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NATIONAL COMMISSION ON AIDS

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MAKING THE HEALTH CARE ENVIRONMENT SAFER: STRATEGIES TO REDUCE THE RISK OF TRANSMISSION OF BLOOD-BORNE INFECTIONS

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Tuesday, November 5, 1991

Embassy Suites Hotel
1250 22nd Street, N.W.
Washington, D.C.

The proceedings convened, pursuant to notice, at 10:00 a.m., before:

JUNE E. OSBORN, M.D., Chair
DAVID E. ROGERS, M.D., Vice Chair

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PROCEEDINGS

CHAIRPERSON OSBORN: I think, in the interest of time, I would like to have us get started and people can finish taking their seats quietly, if they would.

We are particularly grateful to Dr. Bill Roper for coming to join us this morning, and I know his schedule is pressed. He has been kind enough to agree not only to help us start our deliberations today on making the health care environment safer, but, then, after he and Dr. Barondess speak, the first two people who will be on program, Dr. Roper and Dr. Barondess will take some questions, which is not quite what it says on the agenda, but, in that way, we will have full opportunity to discuss those two presentations before Dr. Roper's schedule presses him elsewhere.

With that, I want to introduce Mr. Jeff Stryker, who is the Acting Executive Director of the Commission. Not everybody has had a chance to meet Jeff.

I want, also, to introduce Dr. Roy Widdus, who will take over as Executive Director of the Commission December 2nd. He is currently with us on vacation, actually. He is just taking a busman's holiday today, to be with us for these hearings.

With those comments, let me, again, express the Commission's appreciation to Dr. Roper for having come up after quite a strenuous day of hearings at CDC yesterday.

Bill, I will turn the microphone over to you. Thank you.

THE CENTERS FOR DISEASE CONTROL PERSPECTIVE

DR. ROPER: Let me just begin by thanking you all for holding this hearing and by me to be here with me today is Dr. Gary Noble, CDC's Deputy Director for HIV and AIDS. Again, I appreciate the opportunity to update you on two important issues, first, the one that has captured, surely, the news media's attention last night and today, and the prime focus I know of your session today, that is, preventing HIV transmission from health care workers to patients. But I would also like to touch briefly on our draft guidelines for voluntary HIV testing of patients in acute care hospital settings.

As you know, on July 12th of this year, CDC issued new recommendations on preventing HIV and hepatitis B virus transmission from health care workers to patients during what we have characterized as exposure-prone invasive medical and dental procedures.

Since that time, questions have been raised concerning these guidelines, including concerns advanced by individuals and groups whose full understanding and collaboration are essential to protecting the public health. Our job is easier to do, when our colleagues and our friends are cheering us on, but our job is no less important when they choose to differ with us.

We at CDC want to be certain that we proceed appropriately and carefully on these issues. To this end, we solicit comments and suggestions from you and everyone else. We want to be sure that our science and policy are right, and we will be continually reviewing them.

As I said, some have chosen to differ with our policy recommendations. I would hope that they do this, based on our real policy and not some caricature of it, as I have seen in the press and as I heard at length in Atlanta yesterday.

It might be useful to summarize briefly the key points of our July recommendations. The risk of transmission of HIV and HBV infections from a health care worker to a patient during exposure-prone invasive procedures is very small, but it is real.

We strongly urge all health care workers to adhere to universal precautions and proper disinfection and sterilization procedures as a primary safeguard for themselves, as well as their patients. However, people who perform exposure-prone invasive procedures should also know their HIV and HBV status, and, if infected, should discontinue these procedures, unless they seek counsel from a panel of experts on whether or not they should continue. Informed consent of the patient is important, if the health care worker continues to perform them.

The basis for considering certain invasive procedures, as exposure-prone comes from three sources: First, from episodes of HBV transmission from health care workers to patients, despite apparent compliance with the principles of universal precautions; secondly, from studies demonstrating that sharp injuries continue to occur among surgeons in the area of universal precautions; and, thirdly, the transmission of HIV infection to five patients in one dental practice.

We continue to emphasize the need for health care workers who adhere to universal precautions and proper disinfection and sterilization. But although universal precautions are very important, they do not provide 100 percent protection from infections, as we are reminded by the experience from hepatitis B. So, argue, as we may, about the risk of transmission of blood-borne pathogens, it is small, but the risk is, nonetheless, real. It cannot be wished away.

One final point about the science of these guidelines: Lately, I have heard a number of people raise questions about the Florida dental case and advocate one or another theory for precisely how the virus was transmitted. The fact is we do not know, and probably never will know, the exact mechanism of HIV transmission in this dentist's office. In this respect, it is similar to the HBV experience. In none of the investigations of these hepatitis B clusters, was it possible to retrospectively determine exactly how transmission occurred, although the epidemiological evidence for transmission was clear.

As we gather new information, we will continually review these guidelines. We will continue to have an open mind and to seek input on this issue. We want to be certain that our recommendations reflect the best science available now and in the future.

Yesterday, we met in Atlanta to get advice on the definition of exposure-prone and basic procedures. This itself is a topic on which many have differing views, including whether the term "exposure-prone" is the best expression to use in this instance. In our July 12th recommendations, an exposure-prone procedure was defined as one which represents a recognized risk of percutaneous injury to the health care worker, and if such an injury occurs, the health care worker's blood is likely to contact the patient's body cavity, subcutaneous tissues and/or mucus membranes.

Yesterday, we heard from a variety of groups and individuals who take issue with us on the feasibility and the appropriateness of this approach. We will continue to seek advice on this subject, as we move forward, including a further public comment process.

How do we deal with the consequences of the recommendations? I want to reemphasize that a great majority of health care workers would be assisted by such recommendations. They strongly emphasize that, for the overwhelming number of medical procedures, there is no risk of HIV or HBV transmission. Further, these recommendations strongly oppose mandatory testing.

Let me make it clear that the department is firmly opposed to unfair treatment of health care workers with HIV infection. We recently intervened to prevent a hospital in a northeastern state from discriminating against an HIV infecte employee. We recognize that any recommendations also will have a significant impact on a small number of other health care workers. We need to search for compassionate ways, as a society, to help those colleagues who are adversely affected by recommendations and to protect their rights.

Many people have expressed concern about how this will affect health care services for individuals who are infected with HIV. Nobody has complete answers to this serious problem, but it is one we are committed to seeking solutions for. I believe strongly in the principle that health care workers have a responsibility to care for all patients, including those who are HIV infected.

As you know, legislation has been enacted that calls for the states to institute CDC's guidelines or guidelines that are equivalent to them. CDC is expected to be delegated the authority for implementing this legislation. We will be reviewing the issues raised and developing a process for evaluating the policies submitted by each state to Secretary Sullivan.

In doing so, CDC will take into account the comments and advice received from our colleagues in the public health community, particularly those at the state and local levels with responsibility for public health policy.

Let me move on to a separate, but equally important subject. CDC is currently working on recommendations for HIV testing services for patients. On September 17th, we made available draft guidelines for HIV testing services for inpatients and outpatients in acute care hospital settings. These draft guidelines recommend that hospitals and their associated health care providers routinely offer and encourage HIV testing services for patients, with informed consent obtained in accordance with local laws. Such services are particularly indicated for patient populations with an HIV sero-prevalence greater than 1 percent.

We believe these testing services are important, for several reasons: First, determining a patient's HIV sero-status can assist in diagnosis of medical conditions; secondly, identification of HIV positive patients will enable early medical management of the infection; and, thirdly, the voluntary testing process will provide an opportunity to counsel infected persons, as well as those who are not infected, but who may be at risk.

The draft guidelines call for hospitals to provide such counseling and testing procedures, with three important features, that they facilitate voluntary patient participation, that they include pretest information for the patient on hospital testing policies, with the option to receive more information, and that they provide for confidentiality and the sharing of test results. The closing date for public comment on the draft guidelines was October 21st, and we are now in the process of reviewing the comments that we received.

These are important issues facing us today. While we must acknowledge that there is not universal agreement on some of the issues, I believe it is important to keep our differences of opinion in perspective. Together, we can and must address many challenges in the HIV epidemic, and we must not let differences on a particular issue and the subsequent debate cause us to lose sight of the far greater public health goals that unite us.

We believe that we must approach these matters with energy and confidence, a dedication to purpose that I know you share, but not an arrogance that does not listen to those who differ with us.

Within the past week, I have met with CDC's Advisory Committee on Prevention of HIV and AIDS. We held a public meeting on exposure-prone and basic procedures yesterday in Atlanta, and we are discussing these issues here today. We have heard from many who differ with us on these matters. We are anxious to proceed in a way that builds consensus.

As HIV infection and AIDS continues to challenge our best efforts, let's continue the constructive dialogue that has led to some of our most innovative and effective collaborative initiatives.

Thank you very much for your attention.

CHAIRPERSON OSBORN: Thank you.

Let me ask Dr. Rogers to introduce our next speaker, because he knows him well.

DR. ROGERS: I thought we might perform like the Senate does, and I wanted to welcome my colleague from New York State, Dr. Jeremiah Barondess. Dr. Barondess is a distinguished New York physician, Hopkins trained and viewed as the leading physician in New York City, a former President of the American College of Physicians, just recently has taken on the presidency of the New York Academy of Medicine, where I have the honor of serving as a special advisor for him.

My only complaint about Dr. Barondess is he almost never takes my advice and he makes up his opinions, so I will be fascinated to hear what he has to say to us.

[Laughter.]

Jerry, we welcome you here.

DR. BARONDESS: Thank you very much, David.

I am glad to have a chance to be here this morning to express before the National Commission some views on behalf of the New York Academy of Medicine, a 144-year-old pro bono, politically neutral institution acting in the public weal.

The academy has had an active interest and a number of activities in relation to the HIV epidemic. In March of 1991, we assembled the deans of the various medical schools in New York City, of which we have seven, and the presidents or directors of the major hospitals, to consider issues relating to the testing of health care workers for evidence of infection with the Human Immunodeficiency Virus, and a statement describing the views of that group and of the academy was published shortly thereafter in the JAMA for April 10, 1991.

The problems in managing this continuing tragic outbreak continue to evolve. All of us, in both the public and the private sectors, have striven and continue to strive to do the best we can with the information at hand, whatever its degree of incompleteness. Because the information at hand continues to grow, change and mature, our efforts to manage the epidemic require a continuing willingness to revise and adjust our positions.

I say this not only with respect to the views of private sector institutions like the New York Academy of Medicine, but also with relation to the efforts of the Center for Disease Control, which has had to fight a difficult and often lonely battle in the most exposed position of any of us. Thus, although I will express some variations in emphasis, and even disagreement, with what the CDC has done or recommended, I would like to make it clear that this is done without disrespect and, in fact, with a good deal of compassion for the necessities thrust upon them.

Basically, the academy position is, as follows:

First, the issue of transmission of HIV infection from health care workers to patients, while always a theoretical possibility, was not an active issue until the appearance of a cluster of five cases in a Florida dental practice.

Second, while the discovery of this cluster was bound to produce some public apprehension, the subsequent management of these events was characterized, in part, by a mixture of fact and speculation which served to produce widespread and very substantial public anxiety, which has found expression not only in the mass media, but in the Executive Branch and the halls of Congress. This level of public apprehension, in my opinion and in that of the academy, is a major factor in the development and in the evolution of public policy, and needs to be addressed, we believe, urgently.

Third, among the elements of the situation that have served in a particularly powerful way to heighten widespread apprehension have been the following:

First, ambiguity about the mode of transmission of HIV infection in the practice of the Florida dentist, and early public speculation on the part of the CDC that, in some manner, the dentist had bled into the mouths of the five invested individuals or had otherwise transmitted the virus from himself to these patients.

Second, circulation in January 1991 of a series of calculations conducted within the CDC concerning the probabilities of transmission of HIV (as well as hepatitis B) in the course of health care. These "preliminary estimates," as they were called, were very highly speculative and failed, in my opinion, to emphasize adequately the absence of any other identified instances of HIV infection from a health care worker to a patient, despite 10 years of experience and a million infections in this country.

Third, these calculated estimates were accompanied by indications from the CDC that some medical care procedures were "exposure-prone," and that these, by implication, but without supporting evidence, posed particular risks to patients relative to transmission of HIV infection.

This sequence of events was followed in short order by the adoption by major medical organizations of postures that lent further credence to the CDC projections. In particular, the American Dental Association, the American Medical Association and the American Academy of Orthopedic Surgeons quickly issued statements which, in effect, lent support to the CDC guidelines and their applications. These positions have since been modified, as you know, to a very substantial degree, in most instances.

Additionally, one of the patients tragically infected in the Florida dental practice, a young woman now in the late stages of the AIDS, by virtue of an open letter that she wrote, and very widespread media exposure and recognition of her plight, if not theatricalization of her plight in Congress, became a focal point that has heightened further the public reaction to the implied danger of acquiring HIV in the course of health care.

In mid-July of this year, the United States Senate turned its attention to these issues, and passed two bills, the first criminalizing the involvement of health care workers who know that they are infected with HIV, in treatment involving invasive physical contact, without prior notification of the patient, and the second requiring states to adopt the CDC guidelines within a year.

Similarly, in the House, a bill was introduced in June 1991 requiring testing of health care workers for HIV and requiring them to inform their patients if they are infected. This bill also carried with it a provision providing health care workers with the right to know the HIV status of their patients.

In a latter effort, an attempt to reverse the mandatory prison terms and fines of the Helms amendment, the Senate voted in favor of a bipartisan plan to stiffen government enforcement of universal precautions against transmission of infections. Most recently, conference bill language emerged, requiring states to provide guidelines equivalent to those of the CDC.

Two major questions emerge, it seems to me, from this background. The first, as I said earlier, is what can be done to reassure the public in a realistic, yet forceful and understandable manner. The second general arena is what to do about policies concerning the testing of health care workers.

The academy urges, first, that substantial and continuing efforts to educate and reassure the public concerning the risk of transmission of HIV in the course of health care be made a priority of this Commission and of policymakers and health care organizations. It will be extraordinarily difficult for realistic, meaningful and recurrent efforts to reassure the public to occur, without a substantial CDC campaign to do so.

In my opinion, no private or public sector entity, including this distinguished Commission, can get very far with the public apprehension, unless the CDC leads the charge, and, in particular, puts its views into a more explicitly reassuring context.

It would be my hope and expectation that those in the Executive and Legislative Branches of the Federal Government would be included in this educational effort. If we are, in fact, successful with the general public to a significant degree, this will be reflected also in the kinds of pressures the Congress is receiving from its constituencies.

Second, the academy reiterates its position that, in the absence of any evidence of transmission from an infected health care worker to a patient in the course of health care activities, no policy should be established requiring, directly or indirectly, the testing of health care workers for HIV infection. Such a policy is unlikely to be massively counterproductive, and is likely to drive potentially infected individuals away from identification of their disease and early treatment, and is likely also to deprive HIV-infected patients of at least some proportion of the health care workers currently providing their care.

In my opinion, the continued use of the expression "exposure-prone" contributes significantly to public anxiety. It is a "hot" phrase, and it is based on experience with a different disease, namely hepatitis B, caused by an agent many times more communicable than HIV.

Further, it is difficult to agree with the portion of the CDC guidelines which includes the admonition that HIV-infected health care workers should discontinue these so-called exposure-prone procedures and should seek counsel from a panel of experts on whether or not to continue.

It is, in fact, difficult for me to understand what is held in mind concerning what kind of counseling might be involved. In any case, if the health care worker then follows the CDC guidelines and informs patients of his or her HIV status, that health care worker is effectively removed from the care of patients, at the very least those on whom these presumably exposure-prone procedures are performed, but more likely are much broader a constituency. I can't find any basis, in fact, for these recommendations, and I believe, as I have said, that they contribute to a continuing high level of apprehension on the part of the public and those in government, without adequate basis.

Third, the rigorous application of universal precautions, as previously described, should be made a mandatory part of medical and surgical practice, since it has been demonstrated that these techniques substantially reduce the risk of widely prevalent and highly communicable diseases, particularly hepatitis B.

Fourth, attaching punitive measures to the activity of any sick individual is a regressive and counterproductive policy.

Fifth, attention should be directed to the manner of application of universal precautions in non-institutional practices, including, and, perhaps particularly, dental practices, and guidelines for the application of these precautions in such practices should be reviewed, refined, applied and repeatedly emphasized.

Sixth, mandated routine screening of segments of the patient population would be unlikely to have significant impact on the course of the epidemic, and would probably drive many individuals away from needed health care.

Finally, continued careful surveillance of the population should be maintained, so that all aspects of the epidemiology of HIV are monitored. In this way, new information can be incorporated into public health and clinical practice as rapidly as possible.

Thank you again for the opportunity to express these views.

CHAIRPERSON OSBORN: Dr. Barondess, thank you very much.

I think, at this point, we will deviate a bit from the printed program, in light of the pressing schedules and take discussion and comments from Dr. Roper and Dr. Barondess and Commissioners.

Harlon Dalton.

MR. DALTON: You indicated that the risk of exposure from health care workers was small, but real. My question for you is, is it significant, and I mean significant as that term is used in the Americans With Disabilities Act and other anti-discrimination statutes? This question should be no surprise to you.

One of the concerns that has been raised with reference to the CDC guidelines is that they, in effect, help to define what constitutes significant risk under anti-discrimination statutes, such that people who heretofore were protected or may have been protected by those statutes are now not protected.

Specifically, does the requirement of approval by expert panels and the CDC's notion of informed consent that engaging in exposure-prone activities raises the issue of whether patients have a right to consent to being treated by such health care workers? Does that not suggest that engaging in exposure-prone activity creates a significant risk of transmission of HIV?

DR. ROPER: I am familiar with the issue that you raise. It is involved in the passage of the ADA and the issue is one that we have dealt with.

What we are saying is, within this narrow category of exposure-prone basic procedures, that an HIV or HBV infected health care worker who, after the advice or the counsel of the local panel continues to do such exposure-prone procedures, we would say that those pose a -- what's the term of art -- significant risk.

MR. DALTON; To make it quite precise, you are saying that HBV or HIV infected workers who engage in exposure-prone procedures and were not cleared by expert panels are not protected by disability anti-discrimination statutes?

DR. ROPER: Yes. Of course, implicit in your question and my answer is that the definition of what is exposure-prone, and we demonstrated at some length yesterday that there is a disagreement on that point, so at present we are dealing with some hypothetical issues.

MR. DALTON: So that when, for example, in the OTA report, when they offer the invitation to the CDC to explicitly disavow any attention to affect the definitions under the anti-discriminatory statute one way or another, your position is, well, in effect, you are saying that the risk of an HBV or HIV infected health care worker engaging in exposure-prone procedures, in fact, does rise to the level that takes him out of the situation.

DR. ROPER: Yes.

CHAIRPERSON OSBORN: If I might ask a question, Bill, still absorbing the things that we heard yesterday in Atlanta -- and I found it a fascinating day -- in those professional organizations that tried to come forward with whatever list or lack of list, after looking at the question you posed to them, as I summed it up, there were precious few professional groups that felt that their activities could be described as exposure-prone, once they looked at them.

There were two or three that were suggested might be, but they almost simultaneously suggested they could be substituted for and, in fact, had done the kind of safety thinking that I think motivates us all here and had already found ways to move away from any even vague possibility of exposure-proneness.

As I was coming up on the plane last night, I was trying to think of what list you got left with, and I wasn't sure that you were left with one. I wondered how you had summated that. I know there is lots more discussion to be done, but, in the wake of yesterday's discussions, how do you summarize that?

DR. ROPER: The example of the particulars you refer to, if I remember right, was the emergency physicians who were talking about a nerve block in the oral cavity and a periapicotomy that was done under life-threatening situations.

The exposure-prone definition that we took from our colleagues in California and has been discussed in other situations, we would continue to believe has to do with activities that are done without good visualization of one's hands in situations where, again, if one is injured, you might bleed into the body cavity, and so on. That definition is one that people said they were not able to supply us with specific advice on or specific instances of in the day yesterday. But I think it is still a definition that is understandable and has merit. But, as I said, I think, at several turns in my statement, we are going to be thinking carefully about what we heard yesterday.

CHAIRPERSON OSBORN: I guess the point of my question was that you ended up with an awfully short list, even to start with, before people began to adjust, if you accepted the professional input of the groups most familiar with this procedure, and I guess --

DR. ROPER: With all due respect, I took a number of the professional associations' declination to participate with us as not so much a statement that they could not assist in deciding which were the higher priority procedures, but, rather, they disagreed with our basic policy.

I would just hasten to add that, whatever one believes about the specific recommendations that we made in July, I heard yesterday and I have heard throughout this discussion a variety of people calling for work to be done to make the health workplace safer, to develop better procedures, devices, whatever.

If you agree with that, and I see several heads nodding, then, as in any endeavor, one has to set priorities, and so I would just invite what are the areas that are of greatest concern, highest risk, is that not those that are, as someone else has said, exposure-prone, but I will leave that for another day.

CHAIRPERSON OSBORN: Eunice Diaz.

DR. DIAZ: We heard this morning from you and from Dr. Barondess of the importance of the role of CDC in a continuing consumer education effort to reassure our public regarding what is known and is not known has been learned by you from this entire situation. What current plans and development does the CDC have for continuing to strengthen that educational component that will be really critical? And I think any of us would agree, only CDC can do it, and I would like to hear what you have in mind.

DR. ROPER: Well, it is something I am pleased to talk about, because we do it with your good advice, but we had plans well under way a long time ago to do just this. Secretary Sullivan, in addition, has urged us to.

Our next America Responds to Aids campaign, due out shortly, will have as its prime focus this issue and is designed to lay the facts out and reassure the public and do the things that we each have said we need to be doing. That is the role that we willingly understand that we have and are pleased to be about. So, in addition to the -- I assume you all know what the America Responds to Aids is, but, in addition to that rather formal campaign, we will be doing a number of other things, as well.

DR. ROGERS: Bill, I appreciate you being here. Clearly, we are all shooting at precisely the same goal, and that is evident from your comments.

It seems to me where we are hung up is the often repeated phrase, which I have heard you say before and which I understand, which is the risk is very small, but real, in terms of interactions of patients with an infected health care professional. And in listening to Dr. Barondess' comments, that is clearly where we disagree.

You have, at least from what I have heard, you have the evidence from one dentist and five patients, which most of us who are students of infection, as that has been explored more fully, think it is most unlikely that he bled into the mouth of those five patients, that, in all probability, was infection produced the way infection has been produced since the days of Semmilweiss, he was swopping, he transmitted it by his instruments from one patient to another. And because it was clear he was treating some of his own sexual partners, the fingerprint for the virus becomes explainable, which was the one persuasive piece about that.

Absent that dentist, is there any evidence that the risk is small, but real? Is there any solid, other than the theoretic evidence that Dr. Barondess alluded to, that there is a real risk? That's what I think is terribly troublesome to many of us who are in high incidence states and who view what may be the follow-down effect of this policy as being terribly counterproductive, in terms of what we can do for people with AIDS. And I think it fails to address that central question, which is how do we protect each and every patient in the health care setting, not what do we do with HIV infected health care professionals.

DR. ROPER: I don't want to get hung up over definitions of words, of what is theoretical, what is real, and so on. I guess the perspective that I bring to your question --

DR. ROGERS: It is your word, though, Bill.

DR. ROPER: Well, yours is "theoretical," and I am not going to quibble with your use of the --

DR. ROGERS: Very small, but real, and I want to know what's the evidence that it is real.

DR. ROPER: The evidence is our understanding of the HIV virus and how blood-borne pathogens are transmitted. I guess my assertion to you would be we would not all be so vigorous in urging the rigorous adherence to universal precautions, if we only believe that this was a theoretical risk that we should not be worried about.

DR. ROGERS: Dr. Barondess, do you want to comment on that same question?

DR. BARONDESS: I don't want to be noisesome about it.

DR. ROGERS: That's a good word, noisesome.

DR. BARONDESS: Noisesome. It is a theoretical risk. It is perfectly plain that it is possible to catch some diseases by exposure to infected blood. Hepatitis B is a case in point.

I understand the difficulties, I think, some of the difficulties in the identification of transmission, which Dr. Roper has not spoken about. It's very difficult to recognize transmission, absent a cluster. Nevertheless, there haven't been any other clusters. It speaks, at the least, of the difficulty of transmitting this infection in this manner.

The kinds of considerations that Dr. Roper has referred to, the frequency with which sharp injuries occur in the course of surgical procedures, when you couple that with the absence of identified clusters, and you couple that with the several thousand sero-negative patients operated upon by sero-positive surgeons, it seems to me speaks in the other direction.

I think that these recommendations are, in fact, based on theoretical considerations. They are not based on observation of transmission of the infection under these circumstances. They are simply not. I bow to no one in my respect for theory. I just think that when you are talking about public policy here, when you are talking about impacting on the lives of people, to this degree and on the health care system for a really beleaguered segment of the sick population, it requires something more.

CHAIRPERSON OSBORN: Mr. Goldman.

MR. GOLDMAN. One thing that has disturbed be about this legislation is that, if somebody dropped into this city from Mars at this point in time, who thinks the problem of

HIV infection has to do with the infection of our people by health care workers, where nothing could be further from the truth, and, in fact, they were met -- when we talk about issues of drug abuse and sexual transmission, that those pale, in comparison in terms of the amount of space that is obtained on our public media and our newspapers, and those, in fact, are the problems that have to be dealt with, and that whether or not it is theoretical or real, it is certainly very infinitesimally small.

I have two questions, one for each of each of you, for either of you to comment on. One question I have is that there are so many other things that are problematical in the health care arena. I often jokingly suggest that if I had a test to perform on my surgeon before operating, maybe I would rather give him a bretholizer than an HIV test, as a practical matter, and yet CDC doesn't recommend bretholizers outside of all the surgical operating suites, nor providing patients with an informed consent, if they had a cold and had taken an antihistamine in the morning prior to surgery, where they were told they couldn't drive, but they, nonetheless, could conduct surgery.

