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Washington, D.C.
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NATIONAL COMMISSION
ON
ACQUIRED IMMUNE DEFICIENCY

Friday, November 3, 1989

9:00 a.m.

Pan American Health Organization Building

525 Twenty-third Street Northwest

Washington, D.C.

COMMISSIONERS PRESENT:

June Osborn, Chairman

David Rogers, M.D., Vice Chairman

Scott Allen

Diane Ahrens

Eunice Diaz

Donald Goldman

Larry Kessler

Charles Konigsberg

Susan Neeme [Representing Belinda Mason]

J. Roy Rowland

Irwin Pernick [Representing VA]

David Newhall [Representing DOD]

Jim Allen, M.D., [Representing HHS]

STAFF PRESENT:

Maureen Byrnes, Executive Director

Carlton Lee, Chief Liaison Officer

Thomas Brandt, Director of Communications

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PROCEEDINGS

CHAIRMAN OSBORN: I think we should get started so that we don't overrun the schedule on what promises to be a fascinating but also a very full day. I think one way to stay with the schedule is to have very brief, if any, opening remarks, but I just want to get us underway and I would like, David, if you have any comments that you would like to make to start with, or shall we just get the testimony going?

COMMISSIONER ROGERS: I think we could get the testimony going, but let me make two comments. One, an enormously impressive day yesterday where we got a real feel for some of the heartache that is out there. I think all of us are looking forward to hearing from this distinguished group today.

I might say to our distinguished guests out there that I am delighted that we have your written testimony. We are all pretty good readers and will be reading it. If you feel comfortable in so doing, speak from the heart and don't read your testimony.

I think what the Commission has most enjoyed is when there has been enough time left over for us to interact with you. So you if you can make your comments fairly brief, I can promise you your reports will be studied in some detail, and the more interactions we can have while here I think the better educated we will be. I think that would be my only comment, June.

CHAIRMAN OSBORN: Thank you, I appreciate that.

If then I could go ahead and ask Dr. Phil Lee, Anne Scitovsky, Dr. Peter Arno and Jesse Green to please come to the stand and we will look forward to you introducing yourself as well as your topic as you go. The way we proceeded yesterday, which seemed to work quite well, was to have everybody present their formal presentation initially so that then as a panel we could be asking questions to more than one of you at a time and not getting you to be redundant with your presentation coming later. So if you want to do it just in sequence, and then we'll open the floor for discussion when everybody has had a chance to present.

Thank you and welcome.

STATEMENT OF PHILIP R. LEE, M.D.

UNIVERSITY OF CALIFORNIA SCHOOL OF MEDICINE
INSTITUTE OF HEALTH POLICY STUDIES
SAN FRANCISCO, CALIFORNIA

DR. LEE: Dr. Osborn, thank you very much, and I'm very pleased to have the opportunity to testify. I will follow Dr. Rogers' advice, submit my testimony for the record, and summarize briefly some of the major points in the testimony.

My interests in AIDS go back to fairly early in the epidemic when as Director of the Institute for Health Policy Studies at the University of California San Francisco, we were asked to undertake a study of the cost of AIDS at San Francisco General Hospital. And we asked Anne Scitovsky, who is on my left and probably I would say the leading health economist in the United States on issues relating to costs, to undertake that study.

From that point on we have been engaged in a series of studies looking at the cost of AIDS. The most recent has been a study for the State of California looking at the costs in California. And we would be glad to provide the Commission with a copy of the report which we have submitted to the state.

I also chair the Public Policy Committee for the American Foundation for AIDS Research, and the Institute is in the process of preparing for AmFAR a policy document in the areas of health care financing costs and organization. When we have completed that report we will also submit it to the Commission for your consideration.

And finally I was President of the Health Commission in the City and County of San Francisco. That Commission was established by the voters in 1984 to oversee the Department of Public Health, which includes the San Francisco General Hospital, Laguna Honda Hospital, which is a long term care facility, and as a result of that, of course, had an intimate connection with the AIDS epidemic in the county where the epidemic has had a more devastating effect than probably in any other county in the United States, at least on a per capita basis.

In the testimony--and I want to focus on several things--I first review federal, state and local government policies, and in looking at local government I want to emphasize counties, because when we talk about communities we tend to forget that in our federal system the county is really that local level of government which, in public health at least, has the ultimate responsibility for the execution of policies, whether these be federal, state or local policies.

Municipalities often have police and fire functions but seldom have public health functions except in those rare cases where you have, as we do in San Francisco, a city/county government. But there in fact it is the county that is the agency that has the primary responsibility.

I will also briefly review some of the issues in the private sector, some of the developments in the private sector. I will not discuss in any detail the cost and financing issues because Anne Scitovsky, Peter Arno and Jesse Green are going to cover those. I do want to say a little bit about the drug epidemic and its relation to HIV disease, and I want to say a little bit about long term care, and then I am going to conclude with a few comments about the media.

I agree with the observation that Kristine Gebbie made. She was, of course, a member of the President's Commission and writing recently about what she learned from that experience she wrote, "We looked at the American system through the lens of the HIV infected and found gaping holes, huge problems. We said that if the country did not do something about all of these problems we will never stop the epidemic."

Thanks, I think, to the emphasis that the President's Commission placed on IV drug abuse, a dramatic shift in public policy with respect to that problem has begun to take place. It is not yet begun to bear fruit, at least at the local level, but one of the gaping holes identified by the President's Commission I think has begun to be filled, and clearly this year the Congress in its appropriations process is significantly modifying the priorities, and I'll say a little bit about that later. And I hope the Commission will really carefully evaluate the effectiveness of those policies.

You have taken on an equally difficult, if not even more formidable task, relating to the financing of health care. Mary Ann Baily, who is at George Washington University, and her colleagues there, and at Mathmanica [phonetic], in a report to the Health Care Financing Administration observed, "The HIV epidemic is severely testing the American health care financing system. Most policy analysts who have carefully studied costs and financing would agree. The system of health care financing is being tested," in Bailey's words, "because it stresses the financing system at its weakest points.

Now, what are those weakest points? The uninsured, the care of the poor--and particularly the working poor--those who need long term care services, IV drug users, and the fact that the epidemic has been concentrated in a relatively small number of cities and counties and a small number of states where it has had a devastating effect on both the system of care provision and on the financing.

In San Francisco we have now compounded that problem, of course, with an earthquake, and it is interesting to me that within about 72 hours of that earthquake the Congress appropriated $3.8 billion in earthquake relief. We have yet to see a comparable response to the HIV epidemic, yet in fact it has had a more devastating effect at the human level than the earthquake, and certainly it has had a far more devastating effect in New York even than it has in San Francisco.

Finally, the epidemic is stressing the system because of the nature of HIV infection. It produces social as well as medical problems and our system of financing lacks the flexibility for a person who moves and has needs that at one point may be medical and another point may be social. We don't have a system that very flexibly meets those needs.

I won't say much about federal policies, although I briefly review that in the testimony, except to note that we need national policies with respect to health care financing, and including policies with respect to AIDS. And the key issue I think that you have to address is should those policies be generic policies or can you have some specific steps that you can take with respect to Medicaid, for example, that will move us towards a national policy but will be incremental steps in that direction?

