for these matters?

DR. MCKINNEY. Well, in the House we have 150 people, and we have 63 lawyers and one doctor.

CHAIRMAN PENDLETON. You're in the minority; right?

DR. MCKINNEY. I'm it. In the debate, these guidelines were very well explained—in fact, the CDC definition is in the bill itself. Again, we were trying to pass a law, not necessarily to do the education from the law itself, but to make the law as nondiscriminatory—and it's a real problem in an elected body, with people who have to get elected again, to have them be ahead of the public. And that law is ahead of the public. That law is more understanding—it's more nondiscriminatory than the public as a whole is right now. I can tell you from experience it's very difficult to get 75 people to vote for something that is more liberal than their constituency. And that's essentially what we did with that law.

COMMISSIONER BERRY. Since you mentioned public opinion, what is your view—could you be more explicit?—if the law reflected public opinion in the State of Texas, what would it in general say that would be different? I don't understand what you mean.

DR. MCKINNEY. I hate to pick on Texas. I'll pick New York. I think if you pick any generalized uneducated public, it would say if you have HIV you ought to be put in jail until you die. I think that's the public's opinion. It was 4 years ago, anyway. They didn't know. Basic fear. I think that was public opinion.

I think it has changed since. In Texas, I think that we've not done not an adequate job but we've been working as hard as we can to educate people, and it's not near like it was. The kids don't discriminate. That's like desegregation plans. The kids are doing fine if the adults will leave them alone. It's the same thing with the kids. My kids know more about AIDS than my parents do, I'm sure.

COMMISSIONER BERRY. The only other point I wanted to make—I don't have any other questions—is to say in connection with Ms. Kelly, I understand—I'm saying this for the record—she was subpoenaed for this hearing. And it is my understanding that under the regulations of the Commission and under our statute, while subpoenas are issued under the signature of our dear, sweet Chairman, or any other chairman who might be sitting in office at that time, they are in fact approved and authorized by the Commission. And that is the way it has always been under our statute and under our regulations, and that, of course, means, as everything else in our regulations and statute, when you say "by the Commission," it means by majority approval of the members of the Commission.

I also understand from the legislative history and my familiarity with hearings on our statute, which is in that portion just like it's always been, and the regulations, the discussion in Congress was about making each member of the Commission consider seriously the matter of the issuance of subpoenas because they considered it to be a serious matter, and that is the reason why they wanted Commissioners to be involved, whether it was doing it because we needed a witness or some materials for a hearing, or because someone requested a subpoena—that it is a serious matter.

Therefore, I simply wanted to point that out. And I understand what happened in this case, and to make sure that my understanding was consistent with that in particular of the Chairman and other members of the Commission so that in the future we would not have this issue arise.

That's why I'm raising it, Mr. Chairman. Do I need to say anything else?

CHAIRMAN PENDLETON. But raise your point about future hearings. I think that's important to have in the record.

COMMISSIONER BERRY. But you don't have any problem with what I've said so far?

CHAIRMAN PENDLETON. No.

COMMISSIONER BERRY. Also, what we have done in the past in hearings, during my time on the Commission, is when we vote to have a hearing, we either vote for blanket issuance of subpoenas when they are necessary in connection with it by the Chairman, and then after that they can be issued as the Chairman sees fit within his discretion because we have fully considered the matter.

CHAIRMAN PENDLETON. And trust your Chairman.

COMMISSIONER BERRY. And that has usually been the way we have done it. When we vote to have a hearing, we vote at the same time to have subpoenas issued. And I would think we ought to do that in the future, just raise the issue at the same time and take care of it. It's a technical requirement.

CHAIRMAN PENDLETON. Commissioner Berry is correct, and the Chairman takes the observation in the spirit of cooperation to make the Commission move forward with its work.

Let me go back to one other question.

COMMISSIONER BERRY. Wait a minute, Mr. Chairman. I accept that; I'm moving on.

But as far as Ms. Kelly is concerned, I must say, as her testimony as a witness, if we had voted as to whether we would issue a subpoena to her, I am not sure I would have voted for it, if my understanding is that she was supposed to have jury duty, because as a lawyer and an officer of the court myself, and being aware how difficult it is to get people to serve on juries, at least certain kinds of people, I'm not sure had I considered it I would have had to have somebody persuade me that she was absolutely essential.

That's just my personal view. That has nothing to do with the technical aspects of the issue.

MS. KELLY. Would it reassure you to know that when I called the recording last night, I found there were no jury trials scheduled for today in Federal court, and therefore I would not have had to go today anyway as it turned out.

COMMISSIONER BERRY. That makes me feel better.

CHAIRMAN PENDLETON. The Chairman is persuaded, and thank you for that correction, Ms. Kelly.

Ms. Kelly, just one question of you again—or everybody in a sense. Do you know what liability protections there are for institutions and individuals in the treatment of HIV-positive people, or people with full-blown AIDS? And have insurance companies, in the light of this, raised liability protection rates to a level that gives rise to the question of whether or not you can continue to treat patients?

MS. KELLY. Are you talking about workplace exposure? Is that what you mean—worker compensation payments?

CHAIRMAN PENDLETON. Let me go back again. Not only that, but suppose a patient decides to sue because he or she couldn't get treated at a hospital. Has there been an increase in liability payments because of this, or have you limited it perhaps in Texas? Or has it been thought of in any respect?

DR. MCKINNEY. It's been thought of a lot. We have no limit on liability. In fact, we have a supreme court that just threw out our cap on pain and suffering. Insurance rates have gone up and will continue to go up. You can drop treating AIDS and they won't go down. It's a spiral, and I'm not sure—it would be nice if we could pick this one and blame it, but I don't think we can. There's no indication that insurance rates are going up because of it.

CHAIRMAN PENDLETON. Ms. Kelly.

MS. KELLY. I heard a lot of discussion over the last several years among hospital risk managers who were concerned about worker compensation rates going up because of exposure to hospital personnel, fears or concerns being expressed about that. But I have heard no talk about actual worker

compensation payments going up. In many States worker compensation insurance premiums are so-called experience rated. That means they would go up if you had an increase in claims. Because there have been so few, virtually no claims related to workplace exposure, there should not have been any raise in premiums, and I'm not aware that there has been any.

CHAIRMAN PENDLETON. Then if you cannot disclose, there would be no need to disclose to insurance companies who the seropositive patients are; is that right?

DR. MCKINNEY. Are you talking about insurance companies?

MS. KELLY. Are you talking about third-party payers now, reimbursement—

DR. MCKINNEY. Life insurance?

CHAIRMAN PENDLETON. No, in terms of the liability insurance for the institution itself, not against the patient but against the institution for not treating people. I'm saying anywhere. There's got to be a liability policy for the hospital.

MS. KELLY. Sure.

CHAIRMAN PENDLETON. We heard yesterday—you raised the question, Commissioner Buckley—that only four hospitals wanted to participate in the CDC testing.

COMMISSIONER BUCKLEY. Survey.

CHAIRMAN PENDLETON. Yes, survey. And the rest of the hospitals were reluctant because they didn't want to be identified, for all kinds of reasons, as being the hospitals that cooperated with CDC in this process.

What I'm trying to find out—that may be the case. I didn't ask that question. But would hospital insurance, liability insurance, increase because you participated in a program with CDC that showed a high incidence of seropositivity?

MS. KELLY. I guess I'm still struggling—if we're talking about the hospital's comprehensive general liability insurance, or is it insurance for when the hospital gets sued for medical malpractice or whatever?

CHAIRMAN PENDLETON. Malpractice insurance.

MS. KELLY. I cannot imagine why it would affect that, because the very fact that you have seropositive patients wouldn't increase your tort liability in any way that I could see.

COMMISSIONER BERRY. No, no, no, health care workers in the hospital might get the disease.

MS. KELLY. Now you're talking about the worker compensation. That's what I addressed before.

CHAIRMAN PENDLETON. I was talking about one thing and you were talking about another thing.

MS. KELLY. As to worker compensation, because most of the premiums are experience-based—that is, if you have more claims, then you have to pay higher premiums—there would be no increase now because we

haven't had claims. And, further, I have not heard anybody saying, "Our worker comp payments went way up because the insurance company is afraid that our health care workers may be exposed to AIDS."

COMMISSIONER BERRY. No, no, no, no. The argument is that if you have more people who are seropositive, then the probability is substantially increased that the likelihood that you may have incidents is greater than it would be if you had fewer people who were seropositive. That's the idea.

Ms. KELLY. And my answer is the same. If it's experience rated premiums, it would have no effect on it. If it's not experience rated premiums, I'm just not aware of anyone having increases.

COMMISSIONER BUCKLEY. It should not, but it might happen that somebody in the community might come back and sue the hospital and say, "I picked up AIDS from your hospital," and the liability insurance then would come into play. Hopefully there would be education to where the courts would know that all these other statistics would say that the transmission from a health worker to a patient is not that high, but will there be enough education out there to where your liability insurance won't go up?

Ms. KELLY. If it is a health care worker that we're talking about, a nurse or an employee of the hospital, then there is not a civil lawsuit; there's a worker compensation claim, because worker compensation is the exclusive remedy for employees. If you're talking about a patient or a visitor or someone else who somehow claims that they were exposed at the hospital and contracted it at the hospital, it would be the same medical malpractice claim that the person would file if they had contracted pneumonia or a staph infection at the hospital.

COMMISSIONER BUCKLEY. Would liability insurance then go up in that circumstance?

Ms. KELLY. If there was information that there were a lot of people there that were AIDS positive?

COMMISSIONER BERRY. Yes, seropositive.

Ms. KELLY. I'm not aware of any insurance that has gone up. I guess that's the only way I can answer that.

CHAIRMAN PENDLETON. I raised the question with you before for this reason, that a lot of the discussion we hear about full-blown AIDS patients especially having run out of benefits or benefits increasing to pay for treatment because there is no question in anybody's mind, I don't think, that this disease is so debilitating that you can't just go home and sit down in a chair and wait for the end result to come; you need all kinds of support.

But if insurance companies are going to raise the rates on AIDS patients, then it does seem to me that there's a chance, as Commissioner Berry is assuming and I'm assuming, that the rates not just on worker's comp but on general comprehensive liability for the hospital are going to go up.

And I raise it in another context. I heard not long ago of a supermarket chain in a certain State where the owners know that one or two or more of their butchers have AIDS.

Now, I know we're talking about casual transmission here, but the problem is that the public fear could result in that person losing his or her business, and under reasonable accommodations, can you move that person from one union to the other? What can you really do with that person in the process, based upon what we know to be the law today, Federal law and State law?

So how does that transfer? Maybe a health care worker winds up being seropositive, and the hospital has a problem. Maybe they can get out of this one, but does the next one send the insurance rates up? I guess that's why I'm raising the question.

So you know of no incidents in this case?

MS. KELLY. I know of no incidents where a hospital's insurance rates have gone up on the theory that they had a higher than usual seropositive population and therefore a higher than usual risk of somebody, either a worker or a guest, contracting AIDS.

CHAIRMAN PENDLETON. But why would there be a fear, then? Is it because of the general fear among health care providers, as Commissioner Buckley was saying, that only four hospitals would cooperate with the CDC? Does anybody have any ideas about that?

DR. MCKINNEY. I think it's the same as your grocery store which you described. It's true for hospitals and it's true for nursing homes, that you do not want the reputation of being the, quote, "AIDS hospital." We had one of those in Houston, and they closed down because they couldn't make it.

Like I said, I can educate the kids, but elderly people are primarily the ones who are using hospitals; they are certainly the ones primarily using nursing homes, and the fear is there.

CHAIRMAN PENDLETON. I'm not trying to be prophetic, I'm not trying to say that's going to happen, I don't want to do that, but I'm just raising the question that it may be an issue.

DR. MCKINNEY. Johns Hopkins can probably tell you, because they're fixing to pay out a claim and they probably could tell you.

CHAIRMAN PENDLETON. Johns Hopkins is?

COMMISSIONER DESTRO. They were sued by one of the doctors.

DR. MCKINNEY. A resident.

CHAIRMAN PENDLETON. Do you have a policy about that at the AMA about what you can do about this kind of thing?

DR. DAWSON. No. What I was going to say—

CHAIRMAN PENDLETON. You have a policy about everything, but—

DR. DAWSON. We have a policy, not about everything. But what I was going to say is I think it would be nonproductive for me to speculate on why certain hospitals didn't want to cooperate with CDC. It could be all

the way from the nuisance value of having to do the paperwork to having innate fear of being identified as an AIDS hospital. I simply don't know, but it might be useful to ask them.

CHAIRMAN PENDLETON. It could be that the cost for providing that service is more than they can—

DR. DAWSON. Or that they just didn't see any point. They may not have wanted to for just a simple—

CHAIRMAN PENDLETON. Which may or may not be discrimination.

DR. DAWSON. It may not have been discrimination.

CHAIRMAN PENDLETON. Let me acknowledge the fact that our other colleague is here, the Vice Chairman of the Commission, Murray Friedman, from Philadelphia, who could not be with us this week, but that is the other gentleman at the table here.

Are there any more questions?

Mr. Destro.

COMMISSIONER DESTRO. Just a couple.

I noticed that neither of the medical associations has any statement with respect to the duty of physicians or other health care workers to know their status, their HIV status. I was looking in the BNA's *AIDS Policy Reporter* and came across a reference to Dr. Frank Minyard, who is the Orleans Parish county coroner. He indicates that it is his personal view that doctors and other health care workers ought to be tested about every 6 months to allay public fear and to contain whatever spread in the medical community there might be.

Have either of the medical associations dealt with that issue of the doctor's duty to know what his or her status is?

DR. DAWSON. We have discussed that at the AMA Board, but we don't have any written policy, and I think it's safe to say that the consensus of our Board would be that that's an irrational approach at this time.

DR. MCKINNEY. We have discussed it. We discussed it real heavily because we had a pediatrician who came down with AIDS. But it turns out that most doctors who get AIDS get AIDS the same way that other people do.

CHAIRMAN PENDLETON. They have no special vehicle for doctors to get AIDS.

DR. MCKINNEY. Sex and needles, that's it.

COMMISSIONER DESTRO. I wanted to ask Dr. McKinney if he would comment in response to Commissioner Berry's questions about rights of privacy and how AIDS patients have exactly the same rights of privacy in Texas that everybody else has. You made some reference to depoliticize, that you wished it wasn't a political disease. Could you expand on that just a little?

DR. MCKINNEY. Sure. First of all, it's my opinion that it's a political disease. In all of medicine, it's the only disease I have ever had to deal with that had a lobby, and that makes it hard.

CHAIRMAN PENDLETON. What was that, sir?

DR. MCKINNEY. It has a lobby. It's a disease with a lobby. We have the gay rights activists who are opposed to the disease, and we have the red neck activists who are in favor of the disease. It's bad, but that's the way it comes out. And we've had to deal with the political problems and have had trouble dealing with the medical and ethical problems.

You know, the gay community—and legitimately concerned, I might add—is concerned about disclosure of their disease. It will necessarily be implied that they are homosexual, and discrimination against homosexuals is not only rampant, it's legal, in Texas. It just creates a problem. In their attempts to help, I'm not sure that they're not hurting.

Like I said, in New York or in Texas, we have people who don't want to talk about it, they want to act like it doesn't exist, and they don't want the State legislature talking about it. They probably don't even want you all talking about it.

It is hard to deal with a public who is uninformed and biased helping us make decisions that really and truly don't belong out there. These are not decisions that ought to be made by political bodies. This is a doctor-patient relationship, and that's the way it ought to always be. But we've got politics involved in it. We've got two sides fighting a political issue over a disease.

We didn't vote to get the disease, and I'm not sure why we vote to fight the disease. That's my implication, that it's a political disease that politicians, self included, got their nose into and they don't really belong in it.

COMMISSIONER DESTRO. Could you expand just a little bit further on what kind of political pressure is brought to bear on the politicians, and if any of it translates into pressure on hospitals and other health care providers? Because I know that after the panel in which Dr. Allen from CDC testified, he indicated that one of the reasons they didn't get more than four hospitals in their first go-around of asking for hospitals to contract with them to do some blind testing was that hospitals didn't want to be perceived as AIDS hospitals if the word got out.

So could you tell us what kind of pressures have been brought to bear by either side on this?

DR. MCKINNEY. Well, I can tell you in the passage of this last bill—

COMMISSIONER DESTRO. That's the Communicable Disease Control Act?

DR. MCKINNEY. Yes. For Texas that's not a bad bill. And the gay rights groups—they had paid lobbyists; they're there full time, and they brought lots of pressure to bear.

Now, I have to give them credit for education. They did do that. They have educated their group better than anybody else that we've dealt with. But they have brought pressure in regards to confidentiality of testing. We already did that. I don't go around telling people who's got gonorrhea. That's just not the way we're trained. That's not my job. It's wrong. I'm liable if I do it.

But now we have a specific law—a specific law for this disease—that we don't tell, this particular disease. And there are some real problems with that. Like case investigation or tracing—that is specifically excluded from our law, and only because of that—not only because of that but because also what are you going to do if you find them if you can't treat them? Medical science hasn't reached the point where we can treat them. But that was put in because of pressure from politicians.

Trying to get the votes in Texas—you have to understand this—getting 75 votes for something that recognizes that disease was pretty good. And we put in confidentiality. We dealt with some ignorance in the legislature. They had support.

My district is basically a rural district, and I could stand up and do gay-bashing and be against AIDS. I mean I could do that and make a good speech and get reelected. Doing this other you have to do it real, real careful. Because I can already see my opponent's campaign, you know, "McKinney endorsed by gay rights and lesbians." That gets you unelected in Texas, in Centerville, I promise you. That will get you beat, regardless of whether it's true or not.

Again, it became a political disease. Doctors don't have to get reelected. I just take care of the patients and go home. Politicians have to get reelected. We've got this problem in the wrong forum.

COMMISSIONER DESTRO. I just wanted to check with counsel. Do we have a copy of the Texas law? Because it would be important for it to be in the record. You seem to indicate that you supported it, you thought it was a good response, but there might have been some small problems with it, but in the tradeoff it was good?

DR. MCKINNEY. I think it is. Of course, I'm prejudiced, but I think it was a good bill. It was very forward looking compared to the rest of them. I will get you a copy of it. I will see that you get a copy of it.

COMMISSIONER DESTRO. It does outlaw contact tracing; right?

DR. MCKINNEY. What it says is that the physician—in the part on confidentiality it says the physician may disclose it to a spouse. We would have liked to have been able—in fact, we had it in there—to disclose it to the sexual partner, and the gay rights group took that out. They fought real hard over that one. They said they'd tell themselves or something.

COMMISSIONER DESTRO. Do you have any sense of why? Just a breach of confidentiality?

DR. MCKINNEY. I think that's it.