It seems to me that our society has always tolerated substantial risks, not even real risks, but theoretical risks, and has never really done very much about it, except in the context of HIV, and I wonder whether or not that has something to do with the sociological and dread implications of people being afraid of getting AIDS and HIV infection, and specifically what Dr. Roper thinks of the tremendous amount of focus -- think of the time that he and CDC has spent on this issue, in terms of resources spent, that all of the states across the country are spending on this issue, and that if the recommendations were to be adopted, what kind of resources might be spent in dealing with this issue that would misguide the American people in terms of their focus, as well as, of course, substantial economic resources that might better be used in other areas to improve the health care status of patients.

The second question is unrelated to that. But back in 1986, the Centers for Disease Control made some recommendations that provided that if an incident occurs during a basic procedure that results in the exposure of a patient to the blood of a health care worker, the patient should be informed, and previous recommendations for the management of such exposure should be followed which might include experimental of protocols or certainly perhaps advising the patients as to what is involved, in terms of their own care.

Is that risk of that kind of incident and whether or not it turns into an even likelihood that it is unlikely that it would turn into a real case of AIDS or HIV infection, does merely the fact of having to notify that patient under those circumstances represent a risk in and to itself, namely, the physiological, psychological harm that might exist, and is that something we ought to take into consideration?

I realize that those are two entirely separate questions, but while I got the mike, I thought I would ask them, because I have a feeling I am not going to get it again.

DR. ROPER: With all due respect, I lost you at the last end of the second one.

DR. GOLDMAN: The second question was whether or not the notification of a patient, if an infected health care worker has to -- if there is some kind of incident during an evasive procedure that results in a blood exposure, whether or not the notification of that patient and the psychological potential harm to that patient is in and of itself a risk that ought to be considered in the parameters of decision of advising infected health care workers as to whether or not to engage in procedures.

I would really appreciate you focusing on the first question, and that is why are we spending all these resources on --

DR. ROPER: Again, with all due respect, I am here today at your invitation. I didn't call this session. So, some of the hoopla -- that wasn't your word, but I will use it -- some of the hoopla attendant to this is others' doing.

But I take your question seriously, despite it being rhetorical, I judge. I think what you are saying is how should we properly make decisions on allocating resources, including time and attention and other precious resources. At several turns yesterday, people said how can we get this issue behind us, cannot we get on to more important things, and if you show me how to do that, I will do it right today. We want to do that. I said in my statement and would reiterate to you now, this is not the most important issue in HIV and AIDS, and we have got much important work to do together.

As to the intro to your question, what about doctors, I am charged with doing my job. The fact that somebody else doesn't do their job doesn't mean that I ought not to do my job. I guess that is rhetoric, but I would just give you that, in response to your judged to be rhetorical question.

DR. BARONDESS: I would say that I agree with you, having an operation ought to be as safe as we can make it. There isn't any question about that. The risks of undergoing a surgical procedure have chiefly to do with three things: They have to do with how sick you are and with what, the competence of the surgeon, and a baseline risk of anesthesia. You add those three together, and the relative risk is relatively small.

Nevertheless, if you want to know something trenchant about your surgeon before you get opened up, you might check on that individual's competence, training, the various parameters that are available to measure. That is much more central, and I don't say that it is great as a risk. Surgeons in this country are extraordinarily well and carefully trained, for the most part.

But I say that, compared with this risk on which, as you say, enormous resources and, perhaps more importantly, huge levels of public apprehension are focused, compared with those things, this risk is either zero or so close to zero that it has proven unmeasureable at this point.

I don't want to appear hard-nosed or defensive about this. I would say that, given any evidence, given any sound evidence that this is a risk that is genuine, I think all of us would want to rethink what we are saying.

What I am saying to you today is that, given what we have, given the data that have appeared, I think that we are entitled to say to the public, and that Dr. Roper's agency should do exactly what he says it is going to do sooner possibly than today --

DR. ROPER: I can't do it today, I am here.

DR. BARONDESS: You can't do it today -- to say to the public, look, we are going to put this in some little better and less terrifying context. We are going to stop saying things like exposure-prone, and we are going to tell you what the facts are and how much of this is theoretical and how much is really data based.

CHAIRPERSON OSBORN: Several Commissioners still have questions, and I know Dr. Roper's schedule is tight, so let me ask if they could be quite succinct in their questions.

Harlon Dalton, Diane Ahrens and Don Des Jarlais.

MR. DALTON: Dr. Roper, you mentioned in your earlier remarks that, over the course of the next year, all the states will be developing plans and response to Federal legislation, and that the CDC is developing a process for evaluating those plans and determining whether or not they are equivalent to the CDC guidelines. I wonder if you could tell us some more about what the CDC's process would be for evaluating those plans.

DR. ROPER: The process is essentially one of deciding who his going to be reviewing them and against what framework. Beyond that, I think what you really want me to say is how are we going to decide what is equivalent, and I am not going to answer that question.

MR. DALTON: Yes. Thank you.

DR. ROPER: We want to do it in consultation, especially with our colleagues in state health departments. We got some advice on that point yesterday. I realize that is one of the central issues to this whole discussion, and we will approach it with great seriousness, but I am just not going to give you an off-the-top of my head --

MR. DALTON: I understand, but I just wonder if you could tell me what you mean by equivalent, what about the process by which you are going to decide.

DR. ROPER: Well, the process is set out in the legislation. The state health officer in each of the several states certify to the Secretary of Health and Human Services that that state has instituted the CDC guidelines or equivalent guidelines. Once we have received that certification -- and we have not yet from any state -- we will undertake a review of what that state's activities are and reach a judgment as to whether or not they are equivalent.

MR. DALTON: At that stage, I understand --

DR. ROPER: Of what?

MR. DALTON: You will reach a judgment by doing what?

DR. ROPER: I assume they will send us a written description of their intentions. We have received a draft already from New York and Michigan and California, though they have not yet finalized their policy. We will look at that carefully. If we have any further questions, I assume we will call them on the telephone and talk to them about it, and those kinds of normal activities.

MR. DALTON: And then the we, at what level will this decision be made, and by whom?

DR. ROPER: Well, the report language directs that the Director of the Centers for Disease Control will decide what is equivalent, and I will consult with that person in reaching that -- all kidding aside, Secretary Sullivan is the person deciding whether to turn off the money, so I assume that the Secretary and Jim Mason and others on this will talk about this thing.

Did I answer your question?

MR. DALTON: No, but you didn't really intend to.

DR. ROPER: Is there anybody else's name that I can mention for you?

CHAIRPERSON OSBORN: Diane Ahrens.

MS. AHRENS: I have two brief questions. The first is for Dr. Roper, and the second really is for both Dr. Roper and Dr. Barondess.

It goes without saying, Dr. Roper, that this is a very political disease, and as the scientists continue to debate this issue in terms of health care workers, the political process keeps moving. Legislatures will begin to meet, probably in January, most of them across this country. I am wondering if CDC plans to do any or has done any real education among or for the leadership in those legislatures that will be dealing with this issue. That's my first question.

DR. ROPER: We haven't, and we don't have any such plans. We would be open to doing that. I am quite aware of the legislative calendar in most states and understand the need to conclude our discussions in a timely fashion. Our intention is to do that around the first of the year, so that we will be able to give our summary advice to any legislature or government that would reach that. But if you have suggestions about a more formal process, we would welcome that.

MS. AHRENS: Well, I think the leadership of those legislatures, the leadership in the appropriate committees are the ones that can address this issue, negatively or positively, and I think in many states, at any rate, it might be very helpful if the CDC were to move that educating process ahead, and I am sure you know how that can be done.

DR. ROPER: Yes, ma'am.

MS. AHRENS: The second question I have is really to both of you, and that is what would you like to see this Commission do to address the public fear that is out there, if you had your druthers?

DR. BARONDESS: I would like to see the Commission produce a forthright, reasonably strongly worded statement that puts these risks in context and that also contains a section that attempts to begin to lower the flame under this issue. There really is more heat than this thing deserves, and I think that a series of moderating statements need to appear from this Commission, notably from the CDC, from Secretary Sullivan, and I think there needs to be a campaign. Perhaps this Commission ought to orchestrate it. I wouldn't presume to say that or to know whether that is even possible, but I think strong, recurrent, forthright, at the same time, careful and non-strident statements need to come from distinguished bodies like this.

DR. ROPER: Anything that I say could be used against me.

[Laughter.]

That is not what I was going to say. Anything I say will sound self-serving, but let me try, anyhow. I think what we would most wish from the Commission at the moment is help in dealing with the serious issues here. We don't think that that help would include, from you or anybody else, inflammatory statements alleging political reasons for decisions that my agency or anybody else has taken in this. I think we need to deal with this seriously, and not with political diatribes.

CHAIRPERSON OSBORN: Well, needless to say, we look forward to working with you on this issue, so I hope any additional suggestions you have, we will be very eager to work with you.

Don?

DR. DES JARLAIS: Given that the CDC will have the enviable task of reassuring public anxiety over these issues, I would like your thoughts on the problems of doing that, if there continues to be disagreements as to what constitutes a list of forbidden procedures, if there are differences between state plans the CDC might term equivalent, but the public does not feel equivalent, or differences between what local expert committees are permitting or advising in different areas that potentially all of these might lead to more public confusion and make this task of reassuring the public's anxiety even that much more difficult than the total absence of guidelines at all.

DR. ROPER: Your question is a reasonable one. I think my answer is we need to continue and redouble our efforts to explain the facts to the public in all of the ways that you have earlier suggested we and others do. I think, despite our -- and I use that to mean all of us -- everybody's collective desire to do that, I just think we need to acknowledge that this is a difficult task.

I was involved in an earlier job in trying to allay public fears over the use of a preservative on apples that goes by the famous name alar, and I think, despite the fact that scientific evidence has now shown that alar has, if not absolutely no risk, to use your own word, infinitesimal low risk to human health, there remain public concerns, because of the discussions in 1989.

I think in a democracy that is as media-attuned as ours, where individuals like to think for themselves, there is simply going to be no way for our agency or any others to say here's the answer, you go away, this is all you need to know on the subject. So, my admonition to us all, I guess, is this is something we are going to be dealing with for quite a while to come.

CHAIRPERSON OSBORN: I want to give our special thanks for your patience with our thinking out loud with you and for being here this morning, after an already strenuous week. We do look forward to continuing to work with you.

In your opening comments, you pointed out the common ground, and clearly the common ground is an interest in the safety in the health care setting for patients, for health care providers, and you stressed initially the universal precautions which CDC has very wisely propounded as a major primary strategy for safety since the beginning of these questions some years ago, and I think that we join you in that stress and hope that, working together, we can find ways to both minimize or get rid of, preferably get rid of unreasoned panic and fear in the public, so that that universal precaution approach can become as effective as it might be. I think we need to focus on that very tightly, and I think it will be good to try and find a way past this glitch in the common effort.

DR. ROPER: Thank you.

CHAIRPERSON OSBORN: Thank you.

DR. BARONDESS: Thank you.

CHAIRPERSON OSBORN: We have not scheduled a break, because of the timing of our witnesses, and I would like to proceed, therefore, to ask Mark Barnes to speak to us and give an overview of the broad range of issues that these problems raise.

I invite people, one by one, if they need to leave and come back, to do so and we won't be offended, but I think this way we can take advantage of the important presentations of everyone today.

MR. BARNES: Thank you, June.

I am now an attorney in private practice in New York, but until six months ago, I was the Director of Policy for the New York State AIDS Institute, which is part of the New York State Department of Health. And while I was at the institute, I was one of the primary actors in the drama that resulted in the issuance of the New York State guidelines on the HIV infected health care worker.

So much of what I have to say today, I think much of what I think about this issue is undoubtedly colored by my experience in the New York State Health Department, and so what I would like to do is to give you, as best I can, an overview of the issue, some of the considerations of the issue, and then to address more specifically some of the considerations that we had in mind, when we adopted the policy that we did in New York State. And I should make it clear, also, that I do not speak for the New York State Health

Department. I speak for myself.

I think it is important, first of all, in this entire issue to try to understand why it is that the issue of the infected health care worker and the risk from that worker has inspired so much public fear and so much anxiety in the media. I think it is too easy an answer to say that we are a media-driven society. There are other things going on here in regard to this issue which somehow I think explain the disproportionate response to the actual risk.

There are five different things that I have seen that are sort of forces or trends that have come together that have produced this public anxiety, and I think it is important to understand these, in order to craft an appropriate response to the issue.

First, of course, I think there is a deep suspicion among the public health care providers, in general. There is the idea that doctors and dentists and nurses and hospitals no longer really care about patients, and somehow put profit above their professional duty.

In fact, there is a book that apparently is zooming toward the top of the best seller list which is called "The Great White Lie: How America's Hospitals Are Now Betraying

Our Trust and Endangering Our Lives," and I think just the title of it gives a lot away about what's going on in the public mind about health care delivery.

Then I think there is an idea, an increasing idea that no risk or risk-free health care delivery is possible, the idea that, in an increasingly litigious society and one that is increasingly blame or fault obsessed, that we can achieve no risk and we ought to achieve that standard, regardless of cost and regardless of a cost-benefit analysis.

I think also, third, there is a public idea that politicians and public officials and, no less, public health officials routinely tolerate risks to the public and environmental occupational drug risks, consumer product risks and health risks from dioxin to benedictin to asbestos, when, in fact, they should not tolerate those risks.

Then I think there is continued fear and misunderstanding among the public about exactly how HIV is transmitted and mistaken beliefs about what the real risk factors are for HIV.

Finally, I think partially animating this discussion is a misunderstanding or a distaste for the groups of health care professionals that would be most impacted by policies adopted in this area, and that group of health care professionals I think is defined largely by race, ethnicity or sexual orientation. And I think hatred is too strong a word, but I think there is a misunderstanding of what the costs would be of a policy or restriction, mandatory test and mandatory disclosure.

In New York State, we saw in the late 1980's that this issue would be a major policy issue of the HIV epidemic, and we attempted in the early part of 1989, up until the end of 1989, long before the rumors of Bergalis and the other cases associated with the practice of Dr. Aker in Florida were reported, we attempted to craft an appropriate public health response to what we thought would be a major issue.

We were, of course, given scanty evidence about the point. There were four or five published and unpublished studies, none of which reported transmission of HIV from worker to patient. We had much greater evidence of risk running from infected patient to uninfected worker. We had also the HBV evidence to guide us and the cluster transmissions of hepatitis B in dental and medical practices.

But we were guided, I think, by a set of principles, and I guess I would like to share those principles with you, because I think they animated our discussion and I think they may add to the discussion that you would like to have.

First, I think we had the idea that, in looking at this risk, it was necessary to put this risk, even if transmission was actually reported, as indeed it was reported, it is necessary to look at this risk in comparative perspective and place this risk within the continuum of risk in health care delivery.

It is also important, we thought, to put this risk in the context of risks that flow from the disabilities or conditions affecting individual health care workers from alcoholism to substance abuse to disruptive behaviors in the operating room, stress, fatigue, poor vision, aging, individual surgeon specific wound infection rates, et cetera, and put the treatment of this, for the worker and patient safety, in the context of that risk, so that individuals affected by this problem would receive equal and comparable treatment.

Next, I think we had in our minds the idea of the significant risk standard and the idea that all remote or theoretical risk, it is not possible to eliminate all risk from health care delivery.

Then, I think we had in mind, also, the idea that, of the least restrictive alternatives, that is, even if transmission is reported -- and I will tell you, we expected at some point in 1989 that at some point there would be cases of transmission reported -- what would be the least restrictive way to eliminate or reduce the risk, while preserving, insofar as possible, the most appropriate allocation of social resources.

Finally, I think we had in mind the idea of an individualized examination of workers, that is the idea that some workers, even while performing perhaps minimally invasive procedures, because of poor professional technique, would pose or could pose an unacceptable risk to patients, while other workers performing deeply invasive procedures or what the CDC has called exposure-prone procedures, because of scrupulous infection control practice and scrupulous skill, would pose an acceptable degree of safety, would present an acceptable degree of safety to patients in performing and continuing to perform these procedures.

Finally, I think we also looked simply at the costs an the benefits of policies of restriction or testing, and those costs and benefits, especially in the very high sero-prevalence area like New York State, would include a number of different costs. Of course, the benefits would be of a mandatory testing system that would test everyone for all potential blood-borne pathogens and exclude those individuals from performing invasive procedures.

Of course, the benefit is that you would eliminate, to the greatest degree possible, any possibility whatsoever. However, the social costs of doing that, we judge, would more than outweigh the benefits, and the costs that we looked at were, of course, just the sheer costs financially of mandatory testing and retesting, continual retesting.

The cost of abandoning the resources that had already been devoted to the training of these health care professionals, the cost associated with the loss of the future services of these professionals, whether performing evasive procedures or exposure-prone invasive procedures or whatever.

Finally, the disincentive for providing care to HIV infected patients or patients from geographic areas or from populations perceived to be at high risk for HIV infection, which in our state, New York State, are increasingly, as I said, defined by race and ethnicity, as well as sexual orientation. That disincentive, of course, is the idea of why should the uninfected worker put himself or herself at greater risk by performing exposure-prone or invasive procedures on the patient who is either infected or perceived to be infected, thus resulting in a net reduction in health care services available to largely indigent populations.

Finally, I think we were looking at the idea that attention to individualized suspicion or perception of infection would deflect attention from a much better strategy of protecting patients, which was, of course, attention to enforcing basic infection control procedures and training in basic infection control procedures in all clinical, dental, medical and nursing settings.

With that said, we came out with a policy which was actually pretty much formulated by mid- or late 1989, but which received its greatest attention, really, in January of this year, when we released our policy, at more or less the same time as the AMA released its policy.

Our policy stresses -- our policy, I am speaking really as New York State now -- our policy stressed the need for individualized attention to workers with known blood-borne pathogens, HBV, HIV or other blood-borne pathogens, and attention to their individual infection control records, individual infection control competencies and individual professional techniques, and we envisioned a process, which has been outlined clearly in the more recent guidelines issued by New York State, a more recent iteration of the guidelines, we envisioned a process by which that individual or his or her institution could consult with a confidential expert review panel at the state level, which would be composed of infectious disease experts and other experts who could give counseling to the institution and the worker about possible retraining, possible improvements in infection control procedures and possible improvements or refinements in infection control, of professional techniques, in order to reduce the risk to patients to an acceptable level. That is currently New York State policy.

New York State, I think, envisions its policy as broader than the CDC policy and is more protective of patients than the current CDC guidelines, in that the New York State policy avoids the over-inclusiveness and the under-inclusiveness of the exposure-prone category.

Let me close with just a couple of comments about why I sse, and I think the New York State Health Department sees the exposure-prone category as under-inclusive and over-inclusive.

It is under-inclusive, the exposure-prone category, because it tolerates the performance by infected workers of merely invasive procedures, not on the exposure-prone list, when that worker is using very poor professional technique or has been provided with poor professional equipment by his or her institution, and in which procedures would pose an unacceptable degree of risk to patients.

At the same time, it is over-inclusive, because it bans the entire group of infected professionals from preforming exposure-prone procedures, even when individuals within that group of infected professionals performing exposure-prone procedures may, because of superior professional skill, continue to perform those procedures with a great degree and an acceptable degree of safety to patients.

Finally, a brief comment about the mandatory disclosure provision in the CDC guidelines. As Dr. Roper said, the CDC guidelines currently, as they are formulated, envision a process by which exposure-prone categories are identified, workers should be voluntarily tested, those who engage in exposure-prone procedures and who are known to be infected should go before the expert review panel, the expert review panel would then review the individual situation.

Even if the expert review panel reviews the individual situation and determines that that individual can, because of superior skills and superior record, continue to perform those procedures safely, that individual must still disclose his or her infection to patients, even after going through the expert review panel.

Now, that is, in my opinion, I think, as an attorney, that is a perversion of the informed consent doctrine. If a worker poses an unacceptable degree of safety, that worker should not be practicing. If the worker has been judged to pose an acceptable degree of safety to patients, that worker should be able to continue practice.

The law of informed consent is that only significant or material risks must be disclosed to patients, not all risks or not theoretical or remote risks. But because the CDC has imposed this duty in its guidelines of disclosing a negligible risk to patients, a risk that has been judged by a professional panel to be negligible, it has set in motion, in my opinion, an unfortunate and untoward new liability dynamic which demands the disclosure of these negligible risks. And if that standard, that principal of disclosure of negligible risk were applied to other areas aside from the HIV infected health care worker, then I think that we can see quite quickly that most of health care workers' time would be spent not in health care delivery, but in confessing all possible risk to patients.

So, I will close there. Thank you.

CHAIRPERSON OSBORN: Thank you, Mark.

Before we entertain a few questions, as we need to move ahead, I am going to take a bit of the prerogative of the Chair to interject a couple of comments and a bit of reality that should make it quite clear how somber this set of issues is.

I think that it may not have been obvious to everybody listening this morning that we are talking about an extraordinary small subset of predominantly surgical and dental procedures performed by an extremely few people. Even if we were able to agree on procedures that should be so categorized, which, as you inferred, has not yet been agreed on, so that we are talking, in the abstract, about imposing some kind of state limitations on a very, very small subset of people who are HIV infected, and if some people do and some people don't remember to say HBV infected, so that is a point to be taken.

I think it is universally agreed, including at CDC yesterday, that the vast majority of health care workers who are HIV infected pose no risk and that the vast majority of things that happen in the health care workplace pose no risk.

With that as preamble, let me read, from a state that I won't identify, a letter that is apparently now in use to be sent to physicians who are identified as HIV positive. The letter says "Dear," and there is a place for a name:

"The Board has received notification that you have tested positive for HIV. The Board asks that you identify and provide releases for each physician who has provided care for you within the past 15 years. The signed releases are to allow the Board access to <u>all</u> of your medical and related records within the past 15 years, <u>including all of those records not pertaining to your current health status</u>. For your convenience, I am enclosing 20 release forms for you to complete and return to my attention. The signed releases must be received in this office within 5 days of the date of this letter. Should additional forms be required, please feel free to make photocopies, as needed."

"The Board also asks you provide in writing a complete list of the names of patients and dates where you have trained or practiced since 1977, including your current practice sites. For each site listed, please include detailed description of all of the practice setting, including a description of all procedures performed and the time frame within which each procedure was or is performed. The requested information must be received in this office within 5 days of the date of this letter. Please note that the failure to respond to the Board's request for information is in violation of state statute" -- and then that is listed -- "It is, thus, grounds for disciplinary action by the Board, according to --and another statute is listed -- "Thank you for your anticipated cooperation. Sincerely."

So, we are not talking about theoretical harm in this issue. I would say everybody could agree, we are talking about real harm to the careers of important and well-trained health care professionals who pose not even the vaguest of risks by anybody's definition in the way this issue is playing out.

I thought this was as good a time as any to bring that forward, because I must confess I wasn't able to sleep last night, having read this a couple of times. We are getting into dangerous territory in this society, when we have this kind of stuff going on for theoretical or no risk.

I would now entertain comments and questions briefly for Mark Barnes.

[No response.]

DR. ROGERS: You've left us all speechless with that. That is real reality testing in a horrible way.

CHAIRPERSON OSBORN: I think the point is, as does happen with panic, the horse got out of the barn long before we knew there was a barn, except for Mark's description of some careful advance thinking in New York State and some other states, as well, and my State of Michigan has come through with a reasonable alternative set of policies that we may talk about. California has been working hard. There are other ways to approach this problem, and that is part of the reason for getting together today.

But I must say, as was so common with this epidemic, even though there was no name filled into this particular letter, I went to the trouble to make sure it was real before reading it to you, and I am assured that it is real, it is in use, and it is a matter of great concern that these kinds of things -- there are a couple of other states with somewhat more egregious policies, but without quite such a telling quick way of summarizing them.

As has been pointed out in our discussions, most of the state legislatures are entertaining activities and some of those could turn out to be right in line with what I just read you.

Any discussion?

[No response.]

If not, everybody I hope would just stay comfortably where you are, and I will then turn to the next panel on the dimensions of risk. In the following order, we will hear from Julie Gerberding, a Ph.D., and Assistant Professor at the University of California at San Francisco; Barbara Gerbert, Ph.D., Associate Professor and Chair, Behavioral Science Division, School of Dentistry at U.C. San Francisco; Barbara Fassbinder, R.N. and P.S.N., a nurse from Monona, Iowa; and Mike Osterholm, a Ph.D. and M.P.H., and epidemiologist, Minnesota Department of Health.

I welcome all of you. Thank you for taking the trouble to be with us. If you would in that order present, and then we will have a chance to interact with the whole panel.

DR. GERBERDING: Good morning.

I would like to keep my remarks relatively brief, because I think most of the things that I have to say have probably been said and will be said by others over and over again. Even though I have spent most of my relatively short academic career studying HIV risks in the workplace, and I think I am qualified to talk expertly about transmission risk to patients, I also want to share with you the perspective of a clinician who takes care of AIDS patients, because some of the aspects of the policy situation that we are debating have very devastating consequences for patients, as well as providers.

One of the things that we have to get established right from the beginning is that the risk of transmission to patients really is low. Everything we know about transmission in the health care setting tells us that risk to patients is low, and the data that is available tells us the risk to patients is low.

One of the problems that has come up since the CDC started dealing with this issue is their model of risk in the health care situation. They have taken scant data to begin with, and then created an estimate of what risk to patients and providers might look like under various circumstances. This is a useful starting point for further discussions, but has been taken out of that context and used as factual information. The headlines in our paper said 128 patients infected with HIV in the health care setting. So, I think it is very important to understand the limitations of modeled risk, and to focus more on factual information that we have available about risk.

I have tried really hard to think of some constructive descriptors of the policy situation that we are in and responses to the CDC policy. I know my colleagues at the CDC are people of great integrity, who are good scientists and who are genuinely interested in doing the right thing. Yet, somehow, out of all of this we ended up with a real mess, a mess that those of us out in the world taking care of AIDS patients have to clean up.

I think one way to think about this policy is to refer to it as the "missed the boat" policy, because it is a policy that focuses on restricting infected people from practicing, but does very little to deal with the potential problem of cross-contamination or patient-to-patient transmission of this virus or any other infectious disease in the hospital. So, we have put all of our attention in one boat and not dealt with what may, in fact, be a very important cause of patient infections with a variety of agents.