One example of that has been what has been done in Medicaid for pregnant women. It has now been mandated by the Congress that pregnant women, initially below 100 percent of poverty and in the future below 180 percent of poverty, will be required by the states to be provided with Medicaid benefits, even though they are not on Aid to Families with Dependent Children. We have decoupled Medicaid from welfare in that case.

The question is, should you do that for persons with HIV infection and should you perhaps limit the benefits for those that are preventive and primary care in nature. It is one of the issues I think you need to address.

Another major issue, of course, has to do with the Americans with Disabilities Act, and Congress is currently dealing with that issue and I hope that it will complete that job before this session.

At the state level we find that in the absence of federal leadership, a number of states have taken leadership in specific areas. New Jersey, California, New York, Washington, Florida, Georgia, Hawaii, Wisconsin and Massachusetts each have done in different areas very important things in relation to this epidemic. States most importantly have served as a testing ground for policy development and implementation. We have had about 360 laws passed at the states, some of them very excellent, some of them rather unwise. That is an area that I hope this Commission will look at very, very carefully. You need to look at both the Medicaid programs and what it has done, and the non-Medicaid funding for patient care activities. Those funds, incidentally, have increased very dramatically in the last three years.

The impact, of course, on the epidemic, as I point out in my testimony in Table 1, is very concentrated in a limited number of the states--I don't have to recite those to you--but it is increasing more rapidly in not the original states like California, New York, and New Jersey, but in we might say the second tier states. We now have 19 states and territories--that's about 40 percent of the states--that have reported a thousand or more cases of AIDS. And these states account for about 90 percent of the cases reported to date.

Well, I would like this Commission to carefully assess the role of state governments in the HIV epidemic. Federalism is basic to the effective functioning of our system of government. How we allocate the responsibilities for the epidemic is crucial, and too little attention has been paid to the role of state governments, both as independent actors and as agencies of federal policies, administering block grants, for example, and categorical grants.

One of the criticisms that has been made of the state governments is the slowness with which they administer the block grant funds and the slowness with which funds get down to the local level so that actual programs are developed. That's something that this Commission could take an independent look at so that if that criticism is valid something could be done about it, if it isn't, it won't be repeated.

At the local level, of course, that's where the rubber hits the road. And by "local level," I want to stress the role of the counties. We hear so much about communities, but it is the county, in terms of public health, that has played the crucial role in the epidemic. Of course, these roles have varied from county to county and community to community, and if you just compare in California a county like Los Angeles, with 9 million people, and a county like San Francisco, with 750,000 people, vastly different. San Francisco is a city/county government. Los Angeles has a county government, and I think maybe 50 or 60 different municipalities within the county.

Of course, Los Angeles County is probably bigger than half of the states, or maybe two-thirds of the states in the United States, a single county. We have counties in California with fewer than 100,000 people. So that the county is a very, very diverse institution but critically important.

We have also seen at the county level--and I am very proud of what's been done in San Francisco with the development of the so-called "San Francisco model." That was a local public sector response to the epidemic, closely linked with the University of California and the faculty at the university. But it demonstrated the vitality within our system in the public sector.

These models, of course, the San Francisco model was appropriate for San Francisco, and it has been adapted in many other communities. But because of the differences between the communities, both in terms of the culture, the diversity of populations, and the resources, responses vary markedly from county to county. And I think the Commission should consult with the Robert Wood Johnson Foundation, and certainly Dave Rogers deserves great credit for the leadership he showed when he was president of that foundation, in funding the AIDS Health Services program, which really got this service system going around the country. They have had more experience even than the government in looking at what works and what doesn't work at the local level.

The Health Resources and Services Administration, the General Accounting Office, both have conducted evaluations of activities at the local level. The National AIDS Network and the National Association of Counties should also be consulted with respect to what's happening. We know too little about the local level. The data that is available is grossly inadequate, and I think this Commission could do a great service by both pointing out that problem and stimulating the development of an adequate system of information on which policies can be developed.

The private sector, of course, has been the key to responding to the epidemic. First individuals, then organizations, and we have seen an absolutely remarkable response in that regard. We have nationwide in the National AIDS Network over 700, or nearly 700, local AIDS serving agencies. We are now seeing, of course, a number of the so-called mainstream social service agencies beginning to provide service for persons with AIDS. They did not do that initially. It was largely Gay-based organizations that met those needs in the beginning.

Some private foundations have taken a leadership role, and I would say again the Robert Wood Johnson Foundation deserves particular credit. Some of the community foundations in New York, San Francisco and Chicago have been important. Some regional foundations, like the Sierra Foundation in California, have done an outstanding job, and I would hope you could look at the foundation response. I must say, I have been very disappointed in some of our major foundations. Again, Dr. Rogers has played a key role in stimulating the Ford Foundation to move from a--to say "modest" is giving them more credit than they deserve--program, but that National Community AIDS Partnership is beginning to move, is beginning to stimulate a response, and I think it is important that both the private foundations and the corporations be stimulated to do more.

And, of course, employers in many parts of the country are just beginning to realize what the epidemic is likely to do. We have had fantastic leadership in places like San Francisco, from corporations like Levi Strauss, the Bank of America, Pacific Telesis, in New York, in New Jersey, and we have a tremendous resource in the corporations in responding to the epidemic.

Insurers, who have gotten kind of a bad rap initially because costs looked like they were going to be very high, but the data so far at least suggests--and it is not very adequate--that insurers have not been backing away from taking care of people with HIV infection, and this has been certainly true of HMOs as well as in California. However--and Anne and Peter Arno and Jesse will all talk about this--we are seeing, because of the populations affected, a growing burden on the public sector in terms of financing.

With respect to the substance abuse epidemic, I would only ask that you really carefully look at the present policies and the shift in those policies. In the 1980s emphasis was given to supply control, and now we are beginning to focus on demand reduction. And I think that's a move very much in the right direction.

The President's Commission noted that prevention and treatment of intravenous drug abuse, an important facilitator of the HIV epidemic, must become a top national priority. Hopefully you can continue that Commission's surveillance of the federal and state response to this epidemic. One of the areas I would hope you would like at in relation to that is the relationship of IV drug treatment, and substance abuse treatment in general, to primary care, and the relation of primary care to drug treatment. More and more we need to link those two together. How we do that is a critical problem, and I am sure you'll be consulting with the people in New York and New Jersey, the District, where the drug epidemic has had a particularly devastating effect. We are concerned about it in California. We have not had nearly the experience that they have had in the northeast corridor.

Long term care is another issue area that you must examine, because it is to so important to persons with HIV and AIDS. As our knowledge and experience regarding the course of HIV illness has grown and as treatments have improved, public policy has begun to address a new set of issues regarding the chronic or long term care needs of persons with HIV disease. Chronic care for persons with AIDS has grown in policy significance because of new treatments. The number of persons with AIDS, of course, is increasing dramatically, and we tend to forget that. As the epidemic has progressed and as the numbers increase, we have tended to somehow become apathetic about that.

