THE PRESIDENTIAL COMMISSION on the HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

FINAL HEARING
MAY 16, 17, 18, 1988

August 24, 1988

TO OUR READERS:

The Presidential Commission on the HIV Epidemic held over 45 days of hearings and site visits in preparation for our final report to the President submitted on June 27, 1988. On behalf of the Commission, we hope you will find the contents of this document as helpful in your endeavors as we found it valuable in ours. We wish to thank the hundreds of witnesses and special friends of the Commission who helped us successfully complete these hearings. Many people generously devoted their volunteer time in these efforts, particularly in setting up our site visits, and we want to fully acknowledge their work.

The staff of the Presidential Commission worked around the clock, seven days a week to prepare and coordinate the hearings and finally to edit the transcripts, all the while keeping up with our demanding schedule as well as their other work. In that regard, for the Final Hearings, we would like to acknowledge the special work of Peggy Dufour, Shelley Gordon and the entire staff, in putting together the hearing, and Margo Payne and Macy Moy, in editing the transcript so it is readable.

For the really devoted reader, further background information on these hearings is available in the Commission files, as well as the briefing books given to all Commissioners before each hearing. These can be obtained from the National Archives and Records Administration, Washington, D.C. 20408.

One last note--We were only able to print these hearings due to the gracious and tremendous courtesies extended by Secretary Bowen's Executive Office, especially Dolores Klopfer and her staff, Reginald Andrews, Sandra Eubanks and Phyllis Noble.

Sincerely,

Polly L. Gault
Executive Director

Gloria B. Smith
Administrative Officer

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

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PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

The Hearing was held at the
Interstate Commerce Commission Building
Hearing Room B
12th and Constitution Avenue, N.W.
Washington, D.C.

Monday, May 16, 1988

COMMISSION MEMBERS PRESENT:

ADMIRAL JAMES D. WATKINS (RET.), CHAIRMAN

COLLEEN CONWAY-WELCH, Ph.D.

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POLLY L. GAULT, Eecutive Director

COMMISSION MEMBERS NOT PRESENT:

JOHN CREEDON

CARDINAL JOHN O'CONNOR

BENY J. PRIMM

PENNY PULLEN

I-N-D-E-X

P-R-O-C-E-E-D-I-N-G-S

10:04 a.m.

MS. GAULT: Good morning, ladies and gentlemen, distinguished witnesses, members of the President's Commission. My name is Polly Gault. I am the designated federal official here today and in that capacity it is my privilege to declare this meeting open. Mr. Chairman.

CHAIRMAN WATKINS: Good morning.

This morning marks the beginning of the final set of public hearings held by the Presidential Commission on the HIV Epidemic. These hearings will complete a process of public information gathering begun nine months ago during which the Commission has held 41 full days of public hearings, heard over 525 witnesses in formal testimony and when this hearing is complete, we will have heard from nearly 575 witnesses.

In addition, we've conducted site visits in some of the most severely impacted areas of the nation, including San Francisco, New York, Miami, and have met with persons with AIDS and their families who have given us their individual and very moving stories regarding their personal fight against the disease. We've heard from over 200 field experts, consisting of health care workers, local educators, public health officials, and others on the front lines of the epidemic and have also provided testimony and follow-up assistance. We've also had the opportunity to visit medical institutions that developed early expertise in the fight against AIDS, including San Francisco General Hospital, St. Clare's in New York, Jackson Memorial in Miami and we've also met with their dedicated and hard working staffs.

Additionally, we've met and visited community-based organizations, local AIDS foundations, groups providing support and home care, others involved in targeted education programs and still others in drug rehabilitation.

We've also met with members of religious communities across the country who provide counseling and patient care. The Commission has been singularly impressed with the dedication, the loyalty, and the commitment of these community-based organizations, church organizations and the like, who have done so much to carry the burden without a clearly articulated national policy.

Now as far as this week's hearings are concerned, the Commission will cover many issues. In fact, we're using this week to obtain testimony from witnesses unable to appear at earlier hearings and to obtain additional testimony on uncompleted issues.

Laboratory Quality Control and Regulation

Today begins a panel on Laboratory Quality Control and Regulation. Like so many subjects associated with the HIV epidemic, this one came to light as we investigated something else, in this case, HIV diagnostic tests. We learned that many labs have sprung up around the country that are not regulated by the federal government nor, in many cases, are they adequately by any state and local agency. In this setting quality control can be a nightmare and incorrect test results can bring personal tragedy for patients and their loved ones. So we'll begin testimony this morning with Doctor Lawrence Miike, Office of Technology Assessment, followed by Dr. Paul Weisner, Director of Training and Laboratory Program Office, Centers for Disease Control. Commence with Dr. Miike.

DR. MIIKE: Thank you, Mr. Chairman. I've got some prepared testimony that I would like to submit for the record and I would just like to take a few minutes to summarize the points that I've made and to touch on some of the issues that I think you would be interested in this morning's discussion.

CHAIRMAN WATKINS: Pull that mike right up close to you, DR. Miike, so we can all hear in the room.

DR. MIIKE: Is this better?

CHAIRMAN WATKINS: That's better.

DR. MIIKE: Just to give you some general statistics, there are about three and a half billion test performed each year for about $20 billion, averaging a little bit over $5 a test. Hospitals perform about 2.5 billion of these, independent labs about 336 million, and physician office labs, 529 million. Physician office labs are the largest blind sector in the testing area and I think that's primarily because the ease of the kinds of equipment that are being used, although as we'll begin to see, the equipment's fine performance might be something that's still lacking in some of these areas, especially when we get into some of the more complicated tests.

As you know, regulation of medical labs is a primary responsibility of states and aside for when the federal government pays for a service or when a lab engages in Interstate Commerce, states have the primary regulatory authority. And as you probably already know, regulation is quite varied. I think at last count there were about 37 states that regulated independent laboratories in some fashion or another, about 40 states that regulated hospital-based labs in some fashion or another, and there are now 16 states that now regulate physician office labs, five of which have not implemented the regulations yet, so that again is a growing area.

There have been estimates in terms of number of physician office labs, about 40 to 100,000, maybe as high as 150,000, but the Inspector General of the Department of Health and Human Services recently did a study where his estimate is 98,000. I think that's being a little bit too precise, so let's say 100,000. Of these labs about 9,000 are currently regulated by the states.

Under Medicare hospital-based labs did receive payment for services and independent labs are regulated in some fashion or another and we can get into a discussion later on about how well that regulation is. In the Consolidated Budget Reconciliation Act of 1987, Congress mandated that physician office labs that perform more than 5,000 tests a year are to be regulated in the same fashion as independent labs. Physician office labs that do testing for Medicare, anything over 5,000 test a year will be regulated by 1990.

In general, labs are checked for their quality by several standards procedures. One is the kinds of personnel that direct and run the labs and the specifications of the qualifications can go anywhere from specifying who the lab director has to be or what qualifications he or she has down to specifying in more or less varying detail the qualifications of various levels of personnel in the laboratory.

There are also certain procedures that should be followed in the lab. For example, a common procedure is to have a known standard for every ten test specimens so you're making sure that you're always being accurate in terms of the labs. Certain qualifications in terms of the kinds of reagents that are used. There are certain standards along that basis.

I guess the area that has received the most attention lately is what's called proficiency testing. In other words, doing what I would call open-book tests. You know you've got the sample and let's see what you can tell us whether it contains something in there, if it's something like HIV antibodies, or tell us what levels it is in terms of something like cholesterol testing or tells us whether there is an abnormality in there, say in terms of pap smear testing. I think we'll get into a discussion about how adequate proficiency testing is currently being performed now.

There are also inspections performed by agencies and states agencies often left to a volunteer organizations who are performing these things for other purposes than regulation, for example, accreditation of labs as having a certain level of excellence. Also the proficiency testing, much of it has been delegated to volunteer organizations that were performing those prior to the -- the regulatory authorities.

I think one of the issues that we have to discuss in the proficiency area is that volunteer organizations really are in the business of education and when they've been given the added mantle of regulation, then there's a little ambivalence there in terms of how strong one should be using an educational activity in order to regulate and Dr. Weisner will have much more to say about that because CDC also has revived its HIV proficiency testing program and I know they'll be pressures to turn that into a more regulatory stance. What can we do about these things?

HCFI, Health Care Financing Initiation, is currently trying to revise its Medicare regs with the primary focus on personnel standards, so we can get into that discussion a little later. Congress has been holding a series of hearings on, especially because of the publicity given to pap testing, cholesterol testing, et cetera, and I would guess that the main focus of the Congressional hearings have been the quality of lab performance and proficiency testings situation.

Besides the general regulatory apparatus that I've just described, proficiency testing, standards, quality control measures, inspections, bookkeeping requirements, et cetera, there are some other ways of doing these things. If you look in the general clinical testing area, some states regulate by the sophisticateness of the tests. If a lab performs certain kinds of tests, then there's tighter regulation and if they don't, they don't.

There some analogy to that in the HIV antibody testing area. For example, I believe New York state limits the types of labs that can do HIV antibody testing as one way of doing it. More recently, the Food and Drug Administration in anticipation of home testing kits for HIV antibody has issued a devised letter saying these have to be done under professional supervision, effectively ruling out labs from springing up and doing those kinds of testing.

Also in terms of the use of these tests, we can make an analogy both in the HIV antibody testing area and the urine drug testing. Certain state legislatures have gotten involved from a fallacy point of view saying, for example, that HIV antibody testing, for example, in the District of Columbia and California, placing limits on when those tests can be used and in the drug testing area last year seven states passed laws that addressed who could be tested, under what circumstances, and what kinds of testing needed to be done. Six of those seven states more or less limited urine drug testing in the private sector to reasonable cause or probably suspicion and required confirmatory testing because of the issue about the inaccuracy of basically a screening test. Let me just sort of stop there.

CHAIRMAN WATKINS: Thank you, Dr. Miike.

CHAIRMAN WATKINS: Dr. Weisner?

DR. WEISNER: Mr. Chairman, thank you for the chance to present discussions of CDC's role in the improving quality of laboratory testing for HIV. With me is Dr. James Allen from the AIDS Program and the Center for Infectious Disease at CDC.

We've provided the Commission with a description of CDC's programs in promoting and maintaining the quality of laboratory testing for HIV. Our role in this area is not regulatory, but scientific and voluntary.

The topic of HIV testing is a broad one and in anticipation of the Commission's major interests, my remarks this morning will focus on the introduction of the serologic tests for HIV infection into broad use in the United States. I'll also just focus on CDC's role because that's what we were requested to do and this doesn't mean that we ignore at all or don't respect the enormous contributions of other parties in this area. The research scientists, the manufacturers, the regulatory agencies, the public health laboratory directors, and the professional societies of laboratory testing that contribute to the quality of HIV testing. Why is the maintenance of high quality laboratory testing so important?

It's important because it helps meet specific objectives, to protect the nation's blood supply, to define the problem better through improved surveillance, to identify individuals in need of special counseling, and to aid in case detection and in clinical diagnosis. To accomplish these objectives and because of the social significance of the HIV infections, tests must be accurate and interpretations of the tests must be correct.

We at CDC continue to emphasize that an individual should be considered to have serologic evidence of HIV infection only after an enzyme immunoassay test, the EIA screening test, is repetitively reactive and another test, such as the Western blot, where the immunofluorescence assay validates that EIA result. Physicians and other health care workers who HIV tests must have a clear understanding of the appropriate use of the tests and the sequences of those tests.

As for all medical tests, results should always be interpreted for individuals in concert with other clinical, hypodemeological, historical, and laboratory data. As a general statement, the performance characteristics of serologic tests for HIV antibody match or surpass those of many tests that clinicians and public health practitioners use to detect and

prevent other diseases. What do we mean when we say these tests perform well?

When laboratories use licensed or standardized tests and have good quality control and good performance standards, the recommended sequence of tests yields a sensitivity and specificity that exceeds 99 per cent. Sensitivity is the probability that the sequence will yield a positive result when the specimen is being tested are truly positive. In other words, if low sensitivity is actually a situation where you would miss cases, specificity is the probability that the sequence of tests will yield a negative result when negative specimens are being tested. In other words, if you have low specificity, you would end up with false positive tests.

Now in a population with very low prevalence of infections even a specificity of 99.99 per cent cannot obviate the necessity of applying the test interpretation to individuals in a manner that's appropriate for good clinical, medical practice. Repeat testing with a new sample and a complete clinical evaluation should occur in each situation where there is a question.

Now an increasing number of laboratories are needed to serve the diverse objectives of the HIV prevention programs. It is CDC's role in a voluntary and educational fashion to maintain the excellent performance characteristics of these tests as larger numbers of laboratories become involved. We do this by, first, defining and refining and standardizing the test reagents and test procedures. Second, by determining the feasibility of wide application of the new technology that's developed, including quality control, quality assurance, and guidelines for interpretation. Third, we train laboratory personnel. Now our primary concern there is to train state and local public health laboratory personnel and others who will train others to do these tests correctly. And, lastly, we operate a performance evaluation program that allows for timely detection of problems, active feedback to all parties concerned in the steps of defining the tests, training people, and determining the feasibility of broad views.

From 1983 to 1987 CDC played a major role in the introduction of the EIA and the Western blot tests by conducting clinical evaluations and participating in consensus developments for how these tests should be used. We designed and developed some 35 separate courses or workshops, each one incorporating the rapid development of the technology as it was feasible for wide application. We are now packaging those courses and materials for use in the states in a network of training other people who are doing these tests.

A performance evaluation program was piloted in July of 1985 and expanded in 1987. Presently, 1400 laboratories in the United States have enrolled in this program. Now this program is more than a proficiency testing sending these proficiency testing samples, these kind of close-book or partially open-book tests that Dr. Miike spoke about. We actually are collecting information about the laboratories that are performing these tests, we'll be able to conduct special surveys to address specific problems as they arise, and we're operating an on-line bulletin board information exchange program, so when problems arise people who are doing this testing in the United States can identify problems quickly and resolve them, and we are exploring better ways to have an overall evaluation of the performance of laboratory testing. Above and beyond the question of just the accuracy of the test, we are also interested in the appropriate use of the test and interpretation of the test.

Now I won't go into the detail. In the written testimony of the example of our latest facilitation of the introduction of the new technology of the HIV testing, but by that I refer to the dried blood spot tests for neonatal screening programs which is a new tool for measuring the sero-prevalence in child bearing woman. This rapid introduction since the fall of 1987 involved refinement of the research test developed in New York state and the state of Massachusetts, making the test actually feasible for wider application, training personnel in the new application and establishing quality control and a sophisticated performance evaluation program for that new testing.

In closing, I want to highlight the three recommendations in our report. First, laboratory performance evaluation must receive continuous support to adequately monitor and respond to the inevitable technical developments and scientific advances in HIV testing.

Second, the capacity for state and private laboratory programs to coordinate and offer training and consultation to laboratory workers in routine and accepted methods must be increased. Building this capacity will permit improved responsiveness to the growing number of laboratories doing HIV testing and to the turn-over in their staffs and at the same time assuring that the federal laboratory training resources are directed to the appropriate introduction of new cutting-edge technology when it's ready wide application.

Third, consensus development on a interpretive guidelines, evaluation of new HIV testing kits using a common protocol, and the development and dissemination of new models for performance evaluation, those that go beyond the question of test accuracy into the question of the patient outcome, should be supported through respected national associations, such as the

Association of State and Territorial Public Health Laboratory Directors and the private professional organizations.

I'll be happy to answer any questions and I also would ask permission for Dr. James Allen to assist with those questions as they come up. Thank you very much.

CHAIRMAN WATKINS: Dr. Weisner, let me just start out with one, a general question, and I'll turn it over to Dr. Walsh on my left. When we're asked the question, how good is a laboratory performance in the United States on the HIV, are there things falling through the crack in terms of quality control regulation? What's the measure of the impact of quality control in testing on the nation?

In other words, how do we measure it? In what terms? Is it simple to measure? Can you give us a feel for the degree to which you're going to evaluate the performance of the national testing system with your teams and with the recommendations you've made? How do you really measure? To get the feedback you need to say, yes, we're very close to the line so that OTA coming in could say, yes, we agree. We've got a handle on quality control.

Certainly we had trouble at the outset in the military on urine analysis testing. We had trouble tracing some of the samples to make sure that the quality control was maintained in the transmission process. So quality control becomes a very big issue when you begin to come out with positive results that obviously have to be linked to counseling and all the other difficulties associated with the psychological impact of a positive, whether it's a true or whether it's a false to the individual. So give us a feel, either you or Dr. Miike, how you measure this? How do you intend to measure it?

DR. WEISNER: Well, I think we both have opinions to offer in that area and let me see if I can construct a way that we would think about it at CDC. The first comment I would make is distinguishing between what regulation can do and what individual voluntary education programs can do. A certain level of regulation I think is absolutely required to described a floor below which we can not tolerate performance problems in HIV testing or any clinical laboratory testing.

Now the tools that we have available for establishing a regulatory floor are not perfect and they further ones need to be developed, but they are the ones that Dr. Miike outlined and that is, establishing personnel standards, establishing quality control standards within a laboratory, doing inspections, and providing materials from the outside, unknown materials being sent to the laboratory for testing their performance. None of those tools are perfect, but they do establish a floor on

performance that should be required and expected of laboratories doing this kind of testing.

Above and beyond that, I think there's a lot more that can be done in terms of improving the tests and the performance of individuals through a cooperative effort with the state and local health department laboratory system, and that would involve having voluntary participation in proficiency testing programs that give information back to state trainers and other voluntary organizations to respond quickly to problems. It involves actually having an on-line system of communications so if something seems to be going awry in the AID test in one state that information can be raised to all other states very quickly. They can look at their test kits and test procedures and see if there's something that can be changed to improve it. It involves actually developing tools that we don't have yet and one of the advantages of examining this whole laboratory testing area is that we really don't have a tool for evaluating the total laboratory testing process.

Most of the discussion on the laboratory testing area has been focused in the area of what goes on between the four walls of the laboratory, and that is, how a specimen is labeled, analyzed, and the results are recorded. The most important thing that we're all interested in from the public health and from the individual patient's perspective is how is this effecting the epidemic and how is this effecting that individual's health. And so the very first part of that procedure is using the tests correctly, making the correct decisions to use the test, and then the end result is the appropriate application of these tests to individuals so that we aren't exchanging information that says, "Here's your laboratory test and good luck." What we're doing is, here's your laboratory test, here's what they mean, what is the information that's going on with you as a individual, what other additional information do we have to put in place to analyze that laboratory test and then do we have to repeat the test and do we have to follow-up later.

Now ideally we would like to have in this country for all clinical laboratory tests a system that evaluates that whole process. We don't have that. CDC and other people are working on developing such a system.

CHAIRMAN WATKINS: So we really don't know where we stand? I mean we're watching some results and --

DR. WEISNER: Well, I think we know where we stand to a degree, and that is, if we've matched these test performances and how they are used as compared to other medical tests, I think they actually come, they match or surpass many of the other tests that are performed in the practice of public health in the terms of medicine. And they have a very valuable result in terms that

have already been demonstrated with diminishing the danger of the HIV infection to the blood supply and they will as time evolves provide additional information on the trends of the disease through surveillance programs.

CHAIRMAN WATKINS: Do we have model programs that seem out somewhere in the nation on which you could base recommendations for changed regulations that we could already begin to move on this? Is there something that we could have, more labs, that we could get from you that would be more specific? We've heard a lot of this over time and we're still having a hard time coming to grips with this. It still sounds mushy to me that we're kind of in the growing stages and trying to put a number of things together.

DR. MIIKE: Are you looking for an answer for a lab regulation per se or are you looking for HIV regulation? Lab regulation per se. Okay.

Well, one way to do it is to recognize that not all tests are, the tests are not equal, and so my analogy would be, let's treat some tests as over-the-counter drugs and some tests as prescription drugs so that you, some tests you would say, "Okay, within the general, existing regulatory framework, fine, they can go ahead and do that." Dip stick urine test, et cetera. There might be some tests that you would say, "Well, I'm a little bit more worried about that," but we can either have a more stringent regulatory requirements for labs who perform that or we designate what kinds of labs would do those tests.

How do we go about doing that is open to question obviously because, you know, you've heard a lot about how good are proficiency testing standards and whether there are any teeth behind the proficiency standards. I mean how many people actually fail these tests and if they fail them, how many of them loose their license or loose their eligibility for payment, et cetera. Those are issues I think that you can deal with at a most specific level.

But at a general cut I would say just recognize that not all tests are the same and maybe we should have something like a tiered system like some of the states do for the P.O.L., the physician office laboratory area, but at least not treat all tests the same.

CHAIRMAN WATKINS: Well, we certainly want to do the best we can in making recommendations along these lines. It would aggressively go after the best way and there may be different techniques that can be tried and pushed aggressively working with the states. Resources, support, to test a variety of approaches to build the creditability in the system and it seems to me that's the kind of recommendation we need to get our

hands on. You've given us some and I don't know whether that's enough to --

DR. MIIKE: I also agree with Dr. Weisner that we really need better training programs. You know, the equipment is getting very sophisticated and it seems like it's, you put something in and the answer comes out the other end. We know that's really not true, and as we get into more sophisticated testing, especially as it gets decentralized into physician offices, and as these tests get really sold that's something that can be done very simply.

I think that quality control, especially the training aspects, really needs to be emphasized. And that's one area where I think the federal government has really no objection in trying to improve. Budgets are a different question, but I think training and education versus a direct regulation is always a much more acceptable.

DR. WEISNER: Can I comment with a brief follow-up on that?

CHAIRMAN WATKINS: Yes.

DR. WEISNER: I think, I just want to be sure that I get the point across that regulating the laboratory itself won't improve the base performance of the laboratory. But it is clearly in the general clinical laboratory area that there are as many problems in laboratory testing that will not be addressed by pure regulation of the laboratory and that is what tests are ordered, how they are ordered and transported to the laboratory, we can see that in the area of cervical cancer and pap smear testing, but very important is the use of the information that's comes from the laboratory, appropriate interpretation and application to individual patients.