I think it is also accurate to think of this policy as the cart before the horse policy. We have said that risk to patients is at least theoretically possible and probably will happen under various circumstances. We know that there are two mechanisms by which patients could be infected. One is by direct inoculation, and the other is by cross-contamination.

We have raised the possibility of exposure-prone procedures, but we have not taken any steps to very seriously address aspects of exposure-proneness that might be remedied by changes in infection control technique. There actually is activity going on in various surgical communities to do exactly this. Even the CDC's own study looking at inter-operative exposures define factors that were associated with an increased risk of transmission, and once you know the risk factors for transmission, it is the next step to go about defining policies that would address those risk factors.

The orthopedic surgeons, for example, have defined what I would call procedure-specific infection control interventions to determine that they can reduce the frequency of percutaneous injuries to almost zero, by following a new set of infection control practices in their environment.

So, I think before we go off restricting and testing and resorting to relatively draconian measures, that a sensible approach to solving this problem would be to say what are the hazards and what can we do about them. If you do an exposure-prone procedure, wouldn't the first step be to adjust the exposure-proneness of that procedure?

Let me just share with you an anecdote. A surgeon in my hospital, who is a very fine person and a very good surgeon and very invested in taking care of all patients, including AIDS patients, called me up on the phone and said, "Dr. Gerberding, I'm not infected with HIV or hepatitis or any other blood-borne infection that I know of. Do you really want me to do exposure-prone procedures on patients with AIDS?" He was bringing up the idea that, if the procedure is exposure-prone, nobody should be doing it, not those who are infected with blood-borne viruses, but anybody should not be in the position to have to face that kind of hazard, if it could be avoided.

The other part about risk assessment, which I think Mark alluded to, is that you have to weigh the balance of what you hope to accomplish in solving those risks with the costs, and the costs are many with the CDC policy. We spent many hours agonizing over how we would have to face implementing the policy.

Since the policy has been publicized, I have noticed in my infectious disease clinic, that I have found it impossible to refer patients to community dentists in the City of San Francisco, because dentists are afraid of what will happen to them if they should become exposed in the process of taking care of these patients. So, I think we will see an increasing reluctance to do invasive procedures, particularly exposure-prone procedures, if we continue along this tact of requiring restriction of those people who become or who already are infected.

I have grave concerns about access to care issues for patients, and I think that is a part of this policy that was not really thought through, and a part of the policy decisions that we have to make in the future that we must put at a very high priority.

The disruption in the patient-provider relationship that has been engendered by the media attention it has received and the lack of leadership on the part of public health and scientific community in allaying fears has been very destructive. Individual providers have a responsibility to deal with their patients up-front and act individually to allay fears, and I think we need some real leadership on a number of levels to send a clear message that health care is indeed safe, and where it isn't safe, we will act responsibly to implement risk reduction interventions.

Thank you.

DR. ROGERS: Thank you very much. We all owe you a great debt of gratitude for the nice science based studies you have done. I was thinking that, as we were hearing some of the testimony, and we are grateful to you for what you have put in the literature, sort of the way you have gotten us started.

DR. GERBERDING: Thank you.

DR. ROGERS: We are now going to hear from Barbara Gerbert.

DR. GERBERT: Good morning.

I thought I was going to have some help with turning the lights down. I will be using slides.

[Slides shown.]

Thank you very much for asking me here to present my perspective on the issue for today. I think there is a problem and, as a psychologist, I would say that the problem is something that has been taboo to discuss, and that problem is fear. It is fear on the health care worker side, as well as on the patient side. It is concern and, as well, it is the perception of risk.

I would like to say that I think that this concern is what has been driving policy the past year. Yet, this concern hasn't been mentioned. Once again, it has been taboo. Actually, some of the policies that have been suggested will not change the epidemiology of the disease transmission at all, nor are they going to help concern, until we all focus on concern and fear and have the word come out.

I submit to you that approximately 80 to 90 percent of all health care workers and all of the public are concerned about HIV transmission in health care settings, and I will present data to that effect. I think many of us in this room have been hanging out with each other for the past decade and we think that it is someone else, some minority who is concerned, but, rather, it is a majority and a great majority, and I don't think we can dismiss this concern as representing homophobia or hysteria or stupidity.

What I would like to say about the perception of risk, and this we get from the risk perception literature, is that, on the one hand, experts look at risk as a risk ratio, it is one number, it is very simple. On the other side, the public -- and again, I say the public and most health care professionals -- look at risk in a much more multi-dimensional, much more complex way. They wonder if it is voluntary, they wonder how dreaded the disease is, are they familiar with it, do they have trust in authorities, is there an identifiable victim, such as Kim Bergalis, are there catastrophic consequences.

Now, we have the experts, with their risk ratio, talking to the public with this complex view. Our lesson here is that increasing knowledge will not affect risk perceptions. We have heard the words "education" and "training" this morning. Education and training do not change attitudes, and we need to find new ways to change these risk perceptions. Repeating how low the risk is has not changed risk perceptions, and mixed messages erode trust and authority.

What I would like to do very quickly is run you through three perspectives, the perspectives of providers, the public and the policy-makers.

Concerning providers, there have been two issues, and because there is a reciprocity, I would like to address a issue that will not come up much today, and that is health care workers as providers, and Dr. Gerberding did just mentio that providers are worried about providing care to those who are infected. And the other one which we are here to address today is HIV infected health care workers.

You have seen these headlines, they are mostly from 1987, when physicians and dentists were being chastised for their lack of willingness to treat people who were infected. Again, I bring this up, because of the reciprocity issue.

In 1988, we published a piece in the Journal of the American Medical Association on why fear persists and why health care workers were afraid. At that time, we had been to many meetings where health care workers were called together, and the reason for the meetings was to lower the fears of health care workers. At those meetings, there would be a panel of epidemiologists, infectious disease specialists, and hospital administrators. The purpose of the meetings was to reduce fear and, yet, at the end of the meeting, I would be standing in the back of the room and would see anxiety increased by those meetings, and I wondered why that would be.

What happened at those meetings -- and I call your attention to this, because we should not continue to make these mistakes -- what happened at those meetings was the presentation of epidemiologic data, and there you would see this little piece of the pie that says that health care workers aren't at risk, it is a minuscule risk there. We would also have provision of information on transmission, and the virus was depicted as very dainty and fragile. We would have instruction on infection control and the CDC guidelines on use of infection control, and universal precautions would come out.

The fourth method that was used was authoritative reassurance, and that looked like this, which is don't worry, we will take care of you. It was very paternalistic.

[Laughter.]

Well, we think that why fear persisted was that there was a real risk, there is a real risk. We can debate the wording there. We believe there is fear on the health care workers' side, because infection control measures aren't enough. Health care workers who were sitting in those rooms knew that all of the transmission that had occurred occurred because of accidents, so double-gloving, triple-gloving, whatever, is not going to stop the accidents that can create transmission in either direction.

And the third reason that fear persisted was that authorities and health care workers can't talk to each other. The people on the panel, many of them did not have hands-on experience with patients. Hospital administrators were not respected by the on-line health care workers. In addition, their missions and language were very different.

We also in that article cautioned against using mixed messages, and I caution against that today, that is, use universal precautions that the risk is low. Dentists and physicians at the time kept saying why must we do all of this, why must we wear these space suits, if the risk is low. It is a very mixed message.

So, at that time, we said avoid designating the risk as low, avoid mixed messages, acknowledge what you do know and what you don't know, acknowledge the limitations of infection control, that is that accidents do happen, and try to lower the rate of accidents, and discuss fears. And I say that today we still haven't brought out fears.

Yesterday and today, I have heard the word "anxiety" used a little bit, and I am very pleased. For the most part, we don't say the public health care workers are afraid, and that is exactly what is happening.

Just to show you the impact of our work, we suggested not using the word "low," and, sure enough, people have avoided it. In fact, they've now turned to many synonyms which you see there, so we have "minuscule" and "exquisitely rare" as two of the better synonyms.

So, on the provider side, health care workers are concerned and this concern is leading to unwillingness to treat. In fact, in a couple of weeks, we will have an article in JAMA on the current state of physicians' unwillingness to provide care.

Let's turn to the public. We conducted a survey of the general public, the U.S. public in 1988, and we replicated this summer, asking various questions of the public about their perception of HIV transmission in health care settings. We said would you switch physicians and dentists, if yours were infected, and the surprising finding there is that, in light of the Florida case, the percent who would switch has not changed. It is quite incredible.

Many more patients want to be informed. In fact, everyone wants their provider to tell them their HIV status. Fewer feel that HIV infected physicians, surgeons and dentists should quit working. In each category, that has gone down in 1991. We think that may be congruent with what Gallup has shown recently, which is that compassion for people who are infected has increased. That doesn't mean that people are now willing to go to physicians who are infected or dentists who are infected, but they are willing to allow them the right to continue to work. So, the public is concerned and we are concerned that that concern may lead to legislative solutions to public health problems.

Turning to policy-makers, there are three issues that are under consideration, and that is who should be tested and when, who should tell and who to, restriction of practice, should there be any and, if so, of whom, for what, and the exposure-prone issues.

Right after the first MMWR about the Florida case, we asked dentists if they believed that transmission had occurred from dentist to patient. As you can see, most of the dentists do not believe that transmission had occurred at all in the dental setting. In fact, only 12 percent believed there was conclusive evidence about the CDC report from dentist to patient.

Yet, even though they didn't think it had happened, and we asked other questions saying do you think it could happen and they said no, half of the dentists wanted infected dentists to quit working, and another 38 percent felt that changes or restriction of some sort was necessary.

There is remarkable agreement between our survey of the general public in 1988 and dentists in 1990, that is, both groups felt that patients should be informed, and half believed dentists should not be allowed to work if they were infected.

If we had more time, I would walk you through this sequentially and slowly, but, instead, I will just bring your attention to the right-hand column. We found out the dentists, and we believe dentists would be similar to all health care professionals, physicians I believe have the same attitudes, and that is many physicians feel that health care workers who are infected should inform their patients and should restrict their practice.

The public and dentists were in agreement, and then, after the second MMWR came out in January 1991, the AMA and ADA came over to the public and health care workers' side, and the CDC, again in July of this summer, put out its exposure-prone procedures, as well as the meeting yesterday, the point being that I think this concern that is coming from the bottom is affecting policies today, and so we believe that the force of AIDS policy is coming from this concern in the sphere.

We believe that when people say there is no scientific evidence for any of these policies, what they are saying is there is no epidemiologic evidence. The evidence that I have been supplying, that has to do with people's concerns I think has to be addressed.

I also want to caution against comparative risks. We have been trying for the past 10 years to teach the public and health care workers that they should be more afraid of hepatitis B, and we haven't scared the heck out of them about hepatitis B. We have been trying to scare them about driving to the hospital as a relative risk, they should be scareder of that. We can't scare them about that, and yet there is this minuscule risk down there that we can't even measure that people are worried about.

I would like to close with a quote from Paul Slovic from a well-referenced article in "Science" in 1987: "There is wisdom, as well as error, in public attitudes and perceptions. Lay people sometimes like certain information about hazards. However, their basic conceptualization of risk is much richer than that of the experts, and reflects legitimate concerns that are typically omitted from expert risk assessment. Again, it's the difference between the one number. We have the feeling that if people would memorize this one number and get it right on a knowledge test, we would solve our problem, and that is not true."

Slovic goes on to say, "As a result, risk communication and risk management efforts are destined to fail, unless they are structured as a two-way process. Each side, expert and public, has something valid to contribute. Each side must respect the insights and intelligence of the other."

I call upon the National Commission on Aids to be the group to effect this necessary dialogue and address this taboo entity which is fear.

Thank you.

DR. ROGERS: Dr. Gerbert, thank you very much. It was very refreshing and very new approach.

DR. GERBERT: Thank you.

DR. ROGERS: I would like a copy of your slides. It is very helpful.

DR. GERBERT: Thank you.

DR. ROGERS: We are now going to turn to Barbara Fassbinder, a nurse. Ms. Fassbinder, it is an honor to have you wish us.

MS. FASSBINDER: Thank you.

On behalf of myself and my family, I would like to extend my deep appreciation for the opportunity to share my perspective with you here today.

My name is Barbara Fassbinder, and I hold the unenviable distinction of being the first documented case of a health care worker infected with HIV through a non-intact skin exposure. Now, the significance of my experience does not lie in its complexity. The significance, I feel, lies in its sheer simplicity, for, you see, I am just a very simple nurse.

My story begins in August of 1986, in a 49-bed community hospital in the rural Midwest. A young man came to the emergency room in acute distress and, within a relatively short amount of time, suffered respiratory arrest.

During the resuscitation efforts, I did something that I had done a hundred times before, and that was I was instructed to remove an arterial line that was not working. When I did so, I had a small piece of gauze available to put pressure on the site to stop the bleeding, and approximately half a cc soaked through onto my left index finger, and what I had completely forgotten about is that on that finger were some very small seemingly inconsequential cuts. I simply wiped the blood away when the time was up, and we continued with the resuscitation, which was unsuccessful ultimately. The young man died.

This young man, who was new in the area, for which we had had no written history available, he was able to give us no verbal history, he probably did not know he was infected with AIDS. His infection was found at the time of autopsy, and nor did his friends that brought him min that night. Although I came down with a mono-like illness a few weeks later and I was quite miserable, I didn't connect the two incidents, and, in fact, felt well enough to donate blood in December of 1986, as was a routine thing for me to do.

It just so happened that the hospital that I worked at offered HIV testing for the 15 of us that were involved in resuscitation of this young man, and since my husband and I of 15 years, 13 at that time, had wanted to have a fourth child, we thought it would be a prudent thing to do, for me to be tested. I get tested, in an effort to put our minds at ease, once and for all, about the whole incident.

Well, in mid-January of 1987, I have to say that my mind was not put at ease at all and has turned into a sequence of events that has at times been a nightmare for myself and my family.

I was called into an office at work and shown the written results of my HIV test and asked for a possible explanation. At first, I laughed at the absurdity, and as anger and embarrassment sunk in, I requested another test, because I assumed a terrible mistake had been made. The results came to me about a week later. The results came to me as I was alone at home, with a 3-year-old who was confused and frightened by my reactions. The results came from a stranger on the health department, as well as someone from a blood bank.

I alone had to figure out how to explain this to my husband. I alone had to figure out how to tell him that a state health department investigation into our personal private life was to begin the next morning. I alone had to tell him that he would have to be tested for HIV, as well, and what that would mean.

To their credit, the state department of health did a very thorough and sensitive investigation, and David, thank God, has tested HIV negative repeatedly since then, and I thank God for that.

The Centers for Disease Control used my case anonymously as an example of why the so-called universal precautions needed to be implemented. As I said, I requested anonymity, to protect myself and my children, who were three, six and nine at the time.

Now, the workers compensation system, a system that I had always assumed would take care of me in the event of such a catastrophe, falls far short of my even most modest expectations. It is important to note that the responsibility is on the health care worker to prove infection in the workplace. For me, that was not difficult, but for many health care workers it is very difficult, and workers compensation denies.

The compensation system, which does vary from state to state, is a classic good news/bad news story. The good news is that all and only HIV-related expenses are covered, after close scrutiny, I might add. The bad news is that disability payments are based on a portion of one's wages at the time of the accident. I was working half-time in 1986, so, therefore, I am compensated at half-time 1986 wages, 60 percent of half-time 1986 wages, I might add. And since there is no way a family can survive on that, we have had to rely on the social security system and the generosity of my family.

In addition, since I, like most Americans, many, many Americans, purchased my health insurance through my employer -- my husband is employed in agriculture -- when I was no longer able to work, because of my illness, we were no longer able to pay the premiums on health insurance, so then we began the task of trying to find health insurance for my husband and children, who are free of HIV disease.

They had been healthy. There should be no problem, right? Not so. Many companies would not even consider them. The ones that were kind enough to consider them were likely to ask for bizarre assurances, such as notarized statement from my husband that he would not have sexual relations with me.

I was outraged, by the way, by this request. My husband's was much more humorous, but profound. His statement was, "Do you mean it is okay with them if I sleep with strangers or I shoot drugs, but I just can't sleep with my wife for 15 years, who I already know is HIV infected?" Needless to say, we didn't take that policy. The company that did finally agree to insure my husband and children still will not cover them for anything HIV related, even though the scientific evidence is overwhelming that household contact is extremely safe, and my children are safer in my own home than they are in the outside world, as teenagers.

As for myself, I have just completed the two-year waiting period, after being declared disabled, and I am now eligible for Medicare. As concerns my employment, this was a difficult situation for all concerned, policies and knowledge in place in January of 1987 were vague.

I was transferred to an administrative position, for which I was not prepared, and it was not a part of my overall career goals. It was done partly out of fear of public reaction, if my HIV infection should become known in the community. And although I tried very hard to succeed in this job, my heart was not in it, which only added to my

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already deepening depression. I missed my old job. I missed the patient contact. I missed my former co-workers. I missed my life as it used to be and I mourned for my lost future.

It was all enveloped in a cloud of secrecy. HIV counseling was not readily available in our rural area, and it was not until I sought care at a major teaching hospital a couple of hours drive away, that I began to feel hope again. But as my energies began to wain, tensions increased with my employer over responsibilities for compensation, as well as job expectations, and my health dictated that I finally resign in 1989.

What are the lessons, then, that can be learned from this? First of all, it is very clear that education remains the best weapon against this disease. Educating the public at-large about risky behavior is imperative. Education about how the virus is not transmitted is equally important, to prevent the tragic consequences of hysteria. And educating health care providers in the best method of infection control is essential to protect themselves and their patients.

Secondly, workplace issues regarding HIV must be addressed. Employees and employers alike must work together to develop policies, to familiarize themselves with their individual and their collective rights and responsibility. This must be done in the clear light of reason, compassion and the best medical evidence, and with provisions for qualified independent career and personal counseling.

Thirdly, the private health insurance system as it presently exists is tragically inadequate. Vast numbers of Americans are uninsured or underinsured, which inhibits early intervention treatments for many illnesses, not only HIV. A plan for universal health coverage must be adopted as soon as possible, and I applaud the Commission's efforts in this area.

Finally, how do we at once reassure the public that the health care setting is safe and continue to attract talented young men and women into health care? The answer, I believe, lies in the strict enforcement of infection control measures, rather than in misguided proposals for mandatory testing of HIV status.

Whereas, present HIV antibody testing is a very useful tool in diagnosis and treatment, it is far from instant or perfect, and should never be used as a tool for destruction of people's lives. Testing can never be considered a replacement for sound technique. To do so does not serve in the best interests of the public health. The public's interest is better served by the knowledge that their health care provider is doing everything possible to protect them against all known and unknown blood-borne diseases, for, sadly, we must realize that AIDS is only one recent entry into the litany of diseases that have plagued mankind since time began, and it is a litany that will continue long after AIDS becomes a distant memory.

Thank you.

DR. ROGERS: Thank you very much for that very powerful message.

Dr. Osterholm?

DR. OSTERHOLM: Thank you.

There are a broad universe of precautions as a teem that may have precipitated it, but I think, as a concept, we were all interested in this long before this happened.

Also, during this time period I was the lead investigator on two different outbreaks of hepatitis B associated with transmission from health care workers to patients. One was an outbreak related to an obstetrician/-gynecologist associated with vaginal hysterectomies and transmission there, and one was from a general surgeon to patients, so I also had an opportunity to see hepatitis B from the other side of the fence.

As a state epidemiologist since 1981, we have been actively involved in the issue of HIV, including components of surveillance, public risk education and public policy development. Like many in this room, we were there in the early 1984-85 time period, trying to deal with the issue of children in schools, food handlers, premarital testing, and even to the issue of health care worker and patient, looking at it relative to making sure that patients had adequate care and trying to stem some of the tide of fear that was very prevalent in health care workers in the mid-1980's.

I will say right now that, as a public policy person, I spent a great deal of time in our state legislature, which I think is probably one of the most gifted of all legislatures in the country as relates to AIDS issues.

In 1986, I had the very fortunate honor to be asked to address the Minnesota State Senate in a mandatory three-hour session in the Senate chambers, in which the majority and minority leaders required attendance of all Senators and their staffs, and we for three hours had a very neat opportunity to educate them on AIDS. That was in 1986. I give you that as perspective, because what I have to tell you later on may not sound so good.

In 1990, I was the CSTE, Council of State and Territorial Epidemiologists' representative to the first meeting to address this issue. I sat in somewhat surprise to hear many of my colleagues, particularly those from various colleges, sit there and debate the issue of whether or not the case involving the Florida dentist really existed, or whether this was an aberration of CDC investigative procedures, and not wanting to deal with the issue of could this happen, despite the fact that many of us had been talking about this for some time.

Also, it was on that day that I became very aware that we were no longer talking about the issue of risk on a level playing field, a decision had been made that this risk would be elevated as a side risk issue far beyond that that had to do with a perspective and that was going to require that we deal with that.

My experience with AIDS continued in 1990, late 1990 and early 1991. We had the unfortunate experience to be involved with the investigation of a family practitioner in Minnesota who was HIV infected and who continued to practice for nine months, with severe microbacteria and infection in his hands and arms, with numerous weeping lesions on his hands and arms. During that time, he was involved in a number of procedures which could have, from the weeping lesions, caused problems.

We ended up, in conjunction with the Minnesota Board of Medical Practice, during a look-back investigation on 327 patients related to this -- the summary of this will be published next week in the New England Journal of Medicine -- and with that investigation, documented a number of particular problems with infection control, in general, and we also in this article comment on the prospects for look-back investigations.

It was also during this same time that I led the investigation of an occupation acquired infection in a young man in our community as a result of a needle stick from an HIV infected patient, and have confirmed that as an occupationally acquired case. I, again, have seen it from both sides.

As a result of these efforts, our department has compiled a report -- which I will make available to the Commission -- to the Governor of Minnesota, a report and recommendations on HIV infections in health care workers. This was an extensive effort that required thousands of person-hours to compile, and tries to review all aspects of the issue.

We calculate in these theoretical calculations, which I shall address in a second, that the risk if incredibly low, using those words which I have not yet found a better substitute for. The risk is likely no more even in Minnesota than every 2,100,000 procedures to 21,000,000 procedures that we expect transmission to occur.

We reinforce the conclusion that mandatory testing is not a viable nor effective method for dealing with this issue. We highlight extensive discussion related to infectio control problems.

In this country, as a result of the modernization of health care, lacking a better term, we have witnessed many hospital closings, many corporation mergings and many new corporation formations, such that today in many hospitals throughout the United States, it is not unusual to have four or five different corporations which actually own part of the operations in the hospitals, for which no one really is certain who has charge over someone else, and we have found serious breaches in aspects of infection control related to that, and we deal with that issue as a very important issue and priority.

Finally, we talked about the issue of risk education, as you heard so very eloquent this morning from Dr. Gerbert, that I think it is very important that we understand that this issue of risk is not as we perceive it here in the public's mind, it is how they perceive it, and that I believe is the flame that is driving the heat on this issue. It is not poor policy-making in itself.

With that, let me just comment very briefly about risk. This issue is very unique. I have been involved with a number of various risk issues in product liability, related to outbreak investigations, and many aspects of AIDS. As I said before, I have been there at the school children's side, I have been there in the health care worker issue, the food-handler, and I have never seen anything in the general population like this.

I mentioned earlier about the enlightenment of the legislature. Frankly, we are very concerned about the actions that our state legislature may take in the next session, based on information that we have back, because they are reading the public's perception. It is not poor policymaking. It is the public's perception that this is a real risk, it is a significant risk, and it is one that needs to be addressed.

So, we can talk here all day about government agencies attempting to do the right thing, and what we must not forget in the first instance is that it is public pressure and public perception that is driving this issue.

I borrowed this from Dr. Gerberding, who I think has a slide of this. I think Americans have come to look at this as "lotto America medicine." They believe, just as they do that they can win Lotto America, that 1 in 25 million risk, and they go out and buy their tickets. They also believe that they can contract HIV infection in the health care setting in that 1 in 25 million risk and believe it with the same equal energy.

I would reiterate that all the comments I have to make today are based on the fact that the risk is very, very, very low. I, too, would like to have a bretholizer machine outside the surgeon's office, before I would like to have an HIV test, but, in fact, we must understand that that is not where the action is at today. The action is with HIV.

Given that, I would like to comment on what I perceive as a major shortcoming of our approach to deal with this issue today. I hard it echoed at this table this morning, and I heard it echoed at CDC yesterday. First of all, we do not have good information on the risk of HIV transmission from health care workers to patients. We have falsely reassured ourselves that the risk is very, very, very low, and I think some of the comments this morning echoed that.

We are ten years into this epidemic, but don't forget that only in the last 18 months have half of all the AIDS cases in the United States been reported. Those first six to seven years gave us very little power to find such a potential problem that existed out there.

In particular, we now look at the issue of transmission from health care worker to patient, and we say what are the data that support that. Well, we have 50 health care workers in this country who can tell you about it, including Barbara, as it relates to transmission from patient to health care worker. Where we have looked at that risk in the past, the reverse is true, from health care worker to patient. I believe that it frequently exists.

In addition, we have documented a number of cases where we have rather substantial transmission of blood from health care worker to patient in accidents that occur within the surgical setting, and, therefore, is of growing importance.

I also am taken aback by the data that is cited frequently today. Having been involved with one of the look-back investigations, I can tell you we were fortunate to have no cases of transmission, but we now know, with over 60 health care workers in this country in which look-backs have been initiated involving over 9,000 patients, within those 9,000 patients, we do have well over 50 patients who are HIV infected.

Now, the investigations are not complete. We have no data to support that any of those are, in fact, infected from a health care worker, but I find it very disappointing that, particularly, many of the activists groups are willing to write off gay men who attend gay practitioners as automatically having contracted their HIV infection from gay lifestyle or sexual behavior, as opposed to the potential for transmission from a health care worker to a patient.