And second, or third, new ambulatory care technologies have made it possible to care for people in an ambulatory setting that used to have to be hospitalized. Policies about chronic care needs, like others, have been complicated by three issues. First, a shift in the population affected by HIV, more IV drug users, increasing numbers of minorities, more women and children, more patients with dementia, a very, very difficult problem to deal with at the local level. And then the treatment of asymptomatic HIV positive individuals, or what Peter Arno more appropriately calls pre-symptomatic patients, means that more people require care for longer periods of time.

Long term care for HIV infected individuals, like the elderly and like other disabled who need long term care, is an underfunded system. Fortunately, the U.S. Commission on Comprehensive Care, the so-called Pepper Commission, chaired by Jay Rockefeller, Senator Rockefeller, is looking at this issue very, very carefully. And I would simply hope that this Commission closely coordinate with that Commission, because I would say it has the primary responsibility for looking at long term care, but you must be informed because it is so important.

Finally let me just conclude with a word about the media. The role of the media is important in informing, educating and in some cases mis-informing the public. Colby and Cook note--and I refer to their work in my testimony--that "AIDS did not rise quickly to the political agenda because of the way the problem was defined and the way the epidemic was framed by the media."

If you remember early on, it was, quote, "a Gay disease." It was not recognized as a virus disease, and many of the issues were not well presented to the public. Colby and Cook in a very interesting paper have used Anthony Downs' hypothesis, which he calls the "Issue Attention Cycle," to look at the media response to the epidemic. And that has four phases. First, the condition exists but is not constructed as a social problem. Second, event triggers awareness and the publish demands that something be done. Rock Hudson's death from AIDS was a triggering event.

Third, the public discovers the political and economic costs of solving the problem. And fourth, the revelation of costs forces a decline in public interest. Well, I would submit that we certainly currently have a decline in public interest and media interest in the HIV epidemic.

I think this Commission should devote considerable attention to analysis of media coverage and to considering strategies for working with the media to better inform and educate the public. Without on informed public the problems that you will be considering will not be solved. Changes in public attitude precede changes in public policy.

Thank you.

CHAIRMAN OSBORN: Thank you very much, Phil. That's really a profoundly thoughtful charge to us and one that makes me feel a little pale about being able to respond. But your points really echo some that we were aware of, and you have put it in an excellent context.

As you were going along you made several times reference to the very important Presidential Commission work and report, and I just wanted to welcome Dr. Burt Lee, who is here with us I think just briefly he is able to stop by this morning. He was one of the hard working members of that Commission for whose work we are very grateful because we are hoping--later on we'll be talking about where things stand with respect to their important recommendations--but we do value the work. That gives us a very good platform from which to take our Commission further. And so I am glad Dr. Lee can be with us, too.

STATEMENT OF ANNE A. SCITOVSKY, M.A.

HEALTH ECONOMICS DIVISION

PALO ALTO MEDICAL FOUNDATION/RESEARCH INSTITUTE

PALO ALTO, CALIFORNIA

MS. SCITOVSKY: First of all, let me introduce myself. I am Anne Scitovsky. I am a health economist who is Chair of the Health Economics Division of the Palo Alto Medical Foundation, and I am a lecturer in the Institute for Health Policy Studies at the University of California.

Since 1984, pushed into it largely by Phil, I have done work on the cost of AIDS, both doing empirical studies as well as making estimates of the national cost. I am pleased to have this opportunity to talk to you about this kind of work, although after Dr. Lee's more global talk and some of the very moving testimony yesterday, my talk will be rather dry. As you know, Economics has been called the dismal profession. And compared to yesterday especially, it will be rather dull.

What I am going to concentrate on very briefly are the current estimates of the cost of the

AIDS epidemic in the United States. Secondly, the data gaps that still exist which make more precise estimates very difficult. And finally, the changes in various aspects of the epidemic--you have already heard a lot about it yesterday and already by Dr. Lee--that are currently underway and that will change the economic impact of the epidemic profoundly.

I should say that although it is less than 10 years since the first cases of AIDS were discovered, there have been more than a dozen empirical studies of the medical care costs of persons with AIDS, as well as several estimates of the national cost of the epidemic. I would like you to realize how this contrast with what we know about the costs of other diseases, because we have practically no data on the costs of the other diseases, either nationally or per case.

Rather than review all the estimates that have been made--and there have been about a half a dozen, or maybe eight by now--I want to concentrate on the three most recent ones, because partly they are based on the most recent data, but also because they illustrate the difficulties involved in making such estimates.

Dr. Fred Hellinger of the National Center for Health Services Research estimates the national medical care costs of persons with AIDS in 1991 at $5.3 billion. Dr. Joel Hay of the Hoover Institute at Stanford University arrives at a considerably lower estimate, also for 1991, of $2.5 billion.

Finally, Dr. Anthony Pascal of the Rand Corporation in Santa Monica estimates national costs in 1991 at $15.1 billion. All figures are in 1988 dollars. I have converted the Joel Hay and Pascal figures to 1988 dollars to make them comparable to Hellinger's, which is the most recent.

This wide range of estimates is due to the fact that all estimates depend on two basic assumptions; first, the projected number of persons with AIDS in a given year, and second, the average medical cost per person with AIDS. Of the three estimates, Hay's low estimates assumes both the lowest number of persons with AIDS in 1991--45,000--and the lowest cost per case, a little over $53,000.

Conversely, Pascal is at the opposite extreme with both assumptions. He assumes 150,000 cases by 1991--you see the difference, three times as many cases--and the highest cost per case, a little over $100,000. Hellinger's estimates lie somewhere between the two or on both counts. He estimates that there would be 70,000 cares and about $75,000 lifetime cost per case of AIDS.

It is very difficult, in spite of the fact that we have data--some data at least--which of these estimates is the most likely. With regard to the projection of the number of cases, Hellinger's projection is similar to that of the CDC, the Centers for Disease Control.

With regard to costs per case, Hellinger's and Pascal's estimates are based an what empirical data are currently available, in spite of the fact that this leads to very different assumptions regarding the average cost per case, While Hay estimates what the cost per case should be on the basis of treatment algorithms which he developed. I have no special qualification to judge the projections of number of cases.

With regard to cost estimates, I would tend to agree with Hellinger's estimate that lifetime costs of a person with AIDS currently are probably somewhere between $60,000 and $85,000, so his $75,000 would lie well within my range.

Just to give these figures some perspective, Hellinger's estimate of 5.3 billion represents about 1.2 percent of estimated national personal health care expenditures in 1991. As you can see, it is not a large amount on a national basis. What makes this such a very special problem is the unequal distribution of the cases across the country. And even though the epidemic is now spreading into other areas of the country, the cities that bore the brunt in the beginning will continue to bear the brunt. If you look at the distribution of drug users by geographic area, you are also find that the Northeast will continue to be heavily hit.

I'll go very briefly into the data gaps that we have and that really make estimates very difficult. I have a much longer paper even than what I submitted to the Commission which is coming out in Milbank and

I'll be glad to send it to you. I have sent to you the tables that went with that article.