So the only caution I want to present is to the degree that there are problems in the clinical laboratory testing area and HIV specifically, they cannot solely be addressed by increased regulation of the laboratory.

CHAIRMAN WATKINS: Okay. We're looking for the strategy to build a package though.

We heard the information about how it stands and what we want to do is be a participant in putting incentives into the system to move this more aggressively, so we're looking for the very specific. You've mentioned a lot of variables. I can turn those variables around and put them as elements of a strategy to get going on it. You see, that's what I'm looking for. I'll shift you to Dr. Walsh.

DR. WALSH: I think as physicians we all know that the laboratory has never been perfect. I don't care what the test is. I don't care what the regulations are. When we have a patient with an appropriate history or whatever and an appropriate physical examination, if the test doesn't agree with us we routinely get it repeated. We don't let the laboratory make our diagnosis for us.

I don't think that we can ask you for the impossible. You've cited many reasons for variations. I'm a little bit confused at this point in that I seemed to have heard you say that you felt that the HIV testing was as accurate as most tests that we have. I read in Dr. Miike's testimony here that the great insurance policy that everyone relies on, the Western blot, seems to me in your opinion to be not so reliable as we had been lead to believe.

Now as the atmosphere in the country and indeed all over the world is growing for more and more routine testing, and I've just come back from Geneva and believe me it is growing among all nations that there by more and more routine testing, is the current test under average circumstances given the fact that without disturbing confidentiality that if the patient is referred by a physician or goes in for routine testing willingly, this would imply exposure or that he feels that he may have been exposed, is the test reliable enough for us to base diagnostic conclusions in the vast majority of cases on zero positivity?

DR. MIIKE: Can I go first?

DR. WALSH: Sure.

DR. MIIKE: First of all, as a physician, if I got a test result back that said, "Positive, Western blot II," I would draw another sample, send it off either to that lab or another one and repeat the thing.

DR. WALSH: Exactly.

DR. MIIKE: Okay. I mean I wouldn't depend on one test. I would say that HIV testing is a real special case here. Obviously I don't have to tell you that. And I agree that it's one of the most accurate tests run, the sequence, is one of most accurate tests around.

DR. WALSH: It basically is, in other words, it is basically very accurate.

DR. MIIKE: Right. And you've heard testimony from Dr. Jackson from Minnesota Blood Bank and said, "Yeah, no errors in 250,000." Military is maybe somewhere better than one in a 100,000 error.

But, you know, if you're just dealing with it, but those are the best people and I think those are the people we need to worry least about. What my testimony showed and Dr. Weisner differed a bit with that, was that I said what if we just took the average participant in the College of American Pathologist program, and these are people who know they're being tested, okay. We may quibble about what the error rate is. I would say now with the additional information that's available, it's not as high as what I estimated, but the point is not lost is that here are positive samples, here are negative samples. They didn't get them right. Maybe they called them indeterminate or something like that. But they knew they were test samples.

And so what is the truth? Well, really if you looked at my original testimony from October, 1987, even given those statistics if you're testing a fairly high risk group, I would say that the chances of their tests being positive were very good. But my point in those discussions was talking about a test even of this accuracy level and how we had to really worry about false positives when you're testing really low prevalence people.

I give you an example again. A series of tests that's 99.99 per cent accurate means there would be ten errors, let's call these errors false positives, there would be ten in 100,000. If you have a test that has a false positive rate of one in 20,000 which is really, really accurate, you still end up with ten positives and five false and, you know, one out of three is going to be wrong. So that was the point of my testimony.

There is still some problems with the Western blot. One is that labs still have some problems just smearing this thing up. I mean just preparing it. Perhaps with the Western, licensed Western blot, it will be a little easier. But there's still really no agreement on what is a minimum positive as I said in the past and Dr. Weisner can expand on that. There's still negotiations going on about yet another set of standards about what is a positive Western blot. So you really have to deal with the issue about either trying to find methods to improve the Western blot or finding another alternative. The immunofluorescence assay that Dr. Weisner mentioned is not conducive to fairly massed up type --

DR. WALSH: Is it realistic for us to honestly believe that more regulations and more this and more that will be beneficial? I mean, in other words, I gathered, Dr. Weisner, you were saying that you can give laboratories guidelines and that sort of thing. You cannot go out, as testing becomes broadly done, it's going to be impossible to go out and test every laboratory in the United States that's doing testing unless we devote the whole budget to it. Is the test accurate enough so

that you could rely on unregulated laboratories, unregulated under Medicare or HCFI, to return seriously accurate tests?

DR. WEISNER: I think what Dr. Miike is correct. That the test is very accurate, but there is no test that is so accurate that it can be sent to people who can't perform the test well and that the results are delivered to individuals without full clinical interpretation.

I think it's incumbent on the people who are recommending testing to not only examine the question of the quality of the testing within the laboratory, but is that recommendation associated with a context in which it can be interpreted correctly to patients and it's not permissible from the point of view of general public health practice to promote testing without supporting the full context.

Now we have just an expanding number of laboratories involving in our performance evaluation program. In July, 1985, because it was new, we were starting with 50 to 60 state laboratories. By the end of 1986, there were some 500 laboratories in all. Presently, there is 1400 laboratories. We have a contract out trying to identify every laboratory that is doing HIV testing in the country. If I were a clinician or a public health practitioner, one of the very first questions I would ask of the person who's providing my laboratory services is, "Are you participating in CDC's performance evaluation program?" In some sense when the state, local, or federal resources are expended as is the case with CDC's contracts on cooperative agreements, we specify a requirement that occurs.

DR. WALSH: I understand that you're urging physicians through every avenue possible to ask that question because most of them wouldn't know. I think that most physicians don't even know that there are 1500 or whatever it is regulated labs under Medicare. I don't think they know that

I would hope that as part of the education program that you would bring that out to physicians and get the AMA to bring it out through their journal or through their mail or whatever because I think that's terribly important.

DR. WEISNER: I agree with that. And I think consumers should ask their physicians about who is doing the laboratory tests.

DR. WALSH: Sure.

CHAIRMAN WATKINS: Dr. Lilly.

DR. LILLY: I would like to ask a little bit about the training of the personnel involved in these and I'm wondering if

you could describe briefly what the training is for the technicians who perform the tests and perhaps for the laboratory director as well.

DR. WEISNER: Of course, it varies. The training varies with the test procedure that we're dealing with and what their particular role in that test is.

It really does begin, I probably ought to focus in on what's going on presently because they has evolved over time. One of the more difficult problems for laboratory technicians and the laboratory directors now is the choice of a kit. There are what, eight or so, you know, licensed kits for EIA. There is a licensed kit for Western blot and there are a variety of reagents and test procedures used for Western blots. So some of the training now is more focused on how to evaluate the kit, what's being said to you by manufacturers, what is the appropriate sequence of testing kits within your laboratory that should be used for the purpose for which you're using it and obviously the purpose for preventing contamination of the blood supply is different than the purpose establishing sero-prevalence estimates in the general community.

So a lot of our focus now is bringing people in with a series of kits, sitting at the bench and going through step by step. These are the advantages and disadvantages of these kits.

DR. LILLY: Well, let me ask. Elisa tests are not new. I mean the HIV test was not the first Elisa test.

DR. WEISNER: I don't think so.

DR. LILLY: In what way is this one different technically?

DR. WEISNER: In a most general sense, it's not different technically, but the way things are packaged and presented to people is quite a bit different and each individual manufacturer has his own wrinkle on the tests. So you're absolutely correct. As far as Elisa procedures, the need isn't to learn Elisa testing. It is to learn and be proficient in choosing the correct procedures and knowing that that's going to fit into your particular laboratory context.

Now in the Western blot procedure as Dr. Miike has indicated has been a matter of introduction of a fairly sophisticated and complicated procedure, but that's not being done in the 1400 laboratories that I reference. The best estimate that we have of where Western blots are being done in about 200 laboratories of those involved. The training there did involve at the beginning training a specific technician in either developing the strips themselves or in the use of when the

license procedure became available and that was an introduction of new training on actual bench technician and training others to train the bench technician.

DR. MIIKE: I would guess that if you look at the recent statistics that the number of labs doing the Western blots is increasing since the time of the introduction of the DuPont kit. I've seen some ads by DuPont where understandably they want to sell more of it and so they are suggesting that labs do their own Western blot now because you have a licensed Western blot whereas in the past you only had unofficial sources, good sources, beneficial sources, so it was not as easy for the lab to do. Now with the standardized kit you're going to see a lot more labs doing the confirmatory Western blot testing, so I think that's even more reason why you had better train these people correctly.

DR. WEISNER: Well, the statistics actually confirm what we've just said. I mean when we first started the performance evaluation there were in the range of five or ten laboratories that were doing it and now there's in excess of 200.

DR. LILLY: There's no system of certification of laboratory technicians. Is that correct?

DR. MIIKE: There isn't. For general --

DR. LILLY: There's no standardized concept for training of a laboratory technician?

DR. MIIKE: There are certification in the sense of belonging to recognized, reaching a recognized educational standard, a certified medical technologist, et cetera. But often there's no relationship between that and what you are allowed to do and that's a continuing issue among laboratory people in terms of qualifications. Whether an equivalent training or a formal training and what level in the lab you have to have those kinds of requirements. That's an ongoing issue. It's been going on for a long time.

DR. LILLY: But there's no accepted standard for that then?

DR. MIIKE: Except for I guess the laboratory director commonly --

DR. WEISNER: Well, I think the reason we're having difficulty with that question is whether it relates to HIV testing in particular or all clinical labs for instance.

DR. LILLY: I'm limiting my thinking to HIV testing. I was thinking of laboratory

DR. WEISNER: Oh, okay. As a general statement, there are a wide variety of different kind of personnel standards and certification standards in clinical laboratory testing.

Some of that variety emanates from individual state regulatory programs in which there is almost as many different kinds of patterns of personnel standards and state regulations of clinical laboratories as there are states who have regulations.

With regard to the federal rule of regulation, there are two avenues. One is the Health Care Financing Administration regulates laboratories involved with Interstate Commerce and laboratories involved with Medicare and Medicaid reimbursement. Within those two categories, there are different levels of personnel standards and existing regulations. There's an active consideration within the Department at the present time for unifying these standards of interstate laboratories and of Medicare and Medicaid laboratories.

Then there's a whole category of laboratories that Dr. Miike referred to earlier, and that is, the physician's office laboratory and some independent laboratories that aren't subject to any of these federal regulations, but are subject to a varying pattern of state regulations as far as certification or personnel standards are concerned.

DR. LILLY: Okay. Thank you. I don't know whether Dr. Walsh who has just moved to get to another question or not.

CHAIRMAN WATKINS: Ms. Gebbie.

MS. GEBBIE: I want to try and get very specific and ask you to assume that because of the brilliant work of this Commission or somebody, we're certain that the test is only ordered when it's appropriate to be done and we're equally certain that a brilliant person is available to interpret the results to the patient at the other end, so that we're only looking at the laboratory. A properly processed specimen arrives at the door and a result goes out at the other end. Looking only within that framework, and what I hear is a patchwork of attempts to make certain that what goes on within that framework is right. That the test kits are bought properly. That properly trained people handle them and that so on and that all of that goes on. If you two were in charge of the world, what would you recommend to make certain that what goes on in that narrow window of the laboratory is right 100 per cent of the time at any laboratory in the United States?

DR. MIIKE: Well, first of all, we're not going to get 100 per cent accuracy obviously. I would tend to deal more with the process of making sure that labs are performing correctly and then put a little bit more teeth in what happens when they're not performing up to snuff, and where do you draw the line about performing up to snuff is another issue. I mean is an 80 per cent grade a passing score? Is a 70 per cent grade a passing score? Is 95?

I think that you have to have standards in terms of who performs a lab and perhaps who is attached to it. Maybe you can do a regulatory scheme in terms of the sophisticated procedures that a lab performs and the clients it performs it for. For example, large hospital labs and several of the very large labs that participate in Interstate Commerce. I would say I would grant bigness as a plus in terms of being able to perform correctly.

We can argue about the personnel qualifications obviously and that would have to be depends also on the particular type of tests. I think microbiology tests or the pap smears or the serum levels of electrolytes, et cetera. You would have to make those kinds of judgments.

I think that proficiency testing has to be a part of that. I think a blind testing system in which you don't know that you're being tested is too involved to work on a grand scale. I mean it maybe useful for HIV testing performed by the military because they've got close control over a few contract labs, but it's kind of an administrative nightmare when you've going to sneak in samples with the labs regular clients in order to do testing.

But I wouldn't rule out spot checking on that basis. Just like in the urine testing area where random urine testings would be just as good in averting, in deterring behavior as in mandatory testing, perhaps some spot checking on a blind testing basis can be done and perhaps through CDC. You would have to work out the mechanics of that.

Then I think that the other area is that we've to inspect labs a little bit more. People, again every point that I make people will argue over. People will say, "Well, more inspections really don't much," and, well, I'm not just talking about more inspections. I'm talking about the content of the inspections. I think most inspections just go mainly to see if the books are being kept right and so they're really concentrating on the paperwork requirements. I think that one has to deal into an on-site inspection and see, number one, make sure you've got the people who know what they're looking for rather than just some survey team going along there to check the paperwork. And then just sort of delve a little bit, maybe we

need some research into what exactly needs to be done on inspections visits other than what's being done now. So, in other words, education not just in training people, but what the content of inspections are labs should be.

MS. GEBBIE: Dr. Weisner, do you agree with that outline?

DR. WEISNER: Yes and no, a little bit. Let me be sure again. Are you speaking of all clinical laboratory testing or HIV laboratory testing?

MS. GEBBIE: At this point I did not limit it to HIV. I was talking about making sure that anything that called itself a lab did what was right assuming it got the specimens appropriately and was turning them over appropriately to practitioners at the end.

DR. WEISNER: I think as wide acceptance, and I would support that, for a specificational regulations that are appropriate to the kinds of tests that are being done and to the site of the testing being done for whatever that laboratory is running. So I mean I think there should be regulations and they should focus on those items that identify, that actually are most likely to influence the quality of that laboratory testing.

And the ones that we have available to us are the personnel standards, the standards for quality control and quality assurance, the results of inspections, and I'm sure there's improvements to be made in the content and ability of people to do good inspections, and this external quality control that we call proficiency testing. Our feeling is quite strong that it ought to be a balanced approach of those and to invest in only one or the other is missing an opportunity to make improvements.

Now at the same time, those regulations will of necessity eliminate or because of their ability will eliminate laboratories that are performing quite poorly. Those will not bring laboratories up to the optimum 100 per cent that's implied in the question that you asked. I think that the only way to come up close to that level of performance is a substantial program of education, voluntary participation, and feedback between professional societies and government agencies. So I think it's not one or the other. It has to be a combined approach of regulation and education and voluntary participation.

MS. GEBBIE: Okay. Well, I made out from the two of you five things then. For labs to do what you think they need to do, there need to be regulations that describe the level and type of testing they're able to do; that the personnel then match with that level and type of testing; that they participate in

some kind of performance or proficiency testing, perhaps more expanded than it is now; and that they are physically inspected in broader way than they are now. Then over and above that, their personnel participate in more expanded training programs to continually upgrade them.

If I've gotten that right, my next question is who and how that ought to be done? Ought we propose a model state laboratory law, and is there one around you could point us at, and say every state ought to just as fast as it can adopt a law like that? Ought we put out some kind of federal incentive that says, "States better do it or else," or states if they do it get this kind of money available to do it? Is that hopeless? Ought we go with a single federal law on all of them? How would you answer that question?

DR. WEISNER: I'll start. I think the ideal goal would be to have excellent state regulations and training in consultation programs for al clinical laboratory activities. There is not a single model from one state that we can transpose and say, "All states should be exactly like that." There are ways -- we could combine the good qualities of New York State Laboratory program, California's, Wisconsin's and others, in a package that would identify good state regulation of clinical laboratories. But, again, that won't solve the problem only. It has to be combined with an ability to respond to problems that are identified, provide the consultation and the training that's needed to improve the situation.

MS. GEBBIE: Do you agree with that? That there isn't currently an ideal state law, but one could be constructed and that would be the way to go?

DR. MIIKE: Well, whatever state you will pick, there will always be some deficiencies and people will argue that that's not the model.

In one sense, I guess you can combine a number of elements from many of them. One is that you would like states to do more on-site inspections, but everything costs money. So, number one, you would like states to take the initiatives since they have the primary responsibility in lab regulation.

I would like to see more than the, I mean not all states regulate. I mean I gave you those numbers about independent and hospital labs and physician offices. I would like to see at least all states have some kind of regulatory authority in the Board and inspect and regulate some, some minimal types of labs.

I agree that regulation should be more, even though it may become the administrative nightmare, more on the types of

tests performed then where they are performed. I also think that one can, for example, if you're talking about places that test, I would like to at least know who tests, so perhaps one way to do it is I believe Wyoming has a law, it's sort of like Pennsylvania's, where in you have, in the physician lab area where you have a tier system. Minimal types of lab work to very sophisticated types of lab work. I believe the Wyoming law, and if I'm wrong, at least the principle is there, is that certain types of labs have to register. You don't get inspected, but at least you know that they are performing certain types of tests.

So there should, at least a recognition or identification of the labs that perform tests. Some kind of threshold put in by legislation or regulation that say, "Once you exceed this threshold, you're under regulation."

There are means of getting away around these things now too remember. For example, in Maryland I believe full physician offices if they have a lab are regulated, but under that they are not. So you can simply break the group up into two if you don't want to get regulated. So there are always ways of getting around this.

But the point is that I would like to know who is doing testing at what minimal threshold and I would like to see a scheme that kicks in with a sound regulatory authority with teeth once you exceed a certain either volume or sophisticated types of tests that one does.

MS. GEBBIE: Assuming you're going to try to that, do you agree with Dr. Weisner that the way to go is to push for an ideal state level law that maybe you could between the two of you write down the key elements of or would you take a more single national approach? Which would you recommend that we look at assuming we want to pursue this further?

DR. MIIKE: Well, it seems to me that, well you can do it two ways. One is you can draft model state legislation like what happens in a whole lot of areas and sort of like, "This is the level at which states should strive for." Or alternatively one could draft a minimum federal floor at which states would be free to exceed.

MS. GEBBIE: Which would you recommend?

DR. MIIKE: I'm a Congressional agency. I'm going to defer from answering that question. Actually my approach would be I think would be in the broader scheme of doing things, a model state legislation. But there are hearings going on in Congress dealing with some national standards and that's why I hesitate to talk specifically about national things. But I think they are things that can be done at the national level, if not

for all labs, then at least for those in Interstate Commerce and under Medicare which is a substantial number of labs.

MS. GEBBIE: Thank you. I may have another question later.

CHAIRMAN WATKINS: Dr. Lee.

DR. LEE: For the record Dr. Walsh has brought up the fact that there's undoubtedly going to be more testing of various types, routine, anonymous, mandatory, whatever. I would tend to certainly agree with him.

Now Admiral Watkins asked you what would you have to do to monitor this increased testing properly. The quality control. Given both statements, how many FTEs are we talking about for CDC?

DR. WEISNER: Well, I haven't considered that question, so I would have to spend some time. That's a question I did not anticipate, so let me, because we don't really have the program completely spelled out and described out here. I would be happy to respond to that after we actually describe exactly what it is that we're speaking of.

Presently our budget in the area of training and performance evaluation is about $3.5 million and we have approximately, depending on how you describe the people, ten to 15 people working in that area. The President's request for this coming fiscal year is to increase that to $7 million and there isn't a specification of the FTEs in that request.

DR. LEE: Now if you're interested in having a substantive recommendation of this type in our report, you could think it over but we would have to get the answer by the end of the week.

One other question. I believe it is Dr. Miike who created a lot of controversy originally about the low incidents, the number of false positives in low incident populations. Would the current, and CDC I believe disagrees with you on that, given the current state-of-the-art of testing for the HIV antibody, are there types of populations which this panel would not test at this point in time because of the problem that Dr. Miike brought up?

DR. WEISNER: Can I just interject, that I don't think CDC disagrees with the statement which is quite true.

That if you test in prevalence populations with the tests that are available and any that are likely to be available that the proportion of positives that would be false positives

will increase. So we don't disagree with Dr. Miike in that and our MWWR article did not disagree with that.

DR. MIIKE: My analysis of the October, '87, really didn't say who I would stop testing and where I was going to wind, but it gave you examples of how you could use two factors.

One is the predicted value of the test. In other words, when do you start getting worried that the answer that you get back is going to be wrong. And, second of all, what it would cost? A program to cost to test in order to find each positive, truly positive, person.

So my analysis was really sort of like here are some facts, here is a way of analyzing it in terms of money spent for what you're getting in back and the cautionary point about those false positives.

What I also pointed out in that testimony which was not picked up so much was, there's a fairly large mystery of positive. I have no qualms with the EIA, the enzyme immunoassay. I think it's about as accurate as you can get. But the Western blot, I think that showed you that, and I hope that if one looks at that information from CAP and sees over time that you see improvement in the Western blot. You should see improvement in the Western blot because we were looking at the last two years. But as a general proposition I think it's a waste of money to test real low prevalence populations.

There are obviously reasons for testing low prevalence populations when the public policy is made that we've got to test them. For example, the blood banks is a situation. No matter how low the prevalence was in that area, I think that the public would not stand for that not being tested. So that's where you've got to be extra careful in the blood testing and I was glad to hear Dr. Jackson say that they had no mistakes in 250,000. But that comes from a fairly good lab and with very stringent quality control procedures.

The other is the military. I think there is a lot of skepticism about the original reasons why the military did blood testing and their population prevalence is fairly low although not as low as the blood banking situation.

But I think that when you start talking about testing low prevalence populations, to test low prevalence, then you've got to come up with fairly good rationale and I think that often that's a political judgment. I was just trying to infuse some objective criteria that people could use in arguing either side.

DR. LEE: Do you agree, Dr. Weisner?