If you are going to look for potential transmission, where is it going to most likely occur among people who are infected, who are most likely to be infected in this country? At least as we see it in the risk data, it is gay men who are HIV infected health care practitioners. Who are they more likely to see as patients? In may cases, gay men. Therefore, we have automatically assumed, and I think we have to be very careful about that, and some of these investigations very well may demonstrate that, in fact, there has been some transmission that has occurred there.

Now, why do I say this? Not to heighten fears. I have already laid the premise that I think that the risk is incredibly low, so very low, but difficult to measure. I say this, rather, because I think, for example, in Minnesota, which was the first state in the country to initiate HIV surveillance back in 1985, where we have data on 3,000 additional individuals who are HIV infected beyond the 1,000 cases that we have. We could easily in Minnesota, right now, have HIV transmission from a health care worker to a patient that we do not know about, and that it has been part the lax of surveillance in this country that would allow us that opportunity to find that. With time, I believe we will document it, but I think it is very premature to say there won't be additional transmission.

Why is that important? Because what will all of us say, when a second case occurs? It will occur, and there will be a third, and I have no doubt about that. Just in 1987, as we said at the CDC that this would occur, and it did finally occur in 1990. There will be a second and a third, and I hope that all of us can live with our statements and our conclusions, when the public gets a second or a third outbreak that occurs.

Now, it doesn't change the risk perspective of an epidemiologist, whether it is one outbreak, two outbreaks or three outbreaks. Given the enumerator, with this very large denominator, the risk is still infinitesimally small. it does not deserve the attention that we as public health are applying to it. But will we be able to withstand it, when congressional leaders, state legislative leaders and other people in the community come back and say, see, you didn't tell us the truth, you told us it was so small, it wouldn't happen, it didn't happen, and now you've got a second one and now you have a third one.

I think we have to be very cognizant that they will occur. I am not suggesting it is hypothetical. I am convinced beyond a shadow of a doubt that they will occur, but epidemiologically, it doesn't change the picture.

Given this, I won't go on any addition beyond what Dr. Gerbert said. I think that we have to be aware that we are trying to the very best of our ability. In Minnesota, in a poll taken in the summer, well after the heat of much of this information, 85 percent of Minnesotans still want doctors tested and those results known to them, and I think that it is very important that we understand that this is a very different public perception issue.

I would close by saying I don't agree with all the aspects of the CDC report, but I believe in the spirit in which it was written. It was very hard for me yesterday to see organizations highly critical of the CDC, who have been all over the map on this issue since 1989 and 1990, providing no leadership whatsoever, because you had to figure out who you were talking to on what day, to know what their position was as an organization. And I think at least the CDC has put the word out there, they have put it out there on the firing line, they have been an easy target, and I think we all need to do what we can to preserve the integrity of that aspect of our public health community, while at the same time providing them our best input, so that they may adjust accordingly.

I think it is important we be proactive on this issue with risk in perspective. But if we are not proactive, I would never say this about any other issue I have ever dealt with in public health, but this issue will be decided by others, if we in public health don't decide it.

Thank you.

DR. ROGERS: Thank you, Dr. Osterholm.

Questions? Let's start with Don. He feels maltreated the last time. And then we will go to Harlon.

MR. GOLDMAN: Let me ask everyone, and I am including Mark in this, as well, but let me ask all of you, in terms of risk and the question that I posed to Dr. Roper and to Dr. Barondess earlier. Assuming that the CDC recommendation back from 1986 is correct, namely, that if an accident should occur during the course of where there is a needlestick incident or a risk of contamination of a patient by an infected health care worker, then the patient ought to be informed of that incident occurring, so that that patient can take appropriate action. Are the psychosocial consequences of that disclosure in and of itself and the patient having to live with that worry over the next six months itself a risk that ought to be factored into the considerations of we talk about whether or not the risk is small, tiny, minuscule, et cetera?

MR. BARNES: I will go first, if that is all right with others.

I think what one would have to say about that situation is that, in fact, a patient, if there has been a significant blood-to-blood exposure from a worker to a patient, regardless of whether the worker has a known infection or not, the patient ought to be informed of that, so that the patient could take appropriate action, because the patient perhaps ought to choose to be tested, as well as the worker choosing to be tested for HIV, HBV or any number of other blood-borne pathogens, including hepatitis C that may go from worker to patient.

That would be the situation in which the risk of transmission is greater than hypothetical, because there would, in fact, have actually been a blood-to-blood contact between the worker and the patient.

The analogy I think that one would make would be the botched operation or the operation in which a sponge had been left inside the patient. Of course, the patient should be informed about that. However, the fact that there is a percentage of situations in which there has been poor professional technique applied in the course of an operation, poor professional technique applied in the course of dental care, that does not mean that we stop doing operations or stop providing dental care. It means that when the hypothetical risk rises to the level, at that point I would think of a significant risk, then the patient, of course, should be informed, so that the patient could take appropriate action.

DR. OSTERHOLM: If I could follow up with that, I really strongly agree with that, and I think we could take it one step further. I raised this question yesterday at the CDC meeting, because I have not heard any of the organized medical groups deal with this issue.

To me, dealing with this issue is paramount to protecting the health care worker. I know, without a doubt, that if a health care worker has to tell a patient one time that they are HIV infected and that they may have exposed that patient, that will, in essence, be the end of that health care worker's career as they know it. There is nothing legally or ethically binding to a patient that requires them to keep such information confidential. They could take an ad out in any newspaper on any street corner and do whatever they want to say that John Doe is infected. That is quite in contrast to the health care worker's fiduciary responsibility to the patient, in addition to the ethical and legal obligations, where such information could be disclosed.

So, I would think that a high priority be placed on making certain that an HIV infected health care worker does not ever have to get put in that position of potentially having to tell a patient that, in fact, they may have exposed them, and in doing that, in a sense, you start to get back to that issue of what procedures then don't you want to do, so that you protecting yourself and your livelihood in some other form don't get exposed to that, and I think that issue has been missing in this discussion.

CHAIRPERSON OSBORN: Harlon Dalton, Diane Ahrens, Jim Allen, in that order.

MR. DALTON: My questions are for Dr. Gerbert. A nice presentation, and my fellow Commissioners know I hate slides and I was headed out of the room. I saw the colors, and that was nice and I stayed. The dog is great.

[Laughter.]

I want to press you a bit and find out what the take-home message is. Someone characterized your comments as provocative, and what are you provoking has to do is sort of my global question.

I thought I heard you perhaps saying that nothing works in terms of trying to communicate with people around risk of transmission in the health care setting, talking about comparative risk doesn't work, trying to reassure people, patting the dog on the head doesn't work, indicating presentation don't work. If we can't even get health care workers to understand, how can we expect to education the "general public"?

I suppose that is one message, but I don't think that was your message, and I would like to know what that message was. If nothing works, or at least these particular approaches don't work, why? Is it because the fear is not only there, but real, we can't penetrate it, because we shouldn't be able to penetrate it, or are you saying something else?

Secondly, you said that we should talk openly about fear, and I would certainly agree, but why? What comes of sort of acknowledging the fear the health care workers and others have around HIV? Will that lead us to saner policies, or just being able to talk about fear?

You said we should stop saying that risk is low. Why? Because risk is not low, or because saying it is low creates a barrier to conversation, or for some other reason? You say we should stop giving mixed messages. Why? Indeed, I am not sure that the message is mixed. That is to say the risk of transmission sure as hell isn't low, if we don't use universal precautions.

So, I have taken the message is if we use universal precautions, the risk is low. Now, maybe you still quarrel with that, but that, at least, is not a mixed message. But why should we be clear about that message? And what are the consequences of doing the things that you say? If we stop saying the risk is low, if we stop giving what you characterize as a mixed message, if we talk openly about fear and, in a sense, honor that, what effect will that have on the policies that we are all here to discuss?

Finally, at the end of your remarks, it seemed to me that you were suggesting that there is great wisdom, in fact, in the people. I sort of like to trust the people. They are on to something, you said. There is a wonderful quote by somebody whose name starts with an "S." It was nice, it was cryptic, it was mystical, I didn't understand it a bit. It was like talking to Scott Allen, who is our resident mystic.

[Laughter.]

But I take it the basic point there was that there is something behind, something real behind the resistance of people to the message that we ought to cool our jets and lower the flame. What is that? What is it that the people are trying to tell us, when they say I want to know if my health care worker is infected? Because it is not just health care workers who engage in invasive procedures or exposure-prone procedures. I would warrant that most people in the public want to know if their manicurists are HIV positive. I gather you think there is some wisdom in that, that there is something we ought to latch onto and understand. What is that?

DR. GERBERT: Wow.

[Laughter.]

Am I supposed to say thank you for asking that?

MR. DALTON: Thank you for sharing.

DR. GERBERT: Well, my simple answer to your complex question is that the issue is complex. When I was asked to come today, Jeff Stryker had heard part of that presentation before and said I want everyone to talk about the complexity of the issue, I want them to see that it is not a uni-dimensional issue with one answer.

So, what I was asserting is that the things that we have been doing for ten years haven't worked, and I would like to give a chance to looking at the risk perception literature that says that these are complex, people are wise. In fact, when we first got the data from the dentists that said dentists didn't believe the transmission occurred, and yet they wanted their colleagues who were infected to quit working, we said silly people, silly dentists, don't they understand, you know, how can they hold two discrepant positions at the same time.

Later, we realized that they were seeing it very complex, they weren't willing to have five patients be infected by a dentist, they were thinking of the image of dentistry, they were thinking of the safety of their patients, they were thinking of a lot of things that happens to then create confusion and uncertainty in their own minds.

I have not heard anyone take us up on the fact that it will help. We think, as psychologists, it will help to have people talk about their fears. We think it will help to have others come forward and talk about what this represents to them.

By ignoring it, it hasn't worked, and so something new has to happen, that we listen to the 80 percent. Again, for most of us, that is our colleagues, 80 percent of our colleagues, not just 2 percent and not just "the public," but health care workers, as well.

So, I think it is complex. I think that it can't be answered today here in an hour or in our eight hours, but I think that in a concerted effort to figure out what the whole terrain is, we could make a difference, putting value to what the 80 percent believe, listening carefully, because we haven't found the message to calm those concerns.

MS. FASSBINDER: I would like to address the fear issue just briefly, if I may, and that is that fear must always be answered by the proper information. It is like a group of people getting together and starting a rumor mill. I am sure you have all experienced that, where gossip starts about something and it takes on a whole life of its own.

Fear must always be responded to with reasoned education, and I might add that has got to start very early on. It has got to start in the schools. It is amazing to me how many people will ask questions that they really should ask of a doctor or a medical professional, and they will ask their teacher, ask their child's teacher.

My child, when she is seven years old, they all continue to do AIDS education, in a way. Their friends ask is it okay if we come to your house and use your bathroom. You say sure, that's okay, and that is where it has to begin.

DR, GERBERDING: I would like to also say that I think that I would take issue with the statement that some of the things we have done in the past don't work. I think that the education and the response to having children with HIV infection in school has worked, that we did make it over that hurdle, and there have been other hurdles where the public fear has loomed very large, that we have made it through those crises by a concerted effort to have policies that were consistent with scientific information, to have opinion leaders present that policy information and science in the clear-cut manner, and we had the ability to enact policy changes that were consistent with the scientific facts, so I am reluctant to abandon the approach of science.

DR. ROGERS: Could I piggyback on that, June, because I thought Dr. Gerbert, even your own data was kind of encouraging, not as encouraging as I would like, but where people began to dissociate, they said, yes, I want to know their status, but, no, I won't stop going to him, those kinds of things made me feel, hot dog, a little bit of this is coming through. And if you think how long it took to stop everybody in this room smoking, I mean some of these things do take a fair amount of reiteration.

DR. GERBERDING: In fact, in Florida, after the ental case was announced, there was the expectation that there would be a massive disaster of public response there, and for a couple of days people didn't keep their dental appointments, and then very soon after that it was business as usual in the Florida dental community.

DR. GERBERT: In our survey, we asked the public this summer has anyone stopped going to any health professional, and it was .03 percent who have, so we think that there is not that much behavior change, that there is hysteria, but no behavior change to back that up.

CHAIRPERSON OSBORN: We have Diane Ahrens, John Allen and David Rogers. Let me offer everybody to please be brief. We thought maybe we would change a little bit and take a brief break after this panel, before we go on to the next set. This Commission has the remarkable habit of having late lunches, so we are not scheduled for lunch until 1:30, and I think it might be humane to have a break briefly before that.

So, with that in mind, Diane, Jim Allen and David Rogers.

MS. AHRENS: Dr. Gerbert, I just want to say to you, fear not, when our attorneys speak, I never expect an answer, but I love them, anyway.

[Laughter.]

I have heard something today that speaks to the heart of this issue, and that deals with the psychology of expectation of surrounding, particularly the issue of health care workers, and I don't think we are very good at that. I don't think we pay much attention to the psychology of how people learn and how people change, and we seem to feel that if we just say it is true, well, people should believe it and that is it and go on about their business.

So, I would just like to get a reaction from all of you as to if you agree with that and the fact that the psychology of the issue is really one of listening and informing or listening and responding, and that has to take place almost on a one-on-one, in spite of all of the PR and all the videos and all the rest of it, to change people. It doesn't seem to occur very well that way. It occurs on a one-on-one.

This Commission hasn't been very proactive in this arena, that is, in the health care worker arena, and that has been by decision. But we are taking a look at that now, and so what would your suggestion be or what advice would you have for us as to how we could address this public fear, and should we target our activity and, if so, who should we target it to?

DR. OSTERHOLM: Ms. Ahrens, if I can just address one thing I think is very important is I think we need to set a national agenda for this issue that is not next week or next month or next year, but what is five or six years from now.

I think we have to begin telling the public Florida was not a natural disaster that occurred one time and will never occur again, but I think we have to do that in a way that is also very reassuring, that says when it happens again, it is not like it is not expected and that it doesn't mean now suddenly that everything we have said to date was wrong.

I think we have to continue to put the issue into risk perspective, and so I think that is something that is very important, is making certain that we don't create a crisis for ourselves needlessly in the near future by addressing this issue.

I think the second thing we have to do, as you heard today, is the issue of the psychology of this issue. We are diverting a lot of important resources from a problem that, if you are that individual, it is very important. If you are the health care worker who gets infected, it is everything. But at the same time, we are missing the boat and I don't know how to get around that, unless we can get some consensus from leadership that they will accept that certain amount of anxiety out there and not just automatically knee-jerk respond to it and let's get back to the business of doing our work.

MS. FASSBINDER: I just want to make the comment that, for me personally, the hardest part of my infection has not been the illness itself, it has been all the other stuff that goes along with it. I just wanted to make that comment, and I think that we must address that issue, or we are not going to be able to attract talented people into health care, if they feel that they are going to be set adrift once they become infected.

DR. GERBERDING: I also have concerns about really the consequences of the knee-jerk counterargument to testing and restriction, which is always universal precautions, because I don't think that position has a lot of credibility in the public's mind, either. It doesn't have a lot of credibility in the minds of some health care providers.

If I said to surgeons, use universal precautions, they say, yes, like we haven't been doing that for the last 20 years. I think there is a need to do something, and one of the things that we have to deal with, I think, is that the something needs to be something that health care providers and the public can both agree on.

My own view is that the something should be mandatory education of providers about infection control, very good scientific evaluation of procedure-specific risk introductions, and perhaps monitoring and better checks on what kind of practices infection control people are actually doing. But I do think that we have to take a proactive position and go a little bit beyond the universal precautions jargon in this situation.

CHAIRPERSON OSBORN: Jim, and then David.

DR. ALLEN: I would like to address two questions briefly to Dr. Gerberding and Dr. Osterholm. First, we do need to evaluate the risk, we do need to obtain further information, and it seems that the best way that we are doing that is through so-called look-back investigations. Those are extraordinarily costly. The investigation in Florida cost CDC well over a million dollars and tied up their laboratory resources enormously. They are personnel intensive, they are complex, there are legal ramifications, there are a lot of people that are refusing to provide epidemiologic information, unless their lawyer is sitting next to their side and giving them guidance.

We need the data, however, and what should we do and who should have the primary responsibility in carrying these out and setting the directions?

Secondly, and, Julie, you alluded to this in your last response, but both of you seem to imply that we have real problems in implementing the recommended infection control guidelines. What needs to be done, and should have primary responsibility on the implementation phase, not the development of them?

DR. GERBERDING: With respect to the first part of the question about risk assessment, this is what I do. I think it is very exciting to think of challenging ways to assess risk to patients, just as we assess risk to health care workers, and it is not necessary to rely only on look-back investigations, which, I might add, are fraught with a number of complications.

If we did a look-back in San Francisco, no doubt we would find many, many infected patients, but how we would determine whether they were infected occupationally or not is another story. Every time we have one in the enumerator, where there is some degree of uncertainty about how they got infected, it is not going to help our position in terms of risk communication.

I think that there are already methodologies available for evaluating interoperative exposures for looking more carefully at potential risk factors for techniques that may increase exposure-proneness. By the way, I like using the word "exposure-prone technique," as opposed to "exposure-prone procedures, because I think techniques are changeable.

Second, in that same kind of setting, looking at the impact of the interventions on reducing exposure frequency, those are standard ways of doing risk assessment and risk reduction evaluation, and I think there is a lot of room for creativity in those endeavors.

I will leave the second question to Mike.

DR. OSTERHOLM: Well, I would fully support everything Julie just said. I would add one additional caveat on the look-back issue. Again, we have heard how we have looked back at all these individuals to date and we do evidence of transmission. Even taking the CDC theoretical model, they talked about one transmission in 40,000. Do you realize how many look-backs you would have to do to find that one case, and the point is the statistical power is just not there in look-backs.

We recommend in our article coming out next week that look-backs only be done under the following conditions: (a) if there is evidence of transmission, (b) if there is egregious breaks in infection control, and (c) if it is under a research protocol supervised by an institutional review board, but even that, we emphasize all the problems that you just referred to, Jim, and that Julie just referred to.

I might add that our look-back in Minnesota was not a cost issue, so much. It cost us a quarter-million dollars, but, more importantly, it tied up our agency for six weeks. We did nothing in public health for six weeks that we otherwise would have done, vaccinations, immunizations, et cetera, and I think that is important.

MR. BARNES: May I please add something to that? In response to Jim's question about implementation, there is an area of implementation of better infection control. It really is left completely unaddressed in the CDC guidelines, and I fear also in the various state guidelines, and that is the great multitude of private clinics and medical and dental offices throughout the country, and we have seen the three major cases, the exudative lesion case in Minnesota, the Corham dentist on Long Island, Dr. Feldman using very poor infection control technique, and then Dr. Aker in Florida. Those did not occur in regulated health care facilities. They occurred in private dentists' and doctors' offices.

It seems to me that part of the fear that is out there and part of the real and legitimate fear is that there are these sort of renegade doctors and dentists in private practice who are not using appropriate infection control guidelines, safeguards and techniques, and that seems to me to be the question that the National Commission could address very forcefully, since it has been hitherto unaddressed by the bodies.

CHAIRPERSON OSBORN: Charlie has a quick question, and then David gets the last word before we take a very brief break.

DR. KONIGSBERG: Picking up on the point that you just made, one proposal that I heard in a midwestern state was for actually going in and setting up a regulatory program for inspecting, to use their term, doctors' and dentists' offices. In this particular county, I was told that there were some 5,000 offices. This was a serious proposal.

I bring this up, because the emphasis was on inspection, rather than on testing the health care worker, as if this were more acceptable. It is obviously -- I say it is obviously observed, but I hesitate to say that, because it may get proposed more seriously, but I would like some reaction from Dr. Osterholm and perhaps others as to how you feel about that, because that may be the next thing that we hear. In fact, one of the rationales that was used was to model this after restaurant inspection.

DR. OSTERHOLM: Let me just briefly say that restaurant inspection has never yet been able to assure that food handlers wash their hands after going to the bathroom every time.

[Laughter.]

Just as I don't believe that routine inspection per se will deal with inspection control issues, I think it is going to be a combination of efforts, where there are clear steps taken to make sure that the types of equipment used and the methods that are written down for how they will be used are there and the procedures are there. You will never be able to insure that it happens on a day-to-day basis. The best you can get is just at least they have addressed it and somebody is supposed to be in charge of it and responsible for it and documenting that.

I would like to support what Mr. Barnes just said, and I think what you have said is that in our report here, we detail that in some length, the problem in Minnesota, with the issue of the non-hospital based health care delivery systems, all the same-day surgeries and all the kinds of things that ten years ago were done in hospitals are today being done outside of hospitals, and that I think is a very important issue.

DR. GERBERT: Could I just address the infection control issue for just a moment? What I found in the past few months is that infection control has become sort of the new politically correct answer to the problem of HIV transmission, and that is let's not test, let's vigorously mandate infection control and inspect.

I agree with Julie that it is not the answer. We have been attempting to do this for the past decade, and, in fact, my work over the last few years has been with dentists to improve their infection control. We had signs that things were going really well with dentists, but we took as symbolic the fact that dentists' use of gloves went from something like 50 percent to something like 90 percent, and many of them even change their gloves between patients now.

[Laughter.]

So, things have improved, but we took that to mean that 90 percent were also autoclaving and sterilizing and all the other things they should be doing. In fact, no matte how good we get at educating physicians and dentists about necessary infection control, it is never going to be 100 percent that all providers are doing it perfectly. So, no matter how much "education" there is, we are never going to get to perfection with that, as well as the issue I brought up earlier, which is that accidents do happen. So, for many in the room who have worked with providers on infection control, it is not a new discovery in the past year.

CHAIRPERSON OSBORN: David, the last word. We do have an extended interval this afternoon to continue this rich discussion, and I have let it run as long as I have, because I thought we were getting into a very useful interchange, but if you will excuse a heavy hand for a minute, after David makes his comment or question, let's take a brief break, so everybody can participate happily in the next three-quarters of an hour before the lunch break.

DR. ROGERS: You frighten me, so I should probably just shut up here.

[Laughter.]

I simply wanted to say, Dr. Osterholm, that part of the logic of what you were expressing earlier escaped me. I mean, you were, in essence, saying that risk was low, used whatever word Barbara doesn't want us to use, that it is low, and yet all the stirring and draying, all this attention to the health care professionals is well worthwhile, and then cautioned us about the fact of how are we going to feel when another case happens.

I am going to feel saddened, but, obviously, that is going to happen. What I really feel sad about is the fact we are totally diverting our energies from all those teenagers who haven't got condoms or any education, from all our drug users who don't have treatment slots and we won't give them needles to protect themselves, so that it seems to me you help create the crisis by continuing on with the health professionals, when I think, Jesus, we ought to set some of this aside and get back to where this epidemic is really being played out, and it ain't being played out here.

Now, that won't answer all of Dr. Gerbert's concerns, but it seems to me to put some of it in the context of here is a raging epidemic that is continuing unabated, and we are off here in the corner kind of fooling around. That distresses me a hell of a lot more than when we have -- which most surely will occur -- when we have another case or a case or a first case or a proven case of a health professional infecting a patient. I just would prefer that we put our energies and our resources where this thing is going on in just a terrifying way.

CHAIRPERSON OSBORN: As I mentioned, we will have a good opportunity to continue this discussion. Let's take a 10-minute break, return for the next panel and hope that doesn't put us too late for lunch.

[Recess.]

CHAIRPERSON OSBORN: Let's get started again, if we could, please.

With Dr. Hagan having kindly deferred, Jeff, would you introduce our next panelists.

MR. STRYKER: Dr. Gabor Kelen is an emergency room physician at Johns Hopkins University.

CHAIRPERSON OSBORN: Then, after Dr. Kelen, Dr. Richard Martin, Medical Consultant, from Tampa, Florida, and Bobbie J. Primus, Doctor of Education, M.P.H. and R.N., Associate Professor of Nursing, University of Central Florida. If I didn't do that name right, please excuse me. I am not doing very good from the paper.

Dr. Kelen, thank you and welcome.

DR. KELEN: Thank you.

I appreciate this opportunity to address the National Commission. In fact, I would like to start by commending the Commission. I just hope and wish the administration ultimately listens to your recommendations.

DR. ROGERS: So do we.

[Laughter.]

DR. KELEN: I am a practicing emergency physician in downtown inner-city Baltimore. Approximately 9 percent of all the patients coming through our door are infected with HIV, and most of them aren't aware of it and neither are we. In fact, other studies that we have done have shown that 25 percent of our patients have at least one blood-borne viral infection that poses a risk to health are workers and to each other.

As Dr. Gerberding does, I am also a clinician, and my area of research interest is also in risk and risk prevention, as well.

Overall, the position that those of us in emergency medicine have taken, in broad principles, we support the CDC. As Dr. Osterholm has said, I also think that the CDC has been taking a bad rap, at least the individuals. I don't mean to be naive about the various forces that work on the policy of the CDC, but I know the people involved, and many of them are my colleagues that I have worked with. They are extremely hard-working people, and I know from my conversations with them that they have struggled, as the rest of us have. I think it is fair to disagree with the final outcome and do the best that we can to change it.

We have frequently heard that any recommendations coming forth from anybody, whether it be the CDC or this one, should be based on sound scientific evidence. However, in this particular case, the scientific evidence for transmission from health care worker to patient for HIV is lacking. Regardless of what adjective we give it, significant risk, identifiable risk, meaningful risk, measurable, the evidence is lacking, anecdotal evidence is lacking, in fact.

There is considerable evidence to show that these transmissions do not easily, if at all, take place. Our surgical colleagues at the various CDC and AMA sponsored meetings have repeatedly told us, particularly the orthopedic surgeons and the thoracic surgeons, that they are forever nicking and cutting themselves on bone spurs and with needles in places they can't see their hands and so forth, and they consider this a major risk for them.

We know that they are being exposed to patients' infections, because about a third of surgeons have shown evidence of being exposed to hepatitis B. There is yet to be a documented case of a surgeon being infected with HIV from a patient, so if it is all that transmissible and they are cutting themselves all the time, then a few surgeons should have already been infected with HIV on the job.

We also know, and it is measurable, what the risk of getting HIV is from a patient. We don't know what the risk is the other way around, but it is considerably less. So, surgeons putting themselves at this risk are not getting HIV. I conclude that the risk in the opposite way is virtually non-existent.