As my brief survey of these estimates has already indicated, one of the major data gaps is uncertainty about the future course of the epidemic, the number of cases. I mean, the estimates of Pascal as against Hay and CDC in between show you the wide range that is possible with perfectly legitimate techniques. Until better data become available on the number and distribution of persons infected with HIV, more precise estimates of the future costs of the epidemic are not possible. I should add that the Centers for Disease Control are currently conducting surveys to determine the rate of HIV infection in a number of locations throughout the United States, which should improve the situation, provided they can actually carry them out. I understand they have had considerable difficulties in carrying them out. Issues of confidentiality are really very, very severe.

On the cost per case of AIDS side, there are also considerable data gaps. To begin with, there are no practically no data on the use and cost of medical services of IV drug users. Most of the empirical studies--and there have been over a dozen by now--have studied homosexual and bisexual males.

Similarly, there are no cases--I'll go through these data gaps very quickly--similarly, there are no data on the use and cost of medical care of women. There is a really serious data gap there. They appear to have a shorter life expectancy than men, but whether this affects cost one way or the other is not at all clear.

There are two studies of the cost of HIV infected children, rather than children with AIDS, but again, the data are limited. What it is of interest to note is that both articles point out that much of the cost of children, the direct medical care costs of children, is social rather than medical, and due to the fact of the problem of boarder babies in New York.

There are limited data on the sources of payment for AIDS. It has been estimated, for example, that 25 percent of all persons with AIDS have been covered by Medicaid at some stage during the course of their illness--I am sorry, that 40 percent have been covered at some point during their illness--and that Medicaid has paid for about 25 percent of total medical care expenditures of persons with AIDS. But again, the data are very fragmentary.

There is also a geographical limitation of the studies. Most of them have been conducted either on the west coast or in eastern cities like New York and Boston. And finally, there are practically no data on HIV infected persons other than persons with AIDS.

I will stop there. The National Center--I would like you to be aware of the fact that the National Center for Health Services Research--you probably know about this--has just let a contract for a major national survey of the course of HIV related illnesses which it is hoped will fill many of these data gaps. This survey will be conducted in various locations in the country and preliminary findings should become available over the course of the next two years as this survey is conducted. This does not, however, eliminate the need for local studies, because it is a national survey with small samples at the local areas. So I feel very strongly that further work on the cost of AIDS can be done on larger samples of local cases.

Despite the shortcomings of the studies that I have outlined, the data we have are very useful. However, recent changes that are likely to become more pronounced in the near future fundamentally alter the economic aspects of the epidemic. The principal changes that affect the impact of the epidemic are, of course, what you have already heard yesterday and what Dr. Lee has referred to. First of all, the changes in the medical treatments, and second, changes in the composition of the population with AIDS.

I won't go into details. You all have heard about the effect on cost of AZT, although there is no clear evidence one way or the other whether the use of AZT increases costs or lowers costs. Based on talks with experts that I have had over the last half year or so, and on one small study of the affects on costs of AZT that we conducted at San Francisco General, I would guess--it is really a guesstimate--that lifetime costs of persons with AIDS are pretty much what they were before the new drugs--and AZT is only one new drug--before the new types of management of the disease, and simply spread over a longer lifetime. They still die and will incur at the end of life the high expenses that terminal AIDS patients,like all terminal patients, incur at the end of life.

In addition, the distribution of expenditures by type of service is changing. You have already heard yesterday and again Dr. Lee has referred to it, there are more expenses going for drugs, for ambulatory care, and for long term care rather than for hospital inpatient care.

A less direct effect of the new drug treatments and generally more effective treatment of AIDS may be a renewed trend of more intensive care of patients--AIDS patients--in the hospital. In the early years patients with pneumocystis were hospitalized in the intensive care units. When it became clear that this, in most cases, merely prolonged dying, the use of intensive care dropped substantially. There is now some evidence--and there is a study going on, or proposed to go on provided they get funded--there is evidence that the use of intensive care again increases. This is partly due to the fact that apparently intensive care has become more effective, and partly, I am sure, to the fact that patients are less willing to forego treatment now that the hope of a longer life exists.

The effects on costs of such a move toward more intensive care are substantial. One of our studies showed that the average charge per hospital day for a person with AIDS in the ICU was twice of that of a patient in a regular room, so it has an important effect.

The other major change, of course, that you have already heard about several times yesterday--Dr. Lee has referred to it--is the change in the composition of the AIDS population by risk group. Until a few years ago it was mainly homosexual, bisexual males. Now an increasing percentage of all new cases are IV drug users. I won't give you the statistics, they are in the tables I sent you and you can read them there.

As I also said earlier, there are no good data on the relative cost of IV drug users, women, children and minorities, compared to those of white homosexual and bisexual males. However, whether in the past they were more expensive to treat than homosexual males is really not that important, because I believe that with the recent changes in treatments their costs will be higher than those of homosexual males.

The living conditions of many of the persons with AIDS--and you have heard about one yesterday--are not favorable--I am not saying for all of them, but for a certain percentage of them--are not favorable for treatment on an ambulatory basis, so that likely boarder babies, many may end up in the hospital and stay there longer than is medically necessary.

I also am not sure that voluntary organizations like the ones in San Francisco and in some other cities that were organized mainly by the Gay population will be able to provide services for this totally different population consisting of minorities and the poor. All this, of course, assumes that this population actually gets access to care, which after we have heard yesterday, doesn't go without saying.

To sum up, the changes I have discussed have transforms AIDS from an acute disease with rapid progression to death into a chronic Condition which though still incurable permits patients to live longer and possibly less disabled lives. In addition, the disease is slowly becoming one affecting primarily minorities and poor. It is clear that this will have a profound effect on the financing of care for persons with AIDS. And I won't go into details again because this will be covered also by Dr. Arno and Dr. Green, and Dr. Lee has already referred to it.

But as you know, the majority of intravenous drug users and their sexual partners and children have no insurance of any kind, no private insurance. Yet even persons with AIDS with private insurance may face problems of paying for their area. Private insurance for drugs is very limited. According to HCFA, the Health Care Financing Administration, 75 percent of expenses for drugs and prescriptions are out of pockets. Private insurance covers only 14 percent and public programs another 11 percent.

Similarly, private insurance coverage of ambulatory care is much less comprehensive than that of inpatient hospital care. And private insurance for long term care is negligible. Thus, it appears highly likely that an increasing number of persons with AIDS will become dependent on Medicaid or, as indigents, on their local communities. Again, I won't go into details because this will be discussed later.

I do, however, in concluding, want to stress a point that has come out quite clearly in some of yesterday's testimony, as well as by Dr. Lee. It has been stated very well in the report of the New Jersey Pediatric AIDS Committee, mentioned yesterday by Dr. Oleske, who was kind enough to give me a copy, and I want to quote a statement from that report, and I quote: "While HIV infection is a physical illness, its causes are rooted in societal ills. If our response is to be effective, all of society must address the prevention and treatment of HIV infection in the context of broader social problems." And my emphasis is on that. Thank you very much.

CHAIRMAN OSBORN: Thank you very much, Anne, for another profoundly helpful presentation. We very much appreciate it. Dr. Arno.

STATEMENT OF PETER S. ARNO, PH.D.