CHAIRMAN PENDLETON. How is "spouse" defined by gay rights activists?

DR. MCKINNEY. Oh, I don't know how they defined it. In Texas, in the law, we specifically defined it as a wife or a husband. As far as a homosexual spouse, I can't answer that; I don't know.

COMMISSIONER DESTRO. Not in Texas, in any event.

DR. MCKINNEY. That's the problem. I don't know. Probably there is, but I don't know how we would define it, and I doubt that we'd trace it.

COMMISSIONER BUCKLEY. Marriage of two people of the same sex in Texas is not legal; right?

DR. MCKINNEY. No, but cohabitation still comes out as being a spouse. It turns out to be the physician's interpretation, not a court's interpretation.

COMMISSIONER DESTRO. Dr. Dawson, I wanted to ask you. In the same volume of the *AIDS Policy Reporter*—I'm looking at the September issue—they talked about the Canadian Medical Association debating its ethical guidelines. They seem to be going through the same kind of debate that you all are. Apparently the chairman of their ethics committee—you all, I think, have done a very good job, too, and he made the comment, which I'd like you to comment on, that doctors ought not to be allowed to hide behind their oath of confidentiality while AIDS is allowed to spread.

What they have done is they have allowed for discreet disclosure whenever there is a relative need to know it's okay to disclose it discreetly. Now, I'm not sure what that means, but it's basically the same discussion that I had with Dr. McKinney.

DR. DAWSON. I don't think that there is a wide divergence between the Canadian and the American associations. We encourage discreet disclosure, that is, while maintaining the basic right of confidentiality. From a physician's ethical standpoint, it's always been as Representative McKinney said, we don't disclose things. But in AIDS we have indicated that we counsel with the patient, for example, if there's a spouse involved or a sexual partner, and if that does not make it such that the victim with AIDS discloses to their spouse, then we are encouraging notification of the proper health authority. And then if that doesn't accomplish it, then we recommend direct revelation to the spouse.

Now, we recognize in some States that goes counter to State law, and we have had to discuss and have discussed at our Board meetings that it may well be the physician will have to follow the dictates of his conscience in trying to fulfill, as you have mentioned, that AIDS needs to be controlled, and he may go counter to State law in trying to let a spouse know.

COMMISSIONER DESTRO. That is apparently what the Canadians are worried about, too, that the provincial laws in Ontario may go in one direction and the ethical duty go in another. That goes back to Ms. Kelly's comment about uniformity of—

Ms. Kelly. I was going to inject at this point, of course, under the Tarasoff line of decisions where physicians—not just physicians but in this case a psychiatrist—are obligated under certain circumstances to disclose to someone who is in imminent risk of harm. I mean liability issues come up, too. The tort law comes into play. It's not just what the testing statute says. It's not just what your ethical duties are. It's not just what the AMA guidelines say. It's tort law. It's what the tort law may be 5 years from now when this case comes to court where the patient sues you for disclosure when he didn't want it disclosed, et cetera.

Commissioner Destro. To continue with that, but just one comment, and I know the Chairman has a question.

Chairman Pendleton. I want to follow up about this disclosure business, but go ahead.

Commissioner Destro. I know, for example, having looked into it, as a matter of fact, in my other occupation as a law school professor, the contrast between Texas' law of disclosure in the court context in discovery in the *Tarant County* case, as opposed, for example, to the diametrically opposed view of Florida—

Ms. Kelly. In Rasmussen?

Commissioner Destro. Yes, in the *Rasmussen* case. You have two States, and as the diabolical law professor I posed a conflict-of-laws question on those two things. But you basically have an almost insoluble—you have balancing between confidentiality and the right of whether it's a health care personnel or somebody who got a blood transfusion—and that is what has in part made it political, I think.

Chairman Pendleton. Just let me ask a question here. My colleague's disclosure question gets another question.

We know now that in the *Arline* case that Arline was contagious or apparently transmitted to two students in 1977. We know it was a recurring situation with Arline.

At what point, if you could, should the public health department have disclosed to the school officials that Arline was contagious, or that there was a result of that contagion on the part of these two students?

Dr. Dawson. I don't know the medical facts of the *Arline* case, but I do know—

Chairman Pendleton. I'm using *Arline* as a case, but take Arline out of it. If you know somebody is contagious, and you know that that disease has been passed on to someone, and yet you don't disclose it, and we wind up with a case like this—

Dr. Dawson. Even thought you threw it out, let me throw it back in, only to say that Arline had tuberculosis. Whether it was active pulmonary tuberculosis, I don't know, at the time. I don't know that the two children who got tuberculosis got it from Arline. Those are things I don't know.

Chairman Pendleton. Two children in her class.

DR. DAWSON. Well, two children in her class ended up with tuberculosis, but I don't know where they came from or whether there was tuberculosis at home or other people in the family had tuberculosis. So I don't really know where they got tuberculosis.

CHAIRMAN PENDLETON. I guess my point is about the matter of disclosure. If that was the case, what should have been disclosed?

COMMISSIONER BUCKLEY. She did have active tuberculosis.

DR. DAWSON. Pulmonary?

COMMISSIONER BUCKLEY. If the incidence is back, if she is contagious again, should somebody from the school officials or the health department have notified that class and that school?

DR. DAWSON. Most people who are in that position get an annual chest X-ray, health workers or teachers, depending on State law. But, no, you shouldn't have someone with active tuberculosis.

CHAIRMAN PENDLETON. Now we're going through this case, and now that it's on remand to the district court, this evidence comes up, and at some point—here we have statutes developed based upon *Arline*. *Arline* is codified in the Civil Rights Restoration Act. So we possibly have problems.

Counsel, did you want to clarify something?

MR. HOWARD. Just to clarify a little bit on the *Arline* case. In talking with the attorney for the school board a few days ago, it is my understanding that the homes of the two children who came down with tuberculosis were tested for TB, and there was no TB among the family members. It didn't come from the family members. Certainly there is some question whether it, in fact, came from Gene Arline. But two of the 19 or 20 students in her class contracted tuberculosis.

It is also clear from the record in the district court that Gene Arline argued that she should be permitted to remain as a teacher in that third-grade class. She argued that she was only a minimal risk to the students in her class. It is also clear that the school board did not know from the public health officials in Florida that even the two students had tested positive in 1978.

So I just wanted to add that information for the record.

CHAIRMAN PENDLETON. Commissioner Buckley wants to make an observation on this same situation. It might not require a response but she wants to make the observation.

COMMISSIONER BUCKLEY. It just seems like the health department in these localities—would you think they should have a concern?

I know I had children of a mother that died of tuberculosis in my classroom about 1976, '77, somewhere around there. When that mother died, they informed all the residents of that housing project, and they informed all the teachers in all the classrooms where those children were to go and have a TB test done just in case. But that would be part of an

epidemiologist's normal way of proceeding. In our part of south Texas, tuberculosis is still very high.

I would suggest to you that the difference in an airborne pathogen and a blood-borne pathogen would make the difference, and again the politicization of the disease is part of the problem. But would you like to make a statement for the record as to the difference between these two as an example?

DR. DAWSON. They are indeed different diseases, and I think it is wrong that a teacher be teaching in a classroom with active pulmonary tuberculosis. I would also say that I had an aunt and a grandfather and a grandmother who died of tuberculosis, and I didn't convert to TB positive until after my first year in medical school. But it is a treatable disease today. And HIV can be treated with AZT, but there are different problems. One is airborne and one is sex and drugs, needle-transmitted.

CHAIRMAN PENDLETON. One last question, Commissioner Destro.

COMMISSIONER DESTRO. This is a question which takes the focus on fear of AIDS and changes it with respect to medical treatment completely. I would suspect that Ms. Foley may know a bit more about this because I know it's been a issue more in California than it has been in other States. But I would also like the doctors' opinion on it.

We have been talking about the degree of refusal to treat for AIDS based on fear. To what extent have you begun to see in either your practices or in the things that are coming through your ethics panels on refusal of treatment on the basis of AIDS, along the lines that the people have AIDS and they decide to decline treatment for otherwise treatable conditions, or people making the argument when somebody has become relatively incompetent because of AIDS that you ought to cease treatment, kind of a la the Baby Doe denial of treatment kinds of issues.

I know in California there was even a petition out for voluntary euthanasia, and I will be asking in a later panel the extent to which that has taken on some cogency in the community of people who are affected with AIDS.

Could you comment on that?

MS. FOLEY. Most nurses are in an employee relationship and do not have either support of the nursing profession to refuse to treat, and as an employee of an institution really has very little option to exercise the right to refuse treatment.

I have worked with a few nurses who had reluctance to care for AIDS patients. And one nurse's story was really a very personal one. She had a son born in the early '80s with a severe anemia. He had received a number of transfusions. He is at this point well, but she has fear and anxiety about the blood source in the city of San Francisco at that time. And it was her feeling that she couldn't provide compassionate care to an AIDS patient because of her fear about her own son, and through some really good

counseling and effective education, that fear was alleviated. There was no necessary discipline.

However, it was made clear that had she refused an assignment based on that belief, for whatever reason, she would have been subject to discipline.

COMMISSIONER DESTRO. That is not exactly what I was asking about. I'm sorry if I didn't make it clear. Have you noticed in your practice in the Bay Area of AIDS patients or their surrogates refusing treatment on the basis of the fact that AIDS is terminal and why hang around longer than you have to, given the prognosis for the disease? It's not the fear of AIDS on the part of the provider; it's almost the fear of AIDS on the part of the patient who has to go through it.

MS. FOLEY. There are some individuals—there are some statistics on suicide rates, and there has been an active lobby as part of the passive euthanasia bill. You're right. It's been composed of some of the AIDS groups. That is on an individual basis. That's not an official position.

I would say it's an individual choice. There are patients who have cancers who make an individual choice not to subject themselves to certain treatment protocols. Everyone has a right to their definition of their quality of life. If the services are provided and there is an informed process, if an individual chooses to reject treatment, that's their right.

I have not seen a lot of that. I have had coworkers who have been diagnosed with HIV and with some of the AIDS illnesses. None of them that I know of in the beginning have refused treatment. Ultimately there are degrees of treatment which some of them have rejected. For example, they have said, "Please do not put me on a ventilator if I have an arrest. If the pneumocystis progresses to a certain point, I'll just accept that. I do not wish to be treated beyond that point."

The Nursing Association has refused to endorse the euthanasia bill on ethical reasons. We do not support the arguments, and therefore have really been moderately active in opposition to that initiative process.

But it is individual. I do not see it in large numbers because I think there is a great sense of hope, particularly among the gay community in San Francisco, that much of this treatment is benefitting either themselves or somebody else. Therefore, there is a desire to participate in the research. And for some the quality of life and the length of life has really been effectively prolonged.

DR. DAWSON. I have not had, seen, or known of any patient with HIV seropositivity who was in hospital being treated who has asked that the treatment be stopped. Most of them in there are for pneumocystis or any infection, some with abscesses that need to be drained and treated. The patient subset that would follow that procedure of not being treated end up going to hospices or dying at home with their partner and have said, "I will not go back again."

COMMISSIONER DESTRO. Did the AMA take any position on the proposed California initiative?

DR. DAWSON. Well, we are against active euthanasia.

COMMISSIONER DESTRO. Do you know whether the CMA took any position on that?

DR. DAWSON. My understanding is that CMA is against active euthanasia.

CHAIRMAN PENDLETON. CMA, as I understand it, is the California Medical Association.

DR. DAWSON. The California Medical Association. I hate to speak for them.

COMMISSIONER DESTRO. Would that include the notion of rational assisted suicide?

DR. DAWSON. Yes.

COMMISSIONER DESTRO. The reason I mention that—and I'll ask the Chairman's indulgence for the record—and this may actually take more than 30 days to get it in—there is also a notation that a report has been submitted to the British Medical Association by Sir John Peale, who is one of their leading ethicists on the potential for, as he put it, a war between AIDS patients and others with respect to pressure for voluntary euthanasia, and that's been something that's been raised to me privately by a number of people as the costs go up.

So the question is what happens to people with AIDS, either because the fear hasn't been dealt with adequately or because the costs get too high. And those are important questions that we will eventually probably have to revisit some day.

CHAIRMAN PENDLETON. The record will be kept open for that purpose.

DR. DAWSON. Mr. Chairman, may I make a comment?

CHAIRMAN PENDLETON. Sure.

DR. DAWSON. The focus of the morning has been on the ethical obligation to treat. Ms. Foley has mentioned that the nurses really don't get a choice to accept or reject patients in the main, where we as physicians may transfer, refer, or do other things. And I think it needs to be acknowledged that the nursing profession has been noble, selfless, and giving in this situation, and a clear tribute is deserved.

I think it is also important to recognize that the burnout that Representative McKinney mentioned, as well as the dehumanization that Ms. Foley mentioned, are realities. That is true at any time you have to put on gloves, gowns, barriers, and whatever it might be. You just don't have as many interactions with the patient as you do when you don't have to do that, whether it's HIV or not.

And to acknowledge the fact that the medical profession is responding appropriately now, we need to acknowledge there's going to be a

significant increase in the load that comes onto the medical profession in the next few years.

In conference with the medical residents at the New Jersey Medical School, where in Newark they have on their medical wards 120 beds, 55 to 65 AIDS patients at all times, residents are finding they have no time to learn about other diseases. They find that the applicants for internal medicine are going down in medicine, that they can't learn about heart disease and diabetes and thyroid storm because the AIDS patient takes at least twice as much of their time. They know they are all going to die, and they find that the health care workers in the hospital are taking as much as four times to change sheets and dressings and do those things.

So not to acknowledge that we have an impending increase of significant magnitude would be wrong to just focus on today's situation.

I just thought that should be on the record, if I may.

COMMISSIONER DESTRO. If I could just add something, Doctor—this is again purely unscientific—I know the Chairman mentioned something like this yesterday. But sitting next to a physician on an airplane—I can't remember exactly what his specialty was, but he was here in Washington for some kind of an ethics committee meeting, and he talked about the same phenomenon. He's on the staff of Cleveland Metro General Hospital, and he indicated that as far as he knew all of the hospitals in the New York, and some of the ones in the San Francisco Bay Area, were having the same kind of trouble attracting medicine interns, that people were flooding the hospitals in the Midwest with their applications and just avoiding the hospitals in the larger areas.

Have you seen that in addition to just the New Jersey area?

DR. DAWSON. Oh, yes. I can't speak for San Francisco when there's an expert here, but it is certainly true in New York.

CHAIRMAN PENDLETON. I just wanted to reverse the procedure a little bit before we break for lunch. You don't have to give a response, but I sort of saved this question for the health care providers, for the same reason you raised the point about the necessity to understand the workload and the patient load and the budget load in the future.

We have been severely criticized, in spite of the unanimous adoption of a proposal to have these hearings, and there have been some, including those on Capitol Hill, who have accused us of taking over the work of the President's AIDS Commission. We don't happen to feel that way.

I wonder, having been here this morning—and you were here yesterday, Dr. Dawson—what you feel about our conducting these hearings in the narrow category of the civil rights aspects of public health policies and the prevention and treatment of AIDS. What do you feel—does this kind of forum have value to you? Just what do you feel about it? And if you'd just take a minute or so, I'd appreciate something for the record about this

particular activity. You don't have to, but if you want to comment on it, I'd appreciate it, whether positive or negative.

DR. DAWSON. Do you want to go down the line?

CHAIRMAN PENDLETON. Sgt. Wargo.

SGT. WARGO. I feel this Commission is trying to gain information from people who are dealing with the problem that's out there, and to me it's a very good thing to find out and educate people. I feel that this Commission is doing very well.

CHAIRMAN PENDLETON. Thank you.

Ms. Foley.

MS. FOLEY. I'd like to really applaud the Commission for holding the hearing. I think the doctor has made a very good point. The question of AIDS has been politicized and taken out of the arena of public health policy. And there is obvious debate on discrimination aspects. I have participated in hearings on the funding for education and research and discrimination on Senate and House bills, and it's obvious that the discrimination portions of those bills are not going to survive in a final vote. I think that's the politicization of that process. It is very appropriate for an agency such as yours to be considering specifically issues of discrimination. I think we can attack this illness and the fear and the prejudice from a variety of sources, and this is a very appropriate arena for your work.

CHAIRMAN PENDLETON. Thank you.

Ms. Kelly.

MS. KELLY. Well, I come from a slightly different perspective but I'll make the same plea I did earlier for uniformity in the law. You can never have enough in terms of education and information, and you can never educate yourself too much about what the issues are that are out there and what the laws are. I think having panels composed primarily of medical workers, health care workers, scientists, if you will, is entirely appropriate because the law in this area is responsive. The law responds to what the medical people tell us are the facts. And without that kind of information, I don't see how anybody could pass a rational statute or any piece of legislation from both points of view—one, how it fits into scientific knowledge and, two, how it fits into the greater body of law that might be covered by Congress or other bodies.

CHAIRMAN PENDLETON. Commissioner Allen is pretty much where you are. I mentioned that yesterday. One of these days he's concerned about a uniform kind of code so when we address issues of discrimination they could apply in whatever the arena is.

Dr. Dawson.

DR. DAWSON. The conducting of these hearings has been intensive and it's been impressive, both your attention and your insightful questions. It's been fun to be a part of it in a serious situation.

I think it really depends upon what happens to the information after it is all gathered, how it's compiled in your report, what recommendations you make, and then what happens to that. If it gets buried, then it will not have been of much value.

But as I said yesterday, information and education are the hallmarks of success in the management of the AIDS problem, the HIV seropositivity problem. It's essential that the information be disseminated. I happen to know that *AM News*, our weekly American Medical Association newspaper, will give significant coverage to what has been done here. And to that extent, it will go out to 150,000 or more physicians in this country.

CHAIRMAN PENDLETON. I would just ask you in your lobby, both you and Ms. Foley, occasionally what we do—and we've had reports recently, as my colleagues who remain know, that Congress in some cases said, "Don't send us the information," or, "That's that Ronald Reagan Panel up there, and therefore whatever they say should not be considered seriously." Once we have something put together, someone in the press will say, "That is sloppy work."

I don't think what has happened here has been sloppy. You certainly have not been sloppy witnesses.

I thank you for your comment about the intense discussion we have had here and the capacity of these Commissioners who are not medical people—I guess Mrs. Buckley is as close to a doctor as we know here, being a scientist and teaching it on a regular basis. But we really want to know how to make good policy recommendations.

Dr. McKinney, can you give us some of your wisdom? We've really appreciated that this morning, too.

DR. MCKINNEY. I can give you all of it; it wouldn't take that long.