My group, the emergency physicians, decided to cooperate with the CDC and we, in fact, did develop a list. Our development of a list did not necessarily mean that we agreed with the concept, because we ar worried that anything that goes on this list may be construed by the public and our patients as implying that these procedures are transmission-prone, and exposure-prone is not synonymous with transmission-prone.

We identified at least one procedure and, as Dr. Gerberding had suggested, without making comment as to whether it is exposure-prone or transmission-prone, we found alternate techniques to replace that one, and I think that certainly is the way to go.

I don't presume to talk for all of the medical specialties, but I would agree with the following: Mandatory testing of health care workers as a way of getting at this problem is not warranted, as is the CDC's position. Voluntary testing, of course, is pretty reasonable, particularly for the health car worker's own health benefit.

Since no risk or no measurable or identifiable risk has been shown, disclosure is a moot point. Where no risk can be shown, informed consent from a health are worker, whatever their status is, is also moot. The same with specialty review boards.

A number of societies or individuals have come out saying that they do support testing, identification and restriction of health care workers' practices. I would urge that you listen very carefully to what else they say in the same sentence, because they usually add that they are also for mandatory testing of patients, and I would beware of the individual who, in the same breath, couples the testing and identification of health care workers to that of patients, because their not so hidden agenda, in my opinion, is that they are willing to flush one or two of their own colleagues down, presumably who are gay, so that they can identify patients who are HIV infected, presumably to deny them care, and we have heard much evidence over the last few days and months that this, in fact, is occurring.

What would be the consequences of implementing this type of policy? As Dr. Osterholm said, I think this is the wrong focus, and I think that is what Dr. Rogers echoed. The issue of health care worker transmitting HIV to a patient, I also agree, I don't think this is the last that we have heard of it. There is likely to be another case an another case after that.

In terms of a public health issue, it doesn't rank in the top 10. It doesn't rank in the top 100. It probably doesn't rank even in the top 1,000. There are way more important issues that we should be paying attention to, if we are truly concerned about protecting the public health.

Let me give you a couple of examples, and I showed this yesterday, as well. This is a paper in the New England Journal of Medicine of February 1991, this year. It talks about adverse events of negligence in hospitalized patients in New York:

"More than one in 1,000 patients who walks in and gets admitted to a New York hospital will die of an event not directly related to what they went into the hospital for. It is about 13,500 per year, if you extrapolated New York, being a fairly populated state, to the rest of the country, you can at least conclude somewhere in the neighborhood of 100,000 and maybe even up to 200,000 patients who needlessly die in a hospital from preventable causes." That is the conclusion of the authors on a Harvard based study.

We tolerate 55,000 deaths on our highways, we tolerate work-related death presumably preventable every 50 minutes. We tolerate shootings on our streets, and we in the emergency departments see the end result of that and we euphemistically refer to that as acute lead poisoning, of course.

[Laughter.]

I am also worried, as Dr. Osterholm, about state legislators having the wrong focus. I met with a state Senator in Maryland who will remain nameless, but he informed me that a number of his colleagues are planning to use this issue as their Willy Horton ticket to reelection. This is the same group of legislators who are so concerned with the public health that, in my state, they are willing to let our children ride motorcycles without helmets, so they can avail themselves of every opportunity to smash their heads on pavements and either die or have 40 or 50 years of disability.

The two obviously don't match. If people are really concerned about the public health, all this effort that we are doing, all the hearings, all of our personal time should be going to other types of things.

We frequently hear about physicians and other health care workers doing no harm. I believe that the identification of HIV positive health care workers and imposing restrictions of practice will not do what is intended to do. In fact, I think it will lead to greater harm.

Dr. Gerberding has alluded to increased discrimination. I can speak to that, as well. As I said yesterday at the CDC hearings, in my last shift in the emergency department, a young man came in with severe lower back pain, was HIV positive, but asymptomatic. He told me that he had pangs of guilt and he had let his orthopedic surgeon, who was about to operate on him, know about his sero-status. He thought that was fair. His orthopedic surgeon, according to him, cancelled surgery, he had nowhere else to go, but the emergency department. Fortunately, I am at one of the types of hospitals that is willing to care and find appropriate access for such patients.

Overall, these types of measures that are proposed are likely to hurt the public health, and I can speak to them from my particular specialty. In September, the press had covered the issue of overcrowding in emergency departments, particularly in inner-cities, where the disenfranchised from the medical system have trouble accessing care. That, of course, also happens to be where a majority of HIV positive patients are.

In some of the studies that were done on overcrowding in emergency departments, we know that patients are probably going home to die, because they can't get seen in a timely fashion in the emergency department. The patients who don't get seen within 6, 8, 10 hours and leave for some alternate care are just as sick as the ones who get admitted, many of whom do ultimately die from their problems. We are going to have trouble delivering care in our type of setting to our inner-city patient population and to our HIV positive patients.

We have also heard from state health officials --

and Dr. Osterholm wasn't there, but perhaps he can clarify, if I am misstating this -- but we had heard from a number of state health officials that their resources are being so diverted by this one issue, that they can't investigate outbreaks of disease among children in their state that threatens their children's health, possibly leading to the death of these children. That does not sound appropriate to me.

Usually, I don't speak about manpower issues, because, as a physician, that appears to be self-serving. But after hearing Ms. Fassbinder's comments today, I have to say I am extremely struck by what she said. Previously, I had heard and read about her case in a sterile scientific report, but actually to hear what she said has already had an impact far beyond what I could imagine.

If my wife happened to be in the audience and had heard that, I could tell you, I wouldn't be seeing patients tomorrow. That is going to be the end of it. If she hears that type of an account, and many of our health care worker colleagues hear that type of an account, they are not going to be practicing medicine in the type of setting that I practice in.

Those of us who are doctors, fine, we can make do. But Ms. Fassbinder wasn't a doctor, and many of the people that I work with who may be assisting at surgery and so forth are getting barely above minimum wage or they are working part-time, as Ms. Fassbinder was. If we remove all these people from the system, because they have been identified with one infectious disease or another that has not been shown to be a harm to patients, who is going to end up taking care of everybody? I think in the inner-cities, we are going to have an extremely big crunch.

Thus, overall, the solutions proposed will not really protect the public health and, in fact, I believe, rather, it will cause more ham to our patients than these solutions could possibly prevent.

Finally, in many of the meetings, somebody stands up and says, well, what about us as consumers. All of us here are health care consumers. In the last four years, I have had to arrange surgery four times for my family, twice for my wife, once for my one-year-old kid and once for my elderly father. In none of those situations did I care what the sero-status of any infectious disease was of that surgeon. I cared about the type of things we have just heard today, was he up late at night, did he have an argument with someone, is he or she a drinking type of person. Whether they are HIV positive does not enter in your mind, when you come right down to it.

Well, what is best, if not these type of solutions that have been proposed? Despite some of the controversy, I still do believe that the emphasis should be on infection control, and particularly the type that Dr. Gerberding had mentioned, where you can identify the techniques that may be related to exposures and try and change them.

We do, in fact, have evidence that universal precautions may, in fact, be effective. Since the advent of universal precautions, we were told yesterday there has been no transmissions of hepatitis B from dentist to patient, whereas, in the previous 10 years, there was something in the neighborhood of 220. Since the advent of universal precautions, the number of health care workers with documented infections acquired on the job have virtually stopped. It is, at best, a trickle now.

Is it doable? I would refer you to an article in this months "Archives of Internal Medicine," where we have shown that the institution of universal precautions or infection control as policy with a monitoring concept will, in fact, radically increase the compliance with universal precautions. I agree, it is never going to be 100 percent. Some of it has to do more with how we operate, rather than what we wish to do. But in those situations, it should be understood that it is the health care worker, really, who is assuming the risk,not really the other way around. If the health care worker isn't following precautions, the risk to the health care worker is infinitesimally greater. It is a huge number greater.

In summary, I support the efforts of the CDC, AMA and other medical organizations, and certainly the National Commission on AIDS, for the work that they are doing to help develop rational policies based on sound scientific evidence.

Thank you for this opportunity.

CHAIRPERSON OSBORN: Thank you very much. Your testimony yesterday was extremely important, and today even more so. Thank you.

Mr. Martin?

DR. MARTIN: My name is Dr. Richard Martin, from Tampa, Florida. Presently, I work as a subcontractor for the State of Florida, seeing indigent patients at an indigent clinic in Tampa, and prior to that I have been an emergency medicine physician for 15 years.

I can't be as eloquent as Ms. Fassbinder was, but, basically, I will relate to you my story, which is the only information I have. I don't really have data, I don't have a lot of scientific information. I am simply a clinician, and nothing else.

My journey into this little hell that I have gotten myself into began in the summer of 1989, when I had a needle-stick exposure to a patient in the emergency department who was being combative, and apparently he was sero-positive, and I subsequently converted, as did my lover. That was discovered in April and May of 1990, and at that point in time I don't think that these questions that we are dealing with here had been brought up very much, and I was told by my attending physician that, as long as I didn't have sex or give blood to any of my patients, that I could continue to practice in full as I had been in the emergency department, which involves quite a bit of invasive medicine.

Of course, later that summer of 1990, the information began coming out of Stewart and that caused a lot of concern in my mind, and AMA, I believe, made its policy statement on the 21st of February, and after consultation with my attending physician and lawyer and some insurance people, I disclosed my status to the people I was employed with on the 7th of March, which was the last day that I ever worked in emergency medicine.

That really put a whole new wrinkle in my life, because I don't have a lot of other experience in medicine, so it made it difficult. I kind of had assumed that AMA would have some approach as to what it was that I do next, after I disclose, but I subsequently found out that they had no clues what I was to do. I was just supposed to, I guess, go to an old folks home and die, or I don't know what exactly, I don't know what they thought I should do.

I sent out hundreds of resumes, got very little answer back from anyone, and then, you know, subsequently have managed to secure this type of employment. I think that my only concern about this discussion is that we think about how this would impact on people's lives, you know, if we make these kind of recommendations that there be blanket testing and, you know, no invasive procedures and things of that nature.

I think that, as intensive as these discussions have been this morning, it would do well for the number of people that might be involved in coming out that they are HIV positive. My concern from reading any data is that there is a suggestion that there is going to be a high number of people in the health care professions that may, in fact, test positive, so that would be a big hardship on a lot of them, and I think that it would be important that we give consideration or that you all give consideration to what will become of these people, if, in fact, they do test positive, because it hasn't been an easy road at all.

Things were tacitly suggested and promised that never came to pass. You know, right now I am kind of on this little treadmill, where, if I keep running, I at least won't get any further behind, but we are talking about loss of family, loss of home, loss of personal property. I understand that this isn't the primary concern, when we are dealing with patient care, but, still in all, I don't think that a person needs to be punished, you know, just because they happen to run into an unsafe situation in the workplace.

I have nothing else to add, other than just my personal experience.

CHAIRPERSON OSBORN: That is very helpful. Thank you.

Dr. Primus?

DR. PRIMUS-COTTON: Good afternoon.

I am always able to give up time to serve humanity.

[Laughter.]

I would like to tell you briefly a little bit about myself. Since I am L.B.L., I shall keep my remarks brief, last before lunch, and I don't want to create some long-lasting impressions that are not pleasant.

I sat here and I heard about references to the self by Barbara Fassbinder and also by Dick Martin as being simply or only. It bothered me greatly and I almost wanted to get up and shout, "Are you kidding, only a nurse or simply an emergency room physician?" And I must help the public to realize that we are the vanguards of the whole health system, in that you are the first one into battle, you are the first one who entertains an idea of treatment or giving treatment for people, and there is no such word as "simple" or "only." We are very important to the whole health care system, and I needed to make that point.

I also sat here and, to age-preference myself, I thought about the tuberculosis surveillance and how certain issues were brought to discussions similar to this. Most recently, well, in the early 1980's, the National Cancer Institute's Cancer Prevention Awareness for Black Americans, the 1-800-4-CANCER, the fear, the concern about the incidences and cases were very similar to some of the discussions we are having today.

One of the key issues that always starts out, and all of these discussions that I have been a part are, I keep hearing reference almost to "we" and "they," the health provider and those people whom we serve are the clients, and how to react to that pretty much with the brief presentation that I will make today, because I am of a strong belief that the horse does not come before the cart or the cart does not come before the horse. If we are involved totally, the community, as well as the health care providers in being able to understand through education clearly through interpretation, so that we can change our behaviors as to how to proceed on a personal basis, as well as in the role of a health care provider.

In that context, I must say that I am very pleased to be here, because you must tolerate me just a minute to let you know that I represent many people in coming here. First, I represent and bring you greetings from the National Black Nurses Association, where there are 52 chapters across the country, including the Caribbean, and some association in Africa. We have over 5,000 members. I serve as First Vice President of this organization.

I bring you greetings from the 11th Episcopal District of the African Methodist Church, where Phillip Cousins is the Presiding Bishop. And I also extend greetings from the University of Central Florida, who allowed me to become involved in issues which relate to all people and, most particularly, minorities.

I have taken that time to identify these referenced institutions and agencies, in order to address the topic centering around which we have been assigned to look at on social and ethical implications.

We, by our mere presence here, have been involved somewhat in the process of policy development, and we are ware of the influences which can be imposed on issues, when it is to impact on particular populations and, most specifically, minorities.

The minority populations, nationally and internationally, have not positioned themselves in strategic arenas in order to engage in the decision-making process. Since this is a prevailing occurrence, minority organizations and professionals such as the National Black Nurses are compelled to devise ethnic and culturally sensitive projects to educate and support our population, to be educationally alert to the high risk related to the HIV-AIDS virus.

There are three areas of concentration which I would like to address briefly and I address in this topic:

First, as its central thrust for its 1990-91 regional conference, the National Black Nurses Association conducted a series of "Train the Trainer" Workshops in four major cities, centered around training nurses -- and I will speak to that -- in Cincinnati, Ohio, Baltimore, Maryland, Charlotte, North Carolina, and Oakland, California.

The workshops were designed to train selected members of the association, registered nurses, to return to their individual communities and train other members on the incidence and how to protect an how to educate as relates to AIDS. They were to set up educational programs within their communities. Approximately 200 registered nurses were trained during these workshops. This project was funded in collaboration with the CDC in Atlanta.

Secondly, we, as professionals and members of organizations, must become more knowledgeable to the cultural diversity existing within the sub-cultures within the United States and other countries where the AIDS morbidity and mortality rates have steadily increased.

World customs and cultures of various ethnic populations have become the normal way of life for persons living in the United States. Statisticians predict an even wider proportion of racial/ethnic mix by the year 2000, that minorities will be one-third of the American population by the year 2050. It is predicted that they may well be the majority.

At a recent colloquium on cultural diversity at the University of Central Florida, Reginald Wilson, President Emeritus of the American Council on Education, reported that there are 70 distinct ethnic and language groups in the United States. He reported that, "Due to a combination of immigration and birth rates, the racial minority population representation will continue to accelerate in the years ahead."

I have some statistics that I won't go into to substantiate this, but these are persons where we are talking about high risk, we are talking about education, that we must understand the cultural diversity which exists in this country, we must, as health care workers, be able to relate to the persons and their understanding, their customs, what their mores are, and it does not take an awful lot of high-tech intelligence to do that. These are basic issues that I want to talk about today.

If we are to get their cooperation and be educated in helping to know what to look for when they go into health care provide service, know whether that dentist has changed his gloves, know when the doctor is doing a simple procedure, whether he has used proper techniques. This is where it is. If we are to stop the rise in incidence that is occurring, we must be able to educate the public, we must be able to help them to change their behavior, we must be able to educate them so that they can teach their children, we must teach the children.

I stopped smoking, because my six-year-old would remind me every time I light a cigarette that, "I am going to be a motherless child," and ask me if that doesn't have an impact. He said, "You are going to die, if you continue to smoke." Our children are very intelligent, and, regardless of how we sit here and talk about the technical aspects of how to create a change, we must go back to our communities, we must deal with the realism of the people and how they interpret what is going on, how they look at what is called high risk, what does it mean to them and how is that interpreted to us.

There must be a planned excursion into the study of the cultural, religious beliefs and ethnic values of this population of our citizenry, as well as our international affiliates. There must be created among social and health care providers a deepened cultural insight and appreciation of human life and values, while developing a sensitivity for a culturally appropriate individualized approach to client education and patient care. They are our future, as providers, as well as our clients.

Lastly, religion plays a key role in the lives of many of the clients we serve. For example, the black church has been vital in the lives of the majority of African-Americans. The church has served social, spiritual/healing, economic and political functions.

Lincoln, some time ago -- not Abe, Marcus Lincoln -- wrote in "The Black Family, the Black Church and the

Transformation of Values" and stated:

"The black pilgrimage in America was made less onerous, because of their religion. Their religion was the organizing principle around which their life wa structured. Their church was their school, their forum, their political arena, their social club, their art gallery, their conservatory of music. It was lyceum and gymnasium, as well as sanctum sanctorum. Their religion was the peculiar sustaining force that gave no promise, and the courage to be creative in the face of their own dehumanization."

The black church has served the social, spiritual/-healing, economic and political needs of its believers. For the newborn, it provides a christening service. For the dead, it provides burial rites. It has been an advocate for the troubled and distressed, a refuge for the lonely and for the engaged it provides the marriage ceremony. The black church has served the potential to create a safe environment for those HIV positive and AIDS patients who have no other resources.

The African Methodist Episcopal Church, which I spoke of earlier, has begun to establish half-way houses in nine different areas in the State of Florida. In just talking with Rev. Scott Allen, I understand that these are located in other areas.

These half-way houses report on how they are able to assist the public health agencies in interpreting the need for public health workers to work with HIV positive or with AIDS patients. They have provided the bridge by which these persons can access the community, the public health worker. They are able to also provide social welfare input direct access and being able to identify certain leaders from within the communities who can then assist them in identifying the persons who need to be served.

The Commission's comprehensive report, released in the fall of 1991, referring to "America Living With AIDS," suggests that the Nation's response to the HIV epidemic is "crippled" by both lack of resources and societal attitudes.

Societal organizational and religious groups such as identified in this paper can provide the logistics for the release of the constrained resources and "the dilemma of sabotage of disbelief, ignorance and fear."

I have just a few recommendations that I would like to make, which include the opportunity to provide for education of the high-risk groups via training of multicultural groups and organizations, employ the utilization of already established organizations and voluntary groups.

A lot of times we recreate the wheel. We need to go back and look at some of the things that have already worked. It sounds good when we are planning those things, but we just need to go back and look at something that has already been paid for and already has substance and works.

We should form coalitions between the health care worker, the community and the professional within that community, to provide for the education, the case identification and the support systems. And for procedures already established which I mentioned, we should provide for the education, as was mentioned by Dr. Osterholm, through our legislatures. Whether it comes from us, as health care providers, or whether it comes from our constituents whom we serve, if we educate them, they will educate our legislators, and they stand with the opportunity of the vote to see that this is done.

I feel that we must, if we are to make an impact on the whole incidence of AIDS that we are dealing with today, we must establish trust among the people we serve, so that they will be willing to inform you when they are HIV positive, so that you will have some awareness. We must be able to trust each other, as health care workers. We must be able to support each other. Unless we can do these things, unless we can look positively at the realism of the world and what is needed, all is lost.

Thank you very much.

CHAIRPERSON OSBORN: Thank you very much, Dr. Primus-Cotton.

I am told that the three of you who have just talked with us could stay and be with us after lunch, is that correct? I wonder if we could break now for lunch, come back, hear from Dr. Hagan, and then proceed as was originally planned with the group of the four of you. If that is all right, let's do that, and try to be back.

We have got it scheduled to 2:45. I think we could probably try for 2:30 and be under way a little bit ahead of what is on the paper here, in order to be sure we have plenty of opportunity for discussion.

[Whereupon, at 1:35 p.m., the commission was in recess, to reconvene at 2:30 p.m., the same day.]

AFTERNOON SESSION

[2:40 p.m.]

CHAIRPERSON OSBORN: I want to get us started again, so that we stay close to our announced schedule. We are, in fact, behind our announced schedule, but, by slight of hand, I make it look as if we are on schedule. I think others will rejoin us quite quickly, if we get going.

What I think we would like to do is hear from Dr. Hagan, and then ask the three people who spoke just before our break and him to have a chance to interact with the Commissioners, and then we will go on to the final panel after that.

Thank you for being with us, and let me give you the floor.

DR. HAGAN: Thank you.

I have been invited here today, I think, because of the reputation that I have earned in the last few years as an openly HIV positive physician. Unfortunately, I had to quit practice about three and a half years ago, but I have been able to continue to address the issue that we are addressing today.

Just briefly, a little bit about who I am and my background. I came to USC on the faculty in Los Angeles as the Director of the Family Medicine Residency Program in 1978, and left there in 1981 to join a group practice down in the heart of Orange County. I didn't know much about the politics of Orange County then, but I do today, and I am not sure it was the right thing to do.

At any rate, I also would share with you that an important part of my life has been coming to terms with the fact that I happen to be gay. When I was 12 years old, the son of a Southern Baptist minister in Louisiana, I recognized that my sexual orientation was different, and the self-esteem and issues that surrounded that particular difficult issue were years in getting resolved, and I have to say, about the time they got resolved, I had to come to terms with another stigmatizing issue and that was my discovery of being HIV positive.

I was practicing in Irvine, California, which is a middle upper-class, predominantly white young family, with 2.2 children, developed unusual headaches, knew that I was at risk for HIV, but I had a hard time convincing myself that I should be tested. But as headaches persisted, I was tested in the summer of 1986. I went up to Los Angeles to an anonymous testing site, terrified that someone would recognize me. Fortunately, they did not.

And to make a long story short, I subsequently worked up the courage to go to see the chief of infectious disease at the local university in Orange County, and began to come to terms with what this meant to me, not only medically, but what it meant to my future professionally. And one of the first questions I asked Dr. Tom Cesario at UCI was am I putting my patients at any risk.

He says, "Well, Don, there's no evidence of that at this point." He says, "You don't do any surgery, do you?" I said, "I cut on people every day, I sew up lacerations every day, I see 35 to 40 people a day, and," I said, "I take every precaution, more now, but," I said, "I know that I've been HIV positive probably since the late 1970's or early 1980's, based on my immune panel."

He says, "Well, for the time being, I don't think you need to worry." Well, each time I would go in, I would express this concern. I was seeing 35 to 40 people a day, I was working 12 to 14 hours a day, and I was afraid to miss even seeing one patient, out of fear that my partners, of which there were about 29, would be tipped off to the fact that something was going on with my health, as they knew that I was a gay man.

We reached the point where we felt that it was appropriate for me to stop working, not out of fear of infecting my patients, but all of the intricacies that are involved in this process and in terminating your employment and living with your future all came rushing together.

Issues that I had to resolve were -- you become part of the family of people that you take care of. There were people who looked upon me as, you know, one of the most important people that they had in their lives, and here I was going to have to leave practice, and I figured that I was going to have to leave without telling them good-bye, because I had made a decision a number of years ago that I would not lie again, because I had lied and lied and lied about my sexual orientation, and I knew that was a very negative part of my life.

Integrated with this decision was is my disability going to pay in the fact that I am only so sick, am I sick enough? But whenever you make that decision, you lay the cards on the table, and if you win, you win, if you lose, you lose. The problem was my attorney said if they deny your disability, you are going to be fired by your group and you will have no disability. Those are all of the issues that those of us who are HIV positive must confront.

The hardest thing for me was when I made the decision, and my doctor supported it and he says, "Don, I think we will win with your disability," was to go in and resign. I didn't even feel like I had the luxury of one or two days to act, once I informed my partners. Many of them had considered me a pariah from day one, when they found out that I was gay. But because of my productivity, money was the bottom line, and so I was always welcome in the group.

So, I said, well, how do I leave, with patients' appointments on the book. I said that's not an ethical thing for me to do. So, I scheduled my disability to begin on March 1st, and I went in and I marked out three weeks on my appointment schedule as a vacation. I went in on Friday before that Monday, and I handed in my resignation and announced my disability, in an effort to give them some time, so that I didn't have patients on Monday expecting to see me.

We had to negotiate what I was going to say. They knew that I talked to the press about gay issues. They were scared to death that I was going to name the group and embarrass them or, more importantly, put the group at risk for a lawsuit.

The first thing one of them said was, "Don, don't you think one of your crazy gay patients that is HIV positive is going to file suit immediately that you were responsible for infecting him?" I said, "My attorney and I have discussed that, that is reality. The facts don't support that and I'm willing to fight it, if that happens."

I sort of made a tacit agreement with them that I would not discuss the issue publicly for six months, unless I was asked, and if I was asked, I would not lie. I was asked privately by a lot of my patients. I have a listed home phone number. Many of them called and said, "Where are you? What are you doing?" And I told them the truth.

Fortunately, it wasn't in the press until almost exactly six months later, and since then I have addressed the issues on CNN, on the front page of the Los Angeles Times, and with all of the major radio and TV stations on the West Cost, and I have tried to become a spokesperson for some degree of sensitivity to those of us who are affected by this process.

What message are we sending to the public? I am concerned about the fact that we can't change the public. When this issue originated, casual contact was believed to be capable by most of the public. With Koop's efforts and with your efforts and our efforts, we did change the public's perception, but it took a lot of effort, and I really believe that we should approach this by sticking with the facts and staying on a sound scientific tract, and not getting off on a political binge.

Who wants HIV positive physicians restricted? I think that you have to look at that carefully, and I can tell you in my own Orange County, Congressman Dannemeyer, as you know, is one of the major spokespeople. Does he care about health care? He has been at the forefront in protecting raw milk sales in California, and there have been multiple deaths due to infected raw milk, and yet he says the right of free enterprise is such that those people have the right to buy it and the company has the right to sell it.

Helms, you know, what hypocrisy for this man to be concerned about a handful of deaths, when he has given his right arm to the tobacco industry, where we have probably 300,000-plus deaths per year.

Hypocrisy -- I look at who is it that is after these changes in restrictions, whenever we can't in public school systems talk about condoms, but we can restrict physicians' ability to provide care. Stigma has not been addressed much today, but I believe that that is the driving force behind this whole nightmare.