DR. WEISNER: I agree. But I would add one point and Dr. Allen's got a couple of points to make. One is in any testing circumstance one has to also provide the context for appropriate interpretation. I've said it a couple of times before. It's not only the cost of the actual testing, but it's the cost of providing information in an inappropriate way and the suffering and discomfort that that would cause individuals and that's not a monetary cost that you could fix. So as blood banks appropriately did testing in low prevalence populations for a specific objective, they were also left with the obligation to inform people who had that testing on them done and provide that information in a way that it's understandable and useful for the individuals to prevent, you know, unnecessary grief and discomfort when it should occur related to a false positive test.

So it's not only the costs of the test, but it's the cost on individuals that can result in low prevalence testing. One can meet those obligations by providing the appropriate clinical setting and counseling setting if one wants to invest in that money and that's an additional factor. Dr. Allen may have some points to make.

DR. ALLEN: CDC and other public health authorities have looked carefully at the types of populations that we feel would benefit the most from having antibody testing done and have published these recommendations. In general, they fall into several groups.

One would be a group such as blood donors and I think the reason for that is obvious. A second would be those for whom it is an important part of diagnostic testing because they're ill or because the information is necessary for medical management. And then the third is for public health or prevention purposes where one wants to help a person identify whether or not they have been exposed to the virus so that they can make appropriate lifestyle choices. If they are uninfected, obviously take steps to protect themselves. If they are infected, take steps to protect others and prevent further transmission.

The second point I wanted to make is in terms of the procedure of antibody testing. I agree with Dr. Miike and Dr. Weisner that the licensed enzyme immunoassay tests that we have are as close to being perfect as you're going to get. They are not perfect. I think technically we all agree that this world being what it is we will never have a perfect test. They are really excellent tests. When they are used in a population with a very low frequency of infection, they must be backed up. This has been pointed out by other types of tests, and I think this is where we fall a little bit short.

The test that we have licensed, the Western blot, is really a research tool. It's difficult to perform. It's cumbersome. The Food and Drug Administration has evaluated and licensed only one test kit from only one manufacturer because that manufacturer is the only one that has convinced the Food and Drug Administration that they are able to provide a uniformly quality product for the marketplace. I think it's to the FDA's credit that they have decided to go the licensed route rather than simply allowing marketing under the Device Act. Under the Device Act there would be much less stringent quality control. I think as an example of how difficult it is to produce and market the Western blot, the people from DuPont BioTech who market the licensed test tell me that 15 per cent of every production lot goes into quality control and quality assurance. Now if one is looking at intravenous solutions, for example, we talk about a fraction of one per cent that goes into quality control. With this test 15 per cent of every production lot approximately goes into quality assurance and quality control. That's how difficult it is.

And when we have laboratories that are either using unlicensed tests, tests that are in order words are able to be marketed for research purposes and are clearly labeled for research only and yet they are being used occasionally for diagnostics and we have laboratories that are producing their own test kits without any of the quality assurance that go into the licensed product, I have concern that we will ever be able to move for beyond where we are now. Some laboratories do very well with their own products, others don't. I think we clearly need to set the environment where we move ahead with technical development of other type of test kits that can be used for confirmation. The problem is that we don't yet have anything that most scientists will agree is an absolute standard and define a group of people who are truly infected. We have a long ways to go on this, but I think support in this area would be very beneficial in terms of improving the quality of laboratory testing.

CHAIRMAN WATKINS: Thank you, Dr. Allen. We're going to have to close out this panel now. We have indifference to the schedule of our next witness. We're going to have to move into our next panel. So if we have further questions from the Commission, we would like to be able to ask you those and we'll get them back in writing or verbally from you as quickly as we can for our final report. Thank you very much for coming today.

DR. WEISNER: Thank you for your time and attention.

Federal AIDS Workplace Policy

CHAIRMAN WATKINS: Our next panelist is Ms. Constance Horner, Director of Office of Personnel Management. This is

Federal AIDS Workplace Policy. We have had AIDS in the Workplace hearings. The Commission was impressed by OPM's March, '88, Comprehensive HIV Related Policy Guidelines for all Federal Agencies and we felt it important that she come before the Commission this morning. She is only going to be with us until 11:30 or as long as she can stand to stay with us, so if we have questions for her we may have to get them from her later in writing. Ms. Horner.

MS. HORNER: Thank you, Admiral Watkins. I know we are starting late and I do want to be able to answer all the questions you and other members of the Commission have, so if we aren't able to finish today I would be happy to give you written responses or oral responses on another occasion if you would like.

I appreciate this invitation. I'm going to discuss OPM's Policy and Guidelines on AIDS in the Workplace, the development of those guidelines, and various activities by OPM and federal agencies for dealing with AIDS-related issues in the workplace.

As this Commission is well aware, the AIDS epidemic has raised a multitude of complex, medical, public health, legal, financial, and social issues. These issues have had a direct, and in some cases major impact, on many areas of life not the least of which is the workplace. The strong emotional undercurrents associated with these issues add another difficult dimension to the problem.

OPM's guidance urges an approach that has three parts to it. One is compassion and fairness with respect to affected employees. Another is the need to take seriously the concerns of employees who are afraid to work alongside co-workers with AIDS. And the third is the willingness to address AIDS-related workplace issues openly and constructively thereby enabling federal agencies to avoid disputes, disruption, loss of productivity and needless human suffering. This approach supports the President's deep concern over this issue and the Administration's overall AIDS awareness efforts.

At OPM we have received over the past several years increasing numbers of requests for advice and direction from federal managers and personnel specialists dealing with AIDS-related workplace issues. Although these issues were being handled successfully on a case by case basis, I became convinced last summer that government-wide guidelines would be a more efficient and effective way of communicating with and assisting agencies. Consequently, I directed that government-wide policies be developed which resulted in the guidelines on AIDS in the Workplace issued to all federal agencies in March.

The guidelines were developed with great care and broad consultation. They were drafted and revised in close collaboration with the Office of the AIDS Coordinator of the Public Health Service and the Federal Coordinating Committee on AIDS. Policies of private sector firms were thoroughly reviewed. Directors of Personnel for federal agencies and all the major federal unions were given 60 days to review and comment on the guidelines prior to their publication. Reaction to them to date, both within the federal government and in the private sector, has been highly positive. Many organizations have indicated they plan to use the guidelines as a frame of reference for their own policy development efforts. The basic underpinnings of the guidance are these. We used the Public Health Service assertion that they kind of non-sexual person-to-person contact that generally occurs among workers and clients or consumers in the workplace does not pose a risk for transmission of AIDS. HIV infected employees should be treated with compassion and dignity like any employee with a serious disease. They should be accorded all applicable protections and standards related to such matters as nondiscrimination, benefits, and confidentiality. Early comprehensive and continuing education about AIDS for federal managers, supervisors, and employees will in large measure minimize fear, discrimination, and friction in the workplace and will contribute to the health and well-being of employees and their families.

The guidelines focus on three specific areas; AIDS information and education programs, personnel management issues and concerns, and AID information sources, and I would like to discuss each of these briefly in turn. Education and training programs.

We believe it's vital that federal managers, supervisors, and employees receive accurate and timely information, education, and guidance about AIDS. Ideally, education programs are most effective if they begin before problem situations arise and if they are offered on an ongoing basis. Programs should be designed to provide information about the nature and the transmission of the disease, current medical and research data, confidentiality of information, and assistant sources.

The guidelines encourage agencies to use a variety of educational vehicles and sources of materials. Supervisors and managers should be prepared to deal with employee concerns and other issues related to AIDS in the workplace. Training and education programs should be designed to educate managers and supervisors on the latest research on AIDS in the workplace, to provide advice on how to recognize and handle situations which arise in their organizations, and to convey the importance to maintaining the confidentiality of any medical and other

information about the employee's health status.

The guidance recommends agency training programs be designed to include a team of professional that can address the medical or clinical aspects of AIDS and the personnel management considerations as well as referral and counseling issue and resources.

Second, employee assistance programs and employee health units. Our guidelines state that agency employee assistant programs and health units should play a key role in providing information, counseling, and support to employees with AIDS or those with AIDS-related concerns. These programs can be a good source of confidential information on community testing and treatment facilities and support groups as well as community, educational, and social services. Employee assistance program staff are already experienced in working with employees with serious, personal, or medical situations and, therefore, are likely to be sought out for assistance with AIDS-related issues. Our guidelines encourage the agencies to develop AIDS counseling, referral, and educational capabilities within their employee assistance programs and to advertise the availability of those services.

And the third and final component of our guidelines, or the three of four rather, personnel management issues and considerations. This is the area which has grown the most attention.

There is nothing particularly novel about the OPM guidelines for dealing with personnel issues and problems related to AIDS. That is, they are based on existing federal personnel law and policy, and most issues can be addressed within that framework. Many federal agencies have for sometime now been handling AIDS-related workplace issues sensibly and effectively. And I want to emphasize that very strongly, less the issuance of these guidelines create the impression that there is some serious, unattended to problem. People have been handling it extremely well on an add hock basis.

For example, existing federal personnel policy provides that employees who are incapacitated for duty or are obtaining medical treatment can use leave for those reasons. The guidelines emphasize that agencies should grant leave to HIV infected employees in the same manner as for other employees with medical conditions. Additionally, HIV infected employees may be eligible for disability retirement if their medical condition warrants and if they have requisite years of federal service to qualify. Applications for disability benefits are expedited by OPM when an employee's illness is advanced and life threatening whether the disability results from AIDS or another serious disease or condition.

Health and life insurance coverage is a prime concern for individuals with AIDS. Coverage under the Federal Life and Health Insurance programs is not jeopardized solely because of a diagnosis of AIDS. Under the Federal Health Benefits program, there is no clause for pre-existing conditions. Similarly, death benefits payable under the Federal Life Insurance program are not cancellable solely because of the individual's current health status. Employees who are eligible can continue their health and life insurance coverage into retirement at the negotiated federal rates.

The guidelines address the question of whether and under what conditions an HIV infected employee should be allowed to work. Again, guided by existing policy, the guidelines say, and I quote, "HIV infected employees should be allowed to continue working as long as they are able to maintain acceptable performance and do no pose a safety or health threat to themselves or others in the workplace."

Unfortunately, a HIV infected employee may develop a variety of medical conditions which may effect the employee's performance, conduct, or ability to report for work. At some point the organization should consider whether such employees can be helped through job restructuring, a change in work schedule, a leave of absence, voluntary change to a lower grade, that is, a simpler job, adjustment in workload, and referral to an employee assistance program. The accommodation of HIV infected employees should be handled in the same manner as for employees suffering with other serious illnesses and should be considered on an individual basis.

The Centers for Disease Control has stated that AIDS is not spread through non-sexual, person-to-person contact that generally occurs at work. Consistent with that finding, OPM's guidelines state there is no medical basis for refusing to work with an HIV infected employee. We are aware, however, that there may be situations where fellow employees express reluctance of refuse to work with HIV infected co-workers. Our guidelines recommend that managers should take these concerns seriously and provide employee counseling and education to help alleviate fear and reduce misinformation. However, if the problem is not resolved and the refusal to work with an HIV employee is impeding or disrupting the organization's work, appropriate corrective or disciplinary action should be considered.

In the limited number of situations of this nature that we are aware, education and counseling generally have been effective in resolving co-workers fear and concern about working with an employee with AIDS. Moreover, colleagues of HIV infected employees generally have reacted with sensitivity and

good judgment. Again, it is crucial to emphasize that comprehensive education offered early-on to all employees can prevent or mitigate these situations.

Our guidelines include a list of key federal government resources for AIDS information, including the Public Health Service, the Centers for Disease Control, and the American Red Cross. Additionally, we include a list of AIDS prevention program project directors and coordinators in each state.

At OPM we are establishing a clearing house of federal agency policies and training or education programs on AIDS. This clearing house will provide a central source of information and assistance to federal agencies developing their own guidelines and education programs and we have asked the agencies to send us all information as they develop it.

We have some additional initiatives we've undertaken to help agencies. I held an executive level briefing for key management officials from 28 agencies when the guidelines were issued. We had Dr. Robert Windom and Dr. John Petracciani from the Public Health Service and the Assistant Secretary for Health, the Department for Health and Human Services talk to these key federal officials. Shortly after the guidelines were issued, we sponsored a meeting on AIDS for two key interagency advisory group committees, our Employee and Labor Relations Committee and Employee Health and Assistance Committee. We had about 120 representatives from federal agencies at that. We have the clearing house I've just mentioned and we are participating in and conducting briefings and also training courses for supervisors on AIDS in the workplace throughout the country.

A number of federal agencies have undertaken their own initiatives. I think in the interest of time I might just provide this to you in writing.

In closing, I want to say our efforts to deal with the AIDS crisis do not take place in a vacuum. Rather we are part of a comprehensive, world-wide effort of research, treatment, education, and, of course, policy making.

I'm very grateful for the opportunity to address the Commission today on behalf of the federal sector and to contribute in any way I can to the excellent work and very important work that the Commission is doing.

CHAIRMAN WATKINS: Thank you, Ms. Horner. I want you to know that the large majority of the content of your comprehensive HIV policy is very much in consonance with the hundreds of witnesses that have come before here.

I think it struck a resonant cord with us that you have given it the kind of intensive addressal and careful and compassionate thought that you have. I think it's unique to see that come out early with the federal government when people are still floundering about policies. So I commend you for the courage and the leadership in this area.

We're going to be looking and continuing to look in greater detail at the OPM guidelines and see if there isn't something that this Commission should recommend to be more aggressive in accepting those across the federal agencies. So we'll be in touch with you.

I know you have to go now, but I wanted to let you know we were impressed by what see and the degree to which you reached out to obtain other's views in building a policy that seems to have a lot of common sense in it in addressing the epidemic.

So thank you for coming today and please allow us to communicate with you some more because I know many of the commissioners would have liked to have had a chance to go in further depth, so we may have to do that in writing or meeting orally with you again if that's alright.

MS. HORNER: Mr. Chairman, I appreciate that very much and I thank you for your encouragement.

CHAIRMAN WATKINS: Thank you very much. We'll stand recess then until one o'clock.

(Whereupon, the hearing was adjourned at 11:32 a.m. to reconvene this same day at 1:00 p.m.)

A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

1:03 p.m.

CHAIRMAN WATKINS: We'll recommence our hearings now on the afternoon panel of today's series of hearings. This is a very unique panel, I think, for the Commission and one we felt was very important for us to hear from.

AIDS: An Epidemic of Loss

We've asked for testimony from the arts and creative community, not because it has been singly affected by the epidemic, but because so much of its loss can be universally felt and because so many in the arts have donated their talent to help teach the public about AIDS and raise money to help care for those infected. I've had several occasions on which I have

participated with them and know their dedication and sincerity and the tremendous effort they put in this regard.

We would like to acknowledge a very special contribution to today's hearings. You can see over here on our left a 12 foot section of the AIDS quilt, the first national memorial to those claimed by the epidemic. The quilt was brought to us from San Francisco this morning by the NAMES Project, N-A-M-E-S Project. We're all grateful to them for sharing this great symbol with the Commission.

Mr. Smith, one of our witnesses today, will provide us with additional information, but you should know that this is one of nearly 4,000 panels made up from nearly two miles of fabric and the quilt is now on a national tour. The quilt serves to remind us of the great number of individuals lost to the epidemic. The numbers I read this morning exceed 61,000 men, women, and children who were loved and who will be missed.

Some of the best testimony before this Commission has come from persons with AIDS, certainly the most moving. That testimony and the loss represented by this quilt will continue to inspire the Commission as we complete our work in the next few weeks.

So, we'll begin the panel today with Mr. Michael Smith, Managing Director of the NAMES Project in San Francisco. Mr. Smith?

MR. SMITH: Thank you, Admiral. The NAMES Project is the nation's memorial to those who have been killed by AIDS. Like the Vietnam Wall, the NAMES defines this catastrophe not as a single event, but as a collection of individuals and broken lives. Monuments, after all, don't need to be uniform or carved in stone.

The quilt, now the nation's largest community arts project, is made from the hearts and hands of thousands of Americans who most closely feel that loss. Imagine the Capitol Mall, all ten city blocks from the Washington Monument to the steps of the Capitol covered in three foot by six foot cloth pieces, each intricately sewn with beads and buttons, favorite shirts or teddy bears or covered with the most detailed of paint work. Each panel, like the one on display here today, sewn for a person remembered by a loved one, each panel bearing witness to a vibrant life cut short by AIDS.

Thousands of panels, now nearly 5,000 actually, 600 sections the size of the one you see here, represent mothers and fathers, doctors and nurses, lawyers, policemen, many children, artists, school teachers, farmers, politicians, even street people.

The NAMES Project has three goals. We want to offer those who are grieving a creative and positive way to deal with their grief. We're giving people a quiet time to remember and to transfer to fabric many of those moments and those qualities that recall a personality of a loved one. We also want to illustrate for America the impact of the epidemic, not in statistical terms, but in terms of the humanity and the individuality of those lost. And by displaying the quilt throughout American on a national tour, we're working to raise vital funds and encourage people who are dealing with AIDS in their own lives and organizations that are taking care of those people.

We're a motley group of volunteers, artists and parents, people on their lunch hour, retirees, a number of college students on summer break. All of us are convinced though that our message of love and remembrance can transform a nation. We offer the quilt as a symbol of compassion in this epidemic of fear and ignorance.

A quilt provides warmth and comfort. When I think of quilts, I remember my grandmother taking care of me when I was sick. Throughout our history, Americans have always come together in quilting bees when they need to draw on the strength of their community. The NAMES Project is a reminder of that long tradition and a call for human response to the AIDS epidemic.

As a community arts project, we don't take a position on many of the political issues that your Commission deals with that surround this epidemic, so I don't come here with specific recommendations. I am convinced that if a national AIDS policy is guided by the same kind of compassion and respect for the individual that the panel makers who have built this quilt have exhibited in their work, that the right decisions will then indeed follow.

The quilt is now on a 12,000 mile, 20 city national tour to raise funds and awareness, bringing this message to thousands of Americans around the country. The tour ends here in Washington in October when the quilt will once again be displayed on the Capitol Mall, this time five times larger than it was last October.

My words don't do justice to so many of the individual stories of the quilt and so I'd like to share with you a few of those stories and some letters from the various people who have made panels or who have seen displays of the quilt around the United States.

The first letter comes from Margaret Pallegi from Ohio. It came with the panel she made for her son, Stephen. "I

am so proud to be part of this amazing event. I hope to be in Washington in October to witness my son's name among all the others, the dear, brave victims of this dreadful disease. It will be such a comfort for me and for all who grieve for them to know that their deaths will now serve a very useful purpose in bringing attention to all Americans and to all the world the enormity of this catastrophe."

I brought some slides for other panels as well. This is for Jim and Sidney Soons. The letter with them is from their mother. It says, "I do hope it is acceptable for me to put the names of both of my sons on a single panel. Sidney and Jim would have approved because they were close friends. They are together now in a quiet place here in Princeton. I visit them often, tend their flowers and find solace in the fact that their suffering is over and they are at peace.

"Sidney was brightly intelligent with a wonderful, quick whimsical sense of humor. Jim, with his flaming orange hair, was strong and energetic, exploding with adventurous spirit and a zest for life. I have been well blessed. All my five sons and one daughter have been close, good friends. Now when we are together we speak so often of Jim and Sidney. Pray for all of us. I have two more gay sons and I live in fear."

The next panel is provided by a hospice worker in San Francisco in memory of a woman who died in that hospice. Here name was Christine Williams, but they called her Queen Christine. His letter says, "Being able to express my feelings in memory of a beautiful black woman who touched my heart with laughter is very special. Christine Williams helped me to understand that life is not fair, but that being honest with yourself and others can make a difference. God bless you, Christine. You have helped me to grow and want to survive."

This panel is for Reggie Hightower from Atlanta. It's made up of a collection of his shirts sewn together. Reggie was a deaf black man from Atlanta and the hand symbol in the middle is American sign language for "I love you."

This panel for John Booth is actually a panel in memory of 12 individuals, a group of friends, each represented by a candle. Nine of them had already died of AIDS when the panel was sent to us in memory of John. Of the remaining three candles, only one still shines today and he was hospitalized on Friday with pneumocystis. The video tape you're about to see is part of a series of interviews that Peter Jennings did with panel makers from the NAMES Project that aired nationally last October.

(Video presentation.)

MR. SMITH: The next slide is very hard to read in this light. It's a brick wall and it says in spray paint, "Nancy and Bosco, Jr. were here." The letter that came with it is quite long and quite moving and I've enclosed a copy of it in testimony for all of you, but I'd like to read excerpts from that letter for you.

"Nancy and her son, Bosco, Jr., were my buddies. We met in December 1985 through the local AIDS task force. Bosco died in March of 1987 at two years and eight months old, and Nancy three months later at 26 years of age and weighing 42 pounds.

"My buddies were hispanic. They lived in a filthy, graffiti covered, garbage laden neighborhood. Nancy's landlord served her an eviction notice while she was hospitalized and when, after months of lawyers and court action and apartment hunting, Nancy finally had to move. Her landlord spray painted on her door, 'Nancy, I always win.'

"Nancy carried on, sicker than I could imagine anyone being, frequently rejected and ultimately beaten by her husband who was in his own hell watching his first son die. She cooked and cared for her husband and child. She visited lawyers and social workers. She looked after her life in the best way that she could until she died.

"Nancy was a friend. I loved her and her family. With all the pain we suffered in the year and a half I knew her, I still had fun. We ate together and laughed together and enjoyed being women and mothers together. We met wonderful people from the task force, caring physicians and nurses, self-sacrificing nuns and priests, sympathetic social workers.

"Nancy stands as a symbol of life for me, as a defeater of death, but she stand too for another darker world. There are 50,000 potential Nancy's and Bosco's. Who will help them?" Signed by Hallie Wolf, a volunteer in Yonkers, New York.

The next panel is very hard to read in this light. It came to us in an unmarked package and arrived with no name and we're not sure what part of the country it's from. The inscription on it reads, "I have dedicated this panel to honor my brother. Our parents did not want his name used publicly. The omission of his name represents the fear and oppression that AIDS victims and their families feel. The panel was clearly done in crayon, probably by more than one young person in the family. The next video tape piece is also from the same Peter Jennings series of interviews.

(Video Presentation.)