DEPARTMENT OF EPIDEMIOLOGY AND SOCIAL MEDICINE

MONTEFIORE MEDICAL CENTER, NEW YORK, NEW YORK

DR. ARNO: My name is Peter Arno. I am a health economist at Montifiore Medical Center and Einstein College of Medicine. I just want to say that I too owe a debt of gratitude to the distinguished panel members on my right, Phil Lee and Anne Scitovsky, with whom I have had the great honor and privilege of beginning my work on the economic impact of AIDS back in 1984 at the University of California.

I want to thank the Commission for the opportunity to testify today as we look towards the AIDS epidemic unfolding in the 1990s.

I will be brief. We have now had nearly 110,000 reported cases of AIDS in the United States, but there are estimated to be approximately one million persons who are currently infected with HIV. And absent medical intervention, the vast majority of those who are HIV infected will progress to end-stage symptomatic disease and death. To put this another way, with all the suffering and agony of the individuals ravaged by this disease, and all the dislocation we have already witnesses in our health care system, we still have experienced perhaps only 10 percent of the AIDS cases among all those who are infected. And based on what we know of the epidemiology of this disease, the next 10 percent of AIDS cases will come much more quickly.

More than two years ago the National Institutes of Health designed several studies to answer the question whether early antiviral therapy, using what was then the only known effective drug, AZT, could slow down the progression to AIDS among asymptomatic and mildly symptomatic sero positive persons. There were only two basic outcomes of these studies; either it would work or it wouldn't work. And in our work, or in our research, we set out to explore the implications for the health care system of providing early intervention treatment and services based on the assumption that it would work in slowing down the progression to symptomatic disease.

In mid-August, Secretary Sullivan in two widely publicized press conferences, announced that early treatment with AZT did in fact slow down the progression to AIDS with patients with low CD-4 cell counts and shut down those arms of the clinical trials.

So what has happened in the past two and a half months? In talking with clinicians it has become clear that the results of these trials represent a major clinical breakthrough. Yet all that we have to go on are press conferences and newspaper clippings. The latest medical care is being delivered by the New York Times and the Washington Post. Where are the peer review journal articles? Where are the CDC recommendations? Where are the plans to provide early intervention treatment and services to the hundreds and thousands of persons who need it and fall into the clinically indicated categories for efficacious treatment? Where are the city, state and federal plans to meet the medical needs of the HIV infected population?

We have a limited window of opportunity to act to provide early intervention treatment before the bulk of the infected population moves to the symptomatic end stages of HIV disease when early intervention will be too late. Time is running out for early intervention and we have not even begun. We must move swiftly to bring the missing players to the table to begin providing these life sustaining drugs and services. This includes a greater presence of our federal, state and local governments in terms of leadership, financing and service delivery. It includes the support and cooperation of the insurance industry, employers, physicians and other medical providers, and last but profitwise not least, the pharmaceutical industry as well.

Since the publication of our work last month, there has been a reduction in the indicated dosage level for early antiviral treatment and a modest drop in the price of AZT. And together these factors have led to a drop in the cost estimates, and if we are serious at providing a wide scale early intervention program, the annual costs are at a minimum now estimated to be in the neighborhood of $2.5 billion at the national level, $350 million for New York City, and $40 million for San Francisco. And I just repeat, these are per year costs of providing early intervention.

The enormous financial burden of early HIV intervention is in part artificial. The bulk of expenditures is tied to the price of pharmaceutical agents, and though drug companies have a legitimate need to recoup their investments on experimental drug development, the public also has a right to obtain lifesaving drugs at reasonable prices.

In the case of AZT and pentamidine, the two most widely prescribed AIDS treatment drugs, their high prices do not reflect accurately either development or production costs. Neither either of these drugs were discovered by their current manufacturers. Their prices are, in fact, partially supported by the provisions of the Orphan Drug Act, which has proven to be extremely profitable for some pharmaceutical companies. It is estimated that under the provisions of the Orphan Drug Act and under current tax laws, drug companies are able to reduce their tax liability on clinical trials by approximately 70 percent of all company expenditures.

Now, let me quickly summarize five key

economic points that flow from this discussion. One, early intervention costs are large, but in the context of federal health care expenditures, they represent less than 1 percent of total national health care spending. Two, the quickest, easiest, most efficient way to reduce the cost of early intervention is to lower the price of AIDS treatment drugs. Three, while these numbers sound large, what happens--and I think it is an important question to ask--what happens if we do not provide these services?

We can expect large numbers of individuals to become critically ill with AIDS, and by slowing down the progression rates, we have at least an opportunity to shift some of these costs into the future, to decompress the crisis and crises we have had in our hospitals and emergency rooms, and we can shift some of the burden out of the hospitals and into ambulatory care settings, with the proviso--and an important one--that we provide adequate enhanced reimbursement in the ambulatory care settings to do this kind of work.

Four, by keeping people relatively healthy in a prolonged asymptomatic state we can mitigate some of the economic burden by keeping these individuals employed and as productive members of society.

And my fifth and final point, there is an important convergence in our public health mission and reducing the economic cost burden. By offering life sustaining treatments, we can draw into the health care system the very people we would like to reach in terms are preventive health education and risk reduction counseling. That is to say, those who are HIV infected. This would help to stem future transmission of HIV and economically every future case that is prevented represents significant and real savings in terms of the cost of medical treatment.

The prospect of early intervention holds great promise for extending the lives of large numbers of individuals who are infected with this deadly virus. Prolonging the asymptomatic stage of illness also offers the possibility that more refine and effective treatment will be available to infected individuals in the future.

With early intervention we have an opportunity, albeit a time limited one, to begin rational planning and avoid the crisis driven policy making that has characterized the AIDS epidemic for the past nine years. Thank you.

CHAIRMAN OSBORN: Thank you very much. That's a most eloquent statement of several considerations that don't usually get put into the same thought at the same time. I appreciate it very much.

Dr. Green.

STATEMENT OF JESSE GREEN, PH.D.

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NEW YORK UNIVERSITY MEDICAL CENTER

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DR. GREEN: I brought some colorful posters but I don't know if anybody can actually see them. But it was fun doing them with magic markers anyway.

I want to pick up on a point that Dr. Lee mentioned earlier when he said that AIDS stresses the financing system at its weakest points. I wonder if we can even refer to our health care financing streams as a system at all. In fact, what we have is not a system but a collection of different financing mechanisms that is so complex few experts understand it, and patients often need specialists called case managers just to navigate it.

From the point of view of health care providers, the health care financing system is often seen as what we refer to as a payor mix. For those of you who have my testimony, these charts are in the testimony at the back, but I won't assume anyone can see it in my remarks.

In very brief, terms what is this national payor mix that we have in the United States for health care?

COMMISSIONER ROGERS: Jesse, just to reassure you, I think the whole audience does have this, so feel confident that they can see your tables.

DR. GREEN: And, of course, that they are only going to be able to see them in black and white after the great expense I went to--

DR. LEE: All those magic markers.

COMMISSIONER ROGERS: Dr. Lee will be happy to reimburse you for those.

[Laughter.]

DR. GREEN: That will be a first.