I was invited to speak to a major Protestant church in Orange County on this issue some months ago, and a doctor had invited me there. When I went in about five minutes before the service was to begin, the pastor introduced himself to me and sat down next to me, and he says, "Now, Dr. Hagan, there's one restriction I have on you today, and that is that you're not to mention homosexuality." I said, "Well, how does your parishioners deal with AIDS? He said, "Not very well."

I said, "Well, let me tell you, one of the basic problems across America has been that people don't understand who we are." He said, "What do you mean, who we are?" I said, "Who we gay people are." He said, "You're homosexual?" He said, "The doctor didn't tell me that." I said, "Well, I am." He said, "Well, can you discuss this, without mentioning that issue?" I said, "That is the root problem with AIDS in America, is that these people don't know that we're their sons and daughters, we're their brothers and sisters."

And he says, "Well, I just can't let you do that." I said, "Well, you have a nice service," and I got up to walk out. He says, "Where are you going?" I said, "I'm going home." I said, "I can't be a fraud in your church." He says, "Well, you can't do that, I'll be embarrassed." So, he finally agreed and it went beautifully. The questions asked were good questions and people got educated, and he stood up at the end and he apologized to his church and he told them the truth and he said, "I've learned something today that will be a lesson long lived," and he thanked me for persistin and staying.

But the stigma is an issue, and i bring you back to it, because you have got to keep it in the back of your head at all times. Who are the providers of the majority of people who have HIV? This is a real critical issue in making the decisions about who should be able to practice and who can't.

I agree, when Dr. Osborn mentioned that, when you get down to the CDC standards and what they really want to do, it is going to probably affect a few people, but the fallout has been in our state legislatures all over the state that it is affecting almost anyone who is HIV positive.

There are even suggestions that, to get your license renewal in certain states, that you have to show evidence of being HIV negative. This is really terrifying, because the majority in urban settings of providers of health care to those who are HIV positive are gay men, many of whom are also HIV positive.

Now, let me give you an example: I was recently invited to speak on California treatment standards to another state at a public hospital. They have nine physicians that operate their AIDS department, three of whom are full-time and six of whom are part-time. The six physicians who are part-time, all come from surgical specialties. They are not there because of the money they make, because they get paid probably minimum wage. They are there because of their hearts. They are there because of the sense of community.

Now, if these people are physicians who practice invasive procedures that have been suggested put patients at risk and they lose their livelihood, do we lose them as volunteers, basically, in our public health, in this particular public health hospital, which is just an example, I think, of what exists all across the major cities in the

United States?

In September, I met Dr. Winn, who will be speaking a little later, and I have to share something, in no disrespect to him, but it points out an important point. He indicated in his presentation in association with medical licensure boards that losing 5,000 to 7,000 physicians would be relatively insignificant to the health care of America. And we jumped on him and we had a nice exchange, and I think it was an educational opportunity for all of us, to recognize that those 5,000 to 7,000 physicians, many of them are the people who now provide expertise to HIV positive patients.

So, my fear is exactly what Dr. Osborn pointed out, by reading that little letter that she read. I can share you off the record a statement made by one of our Louisiana legislators, and, you know, we are very -- Louisiana, I am from there, I live in California.

He was quoted as saying this is a golden opportunity to get rid of all the faggot physicians and all of the drug-using physicians in Louisiana, and that from a legislator who may become governor. This is a terrifying implication.

I would not give up on the public. I believe that this Commission putting pressure on our leadership across the country, putting pressure on Dr. Roper can make a difference in what people think about their physicians and whether or not it is safe in their mind to see physicians, without revealing their medical history.

I have one other comment on disability, and then I will stop, and that is I called a couple of major disability firms, including the one that I have insurance through, and there is as very gray zone right now that they are looking at very carefully with regards to paying payments to doctors who are excluded based on CDC guidelines.

If the person is not physically disabled, they are looking carefully at the legal ramifications of whether they have to pay disability, and they are prepared, some have said, to go to court and they feel like the evidence to restrict physicians is not there and that the courts will support them.

So, I share that point with you, because it is as very bothersome point to those physicians who are considering getting tested or considering revealing their status, realizing that the major disability insurers are carefully looking to see whether or not, indeed, they owe these doctors any insurance payments.

I will stop by simply saying that I am proud to be part of the American Association of Physicians for Human Rights, which has created the medical expertise retention program based on San Francisco, a program that seeks to provide places for physicians who have lost their jobs or nurses or other medical people.

I thank you.

CHAIRPERSON OSBORN: Thank you very much.

I would like now to ask the Commissioners to remember the before lunch testimony, as well as this very powerful testimony, and any questions that you may have.

Don Goldman is top of the list.

MR. GOLDMAN: Thank you, Dr. Martin, Dr. Hagan and Dr. Kelen for your testimony. It was very powerful, indeed.

I would like to ask a question of you, as well as the morning panel, the earlier morning panel, as well, particularly Dr. Gerbert and anyone else who wants to respond. My question is why not empower patients, by urging them to inquire about and insisting upon the use of universal precautions among their health are providers, and what might be the psychological effect of such empowerment on their fears, anxieties and reactions, as well as what might be the impact of such empowerment on the enforcement of the use of such universal precautions?

Dr. GERBERT: This summer, I was asked by the CDC to consult with them about how they were going to approach the public, and your idea is one that they are considering, and that is empowering patients.

It is interesting to note that in the mid-1980's, there were all these checkoffs in newspapers and magazines about what to ask your dentist. I think that went away, but I think you are right, that it is something that the public can do that feels empowering.

The specifics of it are confusing, however. You know, it is easy to observe. We have studied that patients can tell you if their dentist wore gloves or a mask, et cetera, but they can't observe sterilization and disinfection procedures, and so there is always that unknown. But it is empowering. It should be part of some package.

MR. GOLDMAN: Assuming that, what kind of psychological impact might that empowerment have, at least on a theoretical or an experiential basis on their levels of fear and anxiety and their reaction?

DR. GERBERT: I'm not exactly sure what you mean, because empowerment is psychology, I mean teach me how to feel like I am in control of a situation, and so I think it could work.

On the other hand, the things, when we have asked patients have you talked to your doctor about A, B, C, patients aren't willing to ask them questions that they want to ask or need to ask. So, when we ask patients have you ever asked your doctor if they were infected, no one had, you know. It is uncomfortable, things they think about and they just don't do.

To question a physician or a dentist about their infection control is something that takes skill in teaching them to do. We can't just put articles in newspapers about it.

DR. HAGAN: I would like to respond and say I have spoken now to over 100 civic and social and medical groups, and I think that the people respond whenever they are called on to respond and when they are educated.

The unfortunate thing is there aren't very many of us that are willing to come out of their HIV closet and talk to groups. But when we do, when I do, people respond and people become educated. I see enormous changes in attitudes from the moment I start to an hour later when I leave. I mean it is enormously important for doctors, especially those of us affected by this disease, to speak to the public, and I believe that we -- yes, I have said, you go in your doctor's office and you talk to them about how they control infection inside, do they wash their hands, do they autoclave their instruments. That is not over their head. We have to give them credit for that, and what it does is it gives them a sense of some control.

DR. MARTIN: I have a perception about this, also, that I don't know that anybody has considered. I doubt anyone in this room would be afraid to go and ask their doctor those questions, but I think that there is as group of patients, maybe even a large group of patients that perceive the medical experience as being something different than people in this room might perceive.

They almost see it as a spiritual type of thing. They go to their doctor very dependent and very expecting, and they tend not to want to know about, you know, how a procedure is performed or whether -- they tend to not to want to be empowered. I don't even have numbers for that, but I know that in a day's worth of practice, you know, you will find people who come in and they are inquisitive and they are interested and they want to know, and then there is other people that just come in there and it is like, you know, "Doc, fix me and send me home, I don't want to know any more about it than that."

So, I think that while patient empowerment might work in many cases, I don't know that it would work in all cases.

DR. GERBERDING: I think it is also important to remember that it is a reciprocal situation. I think a good reason for clinicians to bring up the subject and to offer information in reassurance to patients is because it is sometimes difficult to ask those questions.

I make it a point in my practice in the clinic situation to always wash my hands when I come into the room and then talk to my patients about, you know, what I am doing that for and why and lead into some kind of a dialogue to address people's concerns. Often they could care less, but occasionally they do have -- one person asked me if I had been tested for HIV.

DR. PRIMUS-COTTON: I would like to respond to that, too, because I am a strong believer that when you start to speak of empowerment, if you use education as your frame of reference, that it is presented at a level that people can understand, that it is an opportunity for individuals to develop the trust that I am talking about that feel comfortable enough.

When most patients come into an office, they look on the wall to see what credentials their physician has, and it is the same thing that you're talking about, that you can work out a joint effort, a collaboration. It is really helping the physician, as well, because he or she then is aware of what type of client he or she is serving.

As you mentioned about the hand-washing, then that becomes as very simple thing, but a very important thing. We teach hand-washing in nursing, and you, in turn, teach it to others. This is a simple procedure, but to educate someone to know why you are developing or sharing with them the basis for what these conditions are, what are the symptoms, et cetera.

People are not as dumb as sometimes we health professionals think they are, particularly if they come from an orientation toward being afraid to ask the questions. They may not ask you those questions, but they have in the back of their minds, that if you don't tell me, I don't tell you, and that's why you don't find out a lot of conditions that exist, because then they tell you what they think you want to hear.

But if you get down to the basic trust that we, as health care professionals, will have to establish, and, as I said, look at some of the old models that have worked, where the information has been put out there for the public. We have right, both as a provider, as well as a consumer, to know what our rights are.

We must know that, and empowerment tells me that I can walk in your office -- I look at your wall, but I also observe you and see if you are washing your hands or see what is this instrument that you are going to use on me next, what should it does, what is in that injection that you are getting ready to give me, and I should feel free to ask those things.

CHAIRPERSON OSBORN: Mike?

DR. OSTERHOLM: Could I respond to that, because I think that what I hear here today is good and I think in many cases it can work, but I would raise some more fundamental questions.

How many people in this country have a family doctor? We don't have a medical care system today that lends itself to this type of interaction. We have got people who are in prepaid health plans, if they are in anything, who may never see the same doctor twice in 20 years.

And the whole delivery of health care today speaks against this very relationship developing, so that I think part of the problem we have to address is you are not reimbursed for your time spent 15 minutes discussing with the patient your concerns about HIV infection, when you have 45 patients on a list today, and you are not in an office with your diplomas on the wall, you are in a bare office, because you are shifted to wherever you are at, that is a problem and I think that is part of the whole health care delivery issue today which needs to be addressed.

Second of all, I just want to comment that one of the primary feedbacks that we get is that doctors are resentful of being asked if they are HIV infected. It may not be the experience of this group here today, because, obviously, this is a chosen group, but there is that feeling of why am I being asked, as if I am being put on trial, and I don't think physicians have ever been trained really how to respond back, when it is something about themselves per se, and this came out of a number of our findings in Minnesota when we did this report with physicians, of their resentment and that we haven't done a lot to help physicians help explain to patients what this issue is all about.

Dr. PRIMUS-COTTON: I need to respond also to that. I think you hit on a very key question, and that is about the masses of our consumers who are served by public health departments or other free enterprise, free services. That is even more the reason that they should be educated, because they do have to accept whomever is there to treat them, and that is even more whether they see the degrees or whatever. They should have the basic information that will assure them that they are being treated adequately.

I think there is even more reason that they should be educated, because then it wouldn't matter who you are, if you can respond to what my needs are, which should come first, why am I here and can you help me.

Thank you.

CHAIRPERSON OSBORN: Dr. Rogers?

DR. ROGERS: I am pausing. This is a comment and not a question. I have always felt there was as little safety valve in this and perhaps we agonize more about the question we are now debating than we should.

I think a patient has as right to ask me almost any question they wish, and there are some where I feel I have a right to say I prefer not to answer. But I mean patients can decide to discard me, because I am a Catholic or a Jew or I am black or they don't like the way I cut my hair or all kinds of things, and that is part of the negotiation, that is part of the -- I feel perfectly comfortable, though perhaps I am a different generation, with a patient asking me virtually any question that will help us bond, and I try to answer them juste as honestly as I can.

So, some of this, it seems to me, I agree that this is an idealistic situation. Patients do have a right to say I don't want you as a doctor, I want somebody else, and I am quite comfortable with that. I think they ought to feel trusting of me and feel that I am giving them the straight answers on things, and they do under certain circumstances, not all, have a chance to go elsewhere.

That is why I am kind of troubled by legislating some of this. I think we should say absolutely, ask your doctor anything you wish that increases your comfort level in terms of being taken are of by a doctor. I think, Don, you are saying some of that, too.

CHAIRPERSON OSBORN: Just before going on, if I can take a little liberty with the last word, I have two thoughts on that matter. I am glad Mike spoke up about the fact that an awful lot of people don't have doctors, and I think a lot of us are in a different context, so different that we have moved psychologically away from it for a moment, worry a great deal that people are getting thrown out of the emergency rooms, because they can't fill out the insurance form appropriately to even get the chance to look at the wall. So, that is one caveat to this.

I think what is being stated is as goal that we must go for, as health professionals, because we have inherited a paternalism, maternalism kind of an approach, a guild approach that we know a special fancy language that you don't know, so you don't even know how to ask the questions, so we don't have to answer it, and we have got to move away from that, as we fix our health care system, and I think what Dr. Primus-Cotton is describing is a wonderful goal for health professionals to be working toward, enough dignity mutually in any kind of health relationship, so that questions can be comfortably asked and answered.

But realities, I am going to come from a whole different kind of ball park, because while I have M.D. behind my name, I am a board pediatrician and whatever, I never have been an internist, and certainly never a surgeon, and I work in a context of a school of public health, where the minority of people are physicians and a lot of the people who work at the school of public health and other professional roles don't have any friend access to a physician.

So, I, as their friend, as somebody they work in the same office with, in the dean's office and so forth, am a pretty easy person to come and ask when something happens, and I cannot think of a staff member who has no close medical contact and family or something, who has had a health problem in the last couple of years, the last many years that hasn't come to me with questions that they just didn't dare ask in the doctor's office.

So, I think that the profundity of this problem shouldn't be passed over, and I think your comments are fight on, but we do have to look at them in the context of a health care economics system right now that denies any kind of access to an enormous number of our people and tie it right into the goals that we set for ourselves, which, as we have often pointed out on this Commission, cannot be teased apart very easily, without losing the substance.

With that editorial comment, perhaps we could go to the last panel. If it is not too much trouble to rearrange a little bit, David Barr and James Winn, could I get you to relocate sort of in the center there, to make things easier. Although we expect everybody, we hope everybody can stay and continue to participate in the general discussion that will follow. Take your name tags with you, if you would like, and just find another seat.

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Thank you all for being with us, and if you would, in order, talk to us and then we will interact some more.

MR. BARR: Thanks, Dr. Osborn.

This is hard for me to do today. I talk a lot. I come to a lot of meetings. I testify. A friend of mine is sick, so it is hard today.

I was very moved by Dr. Hagan's testimony, and it made me think that I need to say something else other than my prepared remarks, though I will submit those, as well.

I am also HIV infected. There are a number of us here today. You know, we come to these meetings and we tell our stories and we, along with the people who work us, our advocates, our supporters, our families, you know, we come, we tell our stories, we tell what needs to be done, we create organizations, we create educational programs that help prevent the spread of the virus, we push the FDA and the NIH and the drug companies to get the drugs out faster. We lobby to get the care dollars passed, we lobby to get the education dollars passed.

Frankly, we have been right every step of the way. Everything we have done has been right, and it doesn't seem to matter. It is very difficult, I think, for us to continue, certainly difficult for me to continue to do this. We know how to prevent the spread of this disease, and the programs, the educational programs that can prevent the spread are prohibited by the government. The research budget gets cut, the drugs that get researched don't work.

Dr. Rogers I think really summed it up very, very articulately before: The epidemic is ravaging us, it is raging all around us, and, yet, I have been to too many meetings on this subject since August of 1990, and it made me think of how I felt the day I testified in front of the congressional committee, along with Barbara. We were on a panel of remarkable people, and Kimberly Bergalis testified that day, as well.

It was a very interesting situation for me. I don't know how you felt about it, we haven't spoken, but it was a remarkable day, because I have been doing AIDS work for years now, since 1985, and I have never seen the press whipped into such a frenzy as they were that day. And there was Kimberly very sick, you know, with her father very vicious, sitting at the table, and there were 200 photographers in front of her, and she spoke and then her father spoke, and then Barbara Webb spoke, who is just as infected as Kimberly is.

During Barbara's speech, Kimberly got tired and had to leave the room, and so they wheeled Kimberly out while Barbara Webb was speaking, and 200 photographers got up, right in front of that woman, and walked out of the room while she was speaking. Her AIDS isn't any different than Kimberly Bergalis' AIDS, and they didn't sit in the room when Barbara spoke or when Sonia Singleton spoke or when I spoke.

So, it is difficult. You know, I left that day feeling like, well, some cases count and some cases don't. You know, some people have AIDS and they count and they get listened to, and some people have AIDS and they don't get listened to. We fought very hard to get some attention that day, to get our side of this story told, and I think, because we worked so hard, we succeeded. But I didn't leave that room feeling empowered and I didn't leave the room feeling like I was going to be listened to, and it makes it very difficult to continue.

I want to thank the Commission for the really remarkable work that you have been able to do, and I just wanted to read one thing that I wrote, because I think it is important.

I think that your recent report will stand historically to prove that, even within the government, there were a few voices that knew what to do and weren't afraid to say it. Unfortunately, those voices seem to get lost all too often in the din and the confusion created by the CDC and the

Justice Department and the Congress and, of course, the President, because we know the things that we need to do and yet they don't get done.

You know, I don't talk like this that often. Usually, I just get angry or I talk facts, but I don't feel particularly hopeful these days, and I don't really know where to take that. You know, when I see so much attention being paid to this issue, not that the Commission shouldn't pay attention to it, but that the government and the country as a whole pays so much attention to this issue, and ignores what the real issues are. It is very frightening. It is as very frightening prospect.

You know, it is very difficult for me to think, well, I should get up and go to work every day and that will make a difference, when there is just so much that flies in my face that says we don't care about this problem, not just that we don't care about it, we want this problem to get worse. That is how it feels, you know, we are not going to distribute condoms in schools, we ar not going to distribute needles, we are not going to -- PCP is the leading cause of death among people with AIDS in the United States, it is the leading cause of death among people with AIDS In my city. It is preventable.

We spent millions of dollars on research to prevent PCP, and everybody is dying of it. So, I can't come to any other conclusion but whoever would like that to happen, because it is pretty simple, you now, it is not that difficult to -- maybe it sounds difficult, but somehow it is not that difficult. There is a drug that prevents PCP, it is cheap, it doesn't cost as lot of money and it is not available, it is not there. People don't even know that it exists. So, how can I think that is anything but willful, willful, vicious murder?

I should tie this back to this issue. We get 5,000 calls a month on our hotline at GMHC, 300 come from HIV positive people seeking dental or medical referrals. You know, we have got 30 physicians to recommend, 30-odd physicians to recommend. We have got 8 practitioners for referrals outside of Manhattan. Now, if you cant' get AIDS care in New York City, think of what you can't get outside of New York City.

So, if you think that restricting workers is not going to have an impact on the care that people with HIV infection get, you know, that is just crazy. You know, we don't get much care now, and it will only make it hard for us to get the care that we need, and maybe that's the point.

Thank you.

CHAIRPERSON OSBORN: Thank you, David.

Chai?

MS. FELDBLUM: Well, I am not sure I have significantly more hope than David, certainly, that this will be an easy issue to resolve or deal with, but what I hope to do today is give some sense of the legal principles that are supposed to govern in this area, give some sense of the principles, both in terms of anti-discrimination law and touch on informed consent, to the extent of time.

Before I launch into law, I think it is really useful to go back to what Barbara Gerbert was saying, although perhaps in a different perspective than she was presenting it. Her point was that the public has this fear, and it is as very real fear to the public. It is the Lotto Medical America, as she said, that that 1 in 42 million chance will happen to me. I think that is probably correct.

As I understand Harlon Dalton's question to her, though, it was, well, what is that supposed to me, in terms of policy or in terms of leadership for us who are trying to think about policies, and I think the essence of the question there was are you saying that there was some wisdom in that public, some wisdom in that perception of risk that should be acted upon, or is, in fact, the wisdom to be taken herr, to be taken from the insights, is an acknowledgement of the fear that exists, and understanding an acknowledgement of the fear and, therefore, have that acknowledgement underscore the resolve to, in fact, come out with the policy that will, in fact, be the correct policy, to the extent one can discern it, for the entire health care system, for all health are workers and for all patients.

The reason I think that is a useful framework for talking about law is that law has often been the mediator or the buffer between the passions, the truly felt passions of a public and what is considered at some other level of leadership or policy to be the right thing to do.

I mean, the classic thing is the Bill of Rights, which protects the rights of the minorities against the passions of the public. In fact, I will tell you, it was absolutely the bedrock of the Americans With Disabilities Act, from the perspective of the disability community, because the disability community knew that there were truly felt passions and fears about people with disabilities, that they could or could not do certain jobs, and the whole concept of that law was to say that there should be a requirement that discrimination not occur, and that, in fact, perhaps by hiring someone with cerebral palsy or someone who uses a wheelchair, he will discover it is not such a terrible thing, and that, in fact, the person can do a certain job, et cetera.

So, that I think is the framework for looking at what are the legal principles that apply in this area, and I think there are essentially three important ones. And when I say the legal principles, I am talking about the principle that would be derived from two existing Federal laws. One would be section 504 of the Rehabilitation Act of 1973, which is a law currently in existence, currently applying to basically all hospitals, as well as the principles embodied in the Americans With Disabilities Act that was enacted in 1990, and I think, for purposes of this area, essentially become effective this January, January 1992, for most large hospitals, allowing a phase-in period for smaller health care clinics.

In terms of the principles, the first is that a person must be qualified to do a job. This is a basic principle of disability law, the person even with the disability must be qualified to get the job done.

Now, a basic requirement there, however, is that the individual person can do the particular job. There is an individualized assessment of the person's ability. An employer cant' say, oh, well, I don't want people with cerebral palsy for this job, all people with cerebral palsy need not apply. It has got to be this person with cerebral palsy can't do this job.

Now, in some situations, you can have blanket classifications, like you could say, probably, all blind people cannot be bus drivers. But the reason that would be okay in disability law is because you could not logically have variations within that particular class, that is, all people who are completely blind could not be a bus driver. You couldn't say all people with any form of vision impairment could be a bus driver, because there would be variations within that class. So, there has to be an individualized assessment of the person.

Second is a concept of least restrictive alternatives in the context of qualification standards, that is, an employer cannot have a qualification standard, that is, a standard that says you must meet these physical or mental criteria that end up screening out people with disabilities, unless that standard is -- and I use the words of the ADA now -- unless that standard is "job-related and consistent with business necessity."

Now, these five or six words have actually gotten a lot of palsy in the last month, because of the civil rights bill, but for purposes of our discussion here today, what that standard means is that the qualification standard must, number one, be actually related to the person's ability to do the job, that is, it has to be job-related, and, two, there can be no less restrictive alternatives that the employer could have come up with, other than this standard based on certain physical or mental criteria that would enable the employer to find those employees who could do that job effectively, safely, et cetera. That is the concept of least restrictive alternatives within disability law.

Finally, the third principle is that an allowable valid qualifications standard that an employer can have, or a business, is that the person not pose a direct threat to the health or safety of others, and this we have talked about already today, as the ADA defines direct threat, as it has been defined under section 504. That means that a person may not pose a significant risk to the health or safety or others, and the EEOC, in their regulations, recently explained what that means is that a person cannot pose a substantial or high probability of substantial harm.

Now, that is sort of the three basic principles, and now the question is how those then apply to this area of HIV infected health care workers and the CDC guidelines. Let me say that, although I am going to use the CDC guidelines as a backdrop, I do believe that it is important not just to focus on those guidelines, but also to keep one's eyes on the second prize that is on the arena of states adopting guidelines that have to be comparable or equivalent to the CDC guidelines, and, therefore, what are the principles really that should be governing those states in this area.

The first principle is that of individualized assessment. I mean, a basic flaw in the CDC guidelines, and one which hopefully will not be replicated, is that it does not allow for individualized assessment of particular health care workers.

Now, it is interesting, Larry Gosden, in one of his articles, said this sentence, which is as follows, in his describing their lives: "The categorical determinations to protect the public health are likely to be upheld, provided that all individuals in the category pose a risk to the public health and that no reasonable differentiations within the group are feasible." That is a key basic premise to his approach, which was, in fact, adopted in large part by the CDC.

Well, I responded at one point to that sentence, I think it is worth looking at even more closely, because, in fact, I think everything you heard this morning and a lot of what has been discussed before is that there are reasonable differentiations that can be made within this group. Mark Barnes' point, that the category of exposure-prone invasive procedures is both over-inclusive and under-inclusive is exactly because people have differing levels of infection control, technique and general surgical technique.

Second, in terms of lesser restrictive alternatives, this I think is the point that Julie Gerberding has been making over, again, very effectively in print, as well as in oral statements, that there are, in fact, other alternatives to defining exposure-prone techniques that would reduce the possibility of risk, and instead of having what you have in the CDC guidelines, which is essentially a qualification standards, essentially is a standard that says you must be HIV negative, in order to do these types of procedures, there is a lesser restrictive alternative than this qualification standard based on a physical criteria that could achieve the goal of safety.

Third, I definitely think that it is quite questionable that the standard of significant risk has been reached in this area, given the low probability of HIV transmission in any of these cases.

I think even more significantly is that the Supreme Court, in School Boards of Nassau County v. All-Line, the case where the Supreme Court set out the standard of significant risk, the Court said, in deciding and determining significant risk, courts should defer to the reasonable medical judgments of public health officials.

Now, that was based on the presumption that public health officials would be taking into account scientific data, public health concerns, et cetera, in setting forth the policies. Now, I, too, have compassion for the job of the people at the CDC, absolutely. However, I do not believe and

I believe that many other people are concerned that it was not simply scientific data that went into the end result.