The next panel on the slide represents -- it's an empty bed and it just says, "Baby Jessica," and it's in memory of a child who died of AIDS. Around Roger Lyons' name on this panel is a collection of get well cards that were sent to him by 5th graders at Saint Catherine's school. Unfortunately, the cards arrived the day after he died, so he never saw them.

I'd also like to end with one other letter that comes to us from someone who's seen the quilt on display on the national tour. I think it says a lot about what the quilt is really all about. It's from a letter that the man sent to his mother and father after seeing the quilt.

It says, "Dear Mother and Dad, Comfort and hope sound like simple words, but feelings are hard to find. This weekend a glimmer of hope shined on me as I viewed the unfolding of the NAMES Project quilt. I mentioned a transformation. The quilt is touring the nation to offer a unique message. The message I think I got is that life is very precious. We must enjoy every moment because it may be gone.

"I understand a pamphlet is being mailed to every household in the country with honest, frank information about AIDS. I don't know what it says, but I understand that it says all that is known today. I haven't made a request of you two in awhile that I can remember. I ask that you read about AIDS, the pamphlet and find out everything you can about this disease. I know it's not pleasant, but neither is seeing my best friends die. Lack of knowledge brings fear.

"Mother, after viewing the quilt, I make one special request of you. The lady in your group with AIDS needs a hug. AIDS cannot be given to another person from a hug or holding hands. You remember the fear you had when you had polio. She is feeling that now. "For whatever may happen, I always know that I remain your ever-loving son. I love you very, very much."

You all should have received from me the book about the quilt that was recently published by Simon and Schuster that contains more stories about the panel and more information about the lives of people touched by this epidemic, as well as the video tape of the unfolding ceremony of the quilt in Washington last year.

The message of the quilt is that life is very precious. Each panel is filled with a tremendous amount of love. I'm here today to urge you to make the quilt's message also the message of our government. Thank you very much.

CHAIRMAN WATKINS: Thank you very much, Mr. Smith. Our next witness is Mrs. Kitty Carlisle Hart, Chairman of the New York State Council on the Arts. It's a special privilege and

honor for us, Ms. Hart, to have you with us today in that you represent the largest artistic community impacted by the epidemic.

I'd also like to welcome Mr. Gregory Calovacos. You're Director of the Literature Program for the Council. Feel free to bring him up as you desire on the question and answer period.

MRS. HART: Thank you so much for asking me. I'm deeply honored to be here today. As was already pointed out, but it bears saying again and again and again, AIDS is not an artist's disease but a human catastrophe. We all know that there are lawyers and doctors and bricklayers and everybody else who is open to this disease.

However, the arts have been closely identified with AIDS during this epidemic for two reasons. First, the artistic community cares so deeply about the human condition. The mission of the arts is to articulate and interpret the world around us. The arts sum up our fears, our aspirations. The arts crystalize our experiences and provide us with a vehicle to express ourselves and to feel less lonely and withdrawn.

There have been plays, books, poems, paintings, dances created that deal with the effects and the pain of AIDS. And also this extraordinary quilt. Thank you for telling us about that.

As Ezra Pound once put it, "Artists are the antenna of the human race." My recommendations are to continue and increase as much as possible all efforts in the areas of education, research and care. Whatever steps are ultimately taken, this disease must be guarded against prejudice and discrimination.

I read in the paper the other day that the prison population in New York dies twice as fast as anyone else who has AIDS. There is no medication given at Sing-Sing, there is no help whatsoever for prisoners.

One critical issue for individual artists is that they often have no health plan or any medical insurance, no safety net. Perhaps the government ought to step in and start a program for artists with the necessary funds. Sculptors, painters, writers, individual artists of all kinds have no insurance. They don't belong to labor unions and ordinary insurance is too expensive for them. Therefore, they do not wish to be tagged in any way because they lose whatever jobs they have and they're being discriminated against.

While on the subject of health insurance, I must caution that the insurance industry must not be allowed to test for the presence of antibodies for the HIV virus itself because this could lead to excluding those who test positive from receiving coverage. If anyone is going to be tested, they need to be reassured that it is only to help them, not to hurt or to discriminate against them.

I have one or two specific recommendations. If perhaps stars like Cosby, Michael Jackson, Don Johnson could be enlisted into public service announcements, they would reach more people effectively. On spot on M TV could reach an audience that is not reachable in print. And if CBS and NBC and the other commercial networks could be persuaded to put something like this on at a decent hour -- I've been doing public service announcements all my life and they are never on except at 3:00 in the morning or 5:30 maybe. If the government could encourage commercial television, at no charge, to help give studio time for taping and not, as I said, at 4:00 a.m.

The National Endowment on the Arts and the New York State Council on the Arts could recruit individual painters, designers and artists, visual artists for advertisements for magazines and newspapers in Spanish and other print media. Choreographers would be very happy to donate their time to M TV.

The Association of Hispanic Art has received money from Mutual of New York for street theater. It's a way of reaching people who do not speak English necessarily and people who certainly don't read anything. In the intermission, they are given pamphlets and information in Spanish.

This kind of alliance between the government and the private sector could be the most telling and really the most important. I thank you very much for this opportunity to speak with you on behalf of all artists and arts organizations and we look to you for leadership, for adequate funds to find a cure and for compassion in dealing with this epidemic.

I would also like to add that my daughter and my son-in-law, both doctors -- my son-in-law works at Rockefeller and my daughter is at one of the major New York hospitals. The problem there is legal and ethical and it's a terrible problem for doctors. There should be some kind of resolution to this problem. Thank you.

CHAIRMAN WATKINS: Thank you very much, Mrs. Hart. Our next witness is Mr. R.A. Radley, National Director of DIFFA, the Design Industries Foundation for AIDS. With him today is the foundation's Chairman, Mr. George Slowik. Mr. Radley?

MR. RADLEY: Thank you very much. Thank you all for inviting DIFFA to testify here today. As Admiral Watkins said, we're representing the Design Industries Foundation for AIDS.

CHAIRMAN WATKINS: Would you pull that microphone over right next to you, Mr. Radley?

MR. RADLEY: Okay.

CHAIRMAN WATKINS: So we can all hear it in the room.

MR. RADLEY: I will talk briefly about the Foundation's principal achievements in our four years and I hope you'll get an idea of what one creative community, that being design, has done to respond to AIDS. George will elaborate on the corporate sector response as well as discussing AIDS in the workplace related issued.

Here, we're really representing two capacities. One is our nearly 500 volunteers who stretch East to West Coast, and an organization which was a dream of two people from the design community who more than four years ago saw a developing epidemic taking many of their friends, colleagues and partners and wanted to do something about it. To whit, they decided that they wanted to create a foundation to make grants to AIDS-related activities and organizations and increase their own industry's awareness of AIDS and its implications. And further, with an aim of reducing human pain and suffering in the lives of the members of their industry.

More than $1.3 million has since been raised and over 100 grants have been awarded to AIDS-related activities across the country. The second capacity, if you will, that we are representing is the Foundation, a philanthropic one. As you may or may not know, DIFFA is the only industry inspired foundation in the U.S. devoted exclusively to ongoing AIDS grantmaking and fund raising. We're especially proud to be active partners in this respect with the broader foundation community.

A brief look back at the history of DIFFA. It was initially known as the Design and Interior Furnishing Foundation for AIDS, and it was established as a New York City oriented organization four years ago. A recent name change though to Design Industry Foundation reflects our trustees' intent to expand our outreach beyond interior design, architecture and related fields, including fashion design, graphic design, industrial and so on. Little did DIFFA's founders contemplate the expansion we've experienced from 1984. In addition to the national office, we are now located in ten local communities, including Atlanta, Boston, Chicago, Dallas, Houston, Minnesota, New York City, Northern California, Southern Florida and Washington.

As I mentioned, our principal aim is to raise funds through special events, corporate sponsorships, major donations, membership programs and then, in turn, take that money to make grants to AIDS groups around the country. The national office, in a cooperative process with the local committees, supports both local grantmaking as well as research potential national projects which meet our national goals.

Monies are raised both by the local committees and by the national operation. Eighty-five cents of every dollar collected locally in these ten cities returns to the area where it was raised. The balance, the 15 percent, returns to the national operation.

Funding criteria seek to identify programs of innovation and efforts which we can eventually mold nationwide. Applications are generally reviewed in about a ten week period, but provisions do exist within our committees for special and emergency case situations.

As a matter of fact, our trustees, who are very committed to a responsive and timely process, have in several instances saved organizations such as the ARC Group in New York which eventually opened the Bailey House project for housing, and several other immediate interventions on DIFFA's part have saved several organizations in different areas of the country. You might look in your briefing packet and the extensive listing of projects are cited in the addendum in that.

DIFFA accepts applications from organizations in virtually all areas of the crisis, patient care, housing, education, and advocacy. In addition to our grantmaking of cash grants, DIFFA has coordinated industry participation by providing AIDS organizations donated and discounted product and design services estimated at over $1.5 million.

Just to cite a couple of our grants, and as I say the material that you have gets into it specifically, but we've provided critical sustaining funds, as I mentioned to the AIDS Resource Center, early days of GMHC and AIDS Medical Foundation. We have provided vital monies there for services in research. We funded education efforts with groups like Project and Forum. We've just recently funded a New York City-wide task force on adolescents and we've provided with seven other foundations, start-up funds to set up a New York/New Jersey commission on AIDS and eventually development of ten principals for the workplace.

We've also funded the New York Urban League which has assembled a working group on AIDS. And very recently, we made 20 $1,000.00 start-up and support grants to PWA Coalition organizations in 20 cities.

Our role in philanthropy, especially over the last two years, is very intriguing. In cooperation with many other foundations, we've organized a group called Funders Concerned About AIDS. The group has expanded from about six of us a year and a half ago to include now more than 60 foundations nationwide. It has become an accredited group of the Council of Foundations, the national advocacy group for philanthropy.

We've recently published a bound resource book, which again is in your briefing book. This is aimed at suggesting grantmaking strategies that foundations without AIDS grantmaking experience consider. In addition, it lists all of the grantmakers in the back that have provided any sort of AIDS funding and you'll see the list is becoming more and more extensive.

I commend this material to you. It's very important that you understand that as foundations and philanthropy realize the needs out there. There's more and more collaboration occurring and the guesstimates now for the number of dollars, say through 1987, that philanthropy has supported besides the Robert Wood Johnson Foundation is nearly $20 million.

The collaborative experience helps us to work together in terms of providing great aid. Often there will be an opportunity to set up a matching grant or other kinds of seed grant opportunities for small organizations that might not otherwise be able to undertake certain programs. I'll like George Slowik, our chairman, now to --

MR. SLOWIK: Good afternoon.

CHAIRMAN WATKINS: Mr. Slowik.

MR. SLOWIK: The private sector must embrace its responsibility to deal with AIDS. In 1984, the foresighted Patricia Green, spurred by a personal loss, accepted that responsibility. She inspired activity in an environment that was devoid of initiative.

The reticence of our government to inspire action was a void the Design Industries Foundation for AIDS was established to help full. It was never anticipated that today's hearings would be a necessity. No one believed that the response would need to be sustained, much less accelerated. Nevertheless, it was evident that action was necessary.

The first advertisements which appeared in the professional design publications stated, "We must raise money because we can't raise the dead." This motto is even more valid today.

DIFFA started in 1984 by creating an environment that facilitated action in an arena free of stigma. In fact, its call to action stigmatized those who did not respond. As it has gained momentum, the willingness to respond has become stronger. Progress has been made, but much must be accomplished. Our goal and that of private industry must be to nurture individual energies.

Our government has been slow to address the myriad issues of AIDS. Leadership was lacking under Surgeon General Koop took the reins. He has made eloquent pleas for response from the private sector and in the workplace.

Having criticized our government, let me compliment the work of Admiral Watkins and the Commission to date. It is impressive that you have embraced the needs straightforwardly. We trust that you will continue to avoid ideological view which relate to this illness as anything other than a human disease. The gay community rallied to respond to this issue. However, they cannot handle it alone, nor should they. We must all take our part in this battle. DIFFA has embraced industry support to do just that. By facilitating broad support, we engaged those who were previously unaware of the need.

The design and creative industries have been no harder hit than any other segment. It has been more apparent since the industry is made up of mostly smaller companies which bear the name of the creative force behind them. Some of the best banking, manufacturing and retail minds have been lost to this illness. So too have sports stars, members of our clergy, our government, as well as our children.

None are more worthy humans than others. All are of equal merit. So too must every humane person respond, in an environment of collaboration, not competition; philanthropy, not profiteering; and compassion rather than judgment. By concentrating the energies in support of industry leaders and professional associations, we have been able to help destigmatize this disease amidst our constituency. By eliminating the stigma, an environment emerges where involvement is encouraged and where PWAs can live with dignity.

We have always tried to have the answer to the question, "What can I do?" Involvement can take many forms, money, time, product, emotional support, lending ones name, donating your talent and even letter writing. An industry group should set an example of action. By doing so, a strong foundation for results is laid. By inspiring thought in an environment which facilitates this action, events come together. Further, by becoming a credible source of distilled information, an industry foundation can provide its constituency with an essential resource for action.

The most daunting aspect of involvement can be the disparity of AIDS information. Generally credible sources of information, like Cosmopolitan and Masters & Johnson, have run the gamut of irresponsible reporting. Embracing the volume and velocity of disparate information is a formidable task. The plethora of options often distract an individual from finding an appropriate outlet for their energies. An organization like DIFFA can assist the individual in deploying their resources in an efficient manner. Continued education of the evolving needs incumbent to the AIDS pandemic is the key to progress. The proper deployment of information resources will help to curb proliferation of this formidable disease.

Therefore, we challenge other industries to embrace the AIDS issue and lead by example. Involve the top individuals in your industry. Others will follow. Enlist the support of professional organizations and unions.

Provide a conduit to action in the fund raising arena, and embrace the small efforts as well as the million dollar galas. Facilitate individual efforts and direct those energies; encourage a national response; ask the trade press to participate via public service announcements and editorial coverage. These activities are news to their constituency. Ask the consumer press to cover the events that you create.

Provide a resource center for concerned individuals; help cross pollinate ideas between AIDS service groups in order to help prevent duplication of effort; encourage the establishment of AIDS workplace policies before circumstances necessitate it; become a catalyst by disseminating accurate information in a form which is palatable to your audience; educate your constituency to what it ought to be doing; share the unique perspective that being involved provides.

Assist in the development of activities outside your industry; inform your government officials of the opinions expressed by your industry and support creative initiatives. If nothing else, call us. We're eager to share what we have learned. Thank you for hearing our testimony. I hope that our unique perspective has been helpful.

CHAIRMAN WATKINS: Thank you, Mr. Slowik.

CHAIRMAN WATKINS: Mr. Michael Kearns, our next witness, is co-founder of Artists Confronting AIDS, an organization designed to serve as a clearinghouse for organizations to contact artists who will donate their services for AIDS and public service announcements and fund raising efforts.

Mr. Kearns is an actor himself and is currently appearing at the Source Theater here in Washington, D.C. Mr. Kearns?

MR. KEARNS: Thank you. Over the past three years, I have devoted my life almost exclusively to the challenge of AIDS in my work as an actor and director, including the formation of Artists Confronting AIDS.

Artists Confronting AIDS was initially conceived as an organization to be comprised of artists who were determined to respond to the health crisis in artistic terms. We solicited playwrights, painters, dancers, video-makers. But what I, along with my collaborators, discovered was the need to become more deeply involved with AIDS.

We then expanded our concept and enlisted persons with AIDS, who may or may not have considered themselves artistic, to confront their disease through art. What resulted was a performance piece, entitled "AIDS Us," which depicted 13 men and women who had been transformed by AIDS, seven of whom were diagnosed with the disease. Performed in docu-drama style, the remaining cast members included a widow and her daughter, a mother of a young man with AIDS, a social worker, and a woman who, as a result of her job as a receptionist at a gym, had lost 27 of her friends to AIDS. The piece of shaped from transcripts of interviews with the participants. They, in essence, wrote the material and performed it. This proved to be the most powerful theater experience I've been blessed with in my life.

If the function of theater and of art is to illuminate, educate, and perhaps heal through catharsis. These 13 individuals accomplished that with dignity and grace. That is not to suggest there were not harrowing realities. A seizure in the dressing room moments before the first public performance; the increasingly debilitating blindness of one of the young men with AIDS; the sudden death of a female cast member the night before a performance. There were suggestions by several persons with AIDS that they were being healed by performing, the release was so overpowering. If not healed, there is little question the experience enhanced the quality of their lives while they were alive, and allowed them to come to terms with death and dying in front of an audience no less.

The audience members were no less dramatically effected. If the theater is a catalyst for change, the impact of "AIDS Us" was manifest in very specific ways. Several men indicated that seeing the performance made them rethink their sexual practices. Others became directly involved as volunteers. Many men and women said they grieved openly for the first time.

I strongly suggest we need to consider the potential of all artistic disciplines. Science is not the only road available to confront this devastating killer. Consider the plays which have been written, the paintings borne of pain and suffering, the poetic testimony of novelists. These works of art will serve as a chronicle of our times more effectively, more vividly, more passionately, more compassionately than miles of news reels and news print.

In conclusion, I make an obvious, yet profoundly unsettling observation. While many artists will be healthy enough to confront AIDS in their work, we are simultaneously losing a generation of painters, dancers, poets and dramatists to this monstrous epidemic. This is an irreparable cultural loss, one which depresses the human spirit.

Art uplifts. Whatever it takes, we must painstakingly keep art and artists alive during these perilous times. Thank you.

CHAIRMAN WATKINS: Thank you very much, Mr. Kearns. I'll start the questioning on the general issue and then I'd like to turn it over to the other Commissioners here, starting with Dr. Lee on my right.

Mrs. Hart, I was taken with your very constructive and positive set of recommendations regarding the media and the role they might plan in educating the nation. Do you see in your concept a need to provide some kind of a forum that would allow that public/private partnership to take place just focused in this one area? For example, Center for Disease Control recently paid $4 million to a commercial design firm for the brochure that is to be mailed here by the end of this month to all households in the nation.

Perhaps one evidence of compassion and interest might be a more integrated approach to how we might, on a continuing basis, provide the message, because you opened with the statement that unless we're repetitive and continually recognize that we have a flow of human beings moving through society, that we cannot allow just a one-shot educational effort to take place. We have to continue it. It demands then some sort of a longer sustained strategy. It seems to me here is one area where we need to coordinate something a little bit more than perhaps we have. There's a lot of goodness out there waiting to be, I think, aggregated and put into a more effective unit.

So, you have some ideas in mind of how we might take your idea and implement it? How would you bring the right people together? How should we start this? How might we organize such an effort?

MRS. HART: It seems to me that the Arts and Business Council is a very good way of starting because the Arts and Business Council is located in New York but it's a national organization of business, and important businesses.

It seems to me that if the Arts and Business Council could coordinate with the media, and by that I mean television -- the reason problem is no longer really -- it's a problem of cost, but it's waning. The homosexual population is articulate, its education and it reads. It understands what is going on. Of course, the surgeon general's pamphlet will be very important. But the intravenous users, the street people do not read. Therefore, the Business Council could provide the money and could work with the television people and could indeed create some kind of a catchall that would reach the people who need it the most.

CHAIRMAN WATKINS: Thank you very much, Mrs. Hart.

Dr. Lee?

DR. LEE: Mrs. Hart, it's true that a couple of words from Ali or Dionne Warwick or --

MRS. HART: Cosby.

DR. LEE: -- any of the great baseball players, Reggie Jackson, et cetera, et cetera, can mean more to the educational process of the people we're trying to reach than our report. Our report will probably be read by three or four people in OMB and, of course, the President of the United States.

But I would hope that in the next go around, when we continue this war on AIDS, et cetera, there will really be a concerted program in trying to enlist the stars. Thirty seconds of prime time with one of these people is worth its weight in gold. A small question. What legal and ethical things were you referring to when you were talking about your children?

MRS. HART: Well, it's very personal. My doctors tell me that they have a terrible problem when someone comes to them to be tested. The ones that I'm close to tell me that they will report the testing, whatever it is, to the partner of the person who has AIDS. If that patient doesn't wish to go to this doctor, then they're free to go elsewhere. But my doctors feel that they are obliged for the sake of public health and for humane reasons to alert the partner if the patient tests positive.

But this is a terrible problem also, you see, in hospitals because now the hospital personnel doesn't know what to do with people who have AIDS in the hospital. Nurses, doctors.

Do they get relocated, do they get certain jobs that are no longer allowed to them? That is a very difficult legal problem. The ethical problem is do you tell the partner? Do you report it as you would an ordinary venereal disease? Everybody is floating around in there. It's medical, it's legal and it's ethical.

DR. LEE: We've faced those problems many times in great detail over the last nine months and the solutions are very complicated. Thank you.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: Mrs. Hart, I was particularly touched by what you said about your children --

MRS. HART: About the what?

DR. SerVAAS: About your children.

MRS. HART: Yes.

DR. SerVAAS: I was wondering, have they mentioned to you about knowing when they're admitting a patient to the hospital, if they're admitting them to a private hospital, what their obligation is or how they go about describing -- it's a difficult situation because insurance -- they can be subject to lawsuits if they are giving the truth sometimes.

MRS. HART: That's the big problem. How do you deal with this? Each one, I think, is dealt with on a very special basis. But if you are faced with someone who is going to lose their job and their house and everything else that makes life possible, how do you deal with it? What do you do? Do you report it? No, you don't.

And furthermore, the government really must do something about insurance. This is one of the most important, I think, problems that faces this Commission. We've dealt with it in terms of artists without any medical problems. How do self employed artists get any kind of insurance? But now the problem is not geometrically worse, it's astronomically worse and then everything is at stake. You must deal somehow with insurance and not allow insurance companies, for instance, to withdraw or withhold insurance.

It's also very foolish of the insurance company. If someone comes to the insurance company and it's quite clear is free of any kind of infection, because the incubation period is so long, who knows how long this person has AIDS or may not have it? It makes no sense for the insurance company not to allow

people to be insured. If the government must subsidize it somehow, it will have to be because it will devolve on all of us.