What I found during our hearings in Texas is the problems we are all faced with is not a matter of research, it's not a matter of science. It's a matter of treatment, and we can't do anything about that. The problems are all social, and they deal with discrimination. That is the number one problem we all have to face. And not being a member of the Federal Government except as a taxpayer, I'm not sure I understand why it would be anywhere other than the Commission on Civil Rights. That's what we're seeing is discrimination, based on insurance—you all have talked about that; I assume you're going to talk about that some other time. But the most rampant form of discrimination we have—

CHAIRMAN PENDLETON. This afternoon we will.

DR. MCKINNEY. —is in the insurance industry, housing, losing their jobs. It is strictly a civil rights issue. If it's going to be political, this is the right political arena for it. I appreciate your interest and your work on it. And I guess Ronald Reagan may be interested in civil rights.

CHAIRMAN PENDLETON. Thank you very much.

We will adjourn for the morning. I again want to thank the witnesses. It's been a long morning, and I want to thank our recorder for getting all this down in the proper form and order, and she can now take a short break, too.

Thank you.

[At 11:55 a.m., a luncheon recess was taken, to reconvene at 12:30 p.m.]

Afternoon Session, May 18, 1988

CHAIRMAN PENDLETON. Could we have the witnesses assemble?

Would you please stand and be sworn, gentlemen?

[Russel Iuculano and Benjamin Schatz were sworn.]

CHAIRMAN PENDLETON. The afternoon and almost final session is devoted to a very important topic, insurance testing.

Before going to that, let me make an announcement, that at approximately 2:45 we will have the beginning of the open session. The open session allows people who are not hearing witnesses to take 5 minutes to discuss before the public their concerns before this Commission. The Commission does not ask questions of public witnesses. It is a matter of getting that on the record.

I also want to announce that as soon as the public session is over, we would like to convene the Commission meeting. Those of you who are here are welcome to stay. I just caution my colleagues that as soon as the witching hour of 6 o'clock arrives, people will come to move the furniture. If we are not through, the furniture will be moved and we will not have much more to do.

I see some rather interesting people in the audience, and I'd just like to acknowledge a couple of people.

One is Mr. Sam Austin, who is a classmate of mine, with HHS, who is sitting in the back of the room.

And I do see one of the writers on this topic, who has written quite a bit, Mr. John Wintergreen, who is now at Heritage. He's a fellow Californian. He's over in the corner. And I'm sure John is taking copious notes. I saw him writing this morning. Perhaps John has a new article for *Claremont Review* or some other review. I do want to say I thank Heritage for allowing you the time to come.

Mr. Iuculano, you may start. You have about 10 minutes or so to summarize whatever your paper is, and you, too, Mr. Schatz.

MR. SCHATZ. The letter I got said 15 minutes.

CHAIRMAN PENDLETON. The Chair, at his discretion, has decided for all witnesses, we have abbreviated the discussion because we want to be able to ask questions. We have your paper. We have already read your paper. If that is not helpful to you, then we'd ask you to try to make it helpful, because it has been a long 2½ days, and there are questions by the staff

here, and perhaps you will be able to respond with some of your testimony with the questions.

MR. SCHATZ. I just have written testimony so I will try to cut it as I go through.

CHAIRMAN PENDLETON. Your full statement can be submitted for the record. We will not eliminate anything at all. It can be here for the record, and we would ask you to summarize that as we go along, and certainly again afford us enough time to ask some questions.

I must say to you gentlemen that before you there were a lot of people who raised questions about insurance and insurance testing. I would hope that we could curtail or narrow the conversation discussion to insurance testing without a lot of overlap. There are all kinds of insurance problems—or issues is a better word—and I'm certain we don't want to get to that. But testing is a very important issue to this Commission and the work it has to do.

Panel X: Insurance Testing

TESTIMONY OF RUSSEL IUCULANO, ESQ., LEGISLATIVE DIRECTOR, AMERICAN COUNCIL OF LIFE INSURANCE, WASHINGTON, D.C.

MR. IUCULANO. Mr. Chairman, I have circulated to the Commission a formal written statement.

My name is Russel Iuculano. I am assistant general counsel for the American Council of Life Insurance. That's a national trade association of some 646 legal reserve life insurance companies that represent 95 percent of the life insurance in force. On behalf of our member companies, we appreciate the opportunity to appear before the Commission to discuss the case for the use of HIV antibody testing for both life and health insurance purposes.

Fairness, risk-based pricing in the industry's pursuit of these objectives, has been the subject of much misunderstanding. While the industry believes that AIDS is everyone's problem and all must be involved in the fight against it, we do not believe that AIDS must be given special status in the insurance process. We feel strongly that AIDS must be treated for all insurance purposes just as any other disease.

Now, opponents of AIDS-related testing would have the life and health insurance industry ignore the requirements of fairness and financial prudence and, in effect, issue insurance policies to people infected with the AIDS virus on the same basis as people who are not infected.

While we believe and realize that AIDS is everyone's problem, we do not believe that our present and future policyholders should be the sole source of funds to maintain and care for HIV-infected persons.

A life and health insurance contract obligates the company to pay each legitimate claim made under existing policies, regardless of the conditions causing death or illness. That is why insurers are in business. However, if they are to have the wherewithal to meet their contractual obligations, insurers must have the ability to classify risks.

To treat each policyholder fairly, insurance companies have the responsibility of setting premiums at a level consistent with the risk represented by each policyholder. That means grouping prospective insureds by such characteristics as age, health history, current physical condition, gender, occupation, and the use of alcohol or tobacco. Historically, all of these factors have been considered in the contracting process because they have a demonstrable impact on insurability and, therefore, the cost and availability of life and health insurance.

Testing for the AIDS virus identifies individuals who have a severely reduced life expectancy and severely increased chance of incurring catastrophic medical expenses. As you may know, on March 12, researchers from the University of California at San Francisco concluded a 3-year study that reinforces the growing concern that the vast majority of HIV-infected people will ultimately develop the disease. In fact, their study suggested that some 75 percent of HIV-infected will ultimately develop AIDS.

To ignore this information would be unfairly discriminatory to those persons who, unlike the HIV-infected applicant, have a standard risk of mortality or morbidity. The life insurance system would not survive for very long if individuals were permitted to wait until they have reason to believe they are, or are about to become, seriously ill before they seek coverage and start premiums.

Therefore, the risk classification process is critical to safeguard against adverse selection. However, because of its inherent need to identify and categorize applicants to assure risk-based pricing, the risk classification process is sometimes opposed by gay and civil rights activists when it is applied to AIDS. They say this is a civil rights issue. It is not.

The issue is one of freedom of contract. While insurance is regulated to a considerable degree, it is settled law that an insurance policy is nothing more than a contract between the insurer and the insured, and that the parties may agree as they see fit, so long as no provision of law or public policy is contravened. Neither party to a proposed insurance policy is under any compulsion to accept an offer by the other. An application for insurance is a voluntary act by a person seeking protection. And traditionally, insurers have been allowed to condition their offer to contract on acceptable medical test results.

So my point is that an insurance policy is a contract like any other, requiring the parties to agree to its terms and conditions before it becomes effective. Therefore, absent a statutory prohibition, a life or health insurer

may request a potential insurer to consent to AIDS testing without violation of any civil rights.

Prior to the AIDS epidemic, the right of a life or health insurer to request or have access to medical tests in the risk classification process had not been seriously questioned or impaired by State legislators, regulators, or the courts.

In the minds of some public policymakers, risk classification is easily subordinated when it is juxtaposed against perceived civil or social rights. This has led to a rush to ensure fairness for persons at risk for AIDS and the enactment of three laws that prohibit the use of AIDS-related testing for insurance purposes—laws that mandate the abandonment of time-honored and sensible risk classification principles.

The use of HIV antibody tests by the insurance industry has come under attack by various groups. Some question the accuracy of the tests, others consider the use of the test to be unfairly discriminatory or claim that confidentiality cannot be guaranteed.

Finally, the notion that private health insurance is a social utility that guarantees access for Americans to adequate health care has been proffered by still other industry critics.

Now, reacting in part to these criticisms, California, Wisconsin, and the District of Columbia enacted laws banning the use of the HIV test in all life and health insurance underwriting. New York and Massachusetts have promulgated regulations to a similar effect for health insurance, and several other States have proposed or are considering restrictions on the use of the tests.

To assist the Commission's understanding of why these criticisms are unjustified and without foundation, I have chronologically reviewed the circumstances that led to the adoption of these laws and regulations, and I've tried to point out that the premises upon which they are based are no longer with any form of foundation.

Now, in the interests of time I cannot go through all of them. My written testimony addresses the issue of test reliability. It addresses the issue of confidentiality and informed consent, and the issue of health insurance as an entitlement. I look forward to addressing those in more detail with you during the question-and-answer segment.

Thank you for your time and attention.

CHAIRMAN PENDLETON. Thank you.

Mr. Schatz.

TESTIMONY OF BENJAMIN SCHATZ, ESQ., DIRECTOR, AIDS CIVIL RIGHTS PROJECT, NATIONAL GAY RIGHTS ADVOCATES, SAN FRANCISCO

MR. SCHATZ. I was busy crossing out while you were talking so I didn't get a chance to listen to you as closely as I would have liked to, Russ.

My name is Benjamin Schatz. I am the director of the AIDS Civil Rights Project of National Gay Rights Advocates, a San Francisco-based public interest law firm.

I have been asked to testify about the issue of HIV antibody testing by insurers. In order to present a thorough analysis of this issue, however, I will have to place it in the broader context of the insurance industry's general response to AIDS. While the focus of my testimony will be on health insurance, many of the arguments I will make apply equally to life insurance as well.

There is evidence that both health and life insurance companies have taken extraordinary measures to avoid paying for AIDS-related costs. One researcher found that the percentage of health costs paid by insurers for people with AIDS in San Francisco plummeted from 56 percent between 1982 and 1984 to 34 percent by the third quarter of 1986.

In 1987 a national study of public and private teaching hospitals revealed that private insurance was the source of payment for only 17 percent of patients admitted with AIDS. Perhaps most disturbing are the results of a recent study by the New York State Department of Health which reveals that private health insurance was the primary source of payment for a mere 9.5 percent of New York residents with AIDS in 1984. This number decreased in 1987 to a paltry 5.9 percent.

Insurance companies have attempted to limit their AIDS-related losses in two ways. The first major method employed is underwriting—that is, the process of determining whether it is worth the risk to insure a particular applicant and, if so, what rates to charge him or her. This issue will be the focus of my testimony, and I will return to it shortly.

In addition to screening out undesirable applicants, however, many health insurers are attempting to limit their AIDS-related costs through unscrupulous postclaim underwriting—in other words, by denying financial responsibility after a person already insured is diagnosed with AIDS. Some insurers have used contractual language that disclaims liability for experimental treatments to avoid paying for AZT and other promising AIDS therapies. Others have distorted clauses that exclude payment for preexisting conditions by systematically withholding benefits to policyholders with virtually any medical ailments prior to diagnosis. Worst of all, a growing number of insurers are washing their hands of AIDS completely by declaring in their exclusions and limitations sections that they will not pay for AIDS-related expenses at all.

Although these problems are not the focus of my testimony, they occur with alarming frequency and are critically important to any analysis of the crisis in AIDS and insurance. The industry cannot demand the right to "treat AIDS like any other illness" when it wants to eliminate costs by testing, while at the same time singling out policyholders with AIDS for discriminatory treatment.

This brings me back to the issue of AIDS-related underwriting. There have been two major problems in this area. The first problem is widespread discrimination by insurers against applicants perceived to be gay. In numerous documented cases, insurance companies have attempted to deny coverage to all gay and bisexual men by screening out unmarried males, men who work in stereotypically gay occupations, or live in reputedly gay neighborhoods, men who name "unrelated" males as life insurance beneficiaries or live with other men, or men revealed to be gay through their medical records or even through hired private investigators.

Although such discrimination has been opposed by the National Association of Insurance Commissioners, problems persist. Indeed, a recent study by the Office of Technology Assessment revealed that 30 percent of insurers openly admit that they discriminate against gay applicants.

The second major problem, of course, is the use of the HIV antibody test.

The industry has presented two major arguments to support its desire for testing. First, insurers claim that prohibiting them from testing will endanger their financial viability. While these economic concerns cannot be casually dismissed, they do not withstand scrutiny. Studies by the American Council of Life Insurance and the Health Insurance Association of America have shown that their AIDS-related medical expenses are far less than commonly portrayed. The average AIDS-related claim is $33,000 for life insurance and $36,000 for health insurance, with the aggregate medical costs of AIDS totalling a mere 0.3 percent of the total group medical expenses paid by health insurers in 1986.

Moreover, testing will not significantly reduce the AIDS-related expenses of insurers. Most Americans are already medically insured, and thus insurers are already responsible for their medical expenses due to AIDS. And most new applicants obtain employer-provided group insurance where testing is not performed.

The fact is that insurers can use other techniques besides HIV antibody testing to reduce their AIDS-related costs. They can use alternative underwriting techniques which detect risk but are less stigmatizing than a positive test result. They can expand their use of cost-saving, effective treatments, such as hospice or home health care. They can limit their AIDS-related losses the way they limit losses resulting from other major expenses—by spreading their costs. One way of doing this is simply to increase premiums or reduce dividends. Yet, the most effective way for insurers to reduce the cost of AIDS is to help prevent the spread of the disease. It is clearly in the financial self-interest of the industry to increase dramatically its contributions to AIDS service organizations which are struggling to educate the public about AIDS prevention.

Besides voicing their financial concerns, insurers have argued that a ban on testing would create a special set of rules for one set of applicants and discriminate against persons with other diseases. Yet, several States have banned use of other tests by insurers, such as genetic tests for Tay-Sachs and sickle cell anemia, even though the tests involved have clear predictive value. The ban on the use of these tests reflects a belief that medical tests must not be used to discriminate against unpopular groups. The same should hold true for AIDS.

Contrasted against these relatively weak industry arguments are seven major reasons why such testing is socially destructive.

First, insurer testing continues all too frequently to be applied in a discriminatory manner against gay men. To permit testing by insurers is virtually to guarantee increased arbitrary discrimination against gay men.

Second, insurers have ignored their obligation to include counseling as part of the testing process. The National Academy of Sciences and the U.S. Centers for Disease Control insist that no one should be tested without pre- and posttest counseling. The FDA is so concerned about testing without counseling that it recently took action to prohibit the marketing of home testing kits for HIV antibodies. Yet, insurers refuse to counsel tested applicants, despite the serious potential for misunderstanding of test results and even suicide, because they don't want to pay.

Third, testing by insurers will inevitably lead to discrimination in other areas. Besides the very real danger of breach of confidentiality by insurers, there are other less obvious confidentiality problems. For example, an HIV antibody positive employee, who is rejected for individually-screened small group coverage, risks having this information made known to his or her employer. The employee is thus both denied insurance and left vulnerable to employment discrimination.

Fourth, use of the test by insurers is harmful to the public health. There is an inherent conflict between the threatening character of insurer testing and the efforts of public health officials to convince people that testing can be personally beneficial. Testing by insurers, which is voluntary only in the most strained sense of the word, increases the atmosphere of fear and mistrust which already surrounds AIDS-related testing.

A more obvious medical threat is presented by the practice of questioning applicants about the results of tests that they have already taken. At least two studies have shown that questioning about prior test results directly discourages people from taking the test voluntarily as part of an AIDS prevention program. Similarly, insurer use of the test discourages participation in vaccine trials and in the numerous epidemiological and medical studies which require volunteers to be tested for HIV antibodies. Thus, the National Academy of Sciences has warned that "discrimination in employment or insurance may defer individuals in high-risk groups from being tested."

Fifth, false positive test results continue to occur. Although the industry argues that the use of confirmatory Western Blot testing effectively eliminates the problem of false positives, the Office of Technology Assessment has calculated that fully 90 percent of Peoria, Illinois, blood donors who test positive after confirmatory screening with a Western Blot would in fact be false positives. Indeed, the OTA has recognized that "there is as yet no standard definition of what constitutes a positive Western Blot test."

Sixth, the more the insurance industry successfully evades responsibility for AIDS-related expenses, the more this financial burden will be shifted onto the government. Although insurers claim that other policyholders will be forced to pay for AIDS if insurers cannot test for HIV, this argument conveniently ignores the fact that most uninsured people with AIDS are forced onto government-funded programs such as Medicare, Medicaid, and public hospitals. In short, the enormously profitable insurance industry is trying to shift the bill onto the taxpayers who have already spent large sums on AIDS research, education, and treatment, while saddled with massive budget deficits. If health insurance premiums are not increased to cover for AIDS, taxes may have to be raised instead.

CHAIRMAN PENDLETON. How many of those points do you have?

MR. SCHATZ. This is the seventh—seventh out of seven.

Seventh, I believe the debate we are having today is a mere dress rehearsal for an even more frightening industry desire—broad-scale genetic testing. Make no mistake about it. Genetic tests are rapidly being developed for cancer, alcoholism, and hundreds of other illnesses.

Three weeks ago I joined Carl Schramm, president of the Health Insurance Association of America, in testifying before the Presidential AIDS Commission. Mr. Schramm stated that in 10 years it will be the standard medical practice to run an entire battery of genetic tests on newborn infants.

Does anyone really think that the insurance industry will not demand access to these test results as well, using the very same arguments they have made today? Think about it. Thousands, perhaps millions, of newborns may become uninsurable for life, even before they leave the hospital. If we allow insurers access to newly developed predictive tests which detect factors that an individual is powerless to change, factors such as genetic traits or HIV antibody status, then every scientific forward may in fact become two steps backwards in terms of health care availability.

I have a wonderful conclusion but I'm going to skip it.

CHAIRMAN PENDLETON. Why don't you give us your wonderful conclusion.

MR. SCHATZ. Thank you. You are too kind.

The question is: Where does all this leave us? Clearly, in a private system of insurance, insurance companies need to be able to develop underwriting

schemes that access the risk of their applicants. In addition to helping insurers, however, these underwriting practices have a broad social impact. They substantially determine who can receive quality health care. It may affect access to credit and employment as well. Thus, it is not sufficient merely to ask whether insurance classification schemes are statistically accurate or helpful to insurers. The fundamental question is whether they are, on balance, socially beneficial or harmful.

Clearly, discrimination on the basis of sexual orientation and HIV testing are socially destructive. Each is likely to increase both the extent and perceived legitimacy of discrimination against groups which are already maligned. Moreover, HIV testing by insurers will only serve to increase the acceptability of involuntary mass testing and numb us to the increasing danger that those who test positive will become the new class of untouchables—feared, shunned, and despised.

Even more alarming is the negative impact both practices may produce on the public health. Insurer use of the HIV antibody test penalizes participation in research studies while discouraging voluntary testing among people who wish to use their results to inspire safer behavior. Sexual orientation discrimination by insurers and others inevitably forces gay men to return to the paralyzing dishonesty of the closet, where a climate of fear, denial, and self-hatred makes open discussion with physicians or between sexual partners increasingly unlikely.