And I think Dr. Barondess this morning really said it more eloquently as possible, and given that, I think that it is quite questionable that courts should, in fact, be looking to that standard in terms of reasonable deferral to public health judgments, and, in fact, that is a point that the OTA report, which just came out on Monday, made.

So, that is the legal framework, individualized assessment of individuals, the least restrictive alternatives, and an analysis of significant risk that is based on scientific data, and not public fear.

Let me just talk briefly about informed consent, I guess lay out a few principles, and then if people have questions. Actually, let me stop a second. Would you rather that I talk on--I actually didn't watch my watch right here -- would you rather that I just talk on the informed consent principles, or keep it -- I am very conscious of keeping to time, if possible.

CHAIRPERSON OSBORN: I think if you want to just finish up fairly quickly, we will have a good time for discussion, so you could be brief now or come back to it, whichever way you prefer.

MS. FELDBLUM: I think it is probably worth coming back to, instead of going at length.

There is a whole separate issue of informed consent which really is different from the anti-discriminatory principles. I don't think that the law has at all developed yet informed consent to take into account this particular issue of a physician self-disclosing, issues about the physicians.

It is very clear under informed consent doctrine that material risks should be disclosed to a patient. In about half the states, the standard is that whether something is material should be determined based on the perspective of the patient, which I actually think is the correct standard. It is not what the physician thinks should be told, but what a reasonable patient would have wanted to know in making a decision.

A number of states that have that principle also note, though, that material risk does not include risks that are so remote that they probably won't happen, simply because I think there had to be some limit placed on what physicians would tell. In fact, there have been almost no cases that have addressed, much less decided, the question of whether a physician must self-disclose very remote risks about him or herself.

There was a case in 1989, in Maryland, which has as very strong informed consent doctrine, dealing with a doctor that had an incredible record of incompetence, and one of the reasons the woman did not prevail in her informed consent claim in that case was that she could not prove that the harm she suffered in that case was due to the doctor's incompetence. There is a wonderful footnote, where the court says I think we finally found one case where his incompetence didn't actually result in or wasn't a causal factor for the fact that the operation didn't work.

[Laughter.]

But that court said it is not decided yet, under our doctrine in Maryland, whether a physician must self-disclose risks about him or herself. Now, I think it is going to start coming up in cases, because of this issue.

But I think the reason it has not been decided and the reason why it won't be necessarily easy, as other issues within informed consent, is that if you have a treatment that, let's say, has a 50 percent chance that there will be harm, a patient might still decide to go ahead and do it, because it is an experimental treatment the patient wants to try.

But if you have a physician whose level of risk, potential harm is pretty high, I mean the answer to that is not consent of the patient, the answer is to bar that physician from practice. So, we are clearly only talking about the types of risks that are relatively remote, and in those types of situations you have three countervailing interests to the concept that the physician should self-disclose.

I say this, assuming not just that it will be self-disclosing HIV status, but once that gets into the doctrine, there is just no way legally to differentiate that from self-disclosing a whole range of other physical, mental factors and competency factors about the physician that might have relevance.

Given that, you have countervailing interests of the privacy rights of the physician, what Mark Barnes calls secondary consequences, that this would be a clear disincentive to health care workers to get necessary treatment, physical and mental treatment. For example, if a doctor is told by his or her therapist, "I really think you should consider Prozac, maybe it would be a good idea," the person realizes that they will have to self-disclose if they are on Prozac from now on in, that is a disincentive to getting that care, and, in addition, it is a disincentive to injuring the entire profession, if you know this is a profession where you have to self-disclose all these items about yourself.

So, I say that only to say that I don't think that it would necessarily be an easy case. Properly presented to a court, properly presented and argument, it is not so clear to me that the informed consent doctrine would necessarily develop into requiring this type of mandatory self-confession.

CHAIRPERSON OSBORN: Thank you, Chai. That is remarkably clear and succinct, and we appreciate it.

Dr. Winn, last but by no means least. Thanks for being patient.

DR. WINN: Thank you very much. It is a pleasure to have the opportunity to be here today and to talk with you about the approach that the Federation of State Medical Boards has made towards dealing with physicians who are infected with the HIV or the HBV virus.

On October 28th, the Board of Directors of the Federation of the State Medical Boards of the United States issued a formal statement regarding the role of state medical boards in preventing the transmission of these viruses from physicians to patients.

I need not tell you that the development of that statement was quite a difficult task which required lengthy and extensive study and debate. It would have been quite possible, I think you could realize, that, in the midst of that process, to become lost in the fog of science and emotion and politics which has swirled about this entire issue for over ten years.

The fact is I am not certain that fog has completely lifted. However, I do hope and I believe that the federation has managed to find a very reasonable position on this issue. Given its task to assist the state medical boards in protecting the public interest, the federation had no choice but to address this important issue as effectively, as the nature of current data and the level of public concern required.

Now, to suggest that no action should have been taken, because there is very little evidence of transmission from patient to patient, is to suggest that we can reliably predict the future from today's events and that there is no relationship between horses and barn doors.

We are dealing with an ultimately fatal disease, and the public is not going to accept business as usual responses or evasions of responsibility. The current flurry of legislative endeavor, be that Federal or state, be that proposed or already enacted, is a direct result of the loss of public confidence in the ability of public and private health are institutions to provide protection from infected health care workers. And however narrow the scope of possibility may seem, any potential mode of transmission, over which we do have some degree of control, must be dealt with both in an effective and a reasonable way.

I think that the federation's policy statement clearly represents such an approach. It is based on the best advice which has been available at this time from the CDC. It stresses the professional and ethical responsibilities of physicians themselves, and it places the final authority in the hands of the state medical boards, in which it belongs.

It is a dynamic policy statement which allows appropriate modifications, as new and additional information becomes available. It is intended to serve as a blueprint for the development of rational regulations by each individual medical board of this country, and, thereby, hopefully prevent the adoption of a hodge-podge of state statutes nationwide.

I would like to give you some brief background on what went into the development of this statement, and then talk to you about the statement itself.

Over four years ago, the federation's Legislative and Legal Advisory Committee began to consider the potential problems which were presented by HIV and HBV infected physicians. At that time, the committee determined that any specific recommendation or any other action would be premature. Instead, it elected to maintain a continuing survey of the relevant information available.

In late 1990, after several years of reviewing hundreds of studies and articles from journals and the professional and popular press, this committee drafted a tentative statement for consideration by the federation's board of directors. The board ultimately asked LLAC to further refine that statement. As a result of that request, the committee prepared a final statement for presentation to the board in early October of 1991, and the board adopted that statement unanimously, and that is the statement that has been released as of October 28th.

Additionally, the board approved a white paper which was prepared to assist in interpreting the intent of that statement, and that white paper was submitted along with the policy to every member medical board of the federation, the major media and to other interested medical and legislative groups.

You should know something about the group of people who developed this policy. The federation's Legislative and Legal Advisory Committee is comprised of members and consultants from the medical boards of eight different states. Currently, three of its members are attorneys, four are physicians, one is a state board attorney, and two are state board executives. Among the physicians, one is an orthopedic surgeon, one a general surgeon, one a pathologist and one a urologist.

The Board of Directors of the federation is comprised of 12 members of state medical boards and one state board executive. Of the 12 board members, 10 are physicians and 2 are public members. Included among the physicians are two family physicians, two psychiatrists, a pathologist, an orthopedist, a otolaryngologist, a cardiologist and two general surgeons.

So, together, the LLAC and the Board of Directors represent a wide variety of state medical boards, medical boards of Alabama, Alaska, California, Delaware, Georgia, Indiana, Iowa, Maine, Massachusetts, Minnesota, New Hampshire, Ohio, Vermont, Virginia, Washington and West Virginia.

These 16 state medical boards are represented, as are the seven specialties, including critical surgical fields. In the several years of development, other individuals have served on the Board of Directors and committee and lent their expertise to the process.

I felt this was important as a prelude to the statement itself, because I wanted you to have some appreciation of the thought, care and judgment and experience that went into the shaping of this statement.

The statement that was adopted and has been presented to the state medical boards for their study and consideration basically says that the Medical Practice Act or other appropriate statutes and other rules of the state medical board should include provisions dealing with preventing the transmission of the human immunodeficiency virus and the hepatitis B virus to patients.

These statutes or rules that are implemented should be consistent with the following recommendations: That all physicians should comply with the guidelines established by the Centers for Disease Control for preventing the transmission of the HIV and HBV virus to patients, and that physicians who are infected with HIV or with HBV or HBE antigen positive should not perform exposure-prone procedures as defined by the CDC, except within the guidelines set by the state medical board.

The state medical board should be empowered to do the following: To require that physicians doing exposure-prone procedures as defined by the CDC know their HIV and HBV status, to require the reporting to the state medical board of HIV and of HBV infected physicians, to insure the confidentiality of those reports received by the state medical boards as required under number two, to establish practice guidelines for HIV and HBV infected physicians, and to monitor the practices of such infected physicians.

The statement medical boards should be authorized to provide any disciplinary actions for physicians who violate statutes or rules established or otherwise implementing requirements related to the prevention of the transmission of these viruses. Additionally, the regulations would apply to all other persons regulated by the state medical board.

Now, briefly, in talking about these recommendations, I would read from the white paper in that the Federation of State Medical Boards represents the 66 medical licensing and disciplinary boards of the United States. Each board functions as a separate entity within its own jurisdiction. Totally uniformity in establishing any particular element of the licensing or disciplinary process is virtually impossible.

In its recommendations to member boards on various issues, the federation has recognized this reality and has attempted to encourage each board to act within the context of its own statutes, rules and codes to implement these principles that would best protect the public interest.

Therefore, no single recommendation for an approach to preventing the transmission of HIV or HBV virus from physician to patient can be urged upon the boards. As a result, this policy statement is not a model statute or rule for general adoption. It is, rather, a statement of principles that boards may use to shape their own approaches to the concerns presented by the HIV or HBV infected physician or to evaluate their proposals for action.

Now, it seems reasonable that the boards should require that all physicians comply with guidelines for the prevention of the spread of the virus to patients. It had been clearly shown that employment of universal precautions dramatically reduces the risk of transmission of the HBV virus to patients, and, therefore, could be expected to have similar effect on the risk of transmission of HIV infection to patients.

It is reasonable, therefore, to require compliance with such precautions by all physicians. It is also reasonable to require that the practice of any physician infected with HIV or HBV virus be reviewed by the medical board, if his or her practice includes exposure-prone procedures.

The powers and responsibilities the board should have to protect patients subject to exposure-prone procedures has been outlined. The first, as I said, would allow boards to hold physicians performing those procedures defined by the

CDC as being exposure-prone responsible for knowing their own sero-status. Based on the best available information, each board would determine how to implement this requirement, including what would constitute appropriate methods and test intervals. It should be clearly understood that any physician performing such procedures would be expected to know his or her status, in order to protect the public.

The second requirement would permit a board to require the reporting of infected physicians to the board. All persons and entities, including subject physicians and state agencies engaged in providing and regulating health care services, who are aware of a physician's infected status would be required to report.

The third requirement is that the board would hold confidential all the reports that they receive, because it is very clear that any reports made public, that many physicians would not come forward on their own and many others with knowledge of infected physicians would hesitate to report. Confidentiality actually would be in the best interest of the public.

The fourth requirement recognizes the responsibility of a board to establish practice guidelines for the infected physicians, insuring their continued service to the community in appropriate ways, while protecting the public from unnecessary risk. A board might approach this responsibility in a variety of ways, but should either seek the counsel of competent authorities or delegate the task to an appropriate review body in doing so. In all cases, both Federal and state statutes should be carefully followed, to insure the protection of both the individual and the public interest.

The fifth actually allows the board to develop appropriate measures for systematically reviewing the practice of infected physicians and assuring continuing compliance with the practice guidelines.

The federation recognizes that currently available scientific data and actual experience demonstrate that there is little, if any, risk of HIV transmission from the physician to the patient during exposure-prone procedures, when universal precautions and guidelines for infection control are followed.

That reality, however, does not obviate the need to address the understandable public concern with this issue. Failure to act responsibly in the face of a widely perceived possibility of risk could endanger the public confidence in the health care system and institutions which are charged with this regulation.

Action is also necessary to stimulate more effective compliance with those universal precautions and guidelines known to be essential in preventing the transmission of infection from physician to patient and from patient to physician. State medical boards cannot and must not ignore their significant role in this situation.

I really have appreciated the opportunity to provide this information to you. I, obviously, will be available to answer any questions you might have.

In closing, I would say that the federation believes that the recommendations it has made to its member boards in this statement represent a necessary and balanced response to the current level of concern, as Barbara said, the current level of fear.

In keeping with that understanding, the federation and its member boards will continue to review and assess scientific data on and experience with HIV-HBV transmission and will take further action only when and if reliable evidence indicates that such action would be required to protect the public interest.

Thank you very much.

CHAIRPERSON OSBORN: Thank you, Dr. Winn.

I am now going to turn over the Chair for the discussion to Dr. Rogers. Do we want to do a break first, briefly? I didn't know if you wanted to do that before the break, but go ahead.

DR. ROGERS: Why don't we ask questions and then have a break, and then come back and --

CHAIRPERSON OSBORN: And then we can have a general discussion. Okay.

DR. ROGERS: That would solve all these problems.

[Laughter.]

MR. DALTON: I have a brief clarifying question for Dr. Winn, and then I want to say something to David Barr.

Dr. Winn, as I listened to you, it sounded as if the federation's statement does not itself require HIV or HBV infected health are workers to disclose their infection to their patients, but you do, in a sense, incorporate the CDC guidelines, is that correct?

DR. WINN: Yes, the CDC guidelines that call for universal precautions by health care workers. Of course, the federation policy basically applies to physicians, because that is what the medical boards regulate.

MR. DALTON: I guess my question is are you also, then, incorporating the part of the CDC guidelines that requires disclosure to patients.

DR. WINN: No. Although an individual medical board may take that stance, our recommendation is that it is not required, once the review has been done by the medical board or under the auspices of the medical board, that that physician would not have to disclose his status to a patient.

MR. DALTON: Thank you.

David, it has been a while since you spoke, but your description of the congressional hearings and the press' behavior reminded probably lots of us of the story that Belinda Mason told us about, sharing a platform with Elizabeth Taylor. I believe it was a press conference promoting the Americans With Disabilities Act, and Liz, as Belinda referred to her, decided to leave while Belinda was talking, and, of course, the press went with her, and Belinda's reaction was much more muted than yours today.

Anyway, I just wanted to say that I think we all sort of heard you and thought --

DR. ROGERS: Harlon, could I make one correction?

MR. DALTON: Yes.

DR. ROGERS: Belinda's reaction was not muted.

MR. DALTON: No, it is just the opposite of what I said.

DR. ROGERS: It was very clear what her reaction was.

MR. DALTON: It was clear and rather --

[Laughter.]

DR. ROGERS: Thank you, David.

MR. DALTON: I don't want to talk you out of what you are sort of feeling today. In fact, for your sake, I sort of wish you hadn't come, given what you are currently feeling. You should have gone to the national zoo or something, you know. But you are the kind of person who hangs on in there and fights a good fight, even when you're not convinced that we are getting anywhere.

But I guess I want to tell you that I flipped to the channel the day of those hearings and the next day. I didn't really want to see any of it, but I compulsively went from channel to channel, to see what the press coverage was, and I got a chance to see Barbara Fessbinder, and I got to see Sonia Singleton, who is one of my favorite people, and I got to see you, and it was really important to see you all, especially on that day that all the hoopla and all the build-up, and it is wonderful to see you today, but it was much, much more important that you were there, even though you had to suffer the indignity of it that you described.

Again, I don't want to quarrel with you about what you are feeling, but I want to feed back to you that your being there was felt and it actually registered with what I thought was a significant amount of air time, not that I saw your face, but they had enough so that I could actually hear the argument that you laid out which, of course, was right on the money, so I just wanted to thank you.

MR. BARR: Thank you.

CHAIRPERSON OSBORN: David?

MR. GOLDMAN: Dr. Winn, has your organization taken a position on the issue of the licensure or disciplinary action against physicians who refuse to care for HIV infected persons? I know, for example, in my state, the State of New Jersey has enacted a principle that if a physician refuses to care for HIV infected persons, that can terminate their license to practice, and I think that is commendable. My question is, has your organization, in conjunction with this kind of policy to counter some of the discrimination which all of us have observed and experienced, taken a likewise position on that issue and that question?

The second question is, has your organization taken any position on the question of whether or not a physician's alcoholism, drug abuse or other kinds of medical problems, what to be reported to their local state board?

DR. WINN: Yes, the answer to your last question is in the affirmative, in the fact that all the boards in the federation do have a policy that encourages boards to develop processes dealing with impaired physicians, and if in the event that program is in effective, they are to take action against that physician to remove him from practice, so that the public can be protected. The public safety has to be utmost in the minds of the medical boards.

The answer to the first question is that the federation has no formal policy on whether or not it would be considered unprofessional conduct by a physician to fail to render care to any specific individual. Each case would have to be discussed and decided on by the individual medical board on an individual basis.

CHAIRPERSON OSBORN: Eunice?

DR. DIAZ: I have a question for Dr. Hagan. You have trained literally dozen or hundreds of family physicians in this country in your former role as director of residency training programs. Don, if you were to talk today to the hundreds of students and residents you have had under your tutelage, what would you say about, in this day and age, getting involved politically, as you have, and as a physician in HIV causes to the extent that you have participated here and in many forums throughout this country, what are some of the barriers and difficulties that you have experienced which you would like to leave as a legacy to those who come after you?

DR. HAGAN: My tendency in my heart is sometimes to fold my tent and go enjoy what remaining days I have. I have remained on the clinical faculty at USC and I have gone one half day a month to teach in the family practice program that I helped create, and it has been very rewarding.

But I advised them upon my retirement as to why and that it was their decision as to whether I continued, and they said, well, you know, in a teaching supervisory role, you don't put anyone at risk, and it has been a very educational process, because most of the residents didn't know. And they would say what was your practice like, and I said I don't practice, I have AIDS, and it was like, you know, in the conference room, it has been a very educational process. Many people are in a state of shock almost that one of their preceptors today is here with AIDS.

What would I recommend to those people? You know, what I recommend every day I have an opportunity to speak to people, look at me as a whole person, as a human being, be compassionate and try to make your decisions based on science and not on prejudice, and I think I will continue to pass that message on as long as I can.

DR. DIAZ: Thank you.

MS. FELDBLUM: I just want to add one thing, to follow on, really, on Don Goldman's question to Jim Winn before. The question really isn't whether the licensing boards have policies about impaired physicians, that is, physicians who really have a significant drug addiction or alcoholism problem, because, clearly, there are those individuals who pose a significant risk, there should be policies for making sure those individuals don't practice, including perhaps even this sort of "big brother/big sister" provision in this, that other people who know about this fact should report to the board.

The real question is does the licensing board have policies about other risks that are more comparable to the risk of HIV infection that is not real drug and alcohol impairment, but a whole range of other physical or mental characteristics about the physician, plus just competence factors about the physician, wound infection rate, et cetera.

When you say it, and I take it completely on good faith, that, as you said, we acknowledge that there is no real risk, but we felt that to obviate the need to do something, and this is the balanced approach, as you said, I think, the necessary and balanced response that you came up with.

It seems, though, that -- and this was really, I think, Don Goldman's first question -- when you did that, the question is whether there was analysis also of the attendant costs to establishing this type of policy, not only in terms of the necessary ramifications to also requiring all other things about physicians to be reported, but also in terms of the costs with regard to treatment of patients.

The fact is, we have heard it before, in terms of anecdotal evidence, it is also a fact in terms of the legal concern, as to whether this whole approach won't, in fact, make it much more difficult for patients who are HIV infected not only to get care, as a practical matter, but, in fact, to also be able to demand non-discrimination in care when they seek such treatment.

CHAIRPERSON OSBORN: I think let's take a break and then we will be able to enjoy the participation of all of the people who we have spoken with, and come back in 15 minutes.

[Recess.]

DR. ROGERS: I think we will go ahead and proceed, if we may.

First, as simply a personal comment that I had better share, with the rest of the Commission's view, this has been an absolutely riveting day, with compelling kinds of testimony. I couldn't help but think what a privilege it is to listen to such quality and such intensity of feeling, and I for one learned a lot, and we are grateful to all of you and I hope you will help us through the final mile here.

First, as an item of business, because we operate under a sunshine law, Jeff informs me that I should invite, at 5:15, public comment from anyone who feels they haven't been heard on this issue. If you wish to make a statement and have not been on the program, would you please sign up outside. There will be a listing out there on the table. You would have 3 minutes to make your point, and we are going to try and close promptly at 5:30.

Failing that, if there are none who feel they have not been heard from, we will continue this to 5:30, otherwise we will break promptly at 5:15.

To just remind you of the issue we have been addressing, how can we reduce the transmission of HIV infection in the health care setting, there has been enormous and helpful input today. I did think many of us around this table shared at least part of Dave Barr's view, which is we have spent hundreds and hundreds of hours on this issue, while the epidemic rages around us and that, as a Nation, we should be sad and we should be kind of ashamed, and how in heaven's name can we do something constructive here and then put it aside and get back to the real business at hand, and I think that is the real view of the entire Commission.

We would like to do something constructive here, we would like to set it aside and then we would like to get back to what the real issues are, in terms of where the epidemic is going and who is getting hurt.

In terms of what the Commission could do, you have made a number of suggestions, and I had simply noted those that I heard. We could put out, if you will, a set of principles by which those who are charged with putting together guidelines could operate. We could ask for more data. We could do both. None of these are mutually exclusive. And we could suggest, until the data is in, that CDC declare a moratorium that we permit a period of more sober reflection, with the hope that things would shake out.

But I don't think we could do that, without some very vigorous indication that our concerns about the protection of the public, the safety of patients, that we would certainly have to come out with something very crisp and very clear there, so that the public didn't continue to feel totally frustrated about it.

In that list, obviously, we would clearly come out with what you have all agreed on is central, which is infection control precautions, and could add to that the kinds of education necessary for both health professionals and the public and patients, and some tough set of teeth to try and enforce the kinds of infection control procedures we need.

I think, also, now we could build into it a swift improvement in, as you say, Julie, exposure-prone techniques, in terms of eliminating the kinds of things that are identified as causing hazards now, to use that alternative of yours, Ms. Feldblum, and then I think we should add to that in some way how do we address, even if inappropriate, this very real public terror, public fear that Dr. Gerbert spoke to us about.

So, please help us. What would be most effective from this Commission, and I would ask both Commissioners and others to participate? Is there something we should be doing right now that would help deal with this? You can make both short-range and long-range suggestions here.

David?

MR. BARR: I have two points. The first is I think that the CDC could do a better job at getting a message out as to what the real degree of risk is, what infection control procedures are, what kinds of questions people should be asking of their doctors, if they have doctors that they can have doctors of.

Since the hysteria developed after the Bergalis case broke, I haven't really gotten a sense that the CDC has done what it should do to quell the hysteria. I think that they have added to the hysteria in their handling of the cases, and they should really be engaged in a much more aggressive public media campaign, to let people know that the degree of risk is very, very small, that these are the things that your doctor should be doing to protect you, these are the things you can do to make sure that you are protected. That kind of information can be put out there more and it should come from the CDC.

The second point really just comes from -- Barbara and I were talking during the break, and I thought what you were saying before about the level of fear is very interesting, and I think it is absolutely true that the public's fear on this issue is astounding. I wonder how much of it is actually related to a real fear of AIDS in the health care setting.

I think that AIDS is very difficult. AIDS raises so many issues for people, issues that people are afraid of, issues that we have very little mechanism to talk about, you know, sex, death, disease, different notions of family, the sense that there are all different kinds of people who live, you know, together here, and dealing with AIDS requires that we acknowledge all of those things.

I think the general public, whoever the general public is, has defined AIDS as the disease of the "other," it's the gay people, it's the IV drug user, it's the people of color, it's people who are the "other," and the first wave of reaction was to "keep those people away from me, I don't want to see them, I don't want to know about them, lock them up, put them on an island," you know, and we were able to sort of get through some of that, but not really develop discussion about the fact that there really is no "other," everybody is at risk, so maybe we were able to get across a message that the "other" can really hurt you on the street, in the workplace, in the restaurant, but not --

DR. ROGERS: David, don't give too long a speech.

MR. BARR: All right.

DR. ROGERS: Give me something concrete, it is where do we go from here, and we have only half an hour in which to deal with it.

MR. BARR: All right, I will cut it short. I think what we need to be able to do is get past the issue of this fear within the health care setting, because it is really a fear of AIDS and what AIDS represents.

DR. ROGERS: That is what we are here to do.

MR. BARR: Well, how we do that is we have to be able to talk more about it and we have to be able to talk more about it in every setting, not just in the health care setting, but in the workplace, in the home, in the church and in the social club, everywhere we go.

DR. ROGERS: Charlie Konigsberg, and then Mike.

DR. KONIGSBERG: First of all, Dr. Rogers and Dr. Osborn, I would really like to compliment you and the staff for setting up what I think has been a very excellent session today. It was really excellent, from start to finish.

DR. ROGERS: The bouquets all go to the staff.

DR. KONIGSBERG: That's fine. It really was an excellent session.

Now that I am a state health official again --

DR. ROGERS: They come and go.

DR. KONIGSBERG: I am a glutton for punishment.]

One of the things that is on my desk, was literally on my desk the first day, was questions about a proposed piece of legislation relating to this issue, apparently watered down from some previous proposals, and it strikes me that what we need, not only from this Commission, but I think this Commission ought to say something and say something rather crisply, and there are other groups that need to, is a set of guiding principles.

Several of the people who talked to us today--

DR. ROGERS: Guiding principles.

DR. KONIGSBERG: They are there. We have heard them, and I think it would be relatively easy to put that down.

In a former life, I spent a lot of time at CDC, in fact, some sessions when I think Dr. Gerberding was there, in a small group setting trying to come up with guidelines. One of the things I have noticed about the Federal agency, and the CDC, in particular, is that the whole process has become much more politicized.