DR. SerVAAS: Thank you.

CHAIRMAN WATKINS: Dr. Crenshaw?

DR. CRENSHAW: Mr. Kearns, you spoke eloquently about the absolutely urgent need to protect our artists. Mrs. Hart, you spoke about the fact that I also agree with, that we have to expand our perception to far beyond artists and to it being a human problem throughout.

In relation to doing what we need to do to preserve our art forms to the best that we can, there's one issue I'd appreciate your making some further comments on. I've seen and I've just picked up, I'm not in the art world, some reflections of AIDS in our art, all the way obviously from "A Sudden Frost" in terms of television programs. But I was struck by an article in Newsweek about six months ago when they had the fashion debut in Italy. The way that was written up was the reporter said it was like a dirge. The mission music was played, everyone was in black, Greek mourning type of gowns and fashion. Then in our art, we also see this.

As a matter of fact, I was taking a plane ride the other day and picked up a novel to try to take my mind off AIDS and it was called "The Dinner Party" and it was all about a young man with AIDS who wanted to tell his Senator father about the disease.

I'd appreciate, perhaps, your elaborating. I've just given this a little bit of thought, but what do you foresee for the future in terms of having our human tragedies and conditions and distresses reflected in art and in what way do you foresee this happening? Anyone can respond.

MR. KEARNS: I feel that it's inevitable that it will continue to find a broader base. Of course the gay community has initially responded more openly and more ferociously to the epidemic. But now it seems inevitable that other communities will.

I also want to point out that the play that I was involved in, "AIDS Us," with persons with AIDS, was by no means done in black and done as a dirge. In fact, there were moments of great wit, great humor. It was very uplifting. It was a spiritual high when people walked out of there. So, while it's a given that this is a disastrous, monstrous, horrible disease, but on the other hand of that, art can depict the lightness, the beauty, the sensitivity of the disease.

Of course, in many cases, what's needed for this is funding. Of course, what's needed is government funding in many cases. The small artist doesn't have the opportunity to get their work on CBS Television. There are grassroots arts organizations throughout the country who, I think, will be willing to look at this disease and confront it and humanize it. I think that's the key. So, I don't think it's just the darkness. I think we have to look at the lightness too.

DR. CRENSHAW: Did you have any additional --

MRS. HART: I was thinking about something while you were talking and I wanted to -- I'm a little slow, but I get there eventually. There are wonderful organizations, for instance the Partnership Organization in New York City headed up by Jim Robinson now, formally headed up by David Rockefeller. This is the kind of organization that could, with all the power of everybody connected with it, really do something extraordinary. Those folks have tentacles and antenna out into every part of the commercial and the public sector. This is the kind of organization that should be brought in, along with the Business Council, the Arts and Business Council. They're already oriented toward the arts. But the others could be brought in too.

I know that the federal government really is sort of a little worried about having government do everything, as am I. I feel that that's also -- it's necessary to regulate things like insurance companies and that sort of thing, but when it comes to really dealing with human suffering, the public sector is very generous.

CHAIRMAN WATKINS: I agree with you, Mrs. Hart. In watching the events in the United States on a range of issues, education, health promotion of young people and the like, trying to motivate people back into the mainstream that have drifted aside and so forth, the focus continues to come on partnerships. I know that Jim Robinson in particular understands the broader pictures that are portrayed by or are exposed by this epidemic and feels very strongly about it.

I think there's a role for the conference board in research. I think there's a role for the Business Council in some of the broader aspects, the round tables, both at the national and state level, all have to be participants. I think the things like All State Forum and the other initiatives of American business now to really jump in the saddle and start riding this one, because they have to be a significant part of the education process nationally in the workplace. We've had those hearings. So, I think your idea of insuring that the business partnership is an integral part of the process is very important because they have the political clout, they have the

finances, the resources and they have the sensitivity to local and regional issues that are so critical. When you get New York, say, versus some smaller region in the Midwest, it may have a different outlook towards how to proceed from this point. So, I think it's a very well taken point. We'll continue the questioning. We'll go down, all the way at the other end, to Dr. Conway-Welch.

DR. CONWAY-WELCH: Thank you, Mr. Chairman.

I have one question I'd like to address to any of the members. I've been involved with the symphony in Nashville and our efforts to get matching money from the National Endowment for the Arts.

Following Admiral Watkins' ideas about -- well, obviously the need continues to exist for a greater clarification of the opportunities for partnership between the private and public sector. We've received matching money from the National Endowment for the Arts with the symphony that is not targeted for any particular use, or at least the target is very broad.

But some of the comments that you've made have made me wonder if there's any mechanisms through the National Endowment for the Arts that have matching monies particularly targeted for local community or state groups who are involved in educational opportunities related to the AIDS epidemic. Is that a line of reasoning we might want to follow as a Commission or are there reasons that that wouldn't work?

MR. SMITH: I think right now the National Endowment for the Arts doesn't necessarily target money toward AIDS-related or AIDS education theater or that sort of thing. Speaking for myself and probably also for Mr. Kearns' organization, a lot of the organizations that are now coming forward that are artistically related to AIDS education or AIDS awareness are very small, very grassroots organizations. The National Endowment for the Arts tends to be a relatively large bureaucratic process that can be very well mastered by a number of symphonies throughout the country or the public theater in New York that have full-time development staffs who are very good at grooming that process to come up with several million for a budget.

Perhaps working with the National Endowment for the Arts to target a certain percentage of the budget or something toward smaller grassroots organizations that don't need as much money, but that also find themselves lost in the process might help some of us who are out there trying to do work on a very low community level to work our way through that system.

MRS. HART: I'd like to say a word in defense of the National Endowment for the Arts. I think it's unfair to say

that you have to know the bureaucratic process and you have to be smart at requesting money in order to get money from the National Endowment. That's not fair.

MR. SMITH: Okay.

MRS. HART: But I agree with you. I don't think they do target money for anything like a symphony orchestra educational process, but it's not a bad idea to start it. As a matter of fact, I'll bring this particular request back to my own organization, which is the New York State Council on the Arts. Not a bad idea because we do fund an awful lot of very small Hispanic and ethnic and groups of people of color, a lot. That's where it should be targeted. Very good question. Thank you.

DR. CONWAY-WELCH: Anyone else?

MRS. HART: I would like to quote, just for one moment, something I read in the paper last winter from my dear friend Beverly Sills who said that she had gone to ten eulogies in three months, eulogies for artists in New York, dancers, choreographers. We've lost so many important and really extraordinary creative minds. Something must be done.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: First, a comment. I direct it to Mr. Smith. I've seen a lot of monuments around the world. I've never known one quite so moving as the quilt.

MR. SMITH: Thank you.

DR. LILLY: I went to Washington last fall for the March on Washington, looked at it from afar and decided I couldn't face going to look at it closely. Mr. Radley, I'm quite impressed with the way you've put together this -- or whoever put it together -- this organization of companies that are involved with aspects of the arts. This is the design industry. I sit here wondering what other industries that are heavily involved in aspects of the arts could possibly have banded together the way yours has? The only one that comes to mind instantly is the movie industry where vast amounts of money pass. I'm not aware of anything that they have done as an industry, but I'm just wondering if you know anything more about other types of industries that might --

MR. RADLEY: Well, film and television groups have banded together and done "one time only" events. There have been several successful fund raisers. But there's really no ongoing operation continually providing fund raising opportunities and that sort of thing.

Quite honestly, I don't know of any other organized groups that are doing what we're doing, which is to be running an ongoing foundation. Are you familiar with any?

MR. SLOWIK: There is a new group called Broadway Cares, who are doing a similar thing in terms of presenting events, by and large small events, that are meant to raise money for those who have been afflicted with the disease. In their case, they're going with direct aid to individuals as the outlet of their funding. But they have gotten a 16 theater unions, and Ms. Hart may know more about it, together to agree to help produce these events without charging union fees, which if any of you have done fund raising events know can eat very heavily into the profitability of a fund raising event.

MRS. HART: Have we heard from the musicians union?

MR. SLOWIK: I don't believe so.

MRS. HART: I didn't mention the arts organizations, but there was Dancing for Life, which the choreographers put together. There's the PEN organization, which is the writers organization that had a big fund raiser for AIDS. The industry itself has really rallied enormously. But I think we all know that. I think it's been pretty well publicized that Elizabeth Taylor has raised a great deal of money.

DR. LILLY: But that's individuals. I'm wondering if the industry per se --

MRS. HART: Yes. Well, this is PEN, this is choreographers, stage hands.

MR. RADLEY: There have been other big things, like Music for Life at Carnegie Hall. But that's a concentrated event.

DR. LILLY: They're one time events.

MR. SLOWIK: Right.

DR. LILLY: And that's fine. We need those too.

MR. SLOWIK: The vendor merchandizing industry also did an event at Carnegie Hall called "90 Minutes for Life." It was put together primarily by the people who do the windows. But they brought in all the various retail constituencies to the event. It was an unusual fund raiser in that they did not entertain the audience. They preached to you for 90 minutes about what you could be doing on the AIDS issue. It's a worthwhile video tape to see. It is available from Peter Glenn, the fellow who put it together.

But to my knowledge, there aren't other groups who are trying to facilitate an ongoing approach to the issue. Where the one-time functions miss an opportunity is in providing an outlet for very small efforts. By and large, the money we've raised has come from individual showrooms or product manufacturers who have donated X percent of their sales or who have done a party one night and raised $5,000. All those small amounts really add up to quite a bit of money. So, the benefit of having an ongoing venture is indeed to embrace those activities as well.

MR. KEARNS: One suggestion I've always had an hoped for is that the sports industry would become involved in raising money for AIDS. I think there's an incredible opportunity there which, to my knowledge, has not been tapped.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: I would like to, I think, express a concern as well as a question. Many of us have been involved with AIDS, as you have, for several years now. One of the things that is concerning me is that in the beginning, thanks to the efforts of the gay community, there was a great emotional reaction to the necessity for what had to be faced, what had to be done.

Then we saw also the recognition that this was, as one of you pointed out, a human disease, that everybody gets it. It's not a disease that belongs to any one community. We became conscious of the IV drug users spreading the disease. We've become conscious of the minorities in particular getting increasing amounts of this disease.

As this emotional peak was reached and we came into a valley, all the enthusiasm in the Congress, and granted some of the bills were ridiculous, but there were some 45, 50 bills, gradually they're all disappearing where most congressional bills disappear. I noticed abroad -- I just came back from Geneva where I was at the World Health Assembly -- the same reaction, even with all the excitement of the global program on AIDS. There is not the same excitement attendant with this problem as there was a year ago or two years ago, even though the program is well along, doing a good job, heavily financed and so on.

What concerns me is we're a nation of the quick fix. I'm not saying this critically, but I think what happened is with the efforts initially and primarily of the gay community, we did reach this emotional peak. Now it's gone. We ourselves as a Commission are striving to make recommendations which will recognize that this is a long-term national and worldwide problem with which we are confronted.

To me, what we need from you who are creative is a way to get around the quick fix mentality in this country, which is not easy. We need creativity from those of you who can provide it that will say, "Okay, we don't want to make this an emotional bonanza anymore. We've done that. We've gotten the attention we need."

Now, what can we do to make the American people recognize that if this problem is with us ten years or 15 years before we find a cure or a vaccine or what, what can we do to sustain interest? I am telling you, it was so discernable to me, particularly in Geneva. That really frightened me somewhat because there's a ripple effect of that. We're being very generous with our extra supplemental contributions and so on. The minute that ripple effect reaches back here, our contributions to the Global Program on AIDS will inevitably drop off.

We're recognizing that there's no quick answer in the laboratories, as one of you pointed out. We're recognizing that some behavioral change has occurred, certainly in the gay community. We recognize that the chances of behavioral change in the IV drug community are a much greater job to tackle. They're much more difficult to reach. But something is going to have to be done creatively to recognize that yes, this is not a special disease. I hate to say it, but "This is just another disease," in other words, but it's a disease without a cure and it's a disease without a vaccine.

What can we do to maintain continuing interest because a benefit here and a benefit there, a Hollywood special, that's not going to do a damn thing for us. I mean it will for a day or two days, but how many of you have had friends who have said, "Oh my God, not another special on AIDS," and switched the dial? They just don't want to watch them anymore because there's no answer. It's not because they're not sympathetic, but there's just no answer. This is something that we have got to find an answer to.

You're the creative people. I don't think business is creative. Business is conducted. I think that to think that business though any massive partnership effort is going to go into this with all four feet, I'm sorry, I think you're mistaken.

On insurance, the problems of the 37 million uninsured, the AIDS population is just a small part of it. You've got to solve that whole problem. When you solve that whole problem, the AIDS people will be included in that. But we've got to find a way to sustain interest. You can feel it. We who are with it every day, we can feel it. It's in a valley. Give me some answers or give us some answers. We need them.

MRS. HART: I know what you're saying. What you're saying is very good and it's a wonderful point. We've been concentrating on getting out information to the public, we've been concentrating on small benefits, relatively small. As you say, the American people are very generous and they will respond. What you're asking for is very smart and that is a political response. That's what we need. We need a political response to stimulate the government. That's what we need. Without that, as you say -- How long did it take, by the way, Dr. Walsh, to stamp out smallpox? How many years?

DR. WALSH: Well, once we got the World Health Organization and every nation in the world involved in it, it's been stamped out now. It took about three years, three to five years to finally --

MRS. HART: Is that all?

DR. WALSH: Well, to finally finish the campaign once they started on it. Now, you really don't have it. It was about five years, Frank, once they started the thing. But see, you had something. You had a vaccine for it.

MRS. HART: I understand that.

DR. WALSH: Oh, I think if you've got a vaccine for AIDS that you could do, the whole world would rise up and go to work.

MRS. HART: I understand. But I meant before we had the vaccine.

DR. WALSH: But I think it's more than a political reaction from the federal government. It's a sustained reaction from the American people to understand that just like -- the American people, they're worried about cancer. They're worried about cardiovascular disease. They're worried about cancer of the lung with tobacco and so on.

We have to get somehow, without diminishing the severity of the AIDS pandemic, we have to get them thinking about AIDS in the same way as they're thinking about these other diseases so that you're not constantly looking for the big bonanza to get interest on it again and drive up a sudden emotional peak because Bob Hope or some of the traditional people get up there and make statements.

But we have a sustained problem. That requires sustained funding, sustained activity, that it's one of a half a dozen other problems, but that it will get constant support without trying to reach another emotional peak to get it. I just have the feeling of somehow that strategy isn't going to work

because you can peak just so many times. I don't know what the answer is. I'm hoping that some of you can come up with some suggestions.

MR. KEARNS: I don't know what the answer is, but I also know that we're dealing with issues of homophobia, racism. We throw that into this.

DR. WALSH: Oh, yes, sure. All of that is in it.

MR. KEARNS: That are things that have to be fought politically and artistically as well.

DR. WALSH: Sure.

MRS. HART: I think the problem with solve itself in terms of the interest because it will escalate. When it escalates and it goes off to Grand Rapids and Sioux Falls and it's worldwide --

DR. WALSH: It's there.

MRS. HART: -- then that problem with solve itself. But I still think it's very important to keep some kind of pressure in front of the American people. I agree. That's very important. Something we must all think about.

DR. WALSH: I'd like to see a sustained pressure. That's what I'm talking about.

MR. SMITH: I think a lot of that sustained level of activity will, as Mrs. Hart said, continue. Most of the people that probably have come before you to testify got involved in AIDS because someone close to them died. When they first got into it, they thought they were in it for a little while, that it was a break from the rest of their lives and they would start organization or put on a play or start a little quilt and then go back to the rest of their lives. A lot of them haven't and have made a life commitment to this.

As the epidemic reaches other segments of the population and a broader spectrum of Americans continue to die, their family members and their friends will be drawn into it in the same way. As we burn out, others will be there. It will be a continuous level of excitement within the country and a continuous urgent need on behalf of individuals who are recently grieving over a loss. At a non-profit community level, there will be that. Whether there is the political will to continue a certain level over time is a different issue and I don't know if there's --

DR. WALSH: No. I agree with you and disagree. My concern is that I watched -- you know, like you say when it gets to Grand Rapids or gets to Sioux Falls, as long as Grand Rapids only has five cases or ten cases, really they don't get excited.

I watch nations where they were reporting, say Singapore or Malaysia where they're reporting only 50 cases or 75 cases, other countries with 200 cases. After talking about it for three years and now seeing only 200 cases, they're not looking ahead. What they're saying is, "See, after three years this is all we have, and I've got half a million people dying of infectious preventable disease. Why are we wasting all this time on this?" That's the dilemma and that's bad because that's what the people in Grand Rapids are going to say.

I don't know the answer and I don't think the Commission knows the answer and that's what I'm saying. We are looking for answers to get a sustained support for this program.

MR. SLOWIK: Representing a foundation, my viewpoint may be a little bit different. But one of the things that I think is most troubling for the future of AIDS service organizations is by and large they were indeed people who had been personally affected by the disease and were willing to get involved. That was the only criterion by which they become involved, is that they were willing to. No one else was.

What is going to have to happen is as AIDS service groups become institutionalized, those who were simply willing to be involved will need to be replaced with those who have the professional wherewithal to orchestrate the needs of AIDS service providers and of foundations.

I think one of the things the Commission could do in that regard is do anything it can to encourage the institutionalization of AIDS funding, be it through foundations, through government sources or through private industry. It's clear that it's not going away. I think all of us got involved and truly thought this would be over with in a year. It's not something that will need to be sustained. Clearly, it is.

I can see where you're talking of competition with other diseases in terms of the death toll to coronary. Heart disease is far greater than it is to AIDS. However, I think what Jonathan Mann said at the U.N. when he was speaking of the World Health Organization is that what you're going to find is the population is going to become disenfranchised and disenchanted with public service officials as they get more involved and more aware and the epidemic gets worse and worse.

DR. WALSH: Well, I think that it's good to this extent. The Brookings is having a meeting next week and one of

the things I see as a positive part of this meeting is that there are three -- and it's a meeting for foundations, to create foundation awareness. On the same program, they're discussing three things, AIDS, long-term care and catastrophic illness. Now, to me, that's a positive thing, that they are not discussing in the spirit of competition, but they are discussing them as the three major problems with which we are faced for the next decade. I think that's the beginning perhaps of the sustained effort and maybe Brookings has been smarter than we think in that they're not just having a conference on AIDS. They're putting AIDS in as a serious problem with these others. Maybe that's what we ought to be doing. I don't know.

MR. SLOWIK: Well, one other thing that you need to do is apply resources to the stage of prevention. While it's not a curable disease, it's a preventable disease.

DR. WALSH: Yes, it's preventable.

MR. SLOWIK: And you need to intercept the pipeline somewhere and not just wait for it to come out the other end. We've looked for challenge situations where we could engage the energies of others to help facilitate coming around from the other side and eliminating the higher incidence of AIDS because we can't stop what's already happened.

DR. WALSH: Thank you for your patience, Mr, Chairman.

CHAIRMAN WATKINS: Ms. Gebbie?

MS. GEBBIE: This may, in fact, be related to the previous set of questions. I'll direct it first to Mr. Radley.

MR. RADLEY: I'm sorry, I can't hear you very well.

MS. GEBBIE: I'll try again. I'll direct my question first to Mr. Radley, but I think any of you might answer it. Many of the things which would prevent the spread of AIDS are also tied up with the prevention of other conditions, around which there are voluntary groups that have existed for a long time, prevention of drug abuse, prevention of sexual activity at young ages, prevention of other sexually transmitted diseases. The same behavior change would also prevent HIV-infection.

Sometimes people seem to want to cling to the exclusivity of their own foundation or their own invention. To what extent have groups such as yours explored partnerships with those long-time existent organizations that have parallel missions, that have similar interests that you might reinvigorate with your new energies or where you might tap their expertise?

A related question. Your booklet on funders interested in AIDS is quite interesting. It includes some fairly old-fashioned, long-time foundations. To what extent were they interested in this project or to what extent did you have to kind of pound the doors down to get that interest going? Is there an openness to those kind of partnerships or is it something that takes a lot of building?

MR. RADLEY: There's a lot of potential for those partnerships and certainly this booklet being an example. This is about seven or eight foundations. People from each of those groups got together and spent about nine months preparing that.

In terms of funding, we have a very different sort of scale of economies than the Ford people and all the others that are mentioned. However, we have gone into situations, for example, one in Houston where our $10,000 or $5,000 was able to incite the community foundation in Houston to double our gift, our grant. We've had a number of other very successful partnerships. The Citizens Commission on AIDS in New York and New Jersey went to a number of groups. I think there were about five of us who banded together to fund that.

So, I think there's a tremendous amount of potential, but I really want to answer your question about what about the old timers, what about the steadfast group of philanthropists? It's very much a generally, I would say, a teeth-pulling sort of thing to get some of the bigger ones and the older ones involved. Same way of the corporate sector though too. There's really still a reticence about getting involved publicly with AIDS. It's gotten tremendously better, but it's still an issue.

There seem to be an ample list of reasons why some of the foundations that -- they'll come up with, for example, a policy that they have which is they don't -- it's not a single disease foundation. So, in this book, we've sort of taken what we collected over a year of all the reasons they couldn't do it, the negatives. You'll find a section in there about recommendations about how you can do it. Using that as an example, if groups say, "We're not a single disease donor," we'll say, "Well, do you have an education program?" "Yes." So we'll work it through that way. Perhaps an AIDS education grant might be something they could do. It's gotten a tremendous amount better, I must say.

MR. SLOWIK: Also, as the bigger foundations embrace the issue, the imprimatur of the Robert Wood Johnson Foundation, or most recently the Ford Foundation, with its challenge grant situation in ten communities, the sheep follow. The big foundations really drive the way the rest of the country goes. I think that's starting to happen. We're right at the brink where foundations are embracing it.

In 1984, only five foundations had given any money to any sort of AIDS program. As of now, it's around 185 and some $20 million. So, it is changing. That still, in terms of the philanthropy community, is a drop in the bucket. That is not a lot of money. It's an impressive gain, but it's not where it needs to be yet. I think that's where some of the institutionalization of AIDS will come from, when people realize it's just simply not going away. It's going to be here.