The insistence of the insurance industry that it has a right to take actions which will ultimately endanger the public health calls into question its very purpose. This demand might be more understandable if industry survival hinged on its ability to test for HIV or screen on the basis of social stereotypes. But, to paraphrase Mark Twain, rumors of the industry's death have been greatly exaggerated.

The debate about AIDS and insurance highlights the fundamental irony of an insurance system run exclusively for profit: those who most need insurance to pay for medical care or to protect their dependents are the least able to obtain it. Thus, the problems of sexual orientation discrimination, HIV testing, and postclaim underwriting suggest broader problems inherent in a privately underwritten insurance system. Insurers have strenuously resisted all proposals for national health insurance, arguing that they can manage medical costs better than the government. It is time for them to demonstrate this ability or admit that they have failed to accomplish their mission.

Thank you.

[Applause.]

Thank you, whoever that was.

CHAIRMAN PENDLETON. We will proceed now with questions from counsel.

MR. FUMENTO. Thank you, Mr. Chairman.

Mr. Schatz, you have criticized the HIV antibody test on a couple of grounds. First of all, you state in your written statement that the FDA has cautioned that, "It is inappropriate to use this test as a screen for AIDS or as a screen for members of groups that increase risk for AIDS in the general population."

Second of all, you talked about the Office of Technology Assessment report that said, "Fully 90 percent of Peoria, Illinois blood donors who test positive would be false positives."

First of all, as to that first point, isn't it true that this is the same test that is now licensed for use by blood banks, by the military, and by other people successfully to screen the blood?

Second, do you think it's proper to cite, as you did those FDA words, a letter from U.S. Representative Henry Waxman to the Commissioner of the Food and Drug Administration?

MR. SCHATZ. I appreciate your care in reading my footnotes. I cited it because it was something I had to have the language, but if you want to go to the FDA, yes, they have the same language. This was taken from my *Harvard Law Review* article, and I got a call basically very shortly before this saying, "Please revise your *Harvard Law Review* article," and I did not have time to go through over 100 footnotes in detail. I apologize for that.

As far as the question about blood banks is concerned, you are absolutely right; it is used by blood banks, and I think that is very much in conformance with the labeling of the test because it's used to protect the public health and to screen blood. That's why the test was developed in the first place.

In terms of the military, I think you are right it is being done that way. We could perhaps engage in a discussion about whether that is appropriate, but I'm sure you've already done that and you probably don't want me to get into that.

CHAIRMAN PENDLETON. Mr. Schatz, this is your time to answer like you want to answer. This is a matter of establishing a record for the public. I would not like for you to pull any punches in this process. That would be unfair to you and those whom you represent.

MR. SCHATZ. I think that testing by the military is completely contrary with the appropriate use of the test. The military has stated that they need to use the test because of the possibility of battlefield transfusions, which in fact don't occur at this point. The military could very easily have people—they use the test not only to test people but to exclude people and for the purposes of discrimination. The military could very easily, even if they were to test people, still allow them to enter the military. Even if we assumed the battlefield transfusion situation was one which was legitimate, obviously not all people in the military are on the battlefield. For example, women are allowed in the military and they don't participate in battlefield exchanges.

So I think that, quite frankly, the military's use of the test has been a dangerous precedent, which has been used by others, but I don't see any real justification for the use of the test for purposes of discrimination.

COMMISSIONER DESTRO. May I just get in with one question. We heard testimony from the Army representative, Dr. Burke from Walter Reed, who indicated—actually, he was not contradicted by Dr. Dawson of the AMA—that the amount of false positives is extremely low.

COMMISSIONER BUCKLEY. One in 135,000.

COMMISSIONER DESTRO. Yes, one in 135,000.

This may be anticipating the second part of your question, but how do you explain the discrepancy between the OTA figures and the military's figures?

MR. SCHATZ. One in 135,000—I have never heard anything even similar to that in terms of the amount of false positives. Quite frankly, I don't know where that came from, but I have in my office numerous studies, the Cleary article and others, that detail the problem of false positives.

I do want to say, however, to be fair, that I don't think the false positives issue is the major issue in terms of the testing by insurers. And we can get sidetracked. I don't think that is the major issue, and that is why I devoted very little time to discussing it.

MR. FUMENTO. Then I'll wrap up quickly on that point. The explanation is that, even though the test is extremely accurate in a low-risk population, there is a high probability that a positive will be a false positive. That, in fact, was why the OTA study cited Peoria, Illinois, blood donors because they are a low-risk population. But at the same time, isn't it true, Mr. Schatz, that that was the purpose of the study, and in high-risk populations such as a group perceived to be homosexual, that in fact the possibility of a false positive would be very rare?

MR. SCHATZ. The point is—certainly for life insurers, for example, what they are doing is testing all people who are applying for a certain amount. So it is not necessarily high-risk people that you're talking about. We're talking about the use of the test by insurance companies. When they test across the board all people who are applying for $100,000 of life insurance, then you have in fact a low-risk pool, not a high-risk pool.

MR. FUMENTO. Mr. Chairman, do I have permission to enter the OTA report into the record?

CHAIRMAN PENDLETON. Without objection, it is so ordered.

MR. FUMENTO. Thank you, Mr. Chairman.

MR. IUCULANO. May I address the OTA issue at some point?

CHAIRMAN PENDLETON. How does counsel want to handle it?

MR. FUMENTO. Counsel has a limited amount of time, Mr. Chairman, and a lot of questions.

CHAIRMAN PENDLETON. Counsel is all right today. We're okay. Counsel is fine.

COMMISSIONER DESTRO. It might be a good idea to have it juxtaposed on the record.

MR. FUMENTO. Okay. Mr. Iuculano.

MR. IUCULANO. The OTA report—I guess we should be specific—was issued on September 22, 1987, in testimony to the U.S. Subcommittee on Health and the Environment. It stated that when a very small percentage, such as .01 percent, actually have HIV antibodies, a noticeable percent of the positive test results will be false positives, as you pointed out.

The conclusions of that study are not at all applicable to insurance. First, the insurance-buying population consists primarily of persons in the age bracket of 18 to 54, and it is heavily weighted toward males. Those two happen to be the highest prevalence sex and age groups for AIDS and HIV infection.

And in addition to testing all applicants above certain policy amounts, many insurers request HIV tests in part on the basis of the health history that suggests the possibility of HIV infection.

So my point is that we are not dealing with a low-prevalence population when we're talking about the insurance-buying population. As you pointed out, the OTA report admits that the test will not yield a high percentage of false positives in a high-risk population.

Now, the OTA report also got to the issue of quality control, and it said that when the tests are performed in the best labs, the tests are very accurate. And as I pointed out in my testimony, the laboratories used by the industry are such high-quality control laboratories. In fact, the author of the OTA report, Dr. Miike, has visited the laboratories that the industry has used. And 85 percent of the industry testing is conducted by Home Office Reference Laboratory in Lenexa, Kansas. They are federally licensed. They undergo proficiency testing by the College of American Pathologists, and they have always received excellent ratings.

Let me conclude with one point on the OTA. That was issued in September of 1987, 1 month before the FDA licensed the Dupont Western Blot which, as you know, has a much higher specificity level, and the OTA report has a sentence in it that there is at present no standard for determining a Western Blot. But 1 month later we have a standard, and the industry is in full conformity with that standard through the use of the Dupont test.

COMMISSIONER BUCKLEY. Which test does the industry use?

MR. IUCULANO. We use the three-test protocol: double ELISA, confirmed by the Dupont Western Blot.

COMMISSIONER BUCKLEY. So once you get a positive ELISA—

MR. IUCULANO. It's repeated.

COMMISSIONER BUCKLEY. —you go on to another ELISA, and a Western, just like the Army does?

MR. IUCULANO. That's correct.

MR. FUMENTO. Mr. Iuculano, to get into more of the meat of the subject, a study that came out in March—and there was a news article about it that was sent to the Commission—showed that in 9 years from date of infection, 50 percent of HIV seropositives will develop AIDS, and an additional 25 percent will become sick with ARC.

MR. IUCULANO. Are you referring to the British Medical Journal, the study out of the University of—you say March of '88?

MR. FUMENTO. Yes, March of '88.

MR. IUCULANO. Yes, I am familiar with that study.

MR. FUMENTO. Again, on average, we are told that AIDS victims will die a little more than a year from diagnosis. So in other words, fully 50 percent of seropositives, 10 years within seroconversion, will die.

Do you have similar actuarial information on other groups such as smokers or victims of diseases over which there is no behavioral control, such as congenital diabetes?

MR. IUCULANO. We do, to the extent the mortality levels are. Sure, we've been tracking smoking for years; we have been tracking diabetes. And when you try to compare the mortality levels such as those you have alluded to in the *British Medical Journal* with those for smoking and diabetes, AIDS just takes it right off the mortality charts.

To meet the mortality costs for smoking, companies generally charge a premium that is two times standard. For diabetes, it's three times standard. But even if we took a conservative assumption that only 20 percent of those who are infected will get AIDS over a period of 5 years and die within 7, that is a premium amount of 26 times standard.

Most companies have an upper limit of five times standard in deciding who they will or will not insure. When you get at levels of 26 times standard, it becomes real hard for companies to ignore that.

The other point I wanted to bring out is that Mr. Schatz alluded to the fact that he doesn't feel that the impact of AIDS has been sufficiently profound. Well, it is important to recognize the long latency period of this disease. It's 7 years or more. Today's dying AIDS patients reflect those who were infected with HIV in 1979 or '80. Those dying in 1995 are being infected today. So insurance companies are acutely aware of the fact of something that doesn't come out in debates such as these, and that is that what we are seeing today is merely the tip of the iceberg. And it is very difficult for them to turn a blind eye, in the face of estimates such as those that you have cited from the *British Medical Journal* in the range of 75 percent or more.

CHAIRMAN PENDLETON. Mr. Schatz, is that what you said—what he said you said?

MR. SCHATZ. I certainly didn't say that the effect of AIDS is not profound, no.

CHAIRMAN PENDLETON. I saw you sort of flinch. I just wanted to make sure you got back on the record.

MR. IUCULANO. That's how it came out in my notes, Mr. Chairman.

MR. FUMENTO. Mr. Iuculano, you were talking about problems such as diabetes where you would charge a higher premium because as a group they are at much higher risk.

MR. IUCULANO. Right. They are ratable. Certain types of diabetes can be priced.

MR. FUMENTO. Is there any other illness whereby you generally or often will not insure anybody, period, such as appears to be the case often with HIV?

MR. IUCULANO. Certain forms of cancer.

CHAIRMAN PENDLETON. How about cardiovascular disorders?

MR. IUCULANO. There are some forms of recovered cardiovascular disorders that can be insured at a premium level somewhere around four or five times standard.

MR. FUMENTO. If individuals are hypertensive beyond a certain point, do they fall in that category?

MR. IUCULANO. Hypertension usually falls in the category of two to three times standard mortality.

MR. FUMENTO. But there is precedent, then, for medical conditions whereby you simply don't insure somebody?

MR. IUCULANO. Sure. Full-scale cancer that is untreatable.

MR. FUMENTO. Mr. Schatz, my question for you is: To avoid discrimination against people with HIV, some people might think you're asking for discrimination in favor of them, because there's always a precedent for excluding people on the grounds of very high possibilities that they will die within the next few years, and you're saying let's cut out an exception for people with HIV.

MR. SCHATZ. I would point out that there are other tests that insurance companies are not allowed to use, for example, the test for DES [Diethylstilbesterol, an estrogenlike compound formerly given to pregnant women that resulted in both pre- and postpubescent carcinoma in female offspring.]. In many States, if a woman was exposed to DES because her mother took it, insurance companies aren't allowed to use that. Now, that does predict risk. But it was felt because of social policy considerations, it would be destructive to allow insurance companies to use the test.

What I am arguing is that it is destructive to allow insurance companies to use the test— what you have been focusing on, and legitimately so, is the risk to the insurance companies. I would be a fool if I was to say that no, there is no risk to insurance companies. They will have to absorb some claims if they are not allowed to use the test.

COMMISSIONER BUCKLEY. Are you saying that with DES you would die?

MR. SCHATZ. I believe—someone correct me if I'm wrong—a woman whose mother used DES has increased risk—

COMMISSIONER BUCKLEY. Of dying?

MR. SCHATZ. Yes.

COMMISSIONER BUCKLEY. Dying of cancer? Do you know of this?

MR. IUCULANO. Yes, I am familiar with it. Mr. Schatz is correct that there are about four or five statutes in this country that prohibit the consideration of exposure to DES in determining insurability. But I think it is important to point out that when you try to analogize exposure to DES with infection with the AIDS virus, it's a very strained analogy. When you're dealing with DES, you're talking about a closed block. In 1973 the FDA ordered all the drug companies to take the DES drugs off the shelf. So we are dealing with a closed block here. And moreover, there are some questions in the minds of many in the medical community as to the nexus between exposure to DES and the ultimate development of cancer. I submit to you that there is not much of a question about the causal link between HIV infection and the ultimate development of AIDS.

COMMISSIONER BUCKLEY. Do you know what the life cycle or lifespan in these women would be from the time of exposure to DES? Do they die within 5 to 10 years?

MR. IUCULANO. I don't know.

MR. SCHATZ. No, they were exposed to DES in utero.

COMMISSIONER BUCKLEY. I know, but do they live—

MR. SCHATZ. To be women, yes.

COMMISSIONER BUCKLEY. So they live more than the 5 to 10 years.

MR. SCHATZ. But the reason I raise this is not to say, yes, DES is equivalent to HIV. The reason I raise this is to say—you know, the argument that we often hear is you can't make a special exception for AIDS. And what I'm saying is special exceptions have been made before for social policy considerations. I'm using that to defeat that argument that this is a new special thing that has never been done before. That is why I focused in my seven points on the seven dangers of allowing use of the test because it is destructive to society, both medically and socially.

CHAIRMAN PENDLETON. We have sort of joined counsel in questions, so don't feel we've kind of cut you out.

MR. FUMENTO. I appreciate that, Mr. Chairman.

CHAIRMAN PENDLETON. I just want to understand. Mr. Schatz, are you saying that not only should there be a special allowance for AIDS patients but special rates? There is a difference in making an allowance. I think Mr. Iuculano has talked about diabetes, and my colleague talked about cardiovascular heart attacks, and we've talked about the kinds of actuarial tables that surround, if you will, chronic diseases since we don't get much of the communicable diseases in this respect anymore.

My question, once again, is: Are you talking about a special rate as opposed to a special consideration?

I'm not debating whether they should or should not. I'm trying to be clear on what you're saying.

MR. SCHATZ. I think there are a variety of possibilities that would be better than what is happening now.

CHAIRMAN PENDLETON. A variety of rate possibilities? Because my question was specifically about rate.

MR. SCHATZ. The ideal, as far as I'm concerned, would be to forbid particularly health insurers—I think there is a stronger argument for life insurance in terms of use of the test—to forbid health insurers from using the test in a small minority of applicants who they actually do test, period, and to spread those costs.

CHAIRMAN PENDLETON. But I'm still not straight about rates.

MR. SCHATZ. If they don't use the test, then they don't know who has tested positive or not.

CHAIRMAN PENDLETON. Let me be clear. There's some testing going on right now. Do we agree?

MR. SCHATZ. Right.

CHAIRMAN PENDLETON. When you say "spread the costs," as an almost business person to me that means I have to spread my overhead over as many customers—better still, if I run a public transportation company, I have to spread the overhead over the number of miles those buses travel, and I can assume it takes so much money to operate those buses, and my revenue is depending upon whether or not I can get a payback.

I think what Mr. Iuculano is getting to, and maybe what I'm getting to, is where do you spread the costs? Over that AIDS population? Or do you spread the costs over the entire population?

MR. SCHATZ. Spread the costs.

CHAIRMAN PENDLETON. But why should the cost be spread over the entire population?

MR. SCHATZ. Let me give you two answers to that. One, the cost is going to be spread across the entire population anyway, either through their capacity as taxpayers or in their capacity as insurance policyholders. I think, given the fact that there is substantial evidence, which I cited, that insurance companies are already diminishing steadily the percentage of costs that they are paying for AIDS, I think there is an argument that we need to do this to get it back up.

Secondly, I'd like to point out—and Russ, correct me if I'm wrong on this—I'm sure you would, anyway, but I'm inviting you to—there is precedent for cost spreading in terms of insurance in all sorts of areas. One that comes to my mind, because I signed it recently—I live in California, and there is a 5 percent surcharge if you want earthquake insurance for your house. Now, that's the maximum you can impose, regardless of where

you live in California. So that means people who live in relatively safe houses are subsidizing people who live in the San Andreas Fault.

So this is something that is done routinely in insurance.

CHAIRMAN PENDLETON. When I come here to get a rental car on the government, the rental car might cost me $90 a week.

MR. SCHATZ. You get better cars than me.

CHAIRMAN PENDLETON. That's the government rate. If I am a private business person I can spend as much as $400 a week for the same car, which means that somebody is subsidizing the government rate. Do you agree?

MR. SCHATZ. Yes.

CHAIRMAN PENDLETON. So you're saying that's okay.

MR. SCHATZ. I'm saying that I agree that that's a fact.

CHAIRMAN PENDLETON. Okay. You are not saying it's okay.

MR. SCHATZ. I have no idea if it's okay. Obviously, it's a leading question.

CHAIRMAN PENDLETON. I'm talking about the cost—your term was spreading costs.

MR. SCHATZ. Right.

CHAIRMAN PENDLETON. It's okay to spread the cost from one to subsidize the other.

MR. SCHATZ. In some contexts, spreading costs is okay, yes.

CHAIRMAN PENDLETON. And in the case of insurance for AIDS patients, you believe it's all right to spread the cost—take the public out of it—to spread the cost over the private health insurance route.

MR. SCHATZ. Yes.

CHAIRMAN PENDLETON. Spread all those costs.

MR. SCHATZ. Yes.

CHAIRMAN PENDLETON. Okay. Counsel.

MR. FUMENTO. Mr. Iuculano, is it true that at one time the insurance industry denied coverage to people because they were Jewish?

MR. IUCULANO. Not to my knowledge.

MR. FUMENTO. Have there been occasions where the insurance industry has denied coverage on invidious grounds—race, religion?

MR. IUCULANO. I'm not aware of denials of coverage based on those grounds. There may have been a time 20 or 30 years ago, perhaps, where because of differences in mortality there were race-distinct coverages. But my understanding is that we are talking about a very small percentage of the industry, and over time that mortality improved. I'm aware of very little of that that goes on.

MR. SCHATZ. Can I respond to that? If you want—I don't know the case name but I can point to you case names in which people were denied insurance because of their race, and insurance companies argued that they had the legal right to do so. The change did not happen because of any

change in terms of differential mortality between blacks and whites. The change occurred because of the civil rights movement, and the argument that even though blacks tend to live less than whites and have more medical problems, that that was not something that insurance companies should be allowed to use.