In very brief terms, what is this payor mix that we have in the United States for financing health care? Private insurance, together with patients' own out of pocket payments, constitute a large part of the pie. The remainder consists largely of two programs, Medicare and Medicaid, which sound alike but are not really very similar at all.

Health care providers know these financing sources intimately. Hospitals employ vast empires of financing specialists and administrators to cope with their intricacies, so it does not take long for providers to notice if treatment of a particular illness brings with it a mix of payors that is different from what providers usually expect.

In a study that I have been working on with my colleague, Peter Arno, we are attempting to characterize the AIDS payer mix. Yesterday you heard from Dennis Andrulis regarding the losses being incurred by some providers from AIDS care. Part of this is certainly due to high costs,m but apparently the major reason for these financial losses is that reimbursement for AIDS is unusually low, and we think a great deal of that is due to this unique payor mix that comes along with treating AIDS.

I am focusing on Medicaid a lot in my discussion of payors today, because it is Medicaid that is the unique element in the AIDS payor mix. The Health Care Financing Administration has estimated that 25 percent of the cost of AIDS are funded through Medicaid. This figure is a rough estimate, but it appears to be fairly close to the mark.

What's more important is to place it in a broader context, and that is to say that what is not often mentioned is that 25 percent is a very large share for Medicaid to be funding. It has nearly tripled the estimated 9 percent of the U.S. health care costs that Medicaid funds for all conditions.

In the figure--which you may turn to if you want to see it--we compare Medicaid's share of AIDS costs in a number of different studies with Medicaid's share of the cost of treating all patients regardless of their illness. And in each of these surveys the AIDS patients are being covered by Medicare in a much larger proportion than for all illnesses. In one national study, done by the National Center for Health Statistics, 24.1 percent of AIDS cases were covered by Medicaid, compared with 13.4 for all conditions.

In some other surveys, for example, in New York, the figures for Medicaid are 46 percent compared with 17 percent which Medicaid covers for all conditions. And in the most extreme case, which is Andrulis' survey of public hospitals, these hospitals, which normally have a high Medicaid share of 38 percent, see an AIDS population which is 63 percent covered by Medicaid.

Now, why is the AIDS payor mix so heavily skewed towards Medicaid? One obvious reason is the fact that Medicare, which normally accounts for a large piece of the health care financing pie, is virtually absent from AIDS financing. In New York and California, for example, Medicare funds over 40 percent of hospital costs, but only 4 percent of hospital costs for AIDS. Private insurance coverage of AIDS care accounted for approximately half of the costs in the National Center for Health Statistics survey of AIDS, and somewhat less than that in the CPHA survey. And the insurance industry estimates that its share of AIDS costs is about 50 percent.

Now, that share is actually high if you compare it with all patients in the United States, where private insurance covers about 34 percent. But if you look just at the population of people in the age group less than 64 years old, private insurance in that age group normally covers 74 percent of the health care costs, so that the 50 percent share of AIDS in that age group is actually low.

So that this mix is what characterizes the AIDS patient population from the providers's point of view. What makes this particular payor mix even more disturbing is the fact that as time goes on the trend is to an even greater skew towards Medicaid. And if I can have the second chart, which is also in the testimony, you will see that by examining hospital discharge data from New York and California we have been able to determine that, for example, from the years 1983 no 1986, Medicaid's share in New York went from 36 percent up to 49 percent. The most recent figures for 1988 are that it is up to 54 percent. In San Francisco Medicaid rose from 19 percent of AIDS costs to 30 percent. That's right, 19 to 30 in San Francisco, and 11.5 to 23 percent in Los Angeles.

Now, what is accounting for this trend? This is a question that is actually quite difficult to answer. There are a number of possibilities and we do not have really good data to be able to untangle all of them. Certainly one of the reasons is a changing demographic mix among AIDS patients. Some of it is due to the increasing proportion of AIDS cases among IVDUs where 80 percent of whom are Black or Hispanic, traditionally larger users of the Medicaid system.

However, these demographic trends in the epidemic do not fully account for the shift. We found that Medicaid's share is increasing among all the three major racial ethnic groups with AIDS while private insurer's hairs is declining in the three cities that we studied. For example, among Whites in New York, Medicaid's share went from 16 to 29 percent, and among Blacks the increase was from 55 to 63 percent.

There may be other factors besides these demographic trends that account for the shift upward in Medicaid's share. For example, there have been some changes in eligibility requirements for Medicaid. Also, Medicaid may in some cases be the desired option for some persons with AIDS who need certain benefits, like pharmaceuticals or home care, which sometimes are better covered by Medicaid.

Thirdly, private insurers may be successfully avoiding some cases of AIDS by selective underwriting policies. And finally, perhaps the most important component, persons with AIDS who lose their employment may have private coverage discontinued as they spend down to Medicaid.

Briefly let me just outline what are some of the consequences of the skewed payor mix, and particularly this trend towards greater skew. The first problem is does Medicaid provide good access to health care for those who have it? Most studies which have examined this have found that, in brief, Medicaid is certainly better than having no insurance at all, but it is not the equal of private insurance or of Medicare on certain important dimensions of access.

In one study by Davis it was found that many physicians are reluctant to treat Medicaid patients, and perhaps poor people in general. In a recent study by Blendon, he found a significant deficit in access to health care among Black compared to White Americans, and this problem goes well beyond AIDS.

Very little has been documented about the reasons why physicians in private practice frequently avoid, or at least limit, the number of Medicaid patients they see. If I could have the third chart please.

At least one very important factor is that Medicaid compensates physicians at rates far below those paid for private insurance or Medicare. This is figure four in the testimony.

To cite one well known example, in New York City an intermediate office visit by a new patient is compensated by Blue Cross at $78, by Medicare at $80, and by Medicaid at $7. If the patient enters a hospital and his physician makes an initial hospital visit with a complete history and physical, Blue Cross will pay $102, Medicare $78, while Medicare pays $6.50.

We focused on some of the most common procedures in the care of persons with AIDS, and found that Medicaid pays have the other insurer's rates for chemotherapy infusion and that for a bronchoscopy Medicare or Blue Cross would pay over $600, while Medicare pays $60.

We interviewed a number of physicians who have private practices treating AIDS patients, and found that many of them limit the number of Medicaid patients they see primarily to those of their patients who formerly had private insurance and now have Medicaid, but they do not take on new Medicaid patients. A number of doctors told us that it is a problem for them to refer a Medicaid patient to a specialist for a consultation because of the low reimbursement expectation, and that when a physician does that, he is then in a position of the other physician owes him a favor, or he owes the other physician a favor.

Finally, what are the implications of all this for patients, providers and policy makers? Very briefly, the fact that a large and increasing proportion of AIDS care is funded by Medicaid creates problems for patients because in many poor communities those who have Medicaid must depend almost entirely on hospital emergency rooms or Medicaid mills for their primary care. These are obviously not settings in which complex care like that required for AIDS patients or HIV positives can be adequately provided.