We also worked with a foundation, for example, in Houston where -- we are not a direct service provider. In other words, we fund others. But the Foundation for Immunological Disorders went under in Houston and asked us to take over their program. So, in Houston we have a separate 501(c)(3) that pays the insurance premiums of individuals who are persons with AIDS. But it wasn't part of our original goal to do something like that. I think those who embrace AIDS have to be very flexible to the different needs in each of the communities.

MS. GEBBIE: Thank you.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DeVOS: We got Grand Rapids into this act, so --

MRS. HART: Thanks to you.

MR. DeVOS: I know that. I want to just commend you for the work you've done. I would hate to think you don't feel like the dead have not died in vain, because they have not. I know this is a group that deals with that and is confronted with it and mourns that along with many others.

But in a little town like Grand Rapids, it's evident. We have had seminars in our hospitals. We care for our people. It's unsung, untalked about. It's just done in a very routine manner and very compassionately, I would tell you. I've conducted and participated in such seminars. The public education programs go on, public events have been staged to raise money.

So, the things you are trying to do are being done across this country. You're to be commended for your pioneering efforts. So, as you continue in your work, just don't get too down sometimes. You see it from a very short-range view. The shifting of monies from many needy causes to another needy cause is always a slow process. Of course, sometimes you only see yours. But everybody who's got any other disease sees only theirs. So, you are breaking new ground. Therefore, this Commission not only has to deal with those who are ill, it has to deal with the prevention of this disease for others.

So, I would hope as you move forward that you would put equal emphasis on the need of how to conduct yourself, and I know you do, so that we don't let this disease spread.

We did spend three days in Indianapolis on blood problems and we spent time on protection of the health care worker, the medical professionals, what the hospitals have to do to deal with this. So, this Commission is working on all of that as well. I just want to say be of good cheer. There are a lot of good things happening.

CHAIRMAN WATKINS: We want to close out the panel with, again, a restatement of our concern about the epidemic in the country and also to praise the work that you all have done in the past. It's just been commendable. You're keeping the awareness of the American public up and it's very important that you continue.

If you feel our Commission report has merit when it finally goes into the President, then the arts can have a tremendous impact on seeing that it is carried out as a national policy. That's going to take the arts to do it, because you have the power of the American spirit and you can bring about change if you feel that what we are going to be recommending is the kind of national strategy that will put this whole process on a sustained basis. You will read our initial report to the President.

Sustaining this movement is critical. We too often throw things at it one year and think that solves the problem. We've done that with drugs in the past and we aren't making the headway, so know we want to throw out the baby with the bath water before we've given the program a chance to have a life of five to ten years so we can measure whether or not we're making an impact. We want to throw something at it for a year and then get out of the game and we cannot do that with this epidemic.

And so, it's important then that you also pick up a share of the burden of keeping the continuing flow of information to the American people there. And, as I say, if the report is any good then I would hope that you would carry that message to the leadership in the states, in the Congress, and in the White House, that, "We like it. Let's get on it, and do whatever it takes." We will line that up to the extent we can, listening to the nearly 600 witnesses that will have come before us plus our site visits and plus hearing from people like you.

I'm an optimist on it. I believe the nation is ready for it, because it's a subset of a very larger malaise in the country dealing with the human resources. We have assumed too much about the human resources. Somehow we're going to fit the

supply and demand of material things. And so, we need to build a more compassionate and understanding and caring society and this is an opportunity to do it. And certainly you're in the business to help move it in that direction, This is kind of your business.

So, thank you for your dedication and your work. We hope that you'll be pleased with our final report and can help then carry it out in the nation. Thank you very much for coming today.

State Legislative Update

CHAIRMAN WATKINS: Our next panelist is our attorney, Mr. Richard Merritt who came before us prior to our first preliminary report to the President in December and gave us an update on what the George Washington University Inter-Government Health Policy Project was doing regarding the state legislative efforts in the epidemic. So we're glad to have Mr. Richard Merritt back again to give us an update.

Let us take a few minutes here, Mr. Merritt, and we'll say goodbye to these witnesses and then we'll start in a few minutes.

(Whereupon, at 2:31 p.m., off the record until 2:34 p.m.)

CHAIRMAN WATKINS: Thank you for coming back to chat with us Mr. Merritt. Now, please proceed with your presentation.

MR. MERRITT: Thank you very much, Admiral Watkins, Commissioners. I have brought several members of my staff with me. I hope you don't mind. I will be presenting the testimony, but these are the real experts on the staff and they will be responding to some of your questions, I hope, and will provide some additional insights.

CHAIRMAN WATKINS: Thank you. Just have them introduce themselves as they make their comments so that we can get it for the record.

MR. MERRITT: All right.

CHAIRMAN WATKINS: Their name and their relationship with your organization.

MR. MERRITT: I had the privilege to appear before the Commission last October, and at that time I hope I left the Commission, excuse me, are you hearing me?

CHAIRMAN WATKINS: Yes. Just pull it right up close to you and I think it will be helpful.

MR. MERRITT: At the time I appeared previously, I hope I left the Commissioners with the impression that state governments were indeed playing a significant part in the fight against AIDS and indeed were exercising sound and responsible leadership in the development of programs and policies designed to check the transmission of HIV.

Nothing has happened really in the past seven months to really change my mind with respect to that conclusion, and in fact, I think, the actions that state governments have taken over the past six or seven months have indeed really affirmed that judgment and conviction.

My objective really this afternoon is to try and update you on some of the more recent state actions which have occurred since I was with you last, to point to some broad trends in state policies, and to highlight some exemplary policies along the way, all in the framework of about 20 minutes time. In that time period all I can reasonably do is skim over some of the highlights and hopefully get into some more details during the question and answer period.

Also, given the brevity of time and the breath of the task, I've chosen really to concentrate on state policies and initiatives which have been developed pursuant primarily to state law. This in no way is intended to belittle the many fine initiatives that are taking place within the various state health departments or other state agencies or the Governor's offices and so forth. Just to describe the many things that Kris Gebbie in Oregon is doing alone would take all of my time. So we will concentrate really on those initiatives pursuant to state law.

The first thing that I would say is that measured by the growth in legislative proposals and enactments, the number of various task forces, study commissions, panels, etcetera, and in the amount of state general revenue support, AIDS has become one of, if not the major public policy issue within the states.

In 1984 there were less than 50 AIDS-related bills in fewer than 10 states. In 1987 we examined almost 600 AIDS-related bills in 48 states. Only the state of Wyoming did not consider an AIDS bill. The state of Kentucky was really out of session that year. In 1987, we're still into many of the legislative sessions and we've counted more than 550 AIDS-related bills in 41 state legislatures at this point. There are about six legislatures that are not in session this year. So I think that gives you an idea then from the point of view of the state legislatures, this is a major problem.

Clearly controlling the transmission of the virus is no longer the exclusive concern of only the high prevalence of heavily impacted states. I think an encouraging sign is that there is really a keen awareness among low and moderate prevalent states, which I think are still in the majority, that they have a significant opportunity to develop plans, policies and programs that can effectively curve the transmission of the virus. Evidence of this lies in several facts. Over the past two years about 20 legislatures mandated the creation of state task forces on AIDS, and most of these task forces have really been from states with low or moderate prevalence or lower moderate impacted states.

For example, North Dakota, the state that ranks 51st, dead last, on the list in terms of numbers of AIDS cases has produced 150 page volume in terms of a plan of action for their state. North Dakota has only six cases of AIDS and yet they have managed to develop the committee, the coalitions and so forth to come up with a plan of action. So I think this really should dispel the notion that only the most heavily impacted states are really concerned about this problem.

In addition to that several of the low and moderate states are dedicating as much state general revenue funds on a per capita basis or on a per diagnosed case basis as many of the more highly impacted states. I believe you do have our documents with respect to state AIDS expenditures and you will see in some of those tables that these facts are born out.

I do want to review just a couple of important findings though with respect to state spending. During the current fiscal year state governments have appropriated about $160 million for AIDS programs and activities. This is exclusively state general revenue. This is not federal dollars or local dollars or state Medicaid dollars at all. They are state general revenue appropriations. This is about a 500 percent increase over the $27 million devoted by states just two years ago.

Now, if you add state funding for Medicaid during the current fiscal year, states are putting up approximately $1/2 billion in their own money for programs, research, initiatives, and financing services, all related to AIDS.

Now, it is the case that four out of the five most heavily impacted states really account for about 60 percent of the total state dollars that have been generated in this point. Those are New York, California, Florida and New Jersey, but more and more states are coming on line. We recognize that in our report that over two thirds of the states now have appropriated at least some dollars for AIDS services and programs.

There are early indications now looking ahead to FY'89 is that we expect about a doubling in terms of the amount of state expenditures in FY'89, so I think we're looking at about $300 million plus in FY'89 just from the state governments alone.

Another thing we've observed is there has been a significant in the focus of state funding over the past few years. More and more state dollars are going into patient care or to support services, and those funds are being shifted away gradually from the surveillance, the epidemiological issues that we saw so much attention to before.

Another broad trend, which I think is also an important trend to note, is that two or three years back we were noticing that most of the legislation that was really considered in the states was really very piece meal. That is to say the issues would be addressing, or the legislations would be addressing one or two significant policy issues. More and more states seem to be taking a comprehensive, a more omnibus approach to the development of their legislation, considering a broad range of legal and public health considerations within one legislative package.

So on one package, you're seeing provisions that relate to confidentiality, to reporting, to disclosure, to inform, consent, to testing, to what about AIDS in schools and the work place, public education, disease control measures, all of it contained in one major package. The two best examples of this most recently really would be Washington State and Indiana who passed comprehensive legislation.

Now, moving into some of the specific areas, of all the public policy issues emanating from the AIDS epidemic no other issue has received as much attention and focus by the state legislatures as that of testing, and particularly that of mandatory testing. In 1987 of the 600 plus bills that we saw, more than 20 percent of them related in one fashion directly or indirectly to mandatory testing, and of that 20 percent, the majority of those really focused on the issue of pre-marital testing.

Now, despite all this attention however, most state policy makers including elected officials believe that except in a few limited circumstances mandatory testing is both cost inefficient and needlessly intrusive upon personal choice regarding health care decisions. Such limited circumstances however under which mandatory testing is taking place without consent in the states includes testing of the blood and blood product donations, testing of organ and tissue donations, testing of prisoners or those convicted of sex and drug related crimes, and then a final category patients involving accidental exposure of a health care professional.

Let me talk just briefly about some of these areas. In terms of criminal or incarcerated populations, 11 states now authorize testing without consent of convicted or incarcerated individuals. Most of these states are focusing upon sex crimes or crimes of sexual assault.

Georgia, for example, just recently enacted a law which requires testing of all new prisoners and all prisoners by the end of 1991, and the law permits separate housing of HIV infected prisoners. It does not require it, but give the Commissioner of Corrections the authority to implement separate housing.

The state of Indiana now allows testing of those convicted of a sex crime or an offense related to controlled substances, but only under the following conditions: the crime created an epidemiologically demonstrated risk of HIV infection; the person knew that he or she was a carrier; and finally the person had received risk counseling, either written, or direct, or through the mail.

In terms of accidental exposure we're seeing more attention of laws permitting health care providers, health care employees or patients who are accidentally exposed to blood or body fluids of another patient to petition to have that patient tested.

A couple of laws that have been enacted recently are in the states of Maine and South Carolina. Maine, I think, is noteworthy because it provides considerable due process protections of the individual before that person can be required to be tested.

Other areas where testing is taking place kind of more episodically or doesn't fall into any particular category, but testing can take place without consent. The state of Texas does authorize that patients undergoing medical procedures that could expose health care personnel to AIDS or HIV infection can be tested, but only if there is sufficient time that exists to receive the test results before the procedure is performed. And in Rhode Island, the Department of Health is authorized to develop regulations requiring the testing in the case of a newborn child when there is a high index of medical suspicion by history or physical examination indicating that the child may have contracted the HIV virus in utero or at birth.

Now, let me talk a little bit about the pre-marital testing area because I did mention that it has received most of the attention within the state legislatures. The majority of mandatory testing proposals, as I said, focus on pre-marital individuals, however the trend is really away from what the

states of Louisiana and Illinois have enacted. I think when I was with you last time I did mention that there were two states or two and a half states that had enacted mandatory pre-marital testing programs, Illinois and Louisiana. I say half because the state of Texas did enact the authority to the health department to implement a pre-marital testing program, but only at the point in which the state seral-prevalence rate exceeds .83 percent.

The Commissioner of Health is on record as saying that if you can tell me when that seral-prevalence rate hits .83 percent he'll be glad to hear from you because he doesn't have any idea of how to measure that. So, in effect, it's really a law without the ability to enforce it.

But I did say that the trend, I think, is away from what Illinois and Louisiana have done because we've noted that --

DR. CONWAY-WELCH: Mr. Merritt?

MR. MERRITT: Yes?

DR. CONWAY-WELCH: Could you repeat what you just had. I'm having trouble hearing you.

MR. MERRITT: I'm sorry.

DR. CONWAY-WELCH: I don't know if I'm getting an echo from the microphone or not, but if you could maybe speak a little closer to it.

CHAIRMAN WATKINS: I'll do my best. Is that better?

DR. CONWAY-WELCH: Okay, thank you.

CHAIRMAN WATKINS: I was saying that the trend is away really from mandatory pre-marital testing like what the states of Illinois and Texas and Louisiana require. We've noted in the past year that approximately eight states now have in lieu of a mandatory pre-marital testing program now require what is called pre-marital education programs. That is to say the provision of educational materials through brochures or video tapes to the marriage applicants about the AIDS virus, about how it's transmitted, and about where they can obtain an alternative test if they so desire.

One interesting approach is that of the state of Idaho that has one of these programs. Idaho is now developing, or had developed what they call a confidential self-administered risk appraisal program that really helps each of the marriage applicants understand their potential past exposure to situations or procedures that could have led them to infection. So it

really takes them another step, you know. Just instead of giving them a brochure, it really helps them try to evaluate their own potential risk to the problem.

In the area of routine testing, I know that has been some discussion of that at the federal level. There are no states that are doing this to our knowledge, but one state that is close to requiring this is the state of Rhode Island. Where the Rhode Island legislature is right now, at this time, considering a policy of routine testing for marriage applicants, for women presenting for prenatal care, for hospital admissions, and for individuals who attend sexually transmitted disease clinics, family planning clinics, and drug treatment centers.

Under this policy, all of those individuals would be tested unless they expressly object and are willing to sign a legal waiver stating that they refused to be tested after hearing the arguments as to why they should be tested. Again, this is now a law, but it's coming very close to being enacted in that state.

So to close our here on this particular section, most states really have rejected the idea of mandatory testing of most individuals who engage in high risk behavior, and certainly reject the notion of requiring testing of low risk populations.

State policies at this point, I think, are designed to encourage voluntary testing and counseling by the provision of adequate and accessible alternative testing sites, and also by removing barriers to individuals to seek voluntary testing and counseling primarily through strengthening state confidentiality laws as well as safeguarding against discrimination.

We've seen other trends too with respect to counseling. I think the time when I was with you before, there were no states at that point that actually mandated through legislation that counseling really accompany testing, but now we've seen four or five states that have incorporated that mandate into statute. Washington's law is noteworthy as it's one of the first to establish minimum statutory standards for counseling.

Approximately 13 states at this point specify in statute requirements that mandate that informed consent must be obtained before a health care provider can order and HIV antibody test. We know at this point that about 13 or 14 states are now requiring that reporting of HIV antibody positive status is required. Obviously all states are reporting clinical diagnosis of AIDS. A few states are reporting AIDS-related conditions, but the controversial area is with respect to antibody positivity, and there are 13 or 14 states. Not all of them require that reporting to be done with identifiers however. Several of them

required it be done on an anonymous basis and they use the information primarily for epidemiological purposes, but some states do require that identifiers be associated with the reporting.

With respect to confidentiality, most states continue to reply upon existing statutes or regulations for the protection of confidentiality of medical records and public health information. However, about ten states have enacted new legislation to provide additional safeguards for HIV medical records.

The two states that I would suggest are the toughest at this point are really California and Massachusetts. California's law prohibits the disclosure of HIV antibody results to a third part without the written authorization from the patient for each separate disclosure.

Other states do permit limited disclosure without consent to specified individuals. For example, the subjects provider to the state health agency, to research institutions, and sometimes to blood banks.

All of these new laws do provide fairly severe penalties for breachments of confidentiality. And several states at this point have enacted provisions requiring that certain personnel or individuals be notified of their possible exposure to the virus. For example, emergency medical technicians, funeral personnel, fire fighters and the like.

One highly controversial issue which relates to confidentiality is the notion of the duty to warn unsuspecting partners of their potential risk of exposure. We know, of course, that physician-patient confidentiality has never been regarded as an absolute, and that courts have ruled on occasion that a physician's duty to protect confidentiality can be outweighed in certain circumstances by the need for public safety.

So far no state has imposed a statutory requirement on physicians to warn unsuspecting spouses or partners of HIV infected persons about their potential exposure. However, a few states have enacted provisions which certainly modify traditional physician-patient privileges, and now authorize at least what one can describe as a discretion to warn as opposed to a duty to warn.

California law, for example, exempts from liability physicians who choose to release test results to the spouse of an HIV infected person. A Georgia law allows the disclosure to an HIV infected individual spouse, sexual partner, or children, but the physician must first contact the person and notify that individual that they intend to disclose that information.

There are three or four new laws in the area permitting a physician to disclose information about their patient's antibody status to other health care providers who may be placed in contact with bodily fluids of the patient during a medical procedure.

With respect to discrimination, practically every state has a law or regulation prohibiting discrimination based upon physical disability or handicap. Most state human rights or civil rights commissions have declared so far that AIDS, and in many circumstances AIDS-related conditions, are protected disabilities or handicaps under those states laws. A few states have passed special legislation outlawing the use of the antibody test with respect to employability as well as certain circumstances with determining insurability.

I'm sure you've heard about the District of Columbia's stringent regulations with respect to discrimination in insurance. California also outlaws the use of the ELISA and Western Blot Test for the purposes of determining insurability.

Discrimination in the provision of health care however is a growing concern. Health care is not a protected benefit in federal or state handicapped laws. Courts have never really imposed a legal duty on physicians to treat, and we know that there really is wide-spread lack of access to nursing homes at this point.

A couple of state laws that have come in recently that I think are noteworthy in this area is the state of Kansas recently enacted a law which says that information regarding cases of AIDS reported in accordance shall be used only as authorized under this act, and such information shall not be used in any form or manner which would lead to the discrimination against any individual or group with regard to the provision of medical care or acceptance into any facilities or institutions for medical care, housing, education, transportation and for the provision of any other goods or services. That is perhaps the most sweeping anti-discrimination law we've seen in the states at this point.

There are many other policies. We noted Kris Gebbie's policy with respect to your own health department as I think a model policy with regard to anti-discrimination that other health departments may wish to look at as well. In the area of disease control or personal control measures, over the past three years many states have undertaken a re-examination of their public health statutes or their communicable disease statutes to determine whether or not the provisions contained in those statues are really adequate with respect to surveillance and personal control within the context of the AIDS epidemic.

This re-examination, I think, was really prompted in part by the tremendous attention given to the so-called recalcitrant or non-compliant individual. Now, many states found that these old laws, or these laws that were really enacted back in the forties and fifties were really antiquated as many of them provided perhaps to much power to the state and not sufficient provisions for individual protections.

I remember, Kris, at a conference you spoke at, you stood up and told the audience that as the health officer in Oregon under the old law that you had, you had almost carte balance authority to isolate the entire audience there just upon your say so, and it was because of that, I think, and your knowledge to try to exercise that authority in the context of this epidemic would not have passed judicial muster. And I think the same circumstance has applied in many of the other states who have really recognized that those laws were to antiquated and needed to be updated.

These laws are very complex, and I don't intend to go into the details, but I think the important thing to understand is that many of the states have really, yes, reaffirmed the authority of the state government to, under certain circumstances, isolate or indeed quarantine individuals if necessary but only after a number of measures have been taken, and those laws have now incorporated a great deal of sensitivity to civil liberties and due process protections.

So that they have shifted the burden of proof onto the state to demonstrate than an individual may be an endangerment to the public health. It generally requires a court order for them to provide any sort of restraint, and that the state is usually obliged to provide progressive measures of intervention going from the least restrictive to the most restrictive measures.

About seven states have recently amended their criminal codes to make it a felony for an HIV infected person to intentionally expose another person to the virus without informing the other individual of their infected status.

Indiana, for example, it's a Class C felony now for knowingly donating blood containing HIV. It's a Class A felony if the donation actually results in the transmission of the virus. However, the law states that a person must have had some risk counseling before they can be found guilty of knowingly transmitting the virus. Shifting quickly now to some other areas. In the field of education, Oklahoma was the first state to mandate that AIDS education be taught in public schools. Currently there are about 12 states that have adopted similar mandates either by statute or by requirements through their state boards of education.

Most of these mandates require that the circular stress abstinence as the primary mode of preventing transmission. Practically all of these mandates give the parents an opportunity to review the curriculum beforehand and to excuse their children from participation before they do object.

With regard to public education, more and more state dollars were really being invested with respect to programs targeting at educating the public. I think some of the more exemplary practices have occurred in states like Massachusetts and Alaska and Connecticut, where Massachusetts and Alaska have actually mailed out the Surgeon General's report on AIDS to most of the households in their state.

More states are moving in the direction of requiring training of health care providers. The state of Washington became the first to require appropriate AIDS education as a condition of licensor. The state of Florida has a bill right now that apparently will pass and is expected to incorporate similar requirements.

Indiana adopted some extensive provision requiring the State Board of Health to provide semi-annually to all physicians and dentists current information concerning the etiology prevention transmission and treatment of AIDS.

Now, let me close out with talking about cost and financing issues in the states. I think the good news is that the cost per case, as I'm sure you've heard by now, has come down dramatically due to less use of intensive acute-care services, and far greater attention to out-patient services and case management.