CHAIRMAN PENDLETON. But we still don't live any longer.

MR. SCHATZ. Well, there is still a relative—

CHAIRMAN PENDLETON. I mean we don't live any longer. We have other problems in living longer in terms that you can't do anything, but changing the rates around don't make us live any longer, do they? They don't give you a better benefit, do they?

MR. SCHATZ. I don't follow your question.

CHAIRMAN PENDLETON. That's okay. Go ahead.

MR. FUMENTO. Mr. Iuculano, what I'm getting at is you can understand that there is a natural fear, perhaps, on the part of homosexuals that they are being singled out.

MR. IUCULANO. Sure, I can, and that's one of the reasons why we have said and advocated in every jurisdiction that sexual orientation has no place in the underwriting process. We have supported the NAIC [National Association of Insurance Companies] model guidelines that are now in place in eight States in the form of regulation, and this year the forum has changed and this is becoming a legislative issue. Most recently the State of Vermont passed a law that prohibits the use of sexual orientation. We supported that provision.

MR. FUMENTO. That gets at my question for Mr. Schatz, then. Mr. Schatz, you stated in your written statement, "In no other instance are insurance companies attempting to weed out an entire social class simply because a small percentage of that class is expected to develop that disease."

But insurers reply that this won't happen if they are allowed to use a very specific test for the virus. They are saying, "Listen, if you don't let us use this test for the virus, we're going to use zip codes to exclude places like Dupont Circle or Christopher Street or the Castro section; we're going to use occupation to screen out people like hairdressers or fashion designers. If you don't let us use the test, then one way or another you might try to pass a law against it, but you're going to end up with discrimination against people as a class, discrimination against people strictly because they are homosexual."

Do you see that as a concern?

MR. SCHATZ. Let me respond in this way. I think that is really a dangerous argument that the insurance companies use, and it's dangerous for them. Because what they are basically saying is, "Hey, if you don't let us use the test, then we are going to violate the law by discriminating on the basis of sexual orientation."

MR. IUCULANO. We're not saying that.

CHAIRMAN PENDLETON. There is no violation of the law. In the Federal domain there is no violation of law; right?

MR. SCHATZ. Insurance is not regulated federally; it is regulated by the States. If you look at the Unfair Trade Practices Act, I believe this covers this issue, and I have argued that in my *Harvard Law Review* article, and we can get into a discussion of that.

At any rate, what I'm saying is I don't think that's an argument which the insurance industry really wants to make, because what they're saying is, "Hey, if you don't let us use this toy, we're going to discriminate against gay people," which they have already said they are opposed to doing. If they are opposed to doing it, then they shouldn't threaten that they're going to do it.

Secondly, I think you have to keep in mind—Russ did work on the NAIC guidelines; he and I were on the committee together—the ACLI [American Council of Life Insurance] and the HIAA [Health Insurance Association of America] both supported the guidelines prohibiting antigay discrimination. However, supporting guidelines does not mean that such discrimination does not occur, and I have to say I was absolutely shocked when I read the OTA report in September to see that 30 percent of the insurance companies actually admitted—I mean, they could have hidden it—they actually admitted they discriminate on the basis of sexual orientation. If 30 percent admit it, you can be sure that more are doing it. Just because the chief executive officer says, "Don't use sexual orientation" does not mean that an individual underwriter is not going to do so, and there are many examples in which that has been done and continues to be done.

MR. IUCULANO. I do want to correct the record that we have not been saying, "If you don't allow us to use objective measurements we are going to use subjective." We've said, right from the start, that what we are doing is lobbying for objective measurements of who is infected and who is not. That's been our position everywhere, and I use the District of Columbia as a case study. We have been working for 2 years to try to correct that law, but we have never offered to tamper with the antidiscrimination provisions in the D.C. law which forbid the use of sexual orientation or its surrogates.

MR. FUMENTO. Excuse me, I didn't mean to say the insurance industry leaders. I just meant it's going on.

MR. IUCULANO. Okay. We haven't made an ultimatum to policymakers that it's one or the other. We advocate the use of objective measurements.

MR. FUMENTO. But then would zip code restrictions be a violation of a sexual preference?

MR. IUCULANO. In eight States, by regulation, yes, and most recently in a few States by statute, yes.

COMMISSIONER DESTRO. Generally or across the board zip code? Are you talking about zip code being a violation of sexual preference rules?

MR. IUCULANO. Correct.

COMMISSIONER DESTRO. Or just the use of zip code, period?

MR. IUCULANO. The best example—in the District of Columbia, the law says if you use that as a surrogate to determine who is at risk for AIDS, it is a violation of the law.

COMMISSIONER DESTRO. So basically they are equating using zip code with sexual preference discrimination?

MR. IUCULANO. Correct. The NAIC guidelines expressly forbid that, the use of zip code.

COMMISSIONER DESTRO. But you can use zip code for other things?

MR. IUCULANO. The precise wording of the NAIC guidelines, which I have for the benefit of the Commission and I'll be happy to put it in the record, says you can't use that to ascertain sexual orientation.

COMMISSIONER BUCKLEY. But you can use it for car insurance; right?

MR. IUCULANO. Yes.

MR. FUMENTO. Mr. Schatz, in your statement you stated you thought that the problem had really been somewhat overblown, that by the time you look at the actual payout costs and all the costs combined, the insurance industry isn't saving that much money. Don't you think perhaps that's a decision best left up to the insurance companies? If they're paying for the costs of the tests, and they know they're driving people away by demanding the tests, that they have somehow decided that it is in their interests.

MR. SCHATZ. I think your question is equivalent to saying, you know, "Manufacturers insist that they are not really polluting the air very much. Don't you think that's a decision best left up to manufacturers."

I think this is a question that has a broad social impact. They are using the economic arguments to say, "Look, the sky is falling; the sky is falling. We have to have this test."

And I'm saying, "It looks like it's still up there." I don't want to say that this is something that all you have to do is snap their fingers and pay. There will be a sacrifice on the part of the industry. What I'm saying is it's not as great a sacrifice as they would perhaps lead us to believe, and that the testing part of it is only going to eliminate a tiny fraction of their financial burden.

CHAIRMAN PENDLETON. Mr. Schatz, let me just ask a question here. From this great scholarly journal, *USA Today*, it indicates here that the average medical costs per AIDS patient is $168,000. The total annual costs are $8.7 billion. And in keeping with Mr. Iuculano's argument, and perhaps part of yours, projected by 1991, medical expenses for people with AIDS is estimated to reach $66.5 billion annually. Whereas you may believe that those costs should be spread, do you happen to believe that the public,

either from the public or private domain, general public, is willing to certify to pay those costs, if these costs are accurate? I mean I have some other numbers from another journal.

MR. SCHATZ. I would urge you to look at perhaps other even more scholarly journals.

CHAIRMAN PENDLETON. Well, I'll give you one before you go to your answer, then. I want to submit for the record the "Economic Impact of AIDS in the United States," by David Blum and Geoffrey Collinan, in *Science* magazine. They estimate that the costs would not exceed per patient—let me back up.

"This analysis of several previous studies of the cost of AIDS suggests that the lifetime costs of medical care per patient will not exceed $80,000, an amount similar to the cost of treating other serious illnesses," which is part of your point. "If current projections of future AIDS cases are accurate, the cumulative lifetime costs of 270,000 cases diagnosed between 1981 and 1991 would not exceed $22 billion"—not a small sum. "This amount is small compared to the total U.S. medical spending."

Well, it may be small in comparison, but do you believe that the public is willing to increase the cost by $22 billion?

MR. SCHATZ. First of all, I think even those figures could be played with, but let's just accept them for a moment because we could quibble over figures. I can show you my studies; you can show me yours.

In terms of public acceptance, it depends what question you ask them. If you ask the public, "Hey, General Public, would you like your insurance rates to be raised?" I suspect most people would say no. If you said to them, "Which do you prefer? To have these costs be absorbed by the insurance companies or by the taxpayers, which do you prefer?" I suspect you might get a very different answer to that.

The point I am making is you're talking about the public, and in their role of insurance policyholders they're going to have to pay, whereas otherwise they won't, but they're going to have to pay anyway.

CHAIRMAN PENDLETON. You're very skillful at this, like you were in your paper, but it's not $22 billion for the general public's cost; it's $22 billion for the cost of AIDS alone. And my question to you is: Do you think they're willing to add just for that disease alone?

MR. SCHATZ. No. What I'm saying is that, either way they are going to pay for the bulk of it. If the people are not insured—first of all, in terms of that $22 billion, don't forget that most people are already insured. So theoretically, at least, a lot of those costs can't be shifted from the insurance companies because people are already insured.

COMMISSIONER BUCKLEY. But premiums can increase.

MR. SCHATZ. Right, but that's not related. What I'm saying is the insurance companies have already assumed the risk. Eighty-five percent of

Americans have health insurance at this point. So those costs can't be shifted.

CHAIRMAN PENDLETON. That's not what we're saying. I'm sorry, go ahead, Bob.

COMMISSIONER DESTRO. Let me just break in. I want to be sure we are not mixing apples and oranges because I think that's what we're getting into. Assuming you are correct—and I have no reason to quibble with it—I think the figures I've heard are approximately that 85 percent of Americans have health insurance—that assuming that the person had no preexisting conditions and the insurer accepted them as a risk, as an underwriting risk, then the insurance company by contract is on the hook so they have to pay.

The discrimination issues that we've heard about with respect to health insurance would be more that you fire people and they lose their health insurance. That's one point.

But let me go back to the point we were talking about. I just want to make sure that we distinguish between general risk spreading—and I was privileged to participate in a debate on the D.C. law at Catholic University where Mr. Levi appeared in the debate. And there was somebody from the insurance industry there. I just want to make sure I am understanding you correctly because we made sure we understood each other. As the moderator of that debate, I wanted to make sure the record was clear for the people in the room.

When you talk about spreading the risk in testing, what you are really talking about is somebody assuming the risk without knowledge of what the risk is, for the purpose of spreading the risk.

MR. SCHATZ. Exactly.

COMMISSIONER DESTRO. So, in other words, they are not really assuming the risk; they are just being asked to say, "Look, we'll cover this person without regard to a certain risk."

MR. SCHATZ. You can phrase that however you want to, and to sort of combine the two questions that you are raising, what I am saying is that if insurance companies are allowed to screen out everybody who is seropositive, then the overwhelming majority of those people will go on to Medicaid and their costs will be picked up by the taxpayers.

COMMISSIONER DESTRO. That's your point, that the public will pay one way or the public will pay the other way.

MR. SCHATZ. Right.

COMMISSIONER DESTRO. This is the question I posed to Mr. Levi, and I won't say for the record what he said, but doesn't that then convert insurance into in effect a Medicaid program for purposes of this disease?

MR. SCHATZ. Again, that is a sort of a complicated question. The insurance industry has a variety of special tax breaks because they argue that they are quasi-public. There is case law saying that insurance

companies are quasi-public in terms of their purpose—certainly in terms of health insurance. And I think there's a major difference here in terms of health and life. I think that such a strong argument can be made. The United States is the only Western industrialized country besides South Africa that doesn't have a form of national health insurance. The reason for that is the insurance industry has fought and said that they are better able to manage health care costs. So it seems to me there is a major argument that the insurance industry can't have it both ways.

COMMISSIONER DESTRO. I understand your argument. I understand it perfectly. But I just want to make sure that it's clear, because I think in essence, if I can translate the argument with respect to tax breaks, it's not unlike the argument that is made with respect to tax-exempt hospitals and everything else. You get the tax exemption because you're performing a quasi-public function.

So essentially what you're doing is saying that with respect to health and life insurance, although there is a reasonable distinction to be made between the two, that we ought to see health insurers in particular as performing a quasi-public function for the purposes of coverage of AIDS and just recognize that we are simply asking them to kick in their share of the costs of the epidemic, and to see the tax breaks as their compensation for it.

MR. SCHATZ. I'd say I basically agree with you and add one more thing, which is that when we are talking about the costs being picked up by insurance companies, that's why I said at the beginning I was trying to place this in a broader context of the insurance industry's response to AIDS. We now have a growing number of insurance companies that have provisions that say, "We will pay $1 million for cancer; we will pay $1 million for heart disease; we won't pay for AIDS."

I get at least a new one of those a week at my office in San Francisco. So a part of my concern is I think that the insurance industry is treating AIDS differently from other illnesses. It's treating people with AIDS even worse.

COMMISSIONER DESTRO. Are those special riders that you have to buy, though?

MR. SCHATZ. No, they are across the board.

CHAIRMAN PENDLETON. Is that true, Mr. Iuculano?

MR. IUCULANO. It would be helpful if he identified whether these were insured policies or self-insurers.

MR. SCHATZ. Both—Fidelity Life.

CHAIRMAN PENDLETON. We don't want you to give any names here.

MR. SCHATZ. I can guarantee you it's true. I can get you the copies.

MR. IUCULANO. My point is two or three companies does not a trend make, and I don't think it's fair to say that this is an industry standard. We have been saying that AIDS should be treated as any other disease, and I

have not seen a great majority of companies filing that kind of a rider as he is saying.

CHAIRMAN PENDLETON. Mr. Schatz, one more point. I don't believe you can guarantee that the public will pay the cost of AIDS treatment. We heard some testimony before that the taxpayers will pay the costs, whatever they are. We heard some testimony before that there might be some push and pull to that, and the public might be clearly saying—you and I live in a State that does strange things. There's a gentleman over here who understands about strange things, and he put in Proposition 13. People said Prop 13 would never work. The legislature wouldn't curtail it, and it wound up being what we call Jerry Jarvis' bill. Jerry Brown didn't like it. Suddenly he liked it, so it kind of got to be Jerry Jarvis' support mechanism.

But what I am saying to you is there could be a proposition in a State like California where the public could say, "We're not going to pay these costs," or, "We're going to cap these costs." And I am not giving a threat. I'm talking about the political process that goes on. I don't want to go into the other reasons for that, but in terms of this people could easily say in the public domain either we have some tests or we limit the costs on the medical treatment for people that have AIDS and maybe go back to HIV positive if that's necessary.

That could happen very easily. So I would just caution you not to give to us the assumption that if you don't pay for it through insurance because the testing does some things, that it will be paid for by the taxpayer.

MR. SCHATZ. Let me respond to that. What I am talking about being paid for by the taxpayers is largely through Medicaid, which is a Federal-State program. So I would consider it very unlikely that they could say, "Hey, you will not pay for this life-threatening illness in one State," when there is a Federal problem in terms of that.

CHAIRMAN PENDLETON. I'm only saying to you that at some point a momentum could gather to a point where everybody would have a real serious problem.

MR. SCHATZ. The point is, if it wasn't paid for by Medicaid, it would go through public hospitals. If public hospitals didn't pay for it—there's the problem of hospitals turning away people because they can't pay. In some States that presents a legal problem. But those costs would be absorbed, in all likelihood.

But if we did get to the point where people said, "Okay, if you have AIDS you have to die in the street," I think, yes, it would be a major problem, and I certainly hope we never get to that point, and I don't think it's very likely.

CHAIRMAN PENDLETON. I hope not, either. But I'm just saying to you I would not find comfort in the fact that it's going to be paid for one way or another.

MR. SCHATZ. Well, assuming that we have a marginally compassionate society, that is not going to happen.

CHAIRMAN PENDLETON. That's a good assumption when it comes to money.

COMMISSIONER DESTRO. That's also true, but keep in mind that 100 years ago when there was no health insurance and there was no Medicaid, instead of having people dying on the street, the charitable sector picked up the cost of much of this, too. So I have no doubt that it will be picked up by somebody. The question is who is it going to be.

But I really want to make sure—and I know counsel has another question—that we keep the focus here not so much on who should bear the cost but on the discriminatory activities, and especially those which relate to, for example, people getting fired and then losing their health insurance and all their dependents lose their health insurance. And that does not appear to be as much of a problem in the gay community as it would be in some of the minority communities.

MR. IUCULANO. But wouldn't that be a labor law issue more than an insurance issue?

COMMISSIONER DESTRO. Just like the real estate people told us yesterday, all they do is follow the market. My feeling would be that the insurance industry—their feeling, I'm sure, is who is going to pay for the insurance if it's not the employer. But I do know there have been debates with respect to what happens, up in New England, for example, to people who get fired from their jobs or laid off from their jobs. What happens to their health insurance?

What we heard yesterday was testimony with respect to discrimination on the basis of AIDS which leads to loss of job by either the AIDS victim or the spouse of the AIDS victim, or the family member of the AIDS victim, which then translates into the loss of all insurance. So even though it wasn't the insurance company that did the discriminating, it was the employer, which then had the impact of denying everybody in the family.

MR. IUCULANO. I think it's important to point out that insurance testing has a very limited role in the employment process. Ninety percent of the health insurance that is in force is group insurance, and the vast majority of that does not involve testing to determine insurability. If these people were employable at the time they got their coverage and they took it when it was first available, underwriting was not at issue.

COMMISSIONER DESTRO. What about preexisting conditions? Those aren't covered or are covered?

MR. IUCULANO. Preexisting conditions may be in place in the context of smaller policies and if people switch jobs. There's an underwriting concern there that people would switch jobs solely to take advantage of a richer set of benefits. But the preexisting condition clauses would be invoked for purposes other than AIDS. They've been in existence for many years.

But I do think it's important that we differentiate. When you're talking about discrimination in the employment context, it depends in large part, for example, under Federal law, whether we're talking about the Vocational Rehabilitation Act which recognizes physical handicap and perceived physical handicap, and then at the State level whether there are laws that protect handicap or perceived handicap in State legislatures. You know, that's a growing body of law, and I don't think it's fair to interpose the insurer as furthering that dilemma in any way.

MR. SCHATZ. Can I respond to that?

CHAIRMAN PENDLETON. Briefly, because we have about 20 minutes left, and we have a few more questions here.

MR. SCHATZ. What Russ is saying is generally true but it does not apply in the case of small group insurance. I work for a small organization. When I joined on, my policy was individually underwritten. If you work for a corporation with maybe 50 or 100 people, there's a good chance that you will be individually underwritten. There's a good chance you will be tested. So there is a major interplay between the employment and the insurance context which very often is glossed over. And particularly when you work for a small company and you are declined for insurance, there is a lot of pressure. You know, "What's the story? Why were you declined? What's wrong here? I'll contact the insurance company." And there are major problems between employment and insurance.

Russ is technically right in saying this is not a matter of insurance law; this is a matter of employment discrimination law. But when the insurance industry engages in behavior, which then factually produces employment discrimination, that is obviously one of the fallout factors that need to be considered in terms of the benefits or the liabilities of testing.

CHAIRMAN PENDLETON. Counsel.