So, I think it is incumbent on a Commission like this, because we are an independent commission, to kind of go beyond the politics of it, and I think what is needed is a broader set of principles than what we are getting from the CDC, something that takes into account the costs, to use the word that others have used. There are various ramifications. The potential loss of health care workers is really serious. I think that is something that needs to be said, but I think that we can rise above the whole political process by doing this, but I think the Commission needs to do it.

You said crisply, I agree, it needs to be done quickly, very quickly, because the state legislatures will be meeting, probably most of the, starting in January, and those of us, people like Dr. Osterholm and I, will be faced with these issues immediately, so that would be my recommendation.

DR. ROGERS: So, a set of guidelines, crisp, swift and short, probably.

DR. KONIGSBERG: And scientifically suitable, where possible.

DR. ROGERS: Mike, then Julie, and then Eunice.

DR. OSTERHOLM: Also, I would like to thank you for the opportunity to be here. This was a learning experience for me.

Two recommendations or suggestions: The first one I think is one related to research issues related to risk and fear. You know, we in this country, just because we don't understand human sexuality very well yet, we don't really understand the concept of risk and fear in populations, and no one is really doing a lot of research.

You saw some of the kind of research here today that is very important. I only say that, because we have done a lot of education. The Surgeon General's report mailed to every household was a unique experience in this country, and yet what did we really get back from that? I can tell you right now, we haven't talked -- we said today that there isn't a problem in school food handlers. We are just moments away from a problem there. When we get our first transmission in the school or potentially related to a school, I can tell you, the school children issue will blow up again. We don't really have the issue of fear under control.

The second one, and just a brief comment in response to your summation of my report this morning, is I am not trying to promote dealing with this issue more. I would like to get us away from it. So, when I talk about dealing with future issues, of future outbreaks, we need a preemptive strike. We need to be telling the public now it could happen again, so that all that we have discussed isn't for naught, because we are discounted, because if the second one or a third one happens, we have been basically found not to have been credible. By telling them now, I think we can do a lot to ameliorate any problems in the future.

DR. ROGERS: Thank you.

Julie?

DR. GERBERDING: I have one comment and one suggestion. The comment is that I really agree with what was said earlier, that many Americans believe they are at no risk of HIV infection and the only risk they perceive is the risk they would encounter from their dentist or their health care providers, and I think that is one of the issues that contributes to the public's perception of risk in the situation.

Having said that, and without any data whatsoever to support it, just some observations --

DR. ROGERS: That is unheard of for you. Usually you have data.

DR. GERBERDING: I wanted to clarify that. I actually am becoming increasingly suspicious that this public hysteria is not nearly as dramatic as we are making it out to be. I do not think people are laying awake in their beds at night worrying about whether their provider is HIV infected. I believe that when people encounter their clinicians, that they actually are quite capable of integrating that concern in the context of their health care.

Yes, if you call them up and ask them would you like your doctor to be tested, they may say yes. If you called them up and asked them would you like to know if your son's junior high teacher is gay, they would probably say yes to that question, too. But I really think that this perception of hysteria has been used by politicians to further political agendas that have very little to do with protecting the public health.

So, my recommendation I think would be that, first of all, we concentrate our efforts on establishing risk reduction interventions that are truly likely to have an impact, not just on HIV, but in nosocomial infections, as well.

More importantly, I think right now we work to help the CDC develop a broad definition of equivalency, so that it will be an inclusive definition and one that has credibility in both the public and scientific communities. And those states that have already introduced legislation I hope will be encouraged to share the template legislation with other states, but I think the equivalency issue is going to be a real big deal.

DR. ROGERS: Thank you. That is as fascinating point, and I would simply point out that some of the data that Dr. Gerbert put up, those dissociations suggested, in part, the hysteria is coming down, even though some of those questions are answered in the way you suggested.

Eunice?

DR. DIAZ: I would like to see this Commission look at recommending that there be a priority on the use of Federal dollars for physician or other health manpower training, to really focus on being able to establish trust between patient and client in this epidemic that was so key to some of the things that many of you speakers talked about. Also, that there be a very strong component of education around HIV, and that education be appropriately updated as that physician comes up or health care person or nurse or other health care provider comes up for relicensing, that some mechanism for updating this individual on credible information that is at hand be incorporated, particularly those that are trained with Federal sponsorship.

I would also like to see a recommendation or a suggestion that the campaign for being able to reassure the public of what we know, as was described this morning by Dr. Roper, include more than the CDC, individuals from a broader perspective being able to work along with the mass media with multi-million-dollar campaigns that are going to be designed for communicating to the American public about this epidemic. I really think that is a public trust that we cannot violate, and we really should be able to have multiple areas of input into a public campaign that is directed at reassuring our people about this epidemic.

DR. ROGERS: Others? Don?

DR. DES JARLAIS: I think that this problem really does present an opportunity for a lot more behavioral research to address and, hopefully, allay the public anxiety over AIDS, because I personally feel that this issue is just something that that anxiety has focused on for the moment, and when this issue goes away, that anxiety is going to focus on something else, and we need to address the fundamental problem of that public anxiety about AIDS.

Also, I think having discussed this topic with Europeans, who feel that the U.S. is crazy to be spending any attention to it at all --

DR. ROGERS: You're right.

DR. DES JARLAIS: It is very hard for the public to maintain hysteria for an extended period of time on any one issue, so I think there the solution, then, is to stall for time, and I think, in due respect to some of the Commissioners and some of the witnesses, that there you call in the lawyers and you threaten to sue over definition of what is equivalent or what is not equivalent, over somebody's occupational rights being infringed upon by a new state law. You tell the state legislators, if you pass this law, expect to be sued, it is going to be tied up in the courts for a long time, you won't be able to get anything done fast. The one thing the American legal system is very good at is tying up issues almost indefinitely, and that with a couple good suits, we could probably follow this issue out for years.

DR. ROGERS: That's a one-word message, stall. Well, we have a lawyer to rebut this.

[Laughter.]

Ms. Feldblum?

MS. FELDBLUM: Well, I agree that that is often the case in the legal system, and I agree that there probably will be any number of cases brought here, certainly in terms of equivalency, et cetera. It is actually, though, a somewhat complicated arena here, in terms of various ramifications of bringing different suits.

I have spent my time in my career sometimes advising not to bring a particular case, if I am concerned about ramifications of that case, and this is actually one of those arenas where it is quite complicated.

However, I do believe, in general, sort of not moving quickly to establishing policy, which is really what has occurred already, would have, in fact, been the best approach, and to the extent one can move back towards that in the context of a moratorium, I think that is useful.

What I was going to say, though, in terms of the principles, as you did say there were any number of principles that various of us put out today, but I think it is useful to have as the overarching guiding principle that you are interested in saving the lives of as many people in the health care system consistent with balancing of various social goals.

That is, I think it was Dr. Kelen, I am not sure, but one of the individuals who brought up the report of the number of deaths that occur in, and I guess it was in the New York State system, that really could have been avoided. And I think if the issue is getting the trust of the public, that you do care about what happens to the public, I think one should articulate the goal, because I certainly feel that is the goal of trying to protect the public, trying to have a situation so we don't have someone like Barbara having become HIV infected, because there were not policies in place at the time.

There are people still dying out there, not of HIV, but of all these other infections, and, in a way, maybe it is necessary to scare the public a little bit more about those other concerns, and then say, even if that is our concern, here is the approach we are suggesting, which is, in fact, a much better monitoring of infection control that has happened, a much better monitoring of the recontact injury rates that has happened so far, because it is all based on sort of the honor system, and putting the money into the research in different ways of doing techniques, so that it will be less risky for a whole range of infections, thereby saving lives, getting back to the overarching principle I think you should focus on.

DR. ROGERS: Thank you.

Harlon?

MR. DALTON: I think that Julie is right, that equivalency is going to be a big deal, and I am not sure that I learned a lot about how the CDC plans to go about deciding what systems are equivalent to the CDC guidelines. If anything, it seems to me the message from Dr. Roper is that that decision will essentially be one that is political, in the sense that it will be the result of a lot of back and forth and give and take, and it seems to me the Commission should weigh in in that give and take.

With that, I want to ask, while we have them here, Mark and Chai and David, and the names of anybody else, how we go about defining equivalency in a way that would put a floor under what is equivalent, but allow for states to improve upon -- obviously, this depends on what you regard as improve upon -- the CDC guidelines.

My concern is that we if we simply treat the states as a wonderful marketplace and we want to have kind of an open, free, liberal definition of equivalency, that means that the State of Louisiana can decide that locking HIV positive physicians up is more or less equivalent to the CDC guidelines, and it seems to me that is probably not a good thing. Anyway, that's the question.

DR. ROGERS: Could I simply comment? I think both from Chai and from Mark, we had some helpful suggestions there, which, in essence, said the CDC definition lacks this quality of individual assessment, which I thought you described very effectively, and, Mark, you really made some points on this same thing, that CDC both under and over-defines. Was that your term?

MR. BARNES: Under-inclusive and over-inclusive.

DR. ROGERS: Under-inclusive and over-inclusive.

MR. BARNES: Right.

DR. ROGERS: I am thinking aloud a bit here, but it seems to me if we, in essence, said we want to improve on the CDC's definition, to better protect the public, I am thinking a bit of strategy here, rather than saying you guys are just off on the wrong foot, we might get a little farther with it.

Other comments? Mark? Excuse me, I can't see you in that blinding light.

MR. BARNES: One way of encouraging the CDC to have an acceptable definition of equivalent and one that would be a floor, instead of a ceiling, so that it would prevent the worst excesses, for example, of a wholesale mandatory screening system and exclusion, would be, it seems to me, to define equivalency, first of all, as a policy that would have the same or better effect as the CDC guidelines in reducing transmission both to patients and to workers within the broad parameters of improving infection control, encouraging voluntary testing among health care workers for their own individual clinical management, and I think there are a number of things that could be agreed upon as sort of guiding principles.

The second thing, though, I would say is the Commission, through issuing a set of principles to guide decision-making this area, those principles themselves could be used to define equivalency. In other words, it would be possible to define equivalency in terms of the benefits, but also in terms of avoiding the costs, so that the CDC should be able to say, yes, assuming that Louisiana or another state actually adopted a mandatory testing and exclusion system, the CDC should be able to say, well, your system may well prevent a large number of infections, but at the same time you are incurring a huge deficit in the delivery of health care in terms of delayed, deferred, denied or sub-optimal care to other patients, and, therefore, your guidelines do not meet the overarching goal of improving patient safety and improving health care delivery. I think that is the way that we could encourage, that the Commission could encourage the CDC to define equivalency, and that would have a salutary effect on public health.

DR. ROGERS: That is a very constructive comment. Other comments? June?

CHAIRPERSON OSBORN: I wanted to ask Julie a question, and perhaps you, too, Dr. Kelen. From yesterday's discussion at CDC, one of the point that hasn't come up much today, but that focused the early part of the discussion, was the assumption now made by CDC, sort of a revision of the model as to how one measures risk, that hepatitis B was an appropriate tracer at a level that allowed you to make policy, and as the discussion went on yesterday, a number of people brought that into question.

As a once upon a time virologist, I will summarize what I heard them say as both the increased hardiness of the virus, the much greater concentration in the hepatitis B antigen positive people of the infectious unit than was equivalently so in HIV and so forth, that there were, in fact, a number of biologic features that made it a misleadingly worrisome model.

Since this is exactly your area of work, I thought it would be helpful to get your input and that of others who listened to that discussion yesterday, because it is part of the debate that is going to be happening now at CDC, as to whether or not -- it is quite different from what was presented in February, because there was a theoretical abstract model that dealt with HIV and didn't go at hard data

Yesterday, the meeting started off with the presentation of data that had to do with hepatitis B, and, in fact, part of the conclusion made was that, whereas, dentists in their dental offices, by starting to use gloves and infection control procedures since 1987, had eliminated hepatitis B transmission, and that had not occurred in the surgical setting in the same dramatic extent. Therefore, here we have universal precautions and they don't seem to be working, and so forth.

Now, I know your work relates directly to that, and I think it might be helpful to broaden that discussion a little bit more than it was yesterday, because I was concerned that it got left a bit.

DR. GERBERDING: You know, the hepatitis B model was a useful starting point, when you knew nothing about HIV, to consider risk and risk assessment in the hospital situation. But after really looking at the hepatitis B experience and what we know about transmission of these viruses, in my view, the only comparability is that both HIV and hepatitis B are blood-borne infections, and that is really where the analogy ends.

Hepatitis is extremely transmissible. In our own hospital, the chance of health care workers acquiring hepatitis on the job is about 68 times greater than the risk of acquiring HIV. The levels of irenia are drastically different, and the fact is that using appropriate infection control interventions has resulted or at least been temporally associated with an absence of nosocomial hepatitis transmission.

We know HIV is less transmissible, it is one or two logs less transmissible than comparable needle-stick accidents, and if you then look at E antigen positive hepatitis versus non antigen positive hepatitis and then think about asymptomatic HIV infection versus symptomatic HIV infection, I think you would be looking at health are worker to patient transmission moving even further down the risk ladder, because most of the people practicing medicine with HIV are asymptomatic and much less viremic than the source patients that have been the cause of health care worker infections.

So, I don't find the hepatitis model useful at all in identifying exposure-prone procedures or techniques. I think that it is useful to start from that point and then scrutinize more carefully, knowing what we know about the biology of HIV, but I am afraid that whole approach has gotten us down a pathway that has resulted in this concept of exposure-prone procedures, without really looking very carefully at the two difference between the viruses.

I find the CDC's modeled risk of HIV and hepatitis embarrassing. Again, it was a good starting point, but it has been translated into fact. In fact, no model is any better than the underlying assumptions, and the assumptions that went into that model were very questionable in several places, so I think we should abandon that approach.

CHAIRPERSON OSBORN: Thank you. That was the way I was listening to it, although I am nowhere near so close to the issue as you. But I was disturbed to discover that we were being presented with data on the grounds that then we weren't dealing with theory, but the data dealt with hepatitis B, which I, too, think is a useful starting point, because it is a super-sensitive indicator of trouble, but it is so super-sensitive that I am afraid it has gotten us part-way down the wrong road. It is useful in one sense, but as soon as data start being talked about as if they pertained equally, it becomes troublesome, and I think that is an important point.

DR. GERBERDING: I would like to add one brief comment, to follow that up. There has only been one study of hepatitis transmission to patients that was a controlled study, where they compared risk of hepatitis in patients of an infected dentist to risk of hepatitis in patients of an uninfected dentist, and, actually, there were more patients who acquired hepatitis B from the uninfected dentist, demonstrating that unless you controlled investigation, that you have lots of problems with interpreting even the data we use to suggest nosocomial transmission.

DR. ROGERS: Dr. Kelen, did you want to add to that? And then Don Goldman and Harlon.

DR. KELEN: As I mentioned this morning, the hepatitis B model might have been a useful place to start, and I guess it was inevitable, but perhaps it is unfortunate. The evidence actually goes against the hepatitis B model as being synonymous with the HIV model.

As I mentioned, surgeons at least earlier were sticking themselves fairly frequently 28 percent in one study, but in other studies I found similar values, show that because of this, they had been exposing themselves to hepatitis B from patients. Most of those injuries, as I think even Dr. Gerberding's studies have shown, are from solid needle sticks, those are the predominance of the injuries.

Now, there have not been any solid needle-stick transmissions of HIV, to the best of my knowledge, at least documented ones, in any given direction. The ones that have been needle transmitted have all been from hollow needles. So, whatever it is, HIV, however similar it is, it is dissimilar enough or that it is in several leagues magnitude less, that it really isn't that useful to look at, and many of the areas of transmission have been outliers.

Ms. Fassbinder's form of transmission is really an outlier form of transmission. You wouldn't have normally predicted it, based on what we do know about transmission.

I just want to echo something, because this hasn't come up yet, something that Julie mentioned, this model of the CDC. I guess they are obliged to try, but this is where we are frustrated with what the CDC has done. They have come up with this model, and rather than just kind of swallowing it up, they publicized it, and the press picks up not on the range of 3 to 128, the press reports that the CDC has estimated that there are 128 people running around the country infected by the doctors and dentists.

I think a fair amount of the blame of this hysteria is not the public, it is not even necessarily the legislators, it is not the various people who have certain prejudices. I am sorry, but I blame the press, to a fair extent, for fueling this and making an issue out of it, so they could sell their papers or have various people on their shows, when they are hurting us. I mean they are hurting the public, by publicizing these numbers, without the careful consideration and explanation.

Okay. So, the New York Times has the appropriate staff, the Washington Post and some of the big news agencies do, but the smaller agencies don't, and they are just interested in looking at the divisive issues and sticking microphones up in front of people's faces.

The one message that I would like us to do, if we can, is to learn how to manipulate the press, so that they don't go running amuck like this. I am going to say this somewhat tongue in cheek, but not fully. I agree with the campaign strategy. I think we need to get out and reach the public on these types of issues, and I would suggest that we hire the folks who ran George Bush's campaign, particularly the ones who thought up the Willy Horton, and maybe they can atone by doing it for a right issue, but they can help us get the message out in the right way. Again, I say that somewhat facetiously --

DR. ROGERS: Any more of these extremely practical suggestions?

[Laughter.]

Thank you. Don, and then Harlon and then Mike and then Barbara.

MR. GOLDMAN: I think, notwithstanding the diminishment and the concern in the statement about the low risk of transmission, I get the sense that there is some agreement that if there should be an individualized determination that, based upon either the history of a given practitioner's own techniques, or given something inherent in the particular techniques involved in a particular surgical or practice setting, that that technique or the history of that practitioner's use of a technique indicates some risk of blood-to-blood transmission or exchange, then that setting, based upon what we do know about both legal principles, informed consent principles, medical ethical principles or whatever, do in fact require either the physician refrain from those practices or inform the patient of the risks of those procedures which may be a real live equivalent.

I just want to know whether anybody disagrees or if there is either agreement or disagreement with that, or if there is no understanding of that.

DR. ROGERS: Don, do you have a comment?

DR. DES JARLAIS: From an epidemiologic viewpoint, the data is so flimsy that you can't make a reasonable scientific judgment at a group level about the degree of risk, and if you can't make a reasonable scientific decision at the group level, you are surely not going to be able to make it at an individual level, where you have got so many more variables and you don't have a lot of big numbers on your side.

So, I think the epidemiology is such right now with the data that we have gotten, and probably with the data that we will have for the next five years, that you simply would not be able to come to any sort of reasonable decision as to whether a particular individual is going to be at risk for transmitting HIV. I mean, we have five patients and we don't understand how that happened. We may get a few more patients over the next few years, and we probably won't understand how they happened, either. So, you would be making those individualized decisions really on the basis of ignorance.

Dr. GERBERDING: I just want to interject that I agree with you from the point of public policy, but on an individual assessment, if the health care worker comes to me and says every time I do a blind vaginal hysterectomy, I stick myself with a needle and bleed into the patient's body cavity, I would advise that health care worker not to do that.

There is information that can be gleaned from individual discussions, when people seek counseling on these issues, that might help him or her make wise decisions about practice changes, and I don't think we should categorically say everything is okay, if a person provides a history that they are at risk for exposures by their own account.

MR. GOLDMAN: Or if a given procedure inherently--

DR. GERBERDING: I have a little more trouble with the given procedure inherently, but if such a procedure was shown scientifically to have an increased risk, then we should act accordingly.

DR. ROGERS: Harlon?

MR. DALTON: I guess I think that in our statement of principles, which there seems to be fair agreement we ought to have, and then certainly in a longer document, we should give a sense of a whole set of collateral consequences that flow from the CDC type guidelines. We have already talked about the possible impact on access to health care.

I think we also ought to tease out the potential impact on relicensing of HIV positive physicians, on malpractice standards, whether one of the consequences of these guidelines or other guidelines will be to expose more people to malpractice lawsuits, on anti-discrimination law which we talked about a little bit, and maybe informed consent law.

But the general point is that I think we need to think about some of the unintended consequences of creating guidelines like those proposed by the CDC or, for that matter proposed by some of the states.

DR. ROGERS: Thank you.

Mike, and then Barbara.

DR. OSTERHOLM: We are talking about different kinds of models when we talk about hepatitis B, and I want to make sure that we are certain on that. The model of application of hepatitis B to HIV is the one of the bloodborne pathogen, how it is transmitted, the sexual aspects of it, the nature of other bodily fluids being involved. That is one term of model.

The second one is the CDC statistical model, where they basically tried to make an attempt to define the number of cases that might be expected, given a certain situation. None of us have I think rejected the first model. I just want to make sure that is real clear, because that has important implications for a lot of other epidemiologic aspects of what we do.

The second model, on the statistics, you can argue with. I think that is one that is open and valid for interpretation.

DR. ROGERS: I don't want to get too far afield from what should this Commission do right now.

DR. OSTERHOLM: Well, that is an important point, because I don't want you to come out and reject the hepatitis B model, because if you do, I think that will be a disservice to the epidemiology of what we have done with HIV, and I am just trying to clarify that point. I think that is a very, very important point.

CHAIRPERSON OSBORN: I think maybe, if I understood Julie correctly, that is what she was saying when she said it was an important useful takeoff point, but that it loses its predictive statistical power, as it gets taken further along, because what you are describing are basic biologic similarities, but they do not describe probabilities. Well, they are just sort of fundamental properties, like --

DR. OSTERHOLM: But I am not sure we can even conclude that. Having worked extensively with both of them, we know that hepatitis B, in terms of irenia, with E antigen positive patients, about 10 to the 6, 10 to the 8 virus particles per ML. We know with HIV, asymptomatic HIV, it is about 2 to the 10 or 2 to the 3. We know hepatitis BE antibody positive is 10 to the 0. So, it does fit. What we have seen fits.

CHAIRPERSON OSBORN: We also have reason to wonder whether cell-associated virus isn't the most important means of transmission, in which case viral particle counts make very little difference, so I think we do -- at least there is a lot of disagreement, some right here, about how far you can go beyond the initial suggestive biologic properties, which I don't at all argue, they are very useful, but I think that -- that is why I wanted to bring this argument out a little bit, because I think when you move from there to a rather linear predictive use of that model, you get into some other biologic difficulties. They are by no means the same or similar viruses in a lot of their physical and biophysical properties, and they are survival properties, so it is a complicated issue.

I don't want to distract this much further with that, David, so I will leave it at that.

DR. ROGERS: Barbara?

DR. GERBERT: I would like to reiterate my main position, which is that I think it would be useful to explore risk perception, and that would be of the general public and of health are workers, and to tease out what it is and what it is composed of and why it got stronger all the time, rather than weaker, and only in that way, only in diagnosing it can we find strategies to reduce it.

I would like to clarify the attitude versus behavior issue for just one second, which is Julie mentioned that people aren't avoiding care. This is the behavior part of it. But we find over and over that attitudes inform policy, and that was the point of my presentation, is these attitudes are having an influence, so I think we do need to give them the attention they deserve.

I think all of us here, access to care is the goal of all of our efforts. In closing, what I would like to suggest is something that maybe is new and that I didn't mentioned earlier, which is getting back to health professionals, specifically, I think physicians and dentists, how can we help them act professionally and act as role models who aren't afraid, who aren't demonstrating the negative attitudes.

I did mention that in a couple of weeks we will have an article in JAMA about unwillingness, and I didn't give any value to that. But what I want to say is that half of the primary care physicians who we studied said that if they had a choice, they would rather not treat people who were HIV infected, and, as I said, I think that they are our role model and we need to have some impact with them. Again, it is not just education. They, too, giving them the numbers of risk perception or risk ratios isn't going to change how they are acting in their roles.

DR. ROGERS: Has anyone got any new compelling point they would like to put before us? If not, I am going to try and summarize where I think we are.

DR. PRIMUS-COTTON: To make sure we don't forget, I heard it mentioned several times and I think I brought it up, the need for educating our legislators, I would like to reemphasize that, some way that the Commission can make certain recommendations that our legislators are exposed and informed of the issues that we are addressing, because they are the governing body and the ones who will make decisions ultimately that will affect not only the patients, but all of us as health care workers.

DR. ROGERS: That you. That is a point that a number of us have discussed. Don, I think that is dear to your heart, also.

Let me see if I can reach closure here at the moment. It seems to me I am hearing, and then with a number of suggestions about what they might be, that the Commission try to put together a series of clear, mature, quiet science-based principles which could serve others who are trying to develop guidelines for how they proceed in this area.

We have had a number of suggestions about what those might include, but here I would say were some of the basic messages in terms of what we would hope to impart with that. These are not the guidelines, but that they might help CDC see ways to go at a broad definition of what was equivalence, that it could help reestablish confidence and trust in health professionals and the fact that they were honest and that they were caring, that it had as a basic goal maximal protection of the public, of the patients, that we put that up there right in front, that we suggest that some guidelines might be -- and this relates to the equivalence again -- might be the same or even better than the CDC guidelines in affecting that protection of patients, and then a series of things which I think are probably a broader -- let me back up.

My hope would be that perhaps we could develop a simple, easily understood, agreed upon set of basic principles that we would suggest should govern the development of guidelines, that we would then enter a department of fuller explanation, which would include a whole series of these things that have been suggested, which would include education of our legislatures, which would include addressing the problems of fear and risk perception, which would include concentrating on risk reduction, interventions and a whole series of things that should be further spelled out.

The staff has done some work and they have done some work during the day, and thanks to instant typewriters and so on, I think the staff is willing to share with the Commissioners tonight at dinner at least a rough shot at what those might be, with no particular pride of authorship, I think -- isn't that a fair statement -- just something to get you going and get your juices flowing, s you could think about them overnight and see if they are anywhere close to what we might try and emerge with.

I neglected to say that there was no one who had felt they had not been heard, so that is why I did not deal with that.

I am enormously grateful to all of you, I know all of us are, I know June is, I know the whole Commission is, for all of you being here. It has been just a wonderful day. It has been a privilege to listen to dialogue of this caliber. I have learned a lot and thank you all very much for being here.

[Whereupon, at 5:20 p.m., the commission was adjourned.]