The estimates we were hearing as recently as two or three years back of $140,000.00 per patient case is no longer really tenureable. Basically what we're looking at now are costs per patient in the area of $25,000.00 to $35,000.00 as identified by the Andrulis study.

The bad new however, from the state's point of view, is that it appears that the financial responsibility for the cost and care of AIDS, ARC and HIV infected persons is really shifting more and more towards the public sector and particularly to state and local governments.

The concern is that as a result of a number of actions, or indeed inactions by government in the private sector, those with AIDS, AIDS-related conditions, and HIV infection may be a growing sub-class of the already expanding uninsured population, something you were talking about earlier, Dr. Walsh.

Now, what are states doing to try to close those gaps with respect to coverage? There are a couple of strategies, state policies that really focus on the private sector, and policies that focus on the public sector.

With regard to the private sector, there are several states that have affirmed and enforce regulatory provisions guaranteeing that persons with AIDS not be treated differently than other individuals. For example, prohibiting insurance policies from excluding coverage for AIDS or prohibiting the denial of coverage based on sexual orientation. There is a West Virginia law that provides coverage may not be cancelled or non-renewed because the policy holder has AIDS.

Also a few states have regulated the conditions under which companies can use the antibody test for purposes of determining insurability. But there are really no states that are applying the District of Columbia or the California model. Most of them really have rejected that at this point and have decided not to intervene really in the underwriting process.

New Hampshire law, however, just recently enacted, does allow the Insurance Commissioner to monitor the number of antibody tests that have been given and report to the legislature on the number of persons denied insurance.

Other states like Oregon have suggested that if the state is going to allow companies to use the antibody test for purposes of determining insurability, and then deny insurance based upon those who test positive, the state has an obligation to identify alternative financing mechanisms for those individuals.

Oregon's answer was really the creation of a health insurance risk pool arrangement. Essentially, under this kind of a strategy, the state requires all companies participating writing health insurance in the state, to essentially pool the risk and offer a comprehensive health insurance plan to individuals who, because of existing or pre-existing conditions, makes them "uninsurable." And indeed those with AIDS and AIDS-related conditions would fall in those categories.

One noteworthy thing about the Oregon health insurance risk plan is that they actually make an affirmative policy which tries to really increase opportunities for those with AIDS and AIDS-related conditions to really become qualified for their plan by making those with the diagnosis of AIDS presumptively eligible for their program thus avoiding a six month waiting period under that program. The state of Minnesota has a similar policy.

States are also requiring private carriers to continue health insurance benefits after an individual has lost

employment for a certain period of time or allow that individual to convert to an individual policy.

These are some of the things that states are doing with respect to the private sector, but what about the public sector? The Health Care Financing Administration estimates that during the current fiscal year approximately $600 million is being spent through the federal-state Medicaid program for AIDS patients. States account for approximately half of that amount.

We know that 46 states now are paying for reservoir for AZT under Medicaid. Several states through their Medicaid programs have been adding optional benefits which really will provide significant services for AIDS patients, optional benefits such as case management and Hospice benefits. And yet one of the biggest problems we know of within the Medicaid program is really the unavailability of nursing home beds for AIDS patients, resulting in the fact that many individuals are kept far longer in hospitals and more intensive arrangements and certainly a more costly levels than are really needed.

A few states really have approached this problem by increasing or considering increasing reimbursements under Medicaid to nursing homes that are willing to accept those patients. The state of Illinois is one of those that have developed a quality incentive payment system under their Medicaid reimbursement program.

Four states we know at this point have received waivers from the federal government to operate so-called home and community-based care services for AIDS patients. These kinds of programs are providing traditionally non-medical kinds of services to try and detain or keep individuals out of institutional care.

And then several states are examining possibilities of expedited review under their capital control systems, under their certificate of need control systems for facilities that are interested in actually building or renovating for purposes of providing services for AIDS patients.

In conclusion I believe that the states can really be rather proud of the record that they have compiled so far in this fight against AIDS. Despite the numerous pressures to "do something" almost at any cost, despite the occasionally outburst of hysteria and despite the constant attention and focus on the areas of controversy and conflict, issues of contact tracing, of mandatory testing, of isolation and quarantine, I think any fair assessment of the facts at this point can only reach the conclusion that the states responses have been measured, reasonable and not at all over-reactive.

I close really with one of the modern day philosophers on AIDS, June Osborne at the School of Public Health, who said "AIDS is the most difficult terrain possible for politicians for the wisdom of present policies often will not be validated for five or more years and some of the necessary language of prevention is awkward to use in oratory. But reluctance to embark on difficult programs is predicated on the assumption that the situation is temporary, that it will go away. It will not of course, and a savvy politician is wise to surmount the short term impediments to sound policy for the future will bear out the wisdom of frank and sensible approaches." I thank you once again for allowing me to appear before you, and I hope I've given you at least some flavor of the response that states have been making to this epidemic.

CHAIRMAN WATKINS: Thank you, Mr. Merritt. Let me start out with one broad question and I'll pass it on down to Dr. Conway-Welch on my left. You are in a unique catbird seat, from my point of view, in looking at the states and seeing what they're doing. You've watched the 50 to 600 bill ratio change in only three years. You've looked at both redundancies, and you must be sometimes questioning some of the disparity in policies that don't seen to have a logic train. You've probably seen some convergence in ideas and you talked about some of them regarding pre-marital testing and the like. If you let the process just move that way, eventually it would probably tend to come together to considerable degree in commonality, but there is ways to incentivise that perhaps.

In looking at all of this and knowing, as one of our Commissioners has said, "AIDS walks", and you don't want to have a migratory attraction to the detriment of one state at the expense one of state to their detriment to have some other state to perhaps have a law that really doesn't have the compassion, the sensitivity, the variety of problems that a person with AIDS faces.

So having looked at all of that and you're sitting back here kind of watching what the states are doing, then how do you respond to the question of what is it then that the federal government needs to do where you've seen the problems associated with lack of guidance? Unless we talk about legislation in a variety of areas that may lead to the confusion and to disparity that you don't seem to think needs to be there, where would you harden up the federal legislation, in what areas, for example, as you view it to give the states the guidance they need from the national leadership of Congress that would help, not hinder, or not go to far to prematurely? But what would be a balance approach right now at the federal level for legislation to assist the states in giving whatever they need, the backbone, the spine, the guidance that's necessary to remove some of the policy obstacles that may be there?

MR. MERRITT: Whew!

CHAIRMAN WATKINS: Well, take them in bits and pieces. Let's talk about discrimination, confidentiality, legal liability. There's a package. How about the field of education, do they need any additional legislation there? How about the area of health care delivery, do we need any guidance there? How about the area of drug development, do you need any further guidance there just looking at what they're doing? And the ups and downs of some of the, perhaps, a fragmentation of thought that's out there, is there a way to begin to congeal it more by some sort of legislation, and not necessarily hard hitting, demanding, directive kinds of things, but taking existing laws and straighten them out, pulling or wrapping things under the epidemic in such a way that you can remove some of these obstacles that we're getting from the 600 witness coming before us that need help?

They're crying for help. Many of them call for federal legislation. There have been positions taken that we don't' want to put federal legislation out to fast, you know, let the states do their thing. Well, are we getting to the point where we need to take a look at that concept and maybe tighten it up a little bit?

MR. MERRITT: Well, I have difficulty in making recommendations regarding what federal policies really out to be given the position that I am with respect to our particular project.

We do not represent a particular constituency base or anything like that. My role is really one of more trying to identify innovations, trends, developments that you can then infer from that in terms of what perhaps the particular federal role ought to be.

What I will say, Admiral Watkins, is I think we can take some comfort out of the fact that there is some convergence to the meaning, I think, with respect to some of the state policies. In so many of the areas basically states are very anxious to know what other states are doing, and really what makes -- what are some of the ingredients, principles of sensible policies.

There is an awful lot of information exchange going on between our project, between association state health officers that Kris Gebbie has been active in so long between the Conference of State Legislatures, the Governor's Associations and so forth. And I think it really may be premature at this point to say that there are even any areas, or I would be reluctant to say that there are any areas at this point where federal

legislation is really required or absolutely required at this point. I simply can't say that.

I will say that having been around this town for a considerable amount of time, I am very leery of federal initiatives which actually look out there over the broad terrain of state governmental actions and say "Aha, here is a great idea in Oregon or Wyoming or Texas. Let's nationalize it on the rest of the country."

I've lived and I know Kris Gebbie has lived in her life in state government through the Federal Health Planning Act. I think that may be one prime example of a program really gone wrong because the nationalization of it simply did not take into account the sensibilities of local circumstances and local needs, regional needs.

So I am very leery of nationalizing programs on the states. At the same time I think that there are things that the federal government can do to make the state's lives a little bit easier and to really provide additional progress in some of these areas. I'll talk about the area of financing for example. I know that in the previous panel Mrs. Hart mentioned a considerable amount of her testimony related to the area of insurance.

We know that one of the problems with our health care financing system, as someone once identified, it's really like a three legged stool. You either have it as a fringe benefit in the work place, you have it as a categorical entitlement which is usually conditioned by some sort of categorical eligibility, Medicare or Medicaid, or you have it as a matter of chance and charity. And it's really that area of chance and charity I think that the state governments are really trying to focus on, and I think, Dr. Walsh, is what you were trying to get at in your remarks.

One of the real problems in this area, I mentioned this health insurance risk pool kind of arrangement which I know in several states, Oregon being one of them, it was the problem of AIDS financing or AIDS-related condition financing that to some extent drove the Oregon legislature to enacting that kind of approach.

One of the real limitations to that, however, is that state governments cannot regulate self-insured plans, and we know that about half of the insured population tied to the work force now are really under self-insured plans. And what this means is that it takes out a significant chunk of your base with which you can tax for purposes of providing those kinds of services. The federal government has control of those self-insured plans and so I would encourage you to look into the HIRSA

Act which governs self-insured plans and consider the possibility of giving state government some latitude over the regulation of those plans. I think it would help tremendously with respect to covering some of those gaps at the state level.

CHAIRMAN WATKINS: Let me just follow up, are you saying from your vantage point that the anti-discrimination protections throughout the states are adequate at the present time?

MR. MERRITT: I would say before that you consider going to some kind of federal discrimination action, that there needs to be some serious assessment as to whether or not those programs are adequate or not. From where we sit we simply have no way of judging that.

Now, it's my understanding that the State Health Officer's Association has had some campaign to look at issues of discrimination, and they would be in a much better position -- Kris, am I right, I thought there was supposed to be some kind of report with respect to the inadequacies, perhaps, of some of the state discrimination laws?

CHAIRMAN WATKINS: Well, I was really interested more in your personal outlook. You sit in a very unusual position, I think, and this is why we included the summary of the state's positions on a variety of things in our preliminary report to the President, because I think it revealed a great deal just to look at that mixture of priorities and focus from the various states, where they were at the time, in itself was valuable, and we included it.

You are sitting in a very unusual position to make some personal assessments, and I didn't mean to put you on the spot that you report was going to come out and come up with a lot of conclusions. I know it's difficult for you in open session to separate yourself, but I was talking about Mr. Merritt as an individual more than I was the project and how you might be criticized for taking a position. But you are sitting there watching a variety of things happen in the state.

You mentioned the one area of pre-marital testing, that you seem to be migrating away from the concept in Illinois and in other states, so those are lessons learned already that begin to tell us about things, the variety of things affecting the control of the epidemic. I'll pass it on now to Dr. Conway-Welch.

DR. CONWAY-WELCH: I'm going to try to flip your question around a little bit. You identified patterns of convergence that are occurring across states. I'm wondering if it might be appropriate to ask if you could share with us a summary of those patterns of convergence and at the same time

share a summary of the patterns of dis-convergence if there is such a term? Diverse, thank you.

Again, from your perspective, I think that that might be very helpful to identify places where we may need additional discussion or information or whatever, but that you have a gestalt assessment of both of those patters that I think would be extremely helpful and would save a lot of time if we would somehow have those put together.

I know in your reports you have them done in certain areas under issues and what each state is doing, but there is almost one step further that would be helpful in terms of then kind of extracting from that what the divergence is?

MR. MERRITT: Well, in terms of convergence, I would simply reiterate that the states, I think, support the notion that mandatory testing, with the exceptions that I identified, really the incarcerated populations, with some minor trends with respect to health employees or health providers or emergency technicians that may have been accidentally exposed, and with the testing, of course, of bodily fluids and all that, there is a strong, I think, consensus out there that mandatory testing really has no place in controlling this epidemic.

And that it has become almost a truism to say that really all we have, of course, is the voluntary cooperation of those individuals that are at risk in terms of coming forward to be counseled and to be tested and that I think most of the state policies to this point really are consistent with trying to insure that this did not go contrary to that objective.

I think that there are areas, and I'm not sure we can say they are areas of divergence, but I mean they are just areas that are emerging and no clear consensus one way or the other really has taken place. I think this would --

DR. CONWAY-WELCH: That would be helpful.

MR. MERRITT: -- be, I would consider, in the areas of what to do about informed consent. We are seeing more states at this point statutorily require informed consent take place before antibody testing can occur. Some of those are requiring it in terms of written informed consent and others just are saying informed consent has to be taking place. But how that is actually affected can really diverge tremendously from state to state.

The areas of confidentiality protection, as I said, there are a couple of standards that if you really are concerned about confidentiality, you may take a close look at California and Massachusetts laws, but the down side of that is those stringent kinds of regulations really impede in terms of the

delivery of health care to those individuals. And the legislature in California, I think, is really taking another look at perhaps providing some disclosure of test results without the written informed consent of the individual under certain limited circumstances.

But the states that have enacted legislation in these areas differ considerably with respect to the list of individuals or institutions that can receive or can have the test results disclosed. Mona, do you have anything got add at this point?

MS. ROWE: I was just going to reiterate what Dick said in terms of --

CHAIRMAN WATKINS: Could you state your name please?

MS. ROWE: My name is Mona Rowe. I'm a senior research associate at UIHPP and I also work or devote my time at the AIDS Policy Center which is part of UIHPP.

I'm going to reiterate what Dick said in terms of convergence and divergence in trends in terms of confidentiality and informed consent.

In one hand on the informed consent issue in terms of legislation that we see, we do see laws being passed mandating informed consent before there can be HIV antibody testing. On the other hand there is anecdotal information that there is a backlash at the state level growing from providers who are concerned about what the implications are in terms of informed consent.

Some of that is being taken care of in terms of liability provisions in terms of the statutes. An increasing number of laws are being passed that is removing the liability from a physician particularly in terms of, perhaps, confidentiality and duty to warn. The liability in terms of failing to get duly informed consent.

There is one state and that I think is New Hampshire, New Hampshire has been one of the first states to come up in it's law that removes the liability from the physician if they offer informed consent. If they offered the test and the person says "No, I do not want to be tested", it removes the liability from the physician for malpractice. Let's say if a person does not get tested and then there is a miss-diagnosis and just as long as the physician can document that he offered that test to the person and it's documented in writing, then the physician is covered in terms of liability.

And what that does is, it gives the physician some sort of reason why they want informed consent too. It also ends up protecting them where they can document on a patient's chart "We talked about it, and this person refused it. I fulfilled my duty." That was one state that has done that.

The other area in confidentiality. As Dick said, there --

CHAIRMAN WATKINS: But that doesn't require a law. What you just said is probably medical practice in many states now by doctors who --

DR. CONWAY-WELCH: Right.

CHAIRMAN WATKINS: -- just merely say it was denied and it's noted in the medical records so that there can be some recognition of that. That doesn't require --

DR. CONWAY-WELCH: This is specifically in the statute --

CHAIRMAN WATKINS: I see.

DR. CONWAY-WELCH: -- specifically was with regard to HIV testing and informed consent --

CHAIRMAN WATKINS: Do you think it makes sense to have that in the law?

DR. CONWAY-WELCH: Well, I'm just saying that all I know, and I'm not recommending one way or another, that a lot of physicians have raised that as an issue that they do not necessarily want to seek informed consent for a variety of reasons.

CHAIRMAN WATKINS: But is it a matter of question in the other states among the medical practice that they're very worried about that, that legal liability under circumstances where the informed consent was denied by the individual?

DR. CONWAY-WELCH: Pardon, I'm sorry?

CHAIRMAN WATKINS: Not having a law, are they worried about not having a law that's very clear?

DR. CONWAY-WELCH: I think that the reason they're worried about the other informed consent provisions is because they're to prescriptive. They're afraid that if the law is to detailed in terms of what involves informed consent, if they say A, B and C, and perhaps alongside A, B, C, D, and E they might have -- and so informed consent in very tricky in terms of how

much you want to legislate in terms of what needs to be said and what constitutes informing and counseling. And doctors are also afraid there that they might not say what needs to be said.

But Oregon, again, they have an informed consent form and they produce -- and the doctor can just give it to the patient and they have the information.

In terms of confidentiality, there is a wide variety. A lot of states are addressing that as an issue, and some states are being very specific in terms of what's covered. There is a wide range of exceptions, and in some states there might be four exceptions given where there might be committed disclosure.

In other states there are up to 26 exceptions, and by the time you get to the 26th exception and you figure out who's getting the information, you find out that quite a few people are getting a lot of information and the way that they define what information they can have is, in some states, being defined very broadly.

So that while they are approaching the confidentiality issue, there is some wide variation in terms of the disclosure and who it's going to be disclosed to.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: Just a moment.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: Dick, I'm sorry I missed the first part of your presentation because I had to answer some messages so if I ask any that you've already said, just forget it. I wondered, again on the confidentiality issue, whether you are noticing, not in specific numbers of legislation, but a more relaxed or broadening attitude about confidentiality at least as far as the physician is concerned, and as a sort of followup to the previous question.

I know that in the recent resolution passed at the World Health Assembly on AIDS, which was very strong on anti-discrimination, was very clear in their discussion that confidentiality was no even considered anywhere except in the United States as something that the physician did not have his discretion. Every country in the world leaves it up to the physician-patient relationship except this country. I mean certain states in this country like California and so on where it is up to the physician to determine whether he should disclose to a spouse or partner and so on. So it's never been an issue anywhere else.

I mean the interpretation of confidentiality has always been very broad and in that normal context that physicians and patients have a relationship which is unique, and it's up to the judgment of the physician.

But have you noticed that this is broadening or relaxing here sort of in general in discussions or interpretations? I think eventually it will if it hasn't. It certainly will present a bill, if it becomes law, certainly will cause California to reverse its position else they will get no Medicaid or no federal funding at all.

MR. MERRITT: Well, you know, at the same time, California has one of the strictest standards for maintaining confidentiality of patient records. I did say that it is one of those states now that actually has enacted a law which can be interpreted as sort of a break in the armor of traditional physician-patient privileges by virtue of giving the physician the authority to release information to the spouse of an HIV infected person and exempting the physician from any kind of criminal or civil liability for doing so.

I think in that regard, Dr. Walsh, you can say that there has been a lessening of confidentiality standards --

DR. WALSH: Seems to be.

MR. MERRITT: -- I suppose by virtue of the fact there are now about six states that are allowing that to happen, or have recently authorized physicians to, instead of, like we say, "a duty to warn" or providing concept of a discretion to warn?

DR. WALSH: Well, I kind of had the feeling that in another six months this may be a non issue or --

MR. MERRITT: Perhaps you're right.

DR. WALSH: -- perhaps eventually be a non issue.

CHAIRMAN WATKINS: Did you have a comment on that?

MS. THOMAS: I'm Connie Thomas and I am a Research Assistant to project. The other point I would make in reference to this that's also good is discrimination, or as fear of discrimination really goes down and people are not as scared about, say, this disclosure, I also think that the fear of this privileged information will also decrease and, as you say, relax.

CHAIRMAN WATKINS: Now, on the insurance coverage, have the states been differentiating between health insurance and life insurance in regard to testing to a serious degree? Because, you know, I can see in health insurance where these people should be

insured with it, but I can also where the insurance carriers really need protection against a sudden hit on a $1/2 million policy -- sero-positive.

MR. MERRITT: Yes.

CHAIRMAN WATKINS: But have the states recognized --

MR. MERRITT: Yes, in terms of the actual enactments that have regulated the use of the antibody test for insurability, it has -- those laws have distinguished, in my recollection, between life and health insurance. I think you're quite right. Obviously in terms of life insurance, the concerns of adverse selection are much more considerable than with respect to health insurance by virtue of the fact that life insurance, all of those policies or most of those policies, are individually underwritten.

CHAIRMAN WATKINS: Because, again, it was a very strange experience in Geneva to find the Soviet Union being the leaders on individual rights of the healthy --

MR. MERRITT: Yes.

CHAIRMAN WATKINS: -- which they were. In which they maintained that while every compassion and dignity and so on should be shown to those, and no segregation, no discrimination against those that are sick, that the healthy individuals also had rights and that the state or the government had an obligation to see that they did not suffer reverse discrimination. It was interesting.

They talked about life insurance which I know they don't have, but they apparently had been reading about our problems, and they were being very strong advocates of the fact that Americans should be testing for life insurance so that people would not be prevented from buying it. Whether they buy it when they're here or not, I don't know, but they know all about it. And I've wondered about how strongly some of the states were looking at that.

Did you say $600 million had been assigned by HCFA for Medicaid for AIDS patients this year?

MR. MERRITT: $600 million was the estimated expenditure by HCFA during the current fiscal year for Medicaid expenditures for AIDS, yes.

CHAIRMAN WATKINS: Do you know what they're projecting for the next year?

MR. MERRITT: I don't know. I'm not sure we've seen those projections, but it was about $400 million last year, so you can --

CHAIRMAN WATKINS: So I would imagine it would be $800 million.

MR. MERRITT: Yes, probably doubling, so we're probably looking at $700 or $800 million next year.

CHAIRMAN WATKINS: Because that would make the projected figures that used to be used for 1990 way out of whack.

MR. MERRITT: Yes.

CHAIRMAN WATKINS: I was just wondering about that because, again, when you look at the catastrophic insurance hassle over drugs --

MR. MERRITT: Yes.

CHAIRMAN WATKINS: -- of payment drugs, they're arguing about in '93 less money than they're talking about in AIDS appropriations in 1990 and that's just going to cause all kinds of problems.