MR. FUMENTO. I'm just going to ask one more question before I turn my questions over to the Commission.

CHAIRMAN PENDLETON. Before you share your questions. We shared with you; you share with us.

MR. FUMENTO. Mr. Schatz, we have received calls at the Commission—we often receive complaints. People think we handle complaints, but we refer them out. We have received calls from people who have recently moved to the District who have said that they have just found out that they cannot get insurance. They could under a group plan but they can't as individuals. They think that's a violation of their civil rights. What happened is the District is the only jurisdiction, city, that has prevented HIV testing for underwriting purposes, and all the insurance companies—virtually all of them, perhaps all—have fled. That's the market at work.

Is there any way around that?

MR. SCHATZ. I don't think that's the market at work. You will note that California does not allow testing, and they haven't been fleeing from

California. You could ask that question of me or you can ask that question of Russ. I don't believe the insurance companies fled D.C. as an economic decision. I believe they did it as a political decision, because now this can be held over the heads of all other States who are considering legislation. They can say, "All the insurance companies are going to leave; they did it to Washington."

Washington is a very, very small market. California is a large market. Insurance companies have been thriving in California despite the ban on HIV testing.

CHAIRMAN PENDLETON. Do not forget that it might be a small market, but there's a lot of impact in this small market.

MR. SCHATZ. Exactly.

CHAIRMAN PENDLETON. Political impact.

MR. SCHATZ. Exactly. I think that's why it was done.

CHAIRMAN PENDLETON. On everybody's part.

MR. FUMENTO. I'm going to let Mr. Iuculano wind up, but I believe the difference here is that D.C. is a city with a very high rate of seropositive individuals, whereas in California there are pockets, such as San Francisco, L.A., and San Diego, of high seropositives, but they can spread the risk out throughout the whole State, the insurance companies, whereas in D.C. it's just D.C. and they can flee to Maryland they can flee to Virginia, and they can do just fine, thank you.

Mr. Iuculano, is that correct?

MR. IUCULANO. First, I think it is impossible to compare the California law—as it pertains to insurance, we're talking about one sentence—as opposed to the D.C. law, which is 13 pages. That's number one. And the California law only applies to the use of the antibody tests. It does not prohibit the use of the T-cell test, which is a surrogate test that companies use that measures whether you have a compromised immune system. That has been perfectly legal in California since 1985, the year they enacted it.

That test, the T-cell test, is expressly forbidden in D.C., as is the virus-specific test, even though that is not commercially available yet.

And there is another reason that companies have a difficult time turning a blind eye to the epidemic in the District. In every State in this country you can ask someone: "Have you been diagnosed or treated for AIDS or AIDS-related complex?" which as you know is a precursor to AIDS, and for every one person that has AIDS it is estimated there are 10 that have ARC. That question is illegal in the District. The D.C. law does not permit us to ask someone, "Do you have AIDS-related complex?"

Now, gentlemen and ladies, that is a disease. And it's a hard issue for the companies to jeopardize their fiscal solvency for one class of insurable. The decision to pull out in the District of Columbia, if companies made that decision, I'm sure was a difficult one. But they have never been asked

to turn a blind eye to a full-scale epidemic, as they were in the case of the D.C. law and, frankly, I think the law has been a demonstrable failure.

MR. SCHATZ. If I heard Russ correctly, the difference between the withdrawal in D.C. and the lack of withdrawal in California is that California only bans the test whereas D.C. bans other things. Therefore, since we are here discussing, "Is it the test?" I presume you would say this would not happen if D.C. only banned the test?

MR. IUCULANO. No, my point is there are surrogate tests that California has at least not prohibited for now, and I think it is important to point out that, as we speak, there are six bills that have been introduced in the California legislature that would repeal the prohibition against antibody testing. What I'm saying is that you can't compare a one-sentence law with a 13-page restrictive law, which is what we have here in the District.

MR. SCHATZ. No, if it substituted the 13-page law in D.C. with a one-sentence law that we have in California, we would not have the market withdrawal that we have in California.

MR. IUCULANO. I don't know what kind of market response there would be, but if the D.C. law were in place in any other jurisdiction in this country, companies would have an extremely difficult decision on their hands, whether it be Massachusetts, Maine, Texas, or anywhere.

CHAIRMAN PENDLETON. Commissioner Buckley.

COMMISSIONER BUCKLEY. I have several questions. I think at this point we have come to a situation where we are asking on the question of testing: Which test are we talking about? Is it just the ELISA test? Are we going into some more specific tests that would bring up immune deficiency problems in the system, in the hematic system?

I would ask both of you to answer: If you were to advocate for testing, what testing would you recommend for the insurance agency to go into?

And, Mr. Schatz, would you accept, if we were to ask for more specific tests, one that would determine the presence of the virus—if that were to be asked? Because as I understand it, insurance is a business and they're trying to survive as a business.

So if you would answer that.

MR. IUCULANO. The insurance industry has only been lobbying for the use of the HIV antibody test, and by that I mean two ELISAs and the Western Blot, because those are the best and most current and most accurate tests available from the medical community that assess the risk of developing AIDS. Each study that I have seen has confirmed their reliability and predictive value.

I mentioned the T-cell tests as a surrogate test in California, which companies had no desire to use but used in the face of this law that was passed 30 days after the Food and Drug Administration licensed the ELISA test. It is not a test that they've used by choice. It's what we call a surrogate test. And, frankly, it's not as accurate as the HIV antibody test.

There are people who could have a compromised immune system for reasons other than AIDS. It could be traced to mononucleosis or hepatitis or things of that sort.

So at this point the insurance industry is talking about the HIV antibody tests.

MR. SCHATZ. To answer your question, I may make some people and some of our members in D.C. unhappy about this, but my concern is principally with HIV antibody and viral tests.

COMMISSIONER BUCKLEY. Meaning which one? ELISA or Western Blot?

MR. SCHATZ. Either, both; just the standard HIV testing sequence.

COMMISSIONER BUCKLEY. Which is two ELISAs and a Western Blot.

MR. SCHATZ. Right. We've got that down.

I believe I would much rather see insurance companies use the T-cell test than the HIV antibody test, because it doesn't have the same stigmatizing potential and the same potential for discrimination, et cetera. So I think that I would rather see insurance companies use that. So my concern is with the HIV antibody or viral test.

COMMISSIONER BUCKLEY. I think we have two issues before us, really. We have the issue of health insurance and we have the issue of life insurance. If we separate the health insurance component of insurance and life insurance—if we separate the two, and then say, "We know if you have AIDS you will die within 5 to 10 years," with a certain percentage, whatever it is—the statistics are there. Once you know you have AIDS, you're going to die. Once you have ARC—

MR. SCHATZ. Are you talking about knowing you have AIDS, or are you talking about knowing you test positive?

COMMISSIONER BUCKLEY. Seropositivity, they have certain percentages. In 5 to 10 years you convert.

MR. SCHATZ. Are you talking about testing seropositive?

COMMISSIONER BUCKLEY. You have seropositivity.

Now, would you consider having the test for, say, life insurance versus health insurance, or the other way around? And would it be acceptable, then—if we separate the health insurance issue from the life insurance issue, would you then have a different perspective on whether or not to use the test in these cases?

I think I know your answer.

MR. IUCULANO. I don't think there should be a distinction made. While it is true that health insurance is important, private health insurance cannot solve all of our social health care needs. I guess the question I would pose to you, if I may take the liberty, is: Is it a solution to a national health care crisis to deny health insurers the right to obtain the facts about the people they insure? You can have all the facts about every disease where you need to underwrite for health insurance, except this one. What public purpose

are we serving if we allow those likely to develop AIDS to be offered health insurance without paying a penny more, while other applicants for health insurance are either charged a higher rate or are declined for reasons that don't relate to AIDS? Should we distort the fairness of the health insurance process?

I appreciate the importance of health insurance, and that where health insurers do underwrite—and this occurs predominantly in individual health insurance that is not associated with employment—there are those who won't be able to get coverage in the voluntary market. And that is one of the reasons that the health insurance industry has advocated the establishment of risk-sharing pools. There are risk-sharing pools in place in some 15 States, and in the majority of these 15 States the funding for the losses that these pools encounter is contributed to by general financing or premium tax offsets, recognizing that the funding for the pools ought to be distributed equitably among all aspects of society.

So I guess that's my answer.

COMMISSIONER BUCKLEY. Mr. Schatz.

MR. SCHATZ. I'm going to give a different answer.

I think that there is a difference—you know, both Russ and I come from organizations that are supposed to have sort of party lines on this. Russ can't say that health insurance is different from life insurance because a lot of his companies are also members of the Health Insurance Association of America. I am officially not supposed to say that we would allow testing for any purposes whatsoever.

So let me describe it this way. I am less strongly opposed to use of the test for life insurance than for health insurance. I think Russ earlier said that insurance is a contract like any other; no one is compelled to purchase insurance. I think in terms of health insurance we all know it's a practical matter, the critical importance it is, if we get seriously ill, how important it is to have health insurance.

So I think the equities are much stronger, because I'm discussing a social balancing issue. The equities are much stronger in terms of a health insurance discussion than in a life insurance discussion, although I believe they are strong in terms of both.

In terms of the statement about risk pools, they are in 15 States. There's no more than a few thousand people in all the States who have joined the insurance risk pools because the premiums are so expensive. And I think it is interesting to note what Russ said also, that the financing for those is basically done by the taxpayers. So it is not surprising that the insurance industry supports such an approach.

COMMISSIONER BUCKLEY. Can I ask one more?

CHAIRMAN PENDLETON. Yes.

COMMISSIONER BUCKLEY. Is insurance a right that everybody has?

MR. IUCULANO. It is not a right. It's a contract, just like any other.

CHAIRMAN PENDLETON. How about you, Mr. Schatz?

MR. SCHATZ. I think if I were czar—I think the AIDS insurance crisis—and I'm talking about health insurance here—raises broader questions about the role of private health insurance in America. And I think it points to broader problems that are experienced not just by people who are seropositive but by people who have all those genetic preconditions which I mentioned earlier, which we are going to be seeing down the road. This issue is going to be raised then, and I think the AIDS insurance question points to the need for some fairly major restructuring of our health insurance system. That could be done through private insurance.

CHAIRMAN PENDLETON. But that isn't the question. The question is: Under the broadest definition you want to make it, is insurance a right?

MR. SCHATZ. I believe health insurance is a right.

CHAIRMAN PENDLETON. On what basis?

MR. SCHATZ. I believe access to health care is a right.

CHAIRMAN PENDLETON. It's a right.

COMMISSIONER DESTRO. That's different.

MR. SCHATZ. I mean we're talking about human rights. We're not talking about constitutional rights.

CHAIRMAN PENDLETON. We're trying to find out—what are we talking about then but constitutional rights?

COMMISSIONER DESTRO. He's talking about a human right.

MR. SCHATZ. Right, I'm talking about a human right. I'm not saying it's a legal right. I'm saying in the same sense that justice or equality—

CHAIRMAN PENDLETON. I guess my question is: Is insurance a constitutional right?

MR. IUCULANO. No.

MR. SCHATZ. Constitutionally, no.

CHAIRMAN PENDLETON. Is it a State right?

MR. SCHATZ. What do you mean?

CHAIRMAN PENDLETON. Is it a right among States to provide insurance for people?

MR. SCHATZ. Is it a right among States to provide?

CHAIRMAN PENDLETON. Is it a right in terms of State constitutions, for that matter?

MR. SCHATZ. I'm saying legally insurance is not a right. Factually and morally, it is a right.

COMMISSIONER DESTRO. Basically what you mean is that morally society has an obligation to help people who can't pay for their own health care.

MR. SCHATZ. Yes.

CHAIRMAN PENDLETON. But in terms of a legal right, it does not exist; is that correct?

MR. SCHATZ. I think I've already made that clear.

CHAIRMAN PENDLETON. I'm not so sure you have. That's why I'm asking you again so I understand what you have said.

MR. SCHATZ. Legally it is not a right. Morally it is a right, as Mr. Destro described it.

MR. IUCULANO. Mr. Chairman, this issue was before a New York court recently, and a regulation was adopted by the New York Insurance Department. When the court struck down the regulation, they reviewed the reasons that were advanced for its adoption. And one of the reasons that was offered was that: "Denials of health insureds based on test results, which do not equate to a diagnosis, denies an entitlement to individuals who will never progress to AIDS or ARC."

And the New York decision, which came down a few weeks ago—and I'll be happy to give to this Commission—said, and I quote: "Insurance has never been an entitlement. The state has never created a policy of providing health insurance to everyone regardless of risk or in disregard to known substantial risks."

CHAIRMAN PENDLETON. Thank you, sir.

Mr. Iuculano, would you give us a letter at some point for the record about whether or not insurance companies expect to have the right to distinguish between health care institutions on the basis of the number of AIDS patients as inpatients, and for that matter as outpatients? Are you doing something in terms of the broader coverage of hospitals with respect to the number of AIDS patients?

Thank you. We have to stop.

Mr. Gann is next, but we'll take a little break, because we don't want to run into the meeting.

MR. HOWARD. You may want to announce that anyone wishing to appear during the open session should please leave their names with our clerk here, Joan Connell.

CHAIRMAN PENDLETON. Thank you.

[Recess.]

[Paul Gann was sworn.]

CHAIRMAN PENDLETON. As I mentioned earlier, we have with us Mr. Paul Gann. Mr. Gann is, I guess for lack of some other words, a productive activist in the State of California with national renown, from People's Advocate, Inc. I understand they have just turned in upwards of 600,000 signatures to place on the November ballot his latest initiative, which is the Paul Gann Public Health Act. The initiative repeals what is known as Assembly Bill 403 that California passed in 1985, which made it a crime for doctors to report AIDS patients to public health authorities. It also required confidential reporting of those with positive test results to the public health authorities. This major provision will return the ability of the public health authorities to track and respond to the spread of the AIDS virus.

I'm reading from Mr. Gann's press release. This is not something the Commission is saying, but it's his release. I do that by way of introduction, and I will add into the record the executive summary of the California initiative.

I also would like to add for the public that the record will be kept open for another 30 days or so, depending upon Mr. Destro's request for information from out of the country, and anyone can feel free to submit.

As soon as this session is over with Mr. Gann, we will have a public session, at which time people will be able to address the Commission for 5 minutes. There are no questions asked by Commissioners. If you are not able to finish your petition or testimony in 5 minutes, you may certainly leave with us any appropriate information you might have.

Mr. Gann, welcome to Washington.

TESTIMONY OF PAUL GANN, PEOPLE'S ADVOCATE

MR. GANN. Ladies and gentlemen, I am Paul Gann from California. I had a heart attack in 1982. I went to the hospital, and a few days later they found out I had to have open heart surgery. So on March 6, 1982, I had open heart surgery, and I was unconscious for about 14 days, living on borrowed blood. Some of that blood wasn't very good. In fact, I have AIDS. I have HIV. I don't have AIDS. [The witness has been diagnosed with ARC—AIDS-related complex.] It came from a blood transfusion.

And I feel like AIDS is different from any other known disease that we have. As an example, the doctor just told me recently that the reason it was different is that we had researched cancer for 100 years and spent a trillion dollars, and every once in a while I get a call from somebody that tells me a friend just died of cancer. And I'm saying we can't do that with AIDS because in 100 years, if we let AIDS go the way it's going today, there won't be any of us around to conduct the funeral services.

So we have to be a little different with AIDS. There is no cure for AIDS today, none whatsoever. And I am informed of that by 2,000 doctors that worked with me on my initiative this year, that there is no cure, and the only way that we have of stopping the spread is to stop the spread of AIDS. How do we do that? We have to have a little more rights than we have in California.

As an example, when my doctor tested me and found out that I had HIV, I said, "Doctor, when are you going to tell the department of health?"

He said, "Oh, I'm not ever going to tell them."

Remember, that was last year.

"At this time, if I told the department of health, without your written consent, it could cost me $10,000. That would be a fine because I had made it known that you have AIDS."

I said, "I thought the health department was there for that purpose, to go out discreetly and stop the spread of a disease that kills people."

He said, "Well, if you want a disease that I have to report, go out and get yourself a good venereal disease; get yourself some gonorrhea or syphilis, and I have to report that to the health department."

I said, "Why not AIDS?"

He said, "It's very simple. The difference is that I can cure the gonorrhea and the syphilis, but you are going to die. There is no cure for what you have."

And I said, "Well, my God, doesn't it make it that much more important that we start stopping the spread of this thing? Let's get to the people and tell them, 'Hey, to transfer this disease from you to someone else, you have just issued a death warrant.'"

So we went to the people this year because we have a bill, Assembly Bill 403, that was passed in 1985 that to me is a little ridiculous in that it created those instances when the health department, who is by law given a list of 58 communicable diseases by the doctors when they examine you and find that you have it, but AIDS is not on that list. They aren't allowed to tell the department of health that you have AIDS. They say it's a civil rights matter.

It isn't a civil rights matter. It's a medical issue. And it is a death disease, is what it is.

And I would like to see us try to persuade the people who might have AIDS to please find out if they do for their own benefit. But the doctors that work with me now—and I said I have over 2,000 of them—tell me that as many as 82 percent of the people in California that have HIV are unaware of it—are unaware of it—and therefore are consistently going out living the kind of a life—as an example, my surgery was on March 6, 1982. I found out that I had HIV last year, in May.

Now, I was out moving around and I didn't spread it to anyone, but I could have; I could have. So I think that is very dangerous myself.

And if we win our fight in California we will have made some changes, and that is that the doctor, when he tests you and finds out that you have AIDS, has to report that to the health department. That's what the health department is there for, to try to stop the spread of all vicious diseases. Why we have excluded AIDS is beyond me. I don't understand why we would take the most vicious disease that has ever hit this nation and bar it from being reported to the department of health.

Somebody said, "Well, they don't want to embarrass anyone. We have to think of people's civil rights."

I said, "That's right. I wish someone had thought of my civil rights. I don't enjoy having AIDS."

I was on television with a lady just recently who told me that she went to the hospital to give birth to twins. They were a little premature, a little

boy and a little girl, 6 years ago. They both had to have blood transfusions. The little girl is living, doing well and in school. Do you know what the lady said to me on a live television set? She said, "But, Mr. Gann, we buried my little 6-year-old man with AIDS 3 months ago."

To me that is a horrible story, but it's a true story.

In California we just had a man who has AIDS, and he was so bad they had to put him in the hospital and give him blood. The man is so disrespectful of civil rights that he goes from the hospital to the blood bank to sell his blood. They recognized him. They called the police. He was arrested.

The judge just set him free. He apologized in the *Los Angeles Times* to the people literally of that area, "There's nothing I can do except put this man back on the street, a male prostitute, with AIDS; there's nothing I can do except put him back on the street."

I think that's ridiculous myself. That's like saying, "Hey, give me the gun and let me load it so you'll be sure you have a live shell when you play Russian roulette."