In conclusion, in the early years of the AIDS epidemic health policy was largely directed towards attempts at cost reduction through substitution of outpatient services for inpatient care. Very little has been done to influence the funding streams that finance the cost of AIDS. With increasing incidence of AIDS and an entirely new set of medical needs among asymptomatic sero positives emerging, the financing problem is likely to become paramount. Unless we address these issues, the AIDS epidemic will increasingly reflect the inequities of our two-tiered health care system, with first class treatment for those who can afford good coverage, and a second class of care for the poor.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much, Dr. Green.

Commissioners, I think now is your time to respond and ask questions and comment about this important morning's testimony.

I want to ask Diane to start, if you have any I comments, or if you would like. I just know that a good deal of Dr. Lee's discussion about the importance of the county unit in all of this might prompt you to want to enhance that, and I know with the study that you did with the National Association of Counties there may be some additional input as well.

COMMISSIONER AHRENS: Madam Chair, I was not going to speak to that. I think that as we get into our discussions here and in later meetings I think that will become obvious and we'll be dealing with that.

I guess what I did want to say, with respect to all the panelists, is that you have so clearly to me highlighted the nonsystem that we have in this country in terms of providing health care and that that nonsystem is broke, and somehow as we pursue our concerns with respect to addressing how we will pay for needed services in AIDS, that we cannot avoid looking at that nonsystem and the condition that it is in.

CHAIRMAN OSBORN: Mr. Konigsberg.

COMMISSIONER KONIGSBERG: Yes, a couple of points. I think at least one of the speakers pointed out the problems with the data on HIV, and it is a point that I would like to reinforce, that when you look at the data on HIV prevalence in this country, the figures of one million and one and a half are thrown around. Then there are all sorts of complicated formulas that are used to try to get more accurate figures, and it becomes rather confusing for those of us who are not mathematicians. And one of the most basic lessons in public health in terms of response to any epidemic of any sort is knowing your prevalence--your incidence and your prevalence.

And I think we have a real problem with that in this country, and it begins to become even more glaring as the needs for medical care become very much a part of the response, which is a secondary kind of prevention that goes with the primary prevention, which is preventing new infections. So I just wanted to make that point and something that we may want to try, as we develop the public health kinds of testimony, that we may want to look at. This is not the setting to really get into that, but I did want to make that point.

The other thing I wanted to comment on, having been a local health director for quite a number of years is again the point I made yesterday, the ability of the local health system to respond. I was struck by Dr. Lee's comments that California has small counties under 100,000. In my state, Kansas, there are four counties of 100,000 or more. To us a small county is under 5,000.

The reason I bring that up is not to highlight the geographical diversity of our country, but that that does have something to do with the public health system's--or again, nonsystem, that is a phrase I like to use too--ability to respond. We have seen some of the finest examples of the response of the public system, and specifically the public health system, in this country, for example, San Francisco. And then we have seen other examples of where the system has, both at the state and local level, has had a lot of trouble in responding.

And I guess my point, Dr. Lee, would be to make sure that we recognize that the whole country is not San Franciscos. And that is a unique system in may ways, including the fact--what my understanding is--of the fact that that's an integrated public system involving the traditional public health, the mental health and the hospitals, and was uniquely constituted to deal with something like AIDS.

For those of us that have been out there in the fragmented public care systems, it is a much more difficult situation to try to put together a response to AIDS, and it is something that I hope this Commission will deal with.

DR. LEE: I would just like to add to that. I would hope that in terms of your own experience that you could help the Commission look at the barriers faced by a local health director in responding to the epidemic. I mean, there are barriers due to state policies, there are barriers due to federal limitations on what you can do in terms of, for example, on the prevention side in health education. There are clearly some of the barriers we have talked about here on the financing, the fragmentation of the financing system.

But I think it would be very helpful for the Commission to really get a sense--I mean, obviously San Francisco is different than a 5,000 person county in Kansas. But critical to responding to the epidemic is the capacity of that health department to be able to respond, and the resources that are available, but also the barriers imposed within this very complex federal system. We not only have a complex system of financing, the intergovernmental system is one that is I think often perplexing at the local level, and very, very difficult in order to even respond to let's say federal policy initiatives with categorical grants because simply working through the maze is very, very difficult.

COMMISSIONER KONIGSBERG: I think that is a good point, and Diane I think remembers as well that the tasks force at NACO that she chaired on AIDS took a special look at the intergovernmental relationships. And I know that--again, from the local level--that the confusion between the state and the local level sometimes can be a barrier. And I'm as much an advocate for local health departments as you will find anywhere and I haven't changed in the last 13 months, but I also recognize that there are many counties in this country that have no local health department, or health departments which are rudimentary or who are in some real disarray, to take the term from the recent IOM report on the study of public health.

And again, as we take apart the health

system, which we have been bashing that fairly well for the last two days, let's not forget that part of what we need to look at is the public health system at all levels of government. I think you brought out some very important points.

CHAIRMAN OSBORN: Representative Rowland.

REPRESENTATIVE ROWLAND: Thank you.

Dr. Lee, you pointed out that our system is stressed at its weakest point with this AIDS epidemic, and talked about the possibility of the expansion of Medicaid, and has been suggested by the Energy and Commerce Committee to 185 percent of the poverty level for pregnant women, phased in over a period of time.

I would point out, in that debate that took place there were some states that would be stressed greatly by that. For example, Alabama, I understand, approximately half of the state employees in the State of Alabama would have become eligible for Medicaid under increasing that to 185 percent of the poverty level.

Dr. Green pointed that Medicaid does not seem to work as well as we would want it to in delivering medical care. So I wonder if that is the way that we ought to go in trying to address this problem of AIDS that we are having. And let me ask all of you this question, and I understand this was brought up yesterday, what do you think about having regional centers to deal with the problem of AIDS?

I know in my own State of Georgia over the years we had a facility in Alto which was for the treatment of sexually transmitted diseases, and we had a hospital which was for the treatment of the tuberculosis that seemed to work very well.

I am sure there are pros and cons about that, but I wonder from a cost effective standpoint and from the standpoint of being able to provide the care to the people who really need it, realizing that some hospitals refuse to take AIDS patients, some physicians refuse to treat AIDS patients, what are your thoughts on developing a system like that for this specific disease?

DR. LEE: A couple of comments, and then others can also comment.

First with respect to Medicaid, I would only suggest that the Commission look at that, and look at that only as a step towards ultimately we've got to find a solution for the uninsured. And there are various options currently before the Congress. Certainly with the Pepper Commission looking at that issue as well there will be other generic relations. Ultimately, it seems to me, we can't solve the problem of financing care for persons with AIDS or HIV infection without solving the problem for others who are uninsured. So that I think that the Medicaid option that I suggested would only be a step in that direction.

With respect to the regional centers, we, of course, have had and we do have today regional centers for various kinds of complex, you might say tertiary care problems. Increasingly the care of persons with AIDS is going to be a primary care problem, so that the regional center where you can, as San Francisco General Hospital certainly was one of those early regional centers with a designated AIDS unit, served a very, very important purpose in terms of improving quality of care, providing a mechanism for clinical trials, things of that sort. And I think regional centers still have a place. New York State, of course, has a policy with designated AIDS centers where they receive higher levels of reimbursement for the care of persons with AIDS in those centers.