MR. MERRITT: Well, from the states point of view, the research that is showing that the effects of AZT upon longevity, of course, is good news, but at the same time what that means from the states point of view is that individuals living longer are then in a position to exhaust their resources to, as they say, under states with medically needy programs, spend down those resources and become eligible under Medicaid. So I think there is going to be a heavier impact upon state publicly financed Medicaid programs in the future definitely.

MS. LIPSON: One other quick comment. I'm Debra Lipson, Senior Research Associate with the project, and that is that it's not real clear at this point why there are increasing numbers of AIDS patients who are Medicaid recipients. It could be because of lengthening lifetime from diagnosis to death because of AZT. It could be that, especially in California, there is early indications that more and more of the AIDS patients even in California are IV drug users, which is a population that is more likely to be immediately eligible for Medicaid.

So there could be any number of reasons, and I don't think the states or anybody else really knows how to estimate, you know, what the Medicaid costs are going to be from one year to the next. It's very difficult.

Just with regard to whether or not states are regulating or making the laws in terms of differentiating between life and group insurance, they are to a certain extent -- through the law, they came back and amended it. They do allow testing for the individual and life insurance policies. They've kept the mandate prohibition begins testing for the group policies. And I say in those states that have legislatives in that area, they do tend to differentiate between individual testing and the group testing.

There is a trend, however, that one thing they're doing is many insurers have thresholds and they say that you can, you know, test if you're getting an insurance policy over a certain threshold and --

CHAIRMAN WATKINS: Do you know offhand --

MS. LIPSON: -- they're finding that the thresholds are being lowered so they're testing more people.

DR. WALSH: Do you know offhand if in this long-term care thing that Senator Pepper, or Congressman Pepper is pushing, is that purely for the aged or is that going to include coverage for AIDS patients or any long-term ill patient? I haven't had a chance to review that legislation on that.

MS. LIPSON: My understanding is that that bill is targeted at Medicare beneficiaries so that anybody who would qualify --

DR. WALSH: Would that spill into Medicaid?

MS. LIPSON: No, not Medicaid.

DR. WALSH: It would not spill into Medicaid?

MS. LIPSON: Not that I know of.

DR. WALSH: Okay.

MS. LIPSON: I mean only to the extent that AIDS patients are currently qualifying for Medicare, and there aren't to many of them.

CHAIRMAN WATKINS: Dr. Lilly, you had a followup comment to make?

DR. LILLY: Yes, I just wanted to comment. You were talking about the physician's discretion with respect to confidentiality elsewhere in the world. It's my recollection that Alain Pompedou when he was here stated that in France the physicians confidentiality is absolute.

DR. WALSH: I'm talking about the resolution that was passed last week which was after Alain Pompedou was here and he voted for it.

CHAIRMAN WATKINS: Ms. Gebbie?

MS. GEBBIE: In a number of the areas that we've been hearing about, part of what's been suggested is that we ought to recommend some model state law or suggest that all states have a law doing X, Y or Z. You've been watching state legislatures for quite a while. Do you have any impressions or information on either the degree to which states respond when somebody puts out a model state law or a proposed standard state law, or the time it takes from the publication of such a model law until some substantial percentage of the states had adopted it say three quarters or 100 percent of the states have adopted any model law?

MR. MERRITT: That's a very good question, Kris, and my answer to you is, I don't have any sort of concrete notion about that. As you know, we've been very active in trying to disseminate sort of good principles or options to the states through, I assume this Commission received a copy of our three-volume study.

What we have is sort of anecdotal information from states that have said that that particular book as well as other reports have been extremely influential in terms of carrying the day, if you will, with regard to certain issues in a particular legislature.

Some of our expenditure information, for example, has been extremely helpful to community groups to sort of not beat the legislature over the head but it's legislators really want to know how they compare from one state to another. And when they see that they're state is putting up zero money or relative to their bordering states, I mean it seems to have some impact upon them.

We're not in the business of putting out model legislation, but we do get calls from people all the time saying, you know, what are the principles or what are the guidelines, you know, you would recommend for us to consider. And I know that ASTO has been very influential in doing that as well.

MS. GEBBIE: Well, let me say my question was broader than AIDS bills. I'm trying to get a context into which we might be throwing some recommendations. I know you've been watching health bills for a long time. Take something maybe like the model state statute on vital and health statistics --

MR. MERRITT: Yes.

MS. GEBBIE: -- or I don't know what, what other one, or some model state law on regulation of drinking water for protection of the public health, do you have any sense of how responsive states are and how quickly they respond when some group tells them --

MR. MERRITT: Well, my sense is, Kris, just looking back or just sort of stepping outside of the AIDS area and looking back and some other models of legislation like child support enforcement over the years, there seems to be sort of a quick flurry of activity. There may be eight or ten states that kind of pick it up, and then it takes maybe four or five years to sort of get the others to kind of come around.

I mean I don't have to remind you that legislatures exist in sort of two-year cycles. The federal level -- of course the Congress is two years. Most state legislatures, both the House and Senates, are elected for a two-year periods. And I think that's one of the major problems we have in terms of the education of public officials at this point whereas I still stand behind my conclusions that most of the enactments, policies that we have at this point have been measured and reasonable and fair.

We are now about to engage in an election and they're going to be a whole slew of new leadership health committee chairmen, staff and so forth that are going to have to be grappling with these issues for the next couple of years. And it takes another round of educational efforts really to kind of gear up and attack that.

I'm sorry, I'm not really responding directly to your question. It's just that on my limited experience it's just might -- what I'm recalling in some specific areas is there is an initial surge of energy in the first year or two, and then it takes several years to kind of get the other states to sort of comply.

MS. GEBBIE: That's helpful. Two other real quick examples and I'm not even sure where the first one came -- but in the Organ Transplant's Required Request legislation where essentially hospitals are required to ask patients if they would, or ask the families if they would donate organs. We've seen that legislation which is fairly uniform across the states. Probably, I think, almost every state has passed such legislation in the last three years. We saw that basically go right through just about every legislature over the last three years.

I'm not sure if there was a commission on uniform acts that sent that out or whether there was another group that was very involved in introducing that and getting it passed in each

legislature. Of course you have to remember that's fairly non-controversial legislation, fairly simple to understand, and so it can be implemented fairly quickly.

So you have to look at the degree of complexity of any type of law and the controversy and different opinions about a particular law before you judge how quickly it's going to be adopted.

The second recent example I've been following a lot in the area of long-term care insurance, and in that area I would say that states have a relative vacuum in terms of their legislature regulatory framework for the regulation of these new private long-term care insurance policies.

So that, for example, last year after the National Association of Insurance Commissioners came out with a model that you saw 10 or 11 states immediately adopt it, and several, probably at least, a half a dozen more will adopt it this year. But in those states that already had something on the books, even if it wasn't an NAIC model act, at least they had something in place. Only those states that didn't have anything in place were quick to adopt that.

So, again, there is just two other examples of things to keep in mind. And also the National Association of Insurance Commissioners did put out model legislation with regards to insurance and AIDS, and I think that's a good example of what Debra was saying, I think a variable is how controversial the legislation is and how states will use the model legislation. Perhaps if it's a very controversial legislation also depends on who puts it out is one way to sort of perhaps step around the issues. And I think if you saw a flurry of activity just like Dick said if states, perhaps, instead of going through all the detailed and some of the heart wrenching debate that you have to go through on these issues, they've adopted the insurance NAIC standards.

I probably should have thrown this into the same question, but to me it's a little bit different one, and I know that your responses are impressionistic rather than some kind of research thing you've done, but it's still helpful, and that is what you sense is the response of the states rather than just putting out a model law. It's a model law that has a carrot in it such as you become eligible for matching funds or some new grant program or something like that. Do you have an impression of the impact that sort of thing makes on the speed of adoption?

MR. MERRITT: I missed part of that. You said if it were a model law that would provide some federal incentives to develop?

MS. GEBBIE: Those states that get a law that looks like (X) become eligible for a pot of matching funds or for some kind of support or something like that, does that make a difference?

MR. MERRITT: I think it does, Kris, from the state's point of view really. I mean it's a much better way of approaching it rather than saying if you don't enact this, we're going to take federal money away from you is what you're suggesting if you do comply with these minimum standards, then there is some sort of additional financial benefit waiting for you. I think we've seen that in certain -- there may be some examples in Medicaid law where there is an increased -- are you okay?

CHAIRMAN WATKINS: Let's just recess for a few minutes here.

(Whereupon, a recess.)

CHAIRMAN WATKINS: Let's go ahead and continue then.

MR. MERRITT: I was saying that some examples may be under Medicaid policy where the federal government offered an increased matching ratio to states that were willing to provide management information systems or I believe family planning services were increased match. And most of the states really kicked in fairly rapidly as a result of those incentives.

MS. GEBBIE: Thank you.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: Mr. Chairman, really my questions revolve around the one you asked, and you didn't get an answer, and I don't think that I'm going to get an answer. My problem is that we have an unprotected epidemic, and it's a national problem. And I don't know how in hell 50 states with a million variables can put together a common sense approach to this problem. So I personally think there is room for federal moves and you weren't willing to commit yourself and I can understand all of your problems.

But I can't, myself, make any sense of dividing it into 50 different segments, you know. Can you run a company that way, Mr. DeVos? I pass now to Mr. DeVos.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DeVOS: See you get into that habit, Bert, of having nice clearly defined policies, but that's not the way it

works out there. You have to live with all these people. I have a cute response. If we took all the money we spent legislation and put it in AIDS research, we might not have to worry about all the legislation, but that's another question. I really want to get into something else.

I've been talking about home care and caring for people and that has to do with states legislation, and they tell me that only four states have applied for the waiver on Medicaid to take some of that money and apply it into home care. Do you see any trend there or reasons it's not being done more or why haven't more states done that to get home care?

MR. MERRITT: There is a very complicated formula with respect to the application for those home and community based care waivers, which states traditionally in other areas aside from the AIDS area has had problems in getting federal approval primarily because of the complications of those formulas.

It's my understanding, however, that the Health Care Financing Administration is definitely trying to be more helpful to the states and really providing technical assistance to those states that are interested in applying for home care. And for a couple of years there were only two states that had approved waivers, New Jersey and New Mexico, and now we know that there are, I believe, three new states that have received waiver approvals, and there are several other applications pending. So it's my sense, although I don't have anything to verify this, that things are easing up a bit.

When you move from the public sector to the private sector though, I think it's even more compelling. And that most private health insurance plans do not really provide for home health care. And those that do basically provide for it only if it's going to be rehabilitative in nature. They will not provide for home health care benefits if they're predominantly custodial in nature. So I think that's another area that the state governments need to work on and several have done that.

One of the other areas that states have done is really through mandating benefits on the private health insurance marketplace such that carriers when they offer a policy have to include certain benefits such as mental health or home health or hospice care, and more and more states have been doing that.

MS. LIPSON: One other comment. It's important to understand that on the Medicaid program, a state need not apply for one of these home and community based waivers in order to offer those benefits. And, in fact, many states provide a number of home based services to people needing long-term care.

Now, for those states that want to limit these services to AIDS patients, yes they would have to apply for one of these waivers, but there are many many states including some, I mean New York would be an excellent example, that has a very large personal care services program that allows individuals with AIDS to be taken care of in the home through this personal care option under Medicaid.

So even though you don't see New York necessarily being one of those four or five states that's got the waiver right now, is indeed able to offer those home and community based services or at least that one very important one to their Medicaid eligible population, and that's all those who qualify for long-term care benefits under the Medicaid program according to those income and disability standards.

MR. DeVOS: Is there anything that has to be done to get states to do that, or the federal government to change its regulation so it's easier?

MS. LIPSON: It mostly depends on a state's ability to allocate the resources for all of those people who qualify for Medicaid. Again, that's why some states have gone just to the waiver because they say, gee we've love to be able to offer these services to all of our Medicaid population, we just don't have the funds. What we're going to do is target it to AIDS patients whom we think we can save money by offering these home services.

But it's a dilemma that faces the entire Medicaid program and that every state has to contend with on a regular basis, which services are we going to provide, at what cost, and how are we going to raise those funds to bring down those federal dollars.

MR. DeVOS: Aren't those offset by hospital costs?

MS. LIPSON: Not necessarily. I mean if somebody is not eligible for Medicaid, then theoretically the state may be picking up some of those costs through an -- care program, or a program that reimburses hospitals for uncompensated --. Again, it depends on what their insurance status. It's a difficult question to answer. It really depends on the insurance status of that person and a variety of other programs that may or may not exist in a particular state to help pay for services who don't have health insurance.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SerVAAS: My question is to Mr. Merritt. To your knowledge are there very many states that would have rules that would prohibit voluntary groups, volunteer groups, from coming

into the state and doing confidential free voluntary testing unless they could return to the state.

And if they were doing, for instance, people who have had blood transfusions only at the Iowa State Fair, for example, they couldn't do this in a health fair or in a health van at the Iowa State Fair unless they would be able to return to have a one-on-one post test counseling for each of the negative persons whether they were a seven year old child who had had a blood transfusion three years earlier, or a grandmother who had had a blood transfusion.

Now, I don't know if your following me, but it's a hugh deterrent to economical and efficient testing on the part of volunteers who want to help the government, the state, and the public health people by doing these tests at no cost.

Now, could you tell me how many states have restrictive rules that prohibit or make it impossible for that van to do it because they can't notify by mail? Now, the blood banks may notify, not at all, the negatives. They don't have to notify the negatives at all.

The Army notified the negatives only with a sheet of paper. They didn't get back to them. But there is a kind of double standard in some states that say you don't test at all unless you are able to in person notify every negative whether they need to change their lifestyle or not. So that it makes it hard to test the low risk population. And if we do have a prairie fire out there and we want to help, it makes it very hard for volunteer groups to do that. Could you comment about the states that have such rules?

MR. MERRITT: Dr. SerVaas, I am afraid you have asked a question which is really far beyond my competence to really answer. I'm not aware of any current regulations, but that doesn't mean that there aren't any. I mean basically the states really prescribe the kinds of providers really that may perform the tests, and under what conditions those tests may be offered.

As I said also, many of the states are requiring that those tests be done only pursuant to a written informed consent form by the individual. And they are also requiring, or some of the states now are requiring that counseling, pre and post-test counseling, be offered to the individual.

I know I'm missing the direction of your question here, but I simply don't know what the state rules and regs would be with respect to voluntary organizations in the spirit of the question that -- in the spirit that you're asking it.

DR. SerVAAS: Well, you remember during the tuberculosis problem we had mobile units going around x-raying lungs, doing lungs, and you wouldn't remember that, but now I'll give you an example. A unit going out to the Iowa State Fair was told by the lawyers that Iowa had just passed a law that said you needed in person one-on-one counseling.

Now, granted, the positives you would expect to have a physician and the physician would counsel the positives, but the negatives, the people who should be routinely checked but are not likely to be positive, they would have to be told in person, and that just knocks out any hope of being able to do this kind of inefficient screening of people who have blood transfusions who have summaries and need to be tested but they don't necessarily need to have expensive counseling one-on-one to change their lifestyle.

Our interest is in finding out what you think or how that obstacle could be corrected or changed so that we certainly need private institutions helping, private groups coming in and helping on the counseling and testing.

MR. MERRITT: Mona, do you have anything?

MS. ROWE: Well, if you're asking, as Dick said, there are some states that mandate post-test counseling. And what you're saying is that the mandate of post-test counseling may restrict the ability to increase the numbers of persons who can receive counseling because counseling is very labor intensive and you can't get the folks there. So is such a mandate diminishing or decreasing the number of persons perhaps who are able to get it. That's one part of your question. Well, I don't know of any study that studied that, and as you said the blood banks is one situation where they test and they can inform. And, again, I don't know of any state that has mandated it the other way, and I'm just trying to think, that you can give it by mail, I mean, expressively said that.

There are states though by virtue of coming forward with standards for counseling and training programs that allow more and more people to be easily trained for counseling. And so that it does not diminish your ability to start using volunteer pools provided you could educate people through some sort of training programs, and they have, you know, a little booklet. And they're encouraging that. As matter of fact there are states where they're encouraging volunteer pools of counselors who then become trained, so you can increase the numbers of people at different sites.

DR. SerVAAS: I want to give you another example. Our supervisor wanted to go to Buffalo to do Teen Challenge. These are drug addicts who are rehabilitated, and there are may of them

who are positive for AIDS. He couldn't do it. But he was told in Albany that the state of New York has four free counseling test sites and that's ample. And that is what he alleges he was told. I just wondered, can you do this sort of thing in the state of New York, does anybody know?

MS. ROWE: Can you do?

DR. SerVAAS: Voluntary counseling, confidential --

MS. ROWE: Well, I think what states are doing is that they're trying to become more assertive in terms of the types of standards in the quality control that they see taking place in terms of testing, as you must have heard today, in terms of QA, quality assurance for testing in laboratories. And I think that there is a real concern that there needs to be some sort of quality control for HIV testing and counseling.

You're right, there is a dilemma which is how you make the testing as broadening available as possible to as many people as possible that need it. But I think states in this case really feel that HIV infection at this point in time is a disease that is A-typical. It is not necessarily right now tuberculosis. And there is a vested interest. The state has a public interest in maintaining the quality of the -- you know, insuring the quality of the counseling that's going on.

And I would say that in most states you would see states looking very carefully at that and trying to maintain that, and that goes in some of the Articles of the American Journal of Public Health talking about the increased suicide rate of persons who are getting their test results. And it could be positive or negative going through the HIV antibody test. I've never gone through it, but all my reading and speaking to people that have, it's very traumatic.

So, again, I think states just have a vested interest at this point in time in maintaining a certain quality control. Georgia and Washington have, in fact, -- and I'm not sure about Washington, but Georgia has passed a law prohibiting the sale of mail order test kits.

DR. SerVAAS: I don't think quality was a factor at all because the confirmatories were all being done at Mayo Clinic in Rochester, Minnesota, and they have excellent track record.

MS. ROWE: On quality for the counseling too. They want to make sure that the people who are doing the counseling are sensitive to the needs. But there are model programs there where they have programs for different diseases. Or for STD clinics, it's been the model for 10 or 20 years where they take counselors, volunteer counselors, and you go through a training

period of two weeks and then you start building up CADRES volunteers to start going out. States, I'm sure, are probably going to using that type of system to increase the number of counselors they have available.

CHAIRMAN WATKINS: Do you want to follow up any further Cory?

DR. SerVAAS: Well, does anyone else have any ideas on how we could use this huge private sector group of volunteers who really feel strongly about helping, who could help on the testing and counseling so that we can identify these teenagers who are out spreading it among themselves complacently not knowing they're positive. And this worries me a great deal that we have an inexpensive test, a very good test, and medically it's one of the finest tests we could have and we're not using. And we're under utilizing the people who could be helping.

It's seems as if there is a bottleneck on the testing part. We did indeed last year or last fall, when our associate called, if we did indeed only have four sites in New York, and I couldn't believe that, and I must be wrong, I mean, he must be wrong, but it does seem like it's a bottleneck in the State Health Departments. And for the small amount of money it costs for the army at $4.00 to do these tests, and Damon Laboratories do 8,000 every night, that I wish you young people would think of some way that we can hitch our testing to something that's good enough quality, because it's an excellent quality and Damon Laboratories have excellent results, no false positives. They really are tested all the time with 40 known -- and then they don't pay them if they don't get them all right.

So this laboratory is commercial and there are others, not just Damon, the big one, but there's one in Arizona I understand that we could make contracts with and get out of the bottleneck. We have a survey that shows that 70 percent of people want to be tested, and would be willing to be tested, and if we just go test all those people who are wanting to be tested voluntarily, we'd make a big difference in what we know about this disease, especially the blood transfusion people because we know when they became infected.

We could learn so much about the disease if we could just get out and test all of those. But the state rules do make it difficult in some states even for those who would voluntarily try to get in and help. Do you have any thoughts about how we could use the people who want to help voluntarily for free testing?

MR. MERRITT: I'm afraid we're fresh out of ideas on that, Dr. SerVaas. I understand your point now, and I --

MS. ROWE: We'll look for examples of programs, and they said they're volunteer training programs for counselors and states are looking at the right of ways to increase their ability to do more counseling. I think the question is not the proficiency of the tests, but also the proficiency of the counseling that goes along with it. So those are two issues that the states are looking at.

DR. SerVAAS: In our state to become a counselor takes two days of training. Now, that may be wrong in your book, but that's what it takes in Indiana to be an AIDS counselors. I don't know what you mean about quality of counseling, but it just seems to me that we should be counseling the positives and targeting the positives and getting them identified and counseled first, it would appear to me. This is where I wonder how you public health people could use the private sector people, the Kiwanis, the Lions, and the Junior Leagues, and all of the other people who would be willing to get in and help. Phlebotomist and counselors are not hard to train, and the tests can be shipped off, and the serum stays good, and it's good almost for weeks. It's perfectly fine in the mail and it's very light weight and you can send enough in a little bottle this big to do three tests, and confirmatory and everything else, and it seems to me that we're making it so complicated. It can be as confidential as it is in the military, and they certainly have a lot of tests without any problem. The military and other medical tests that we've always done have been done with great confidentiality. That's my finish.

CHAIRMAN WATKINS: I want to thank the panel, and particularly you, Mr. Merritt, and your colleagues for doing the work you're doing. It's very helpful to us and I know that HHS is providing resource support for you. But it's fortuitous for us that your project is moving in parallel with the Commission. I think without your project having been underway and well established we would have had a very difficult time getting the kinds of data and insights into the state movement that you've given us, and I've used your data of 50 to nearly 600 many times publicly because that gives you a feel for what the states are doing in ramping up to respond, and we can all commensurate about the slowness of the national or state response, but that's the way it's been and it's encouraging to know that it's still on the increase.

Our whole objective of the interim report was to get something out in time to make it relevant to the legislative cycle underway otherwise you become irrelevant for a total year, so that's why we moved in the areas we did, and I assume that you applaud that initiative to get things out on the street to try to bring some calmness and put some oil on the otherwise stormy seas that have been raging out there on this thing.