I think it's ridiculous. I think the court should have had the authority to put the man in the hospital, do something with him, and don't let him run around spreading that. He's going to die very soon himself. But that isn't the idea. How many people is he going to leave behind?

So my point is very simple. If we don't come up with a cure very soon, then I say we who have AIDS are going to die. Even your Federal Government says that now. They used to say 90 percent, 80 percent, 95 percent. Now they say 100 percent.

But let's don't continue spreading the thing so that you will be dying 100 years from now. Let's stop the spread. That's the only cure there is for AIDS in the world today.

By the way, I am invited to come to France because they have a problem over there, too.

But, you know, our bill will simply do this. It will say that the doctor, when he tests you, will use the same test for AIDS that he does for any other blood disease. We are just saying that AIDS is a communicable disease, and it should be on that list of 58 diseases. And the doctor, not only when he tests you and finds out that you have the virus, he can report his fellow health workers. And by the way, he can even tell your wife. Isn't that hallelujah time in Georgia?

Now, we are repealing that bill. We just filed an initiative, and I'm sure we'll be on the fall ballot, and I feel sure that we will win.

That's what I'm doing. And I'm not doing it for me. You see, I have it. But I have a great grandson—believe it or not, as young as I am—who is 4 years old. I'd like for him to be able to grow up and become a man without having to worry about AIDS. I'd like to see your family in the same position. I'd like to see you in the same position.

That's why I'm here, not in defense of me but in defense of this wonderful country that I was fortunate enough to have been born in.

Thank you for having me here and letting me talk to you, and I'd be happy to answer any questions that you might have.

CHAIRMAN PENDLETON. Mr. Gann, thank you for your illuminating testimony. The Chair's position is that I can only wish you well, sir.

MR. GANN. Thank you.

CHAIRMAN PENDLETON. As you have indicated to me, you have gained some weight and feel a lot better, and I hope that, as powerful an example as you are for us in a lot of things, this can turn around for you.

Do you have any questions, Counsel?

MR. FUMENTO. Mr. Gann, your condition is—we know you have HIV—you have AIDS-related complex; is that right?

MR. GANN. Yes.

MR. FUMENTO. So you have suffered, then, the manifestations of the disease?

MR. GANN. Oh, yes. In fact, I started out at 185 pounds and wound up at 129. People ask me: "How in the world did you lose all that weight?" I said, "I'm sure you wouldn't want to lose weight the same way." But, by the way, I am gaining again, and I am up to 135 now, and if that sounds like bragging I'm bragging. But I am getting better and I'm getting stronger every day. I was so weak that Mrs. Gann would have to help me from the bedroom into the living room. But now I'm on the road again and working every day, and I'm just very thankful for that.

By the way, we do get word from all over the world on this question, and it looks like we just may have something that is going to help slow the spread of this medically. I am looking forward to knowing that to be true, because I have volunteered to let them find out if it really works. And if it does, I'll be telling you from the housetops, form everywhere. But wouldn't that be wonderful?

CHAIRMAN PENDLETON. It would be wonderful.

MR. FUMENTO. Mr. Gann, a general question here. You have told us you don't think this is a civil rights issue; it's a public health issue. Are these totally exclusive?

MR. GANN. I don't see how civil rights—if we are going to make this a civil rights issue, as I said to the Congress about 3 months ago, then give me $100 million and let me start a school. I want to start a drunk driving school and teach the drunk how to drive safely; what the hell. If we're going to protect your civil rights, let's do it like we do in California, jerk him out from under that steering wheel and throw his fanny in jail if he's been drinking.

Yet, when you deliberately, knowingly—remember that, knowingly—pass this vicious thing on to someone else, you have just issued a death warrant.

Why is that a civil right? Who has that right? Who has the right to tell me that in another 4 or 5 years—some lady just called me day before yesterday in my office and said, "I just wanted you to know that my husband had surgery at the same hospital you did in 1981 and we buried him in January." Well, I had mine in '82, so maybe I have until January to go.

But my point is very simply this: Who has the right, the civil right, to pass this disease on to someone else? I think it's a simple question, but it should be answered. The people out there are asking me. The only answer that I have for them is that it isn't a civil rights issue; it's an issue where we should do everything that we can, not only to protect the people from death but also protect them from financial ruin. As I listened to some of the testimony today, it's going to be very expensive for you lucky people who live.

So I would like to see us do what we can to stop the spread—and it's still spreading rapidly in California.

MR. FUMENTO. Mr. Gann, 2 days ago we took testimony from a Dr. Pence who said he believed that public health policy was being affected by certain pressure groups. So let me ask you a bifurcated question.

First of all, do you think the Public Health Service has fallen down in its responsibility to protect the public from AIDS? If so, how? And do you think the formulation of public health policy has been affected by political pressure groups, specifically the homosexual lobby?

MR. GANN. Well, they tell me—in fact, doctors tell me that they haven't been very effective, simply because they haven't had the opportunity to be effective in this. As an example, the department of health is very discreet. They don't ask you to wear a T-shirt saying you have a venereal disease when they come out to your house to check with you. They do it very discreetly. So why would they advertise the fact that if you had AIDS they would advertise it?

No, I think they should know it, and one of the basic jobs of the department of health, to me, is to stop the spread of communicable diseases. They don't have that opportunity in California, particularly if they don't know that you have the virus.

Yes, I think they would do a good job if they had the opportunity.

MR. FUMENTO. But have you seen evidence of pressure by any groups in the direction that you don't think is a smart direction for the public health?

MR. GANN. No, I haven't. I haven't because I don't know of a group that is trying to pressure the public health department. I have a group of doctors—and I have their address here and their phone number here if anyone would like to call them—that helped write my bill because, quote, they didn't think the health department was doing its job really, "because we aren't doing anything to stop the spread." It's not a fault of the health

department, but a fault of the health department not being able to know who has the virus.

MR. FUMENTO. I guess I should clarify that point. I'm going to ask you about your initiative in a moment. Who opposes your initiative? Do you think there are any organized groups opposing your initiative because they don't have the public health of the people of your State as their first objective?

MR. GANN. Well, the only real opposition that we have had so far—and that's been strictly by conversation—is that we do have some people who feel like we will be invading the homosexual's civil rights, and I don't see how we will. Because as the people in the department of health that I know and can talk to in California tell me, they aren't necessarily going to ask you whether you are a homosexual or not if they come out to your house to check up to see who did you get AIDS from and who have you had sexual relations with since you've known you had it, so we can try to stop the spread of this thing.

But they aren't going to advertise your sexual relationship. I don't think they care what your sexual relationship is.

MR. FUMENTO. Could you tell us about your initiative, then?

MR. GANN. Yes, the initiative—in fact, I'll just tell you quickly what it does. We repeal AB–403, which was put there in 1985, and somebody put it there for protection because it stopped us from doing the things that normally we would have done and that we do do with 58 other communicable diseases in California.

We think a physician's duty to obtain consent to conduct tests for virus for AIDS will be no different than the duty to do the same thing for other blood-borne diseases. In other words, we just want AIDS put in that 58, to be number 59, as a communicable disease. Because we do have the most brilliant people in the world in our legislature. I know that because I've been there for years working with them.

I went down the other day, and since they said it wasn't communicable—I went down and asked them a very simple question. I said, "Gentlemen, if it isn't communicable, how in the hell did I get it?" And I was terribly disappointed because they couldn't tell me.

But we repealed the bill in California that says an insurance company can find out whether you've had a heart attack or not, they can find out whether you have syphilis or not, but they can't ask you if you have AIDS. So we are repealing that. And that was in AB-403, and we will be repealing AB–403.

Now, one other thing we do here is that we mandate that persons who test positive for the AIDS virus, after confirming it with a second test, are reported in confidence to the public health authorities. And that's where it should go—to the public health department.

We do one other thing. We make it a crime for persons with AIDS, with knowledge of such fact, to donate or sell blood to the blood bank. Because the people getting that blood—I used to say that I got AIDS free. They gave the blood. But Mrs. Gann is in the audience so I can't repeat that. She said, "Nobody gave us the blood; we paid for it." So I did buy AIDS, but I bought it through a blood transfusion.

I resent the fact that we can be careless enough to continue spreading a disease that we know is a killer, and we know there is no cure for at this time—scientifically there is no cure for it. I think we have to put a stop to the spread.

What do we have to do to stop the spread? The health department has to know who has it, and then do its job as it has done for years very well.

MR. HOWARD. Just a followup question, Mr. Gann. Are you aware of what other States follow the same procedure as the State of California with respect to not reporting HIV positives to their public health authorities?

MR. GANN. Yes, there are some. However, they are changing rapidly. In fact, I just read—I believe it was Colorado, wasn't it, by going to the people, passed a bill that says that the health department must be notified of people who are tested with AIDS, that is, with HIV.

The thing about it in California, I understand they can report AIDS but they can't report HIV. So I said to a doctor just recently on a show, "Well, Doctor, are you telling me then that we can't report HIV; we have to wait until the guy is so sick and ready to die that he can no longer transfer it to a companion through a sexual act, as an example?" I said, "If you're telling me that, then I think it's very stupid. It's a very stupid way to go."

As an example, the average person out there, I am told by New York doctors as well as California doctors—many of them live 8 or 9 years after they know they have the virus.

MR. FUMENTO. Mr. Gann, we don't need to know the name of the individual legislators, but who pushed AB–403 as a group? And as a group, who do you think will oppose your initiative?

MR. GANN. Well, we will have some opposition—if you'll pardon me for using the expression—out of the Bay Area. We know that, because they have opposed us before. But we believe with all of our heart that it will enhance the opportunity of getting the "yes" vote, simply because the people in California have changed tremendously since June 9 last year.

The reason I went public—I didn't go public until I called my family together and I said, "My PR people tell me that this could destroy me, and it could hurt you and you might lose friends. On the other hand, we might save a life."

My family said, "Go ahead." And I have an 18-year-old granddaughter that's a real smart aleck, and she said, "Granddad, if I have a jerky friend

that won't be my friend after finding out my granddad has AIDS, then I don't have a friend anyway, so go ahead."

So we went public on June 9 last year, and we told the people that we had AIDS. I was told by some of my PR people that nobody would shake hands with me again. I said, "So what? My hand has been shook ten thousands of times anyway, so I'll be all right."

But, you know, I was in O'Hare about 6 weeks later, maybe 2 months, and two ladies came up to me and said, "We are so grateful for what you have done, because we have lived under this shadow for 4 or 5 years, wishing somebody would come out and talk about it. And you said that your PR people said nobody would shake hands with you. Well, we don't want to shake hands with you, Mr. Gann; we want to hug you." And my wife was with me so it was all right.

But, you see, people were running from something; they were afraid. And don't get me wrong, I'm no hero. I don't want to die. I'm 75 years old. I've had a very productive life. I have a wonderful family. By the way, I have a home in heaven so I won't be losing anything when I go.

But basically I would like to leave the country better when I go than it was when I got here. That's my desire. And I believe we can, by getting the people who are the government of the United States of America and the State of California to get involved, and let's put a stop to the spread of the most vicious disease that has ever hit the United States of America.

MR. FUMENTO. Mr. Gann, I have just one last question, and then I'll turn you over to cocounsel.

We have heard testimony on discrimination against homosexuals with HIV, against hemophiliacs with HIV. Have you personally experienced discrimination because you have the AIDS virus?

MR. GANN. No, I haven't. It's been the reverse with me. People come through audiences of 100 to 500 people to shake hands with me and tell me hello and thank me for having brought this thing out from under the carpet that we had managed to kick it under.

But, you see, to me freedom and personal responsibility are Siamese twins. And for people with AIDS to go around—if they are aware of the fact that they have it—spreading it, they are no longer responsible. You see, that is very irresponsible, tremendously irresponsible. And I think we should try to persuade those people to go in for a blood test; please go in for a test. You don't have to tell me. Don't wear a T-shirt saying, "I'm a homosexual," or, "I have AIDS," or anything else. But be responsible; be a good American. Live up to the thing that you eventually have to live up to if you are going to be free, and that's just personal responsibility.

MR. HOWARD. Just one last followup from staff. The Commissioners have been exploring to a great extent the delicate balance between public health and civil rights, and we have also heard testimony on transmissibili-

ty, and it seemed very evident from the panel on transmissibility that HIV cannot be transmitted through casual contact.

MR. GANN. No.

MR. HOWARD. It seems very appropriate that there be some civil rights protections for persons with HIV—

MR. GANN. Oh, yes.

MR. HOWARD. —certainly in the area of housing. Could you talk to us about that?

MR. GANN. We have that in California, in fact. We have an act that protects them for housing. And our city of Sacramento has just come out recently that you may not dismiss an employee because you find out the employee has AIDS.

No, I don't want to see us make a mean thing out of this, but I do want to see us make an intelligent thing out of it.

I was told in Washington about 4 months ago in D.C. here that it would cost $100,000 to $125,000 per AIDS patient. And contrary to some of the testimony I heard just a little while ago, everybody doesn't have personal insurance. I do. I'm not going to cost you a dime. But I understand that many, many of them don't have insurance. And if so, then the taxpayer is going to have to pick up the tab.

And if you talk about '91, when they're talking about running into hundreds of thousands of people with AIDS in the United States of America by that time, then you multiply that—and they say I shouldn't talk about that since you're talking about something that kills people. And I said, "In the field that I've been in for years, it's taxation that kills some people and I don't want to see those that are left behind taxed beyond their ability to survive." And that's a fact.

But let's do it discreetly. We can do it discreetly. But we have to have the person at fault be discreet also, you see. I don't know why my civil rights should have to be invaded by someone's civil rights who is doing a thing that will kill me or my family. I really don't understand that.

CHAIRMAN PENDLETON. Mr. Gann, thank you very much for spending time with us today, and good luck to you. Your testimony was illuminating. Thanks again.

MR. GANN. Good to see you.

COMMISSIONER DESTRO. Could I just ask you one question. Your press release indicates you turned in upwards of 600,000 signatures.

MR. GANN. Yes.

COMMISSIONER DESTRO. Could you just tell us for the record how many valid signatures you need to put it on the ballot?

MR. GANN. We need 366,000.

COMMISSIONER DESTRO. So if you get a little over 50 percent you're on the ballot.

MR. GANN. Yes.

COMMISSIONER DESTRO. And that would be for November?

MR. GANN. We have been doing this for some time, and we always like to have a few for them to throw away just in case they won't do. But we do believe we will make it.

It's been a pleasure, and I thank every one of you.

Open Session

CHAIRMAN PENDLETON. We will take a short break and then we will have the public witnesses. Let me give out the names of those witnesses. Those who want to come forward may do so. We'd like for all five to come at one time. I think we can swear you in together.

Lloyd Anderson, Father Leo, Samuel Wallace, Timothy Powers, and Robert Kunst.

Just have a seat, gentlemen, and we'll be right with you.

VOICE. I don't swear, I affirm.

CHAIRMAN PENDLETON. I haven't even given you the oath yet so you don't have to worry. Just relax a little bit.

VOICE. I just wanted to point that out.

[Lloyd Anderson, Father Leo, Samuel Wallace, Timothy Powers, and Robert Kunst were sworn or affirmed.]

CHAIRMAN PENDLETON. Gentlemen, I will hold you to the 5 minutes. As you know, in our rule, fortunately or unfortunately, we cannot have any discussion from Commissioners. As I indicated earlier, we would be happy to take any written material you have and listen to your five minutes. We appreciate the fact that you came to spend some time with us. But those are the rules we have to play by. Those are not just for this Commission hearing but for any Commission hearing that we have.

Mr. Anderson, go right ahead.

TESTIMONY OF LLOYD B. ANDERSON, ECOLOGICAL LINGUISTICS, WASHINGTON, D.C. 20003

MR. ANDERSON. Thank you.

I have been given to understand that you have copies of some written material, and I will be amending that within the period.

I am a professional linguist. I have long had concerns with minority issues, the not bilingual education, particularly with deafness, which is another invisible handicap in most situations. The only hearings I have been to before were the ones on the effect of TV advertising language on children, so I am not entirely familiar with this.

I want to say at the outset I agree with everything Mr. Gann said just preceding me, but he hasn't yet solved the dilemma between what appears to be a balance between civil rights and health issues. I don't think there is any contradiction. But imagine the effect on public perceptions if he were to have submitted a referendum in California which both provided for all

of the health needs of disclosure, et cetera, et cetera, and in the same breath provided for the protections in housing and employment and/or reaffirmed that.

That, which is apparently a contradiction to most people, is not a contradiction at all. And that is, I think, the major solution to our problems. That is how I listen to these things—checking for odd combinations which people normally don't see.

The violations of civil rights in the area of AIDS usually occur because it is treated differently from other threats which are, as a matter of fact, equally serious. So if it is the case that insurance companies, as we just heard, are putting a cap of a million dollars on cancer and heart disease but refuse to do that for AIDS, that would be a clear violation. It is the differential treatment of what are objectively the same.

One of your Commissioners—sorry, the name is missing at the moment—asked Dr. Fauci earlier about the implications for public policy of his findings. He mentioned the tragedy recently of the school bus. I think if you could, in your findings, point out that this is exactly like the AIDS situation—both have death as a consequence; both have very small risks, yet they do occur—that was his point—it will help people to deal with them objectively. Those are the kinds of issues I am dealing with.

Another issue, of course, which was mentioned by Mr. Gann, is the carriers of HIV who continue to endanger the lives of others through dangerous sexual relations. This is not something special or unique, and I have never seen why special laws would be needed or even concealed weapon. It is simply negligence with death as the result, therefore it is capital homicide. I don't see any problem with that. I don't see any contradiction at all between civil rights and health issues.

A more difficult area is the violation of civil rights which does occur when you see differentiations made between "us" and "them." Our society has essentially decided that these are not legitimate distinctions in public life, that we're all in it together. So you see the words sometimes, "the general population" very often used in contrast between one group in society, such as Hispanics or Arabs versus the general population. And it's been used in these hearings this way, providing a sense of relief for the person using the phrase, that the AIDS epidemic has not yet reached into the general population to the extent that might be true.

Most of you may not regard this as a serious matter, but we language professionals use such phrasings in a diagnostic way, diagnosing the thinking, the discriminatory thinking, just as a medical professional uses certain symptoms to diagnose disease.

Certain very public and official labelings of "us" versus "them" are like crying "fire" in a crowded theater and are acts. By labeling the group as outside the pale of society or the general population, they act as direct support for and justification of hate crimes.

So it's a matter of factual determination to ask whether the risk of AIDS transmission in police arrests would justify the use of gloves, and whether police also wear gloves for other equivalent risks. However, when the gloves are bright yellow, so as to draw attention to themselves, they are something else entirely—a deliberate labeling of untouchables in the sense of the untouchable caste of India. Hospital workers do not in general use such obvious visual labeling, so there is no reason for police to do so. Such official labeling should be prosecutable as a substantive attack on a group's membership and normal full rights in society. It is not merely speech. It directly encourages hate crimes by clearly conveying police sympathy for attackers.

What I am trying to convey is that things that are very subtle about language may in fact be very serious, either diagnoses of discrimination or discriminatory acts in and of themselves, like crying "fire" in a crowded theater.

I will try to elaborate this further in written things I will submit, and I hope the Commission can do something rather surprising by resolving what appears to most people to be a conflict of the civil rights versus health issues, and showing that it is no conflict at all. I will try to work further on what that is.

CHAIRMAN PENDLETON. Thank you very much.

Mr. Anderson, before you go, would you identify yourself or some organization, and your address, if you will.

MR. ANDERSON. I am not representing any organization. I am simply a specialist in subtleties of meaning differences. I've worked on it for years. I do a lot of work with sign language, dictionaries for deaf populations in different countries around the world, and I work with unusual alphabets for McIntosh computers—India, Southeast Asia, things of these sorts. So I've had always a multiculture perspective.

CHAIRMAN PENDLETON. Thank you very much,

Father Leo is next. Would you identify yourself and your address for us, please.

TESTIMONY OF FATHER LEO TIVO, ORDER OF FRIARS MINOR CAPUCHIN, PROVINCE OF ST. MARY, NEW YORK, AND NEW ENGLAND

FATHER LEO. My name is Father Leo Tivo. I'm a Roman Catholic priest of the Order of Friars Minor Capuchin, Province of St. Mary, New York, and New England. I'm a chaplain at the Westchester County Medical Center at Valhalla, New York, approximately 45 minutes north of New York City. I am also chaplain to the Westchester County correctional facilities comprising three men's penitentiaries and a women's unit. I am also responsible for PWAs [People with AIDS] in Long Island, other New York City hospitals, and southwestern Connecticut.

I am here not to pass judgment on people with AIDS nor those entrusted to their care. I am here to briefly describe what I see and hear.

I see an inmate requesting a legal deathbed visit to his wife in a nearby hospital and told he is unable to go because the parole officer who by law would make the trip possible and escort him refuses to assist because, and I quote, "The inmate has AIDS." He has simply tested seropositive. The visit occurred 3 days after the request, a few hours before his wife expired, by virtue of a plea which I made to the State Corrections Commissioner, a complex process that could have been easily avoided. His hope was that his wife heard his voice through her coma. Had the visit taken place at least a day earlier, they would have communicated.

I hear an intensive care charge nurse on the phone to her supervisor discussing a new admission with an infarcted spinal column. She mentions, quote, "He looks a little on the gay side. Should we put him on precautions?" He is indeed placed on precautions, and this recently.

I see medical students and residents penalized for whatever it is they are disciplined for by being given difficult AIDS patients.

I see needles left outside patients' rooms, and if they make it to the bedside, what should be warm is cold and what should be cold is warm.

Last August I heard of a body taken from the hospital to a mortuary only to be immediately returned when the cause of death is read. The deceased's wife became not a little confused when several days passed without her knowledge of the incident.

When several PWAs learned of my being here today, my phone rang numerous times asking me to make mention of the fact that if they are without financial resources, there is little support, medical or social, available to them because of the expense, and their pain continues and deepens.

I often hear, "Say no to drugs." A colleague, who is the executive director of a nationally recognized drug rehabilitation program, called Enter, in Harlem, New York, is aware of 153 people who have indeed said no to drugs but cannot be a part of the program because the treatment center has been financially reduced by State and Federal funding.

We do not have a cure for AIDS but we do have available and very effective treatments for IV drug addiction. I see people being denied entrance into therapy and the addiction continues and spreads.

These scenarios may appear trite to some people—I have been told they are—but to the people I minister among they are confrontations that would be inhuman. But we have had civil rights for nearly three decades, by virtue of the act. Prejudice and racism are still as evident as the day they were conceived. A change of heart cannot be legislated. I pray this Commission can somehow come up with comments and provide some sort of action that will set the tone for how Americans will intelligently and compassionately form their educated attitudes and response toward people

with AIDS, because in a few years learning to live well with the dying will be a way of life. The fact that no one is immune may end it all.

This morning, I believe it was you, Mr. Chairman, who said something like "sex and needles." And to me it sounded like it's the bottom line of a lot of what we are discussing. We are very uncomfortable with sexuality. We are certainly very uncomfortable with addiction. Even my own Catholic religion, if you are an alcoholic you are in really tough shape. That has changed considerably.

I go through the neonatal intensive care and I see little preemies with AIDS right next to Baby Joe who is as healthy as anything else, and that baby with AIDS is integrated into that unit as any other child. I will go up to one of the floors, and the IV drug user or the homosexual is incredibly isolated, literally, in many kinds of ways. It's more than an illness that we are dealing with.

Before coming here I went to the Capitol and I was amazed to hear Congress speaking of—what is it called?—the Hate Crimes Act. I am seeing a whole lot of prejudice, and I'm glad that they have passed that legislation because we need things like this, because it's only going to show itself more and more as AIDS people become more evident. We need whatever help we can get. Thank you for doing something.

CHAIRMAN PENDLETON. Thank you very much.

Counsel reminds me that PWA means "people with AIDS," in case there is some editing needed in the record.

FATHER LEO. May I clarify that further. We have a way of using "AIDS victims," which falls pretty hard on the ears of people with AIDS. They don't want to be understood as victims.

CHAIRMAN PENDLETON. Mr. Wallace.

TESTIMONY OF SAMUEL B. WALLACE, WASHINGTON, D.C.

MR. WALLACE. I was particularly interested in the testimony of Mr. Gann who is proposing a new proposition in California, and I have some reservations about certain aspects of that proposition.

I have done medical research in Brazil. I have done medical literature research in this country. I have also done medical library research. And I have testified before the Congress of the United States five times on the issue of improving cancer therapy and AIDS therapy.

With respect to Mr. Gann's proposals, I'd like to say just a word or two on that. That does affect a lot of people's civil rights. And I think if you destroy the doctor-client relationship, and if you make public knowledge whatever effect the patient has in terms of his illness, whatever his illness is, once you make that public knowledge there is a great reluctance on the part of individuals to go to a physician. And that would have an adverse effect if a cure or formula is found to be effective in treating AIDS because

many people would be reluctant to go to the doctor simply because it would be reported publicly to public health officials.

So I think you have to protect the blood banks, and if any person is flagrantly violating the laws and the mores of the community in spreading AIDS, I think there should be some way found to take legal action. But I don't think you should destroy the doctor-client relationship because that is a means of achieving public health and not destroying it.

I want to thank the Commission on Civil Rights that it was a good idea for this Commission to have this thing on AIDS, and I think regardless of the moral position that we take on AIDS, there is one common factor. That is that all AIDS patients as human beings have the human right and, yes, the civil right also to the best possible medical treatment that there is available, whether that person is an American, a European, an African, or an Asian. People of any country have a common right to medical care, and the State has a civil duty to provide such care we are otherwise lacking.

I think that should be obvious. I can't go into insurance rates because that's a slightly different question about providing insurance. But at least we know that people should get the best care that is available.

My problem has been that, unfortunately, AIDS has been treated differently than cancer and other illnesses. My experience has been that the best possible care is not being provided. There is no scientific approach to the treatment of the AIDS disease. Those medicines that are known to be effective against the HTLV are leukemia virus—and by the way, adriamycin has proven to be 60 to 90 percent effective against leukemia and breast cancer, and it has been documented to be effective against HTLV virus. And in 1970 I discovered the [inaudible], which is penicillin combined with naphazoline Hcl. That was in 1970 in Brazil.

Now, adriamycin is tetramycin, a derivative combined with naphazoline Hcl, so there's only a slight difference. And as I said, adriamycin has been effective against leukemia. However, you can't get it tested against the HIV AIDS virus, and therefore there's a big distinction between the way they treat cancer patients and the way they treat AIDS patients. They do not use the proper curative antibiotic medicines to treat AIDS. And this is one reason you have an incurable disease, because you're not using curative medicines to treat that disease.

They are using interleukin 2 and 3. It has a zero percent cure rate against cancer. It has maybe a 5 to 10 percent cure rate against asthma. The formulas that I developed, for example, penicillin combined with phenylephrine, which is the same as neosynephrine, which you can purchase in the drug store, has a 90 percent cure rate against asthma and has a 3-day cure rate against pneumonia.

Now, when I sought the NIH and the NCI to test one of these formulas, I have simply indicated they could run a 1-day pilot test against viral fevers, because it reduces the viral fever as soon as the medication is

applied nasally. I pointed out they could run a 1-day test against asthma because it cures asthma with one treatment.

Now, the reason it's so effective, the formula that I developed, which is penicillin combined with naphazoline Hcl or phenylephrine Hcl, is because you're applying it to the entire lung immune system.

Now, I cannot get the medical doctors at the NCI to test this formula, and it has no commercial value because it's unpatentable because it's two known medical medicines, and it has no commercial value for that reason. However, it has been very effective.

And as I said, adriamycin has already proven to be effective in the treatment of HTLV cancer, which is another form of the HTLV virus.

As I said, the civil rights of people who have AIDS are definitely being violated because they are not using curative medicines to treat that illness.

There are some other things I would have to say about that.

CHAIRMAN PENDLETON. You have less than 1 minute.

MR. WALLACE. Okay. There have been studies by the Japanese that show that adriamycin has an effect on the genetic structure of the HTLV viruses. There have been studies on PD-3 and penicillin diversum, which is almost identical to my formula of phenylephrine Hcl combined with the antibiotic, and those studies have indicated that against the Yoshida sarcoma or bone cancer, the PD–3, which is documented in the *Chemical Abstracts,* April 15, 1985, has been 98 percent effective in test tube against Yoshida sarcoma.

CHAIRMAN PENDLETON. Your time is up. If you have some more you want to submit, fine.

MR. WALLACE. You let this other guy talk for 30 minutes about—

CHAIRMAN PENDLETON. Mr. Wallace, there is no debate here at all.

MR. WALLACE. What I'm saying is you are using this as a political tool, not to find the proper treatment or to find the proper approach to avoidance of this illness. Because if you allowed that other person 30 minutes—

CHAIRMAN PENDLETON. Mr. Powers, it's your time to talk.

TESTIMONY OF TIMOTHY POWERS, AIDS COALITION, NEW YORK CITY

MR. POWERS. My name is Timothy Powers, and I'm a gay man with AIDS-related complex. I'm a member of the AIDS Coalition to [inaudible] of New York City.

From the outset these hearings should never have taken place. This Commission does not possess the medical or public health experience to be handling the questions of this disease as it applies to the public health. Your sole responsibility is to investigate the civil rights violations involved, and it is this concern which you have systematically dismissed during the last 3 days of testimony.

People with AIDS in all its forms comprise this country's most misunderstood and most discriminated against minority. We are comprised mostly of people who also belong to other minorities with a history of discrimination—gay men, IV drug users, blacks, Hispanics, the poor. It is outside of your scope to answer questions of public health, yet this is all you have tried to accomplish here. It is your responsibility to investigate the violations of the civil rights of people with AIDS. Yet you ignore them.

This administration has not dealt with this epidemic. It was 6 years after the discovery of the disease before any action was taken whatsoever. In 1986 President Reagan asked the National Academy of Sciences and the Institute of Medicine to study the AIDS epidemic. They came back with a series of clear recommendations for ending the health crisis. Not a single one of these recommendations has yet been followed.

In 1987 President Reagan formed the Presidential Commission on HIV to study AIDS issues once again. They supported the findings of the Academy of Sciences.

Now in 1988 we have your Commission covering the same ground all over again. Obviously, the sane and compassionate advice of experts in public health is not the answer which this administration is fishing for. So now they have gone to a panel of people who are not experts in public health to get their answers on public health questions.

Perhaps you will give them the answers which they want to hear, but it is not your place to do so. It is not the place of this Commission to question the legitimacy of any citizen's claim to civil rights. When this Commission begins to do that, then there is no place left in the Federal Government for the victims of discrimination to turn. Rather than questioning how the civil rights of people with AIDS have been violated, you question how people who have AIDS are inconveniencing the rest of society. This is how far your Commission has fallen away from the ideals which you are here to protect.

People with AIDS are being openly discriminated against in housing and jobs, but you stop to question whether this might be a way of protecting the rest of society which is uninfected, a belief that only shows ignorance of the realities of HIV transmission.

Saddest of all, people with AIDS are being isolated away from treatments which are showing promising results in tests overseas, treatments which the Federal Government is stopping at the borders, treatments which can save our lives.

The few treatments which the government has approved for release are being sold by pharmaceutical companies which price-gouge, keeping treatments from the poor who comprise the majority of cases. Is this a violation of basic civil rights? Yes. We cannot live free and equally in society if society is preventing us from living at all.

These questions of discrimination against people with AIDS will be raised nowhere else in the Federal Government if they are not raised here. Yet, you ignore them. Instead, you spend your time reexamining questions of transmissibility which have already been laid to rest. The National Academy of Sciences reported epidemiological data indicate the transmission of HIV is limited to sexual, parenteral, or maternal-infant routes. There is no evidence for other routes of HIV transmission.

By raising the question of transmissibility again here, you are simply pandering to the unfounded fears which are already a needless and dangerous part of the prejudices in society rather than trying to put an end to the hysteria which is causing discrimination in the first place.

People with AIDS do not pose a direct threat to the health or safety of other individuals in society. But for needlessly promoting doubts about the reality of transmissibility, this Commission is a direct threat to the health and safety of people with AIDS in society.

CHAIRMAN PENDLETON. Your time is up, sir. Thank you very much.

[Applause.]

Mr. Kunst.

TESTIMONY OF ROBERT KUNST, DIRECTOR, CURE AIDS NOW, COCONUT GROVE, FLORIDA

MR. KUNST. Thank you. It's a hard act to follow. I'm director of Cure AIDS Now in Miami. I come from the State that has the third largest number of people with AIDS, people living with AIDS. Forty percent of our cases are heterosexual statewide and 45 percent in Miami are heterosexual.

We handle two different programs. One is an international clearinghouse to let you know that there are six viruses. HIV has over 1,000 mutations, an 8-to-15-year incubation period, and projections from World Health Organization and Surgeon General Koop, who is selling condoms every other day, and the very fabulous Government Accounting Office that we'll have 100 to 160 million infections around the world in the next 5 years, doubling annually. But you're still stuck on gays and IVs and so limited it's unbelievable.

I want to tell you that Miami in the State of Florida has the highest heterosexual spread, and on a local level our organization is feeding right now 107 people living with AIDS from ages 2 to 60. Thirty percent are black, 30 percent are Hispanic, 30 percent are Caucasian. Seven of them are babies. They are all black. Fifteen of them are over age 50. Twenty of them are women—IV drug use.

By the way, Miami, which has the reputation of being Casablanca and drug capital of the planet besides the holy land of gay rights only has 13 percent IV drug use to a national 18 percent, in case you want to cough up that little issue.

In Jamaica, which is just in our backyard, are the 44 cases they want to report. Twenty-five are heterosexual, evenly split between men and women—none of them IV drug use. That's going on in pandemic form throughout the entire Caribbean, but God forbid you should want to talk about it. In fact, the issue is completely out of control in 138 countries out of 166.

Being a direct service agency, and really tired of listening to the government nonsense that says, "Well, we have no cure," because, God forbid, they should actually look for it, and therefore the only tool we have left is education, which really means playing out the politics of this administration to regulate public behavior instead of going after the viruses. What we have is a major ultimate threat that is going to destroy humanity unless you get off your behinds and start dealing with the issue on a legitimate level.

We are sick and tired of watching people fall through the system by a phenomenal amount of malpractice from the medical profession that really doesn't give a damn. If we have a dozen doctors out of 16,000 in Florida who even know what they're talking about it would be a miracle. Thank God at least one element of the Florida legislature has just mandated that anyone in the health care services has to have a complete education on AIDS or they can't keep their license. Maybe you ought to look South for a little bit of radicalism.

Secondly, in terms of discrimination, Florida was the first to say AIDS has to be treated as a handicap. Even in Dade County I have to say I had the pleasure 11 years ago of throwing Anita Bryant out of Dade County and the State of Florida. We have passed resolutions that said you can't discriminate with people with AIDS in housing, employment, and public accommodations. That hasn't saved one life.

The point is that the discrimination is on top, whether it's the Food and Drug Administration that won't let dextran sulfate [an antiviral drug] in from Japan or anywhere else that's saving lives, whether it's the Centers for Disease Control, which is not only completely off the wall in terms of its findings on statistics that are understated but actually involved in sabotage of research, whether it is the National Institutes of Health with its own internalized politics—nobody is in charge,—nobody is in charge, no or enough experiments, not enough money, nobody is collaborating internationally, and you all are playing a giant joke with the public's health;and we who are in the trenches, dealing with life and death every day, are so sick of it we can't stand it anymore. There is major rebellion afoot.

Yet, we are delivering food, keeping people alive, giving people hope. We are the dumping ground for all the minorities and indigents. We're not sitting here talking for an hour and a half about insurance.

The bottom line here is that people are really hurting, and the State of Florida is willing to admit that we will have 32,000 AIDS cases in 4 years, and we don't have 32,000 hospital beds—and half of that is in Dade County. And that's what they're willing to admit to.

Now, what are you people doing about reality instead of all this other nonsense that's going on? I'm sitting here livid watching this insanity. Because it's always going after the people who have the virus instead of the people in charge who've got the bucks and have got the power and won't do a damn thing about it because of their own personal prejudices. And what AIDS is doing is enlivening the whole issue of sexual debate, and enlivening the whole issue of racism and classism and antisex behavior and everything under the sun.

The bottom line here is we've got to stop playing games with the public's health and stop playing politics in this global emergency. Either we're going to get a handle on it—and I want to tell you something. We have 2 years left, and that's the agenda. Because if we only had 2 years left, all the sex, all the carrying-on that's been going on for ages—in Miami 42 percent of the prostitutes are testing positive.

We have 24 million people that come into Dade County to party, every year, just through the airport. What do you think? Everybody isn't partying and hasn't been doing it for the last 15 years of the incubation period? I mean, what are you talking about?

But you're not dealing with reality, which is that the people who are already infected are expendable, have been written off, and everyone has to fend for themselves. And that is what is creating the anger, and that is what is forcing people to go out and say, "If you're going to make me pay with this type of dehumanism, I'll make you pay. I'll infect so many people you'll have to deal with the issue."

CHAIRMAN PENDLETON. Thank you very much.

[Applause.]

The open session has now been completed. It is a part of the record. Thank you very much, gentlemen.

We'll take a short break and move to the Commission meeting.

[At 4 p.m., the hearing was adjourned.]

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