So that I think that it does have a place, but increasingly we are going to have to train primary care physicians in the care of HIV asymptomatic individuals, and I think that's where we must give more attention.

One final point, I think that some consideration should be given by the Commission to what we used call impact aid in terms of education. Where there were a large number of military personnel in an area, those communities received greater federal subsidy for the support of education. And I think the concept of impact aid might be one that the Commission could consider. Then the communities could decide, or the counties could decide, what's the most appropriate allocation of those resources as opposed to that decision being made let's say at the federal level when the problems are quite different, for example, in New

York and Los Angeles.

MS. SCITOVSKY: I have little to add on the subject of regional centers. I think yesterday in the discussion it became quite clear that the main function of these regional centers would be to do the initial diagnosis but to refer patients to the system so that they would be receiving appropriate care.

As AIDS is becoming more and more of a chronic condition that doesn't require lengthy hospitalization, I don't think regional centers have the same role as they did in the beginning of the epidemic. As more of the care becomes ambulatory care, I think, as Dr. Lee also said, it becomes more a problem of primary care in the community where they are. Especially with the IV drug users where their sexual partners, their children can also be monitored. I see travel problems to a regional center for that kind of care as a major problem.

DR. ARNO: I would just briefly echo those comments and add that I believe in the route towards primary care for the treatment of persons with AIDS and HIV infection, it will become more routinized, it will become simpler. The problem and the challenge will be to train medical professionals, not just physicians but nurses and other ancillary personnel, to take care of these persons. And the care will be relatively simple and should be done in the community, and it seems to me that is clearly the direction we are headed.

DR. GREEN: I would like to underline Phil Lee's comment about the uninsured, which I didn't stress enough in my remarks about Medicaid. Those people's problems are just that much worse than those who are at least covered by Medicaid.

In terms of regional centers, I am skeptical of the concept, although I certainly wouldn't rule it out for some areas of the country which have very few cases. But I think probably a better approach, given our system--or nonsystem--is to take some of the financial risk out of providing care to AIDS patients.

Andrulis' results are really devastating, when you talk about outpatient care that costs $237 to provide and is reimbursed at $63. If you remove some of the financial risks so that it is not a losing proposition financially to provide care, then all kinds of things will happen. There will be regional centers in some places. Hospitals will not turn AIDS patients away. Primary care providers may go into AIDS specialties and will want to be trained in the delivery of those services. But as long as the financing is not there, all of these problems are going to just get greater.

MS. SCITOVSKY: May I add something to this, however. I would hate to see the Commission recommend taking the path of end-state renal disease. I am very, very dubious about singling our another disease for special treatment. That's the only point I wanted to make.

REPRESENTATIVE ROWLAND: I was not here yesterday for your discussions, and I understand you have been doing a lot of bashing of our present health care delivery system, so let me add my voice to the bashing. Because I think we have a system that is so badly flawed that it just does not function as it should, and we have been trying to incrementally deal with that system for almost 20 years now and we have finally learned, I think, perhaps with a passage of this Catastrophic Health Insurance Act, that you cannot address it incrementally. There have got to be some fundamental structural changes made in the whole system in order that we provide the kind of health care that we should to the people of this country.

One other thing that I want to Dr. Lee that has not been mentioned, and that is the role of the Veterans Administration, now known as the Department of Veterans Affairs, in this AIDS epidemic. The VA has approximately 10 percent of the AIDS patients now. I had the opportunity last year to visit USC School of Medicine in San Francisco, the Veterans Administration there, and I was really very pleased to see the amount of research that was going on there and what was taking place also at the Belleview in New York, and saw what was taking place there. I was very impressed with how much the Veterans Administration has been involved in research and in the treatment and care of AIDS patients.

And Dr. Lee, it seems to me that there is almost a cloistered group of patients in the hospital system in the Veterans Administration that would lend itself to investigation of the problem of AIDS. Would you comment on that?

DR. LEE: I think there are a couple of issues with respect to the VA. One, the population that it deals with, of course, is largely male. It is significantly a higher proportion of persons with substance abuse, including alcohol, so it is a population that is at greater risk in relation to the epidemic. And I would say that in some areas they have done an outstanding job in terms both providing care and conducting research, and also in training. They do a huge piece of the training that is done for medical students, for example, and residents are rotated through the VA system.

Two problems I think currently. One is the financial problem, but the other is the lack of, I think, sufficient authority in terms of primary care and ambulatory care, and I think that that needs to be looked at to see what are the current restrictions with respect to both--the service connected disability individual has a pretty wide range of services. For those who are not service connected but access the system for financial reasons--and there are lots of individuals in that situation--the increasing restrictions that have been placed on the individual who is a veteran but doesn't have a service connected illness, let's say an HIV infection, there I think that there are severe limitations, particularly with respect to ambulatory care.

And if this Commission could look at those, I think that those ought to be eliminated, so that that system could play a much more significant role in helping communities deal with the epidemic, both from a standpoint of care, but second, from the standpoint of training, because they have done such an outstanding job, and then third, playing a significant role also in research.

CHAIRMAN OSBORN: We have Larry, David, Eunice, Diane, Don. A lot of interest. Go ahead, Larry.

COMMISSIONER KESSLER: Dr. Arno, I appreciate your passion about the problems in terms of early intervention. I was struck, however, in your five points and pros and cons of access to early intervention, that you didn't include in there drug treatment or treatment on request, and also perhaps even job training and placement. Because of the changing demographics, I am not sure that people are going to have jobs to go back to once they get into early intervention programs.

Do you have any feelings about that or have you given any thought to including in your list of goals and objectives in terms of early intervention that we work on the whole access to treatment issue?

DR. ARNO: Absolutely. One thing I didn't emphasize but I think it is coming out a little more now is that it is one thing to talk about early intervention in San Francisco where Jesse and I were out there a couple of weeks ago before the earthquake, trying to model an ideal program of early intervention.

It is another one to go to my institution at Montifiore in the Bronx and talk about how we are going to do early intervention in the Bronx with our population of IV drug users. But I think it is doable, and I think--I agree with you that--I presume you are talking about substance abuse and its link to treatment, and at Montefiore Phil I believe mentioned, we are doing some of the, I think one of the important directions that we need to go in with this epidemic, which is primary care and drug treatment integrated together in a system. And in our methadone programs at Montifiore, for example, we provide free primary medical care, and we also provide early intervention and treatment of severe HIV disease.

And I always like to underline that it is basically a rumor, there is a lot of falsity to the notion that IV drug users cannot be enrolled in sophisticated treatment protocols. In Montreal at the last International AIDS Conference there were half a dozen presentations from drug programs around the country showing excellent compliance of drug users in complicated treatment protocols. So I think that it is doable. The challenge is to provide access and affordability and in an efficient way and in a user friendly environment for people to come to.

DR. LEE: Larry, there is in the appropriations in the Senate right now an increased appropriation of $65 million of funds within the block grant to shorten the waiting list. This last year there was a very significant action taken by the Administration in I think allocating upwards of a hundred million for--they don't wall it treatment on demand, but they call it shortening the waiting list. And they have got now methods for really determining the waiting list and ways to do that. And I think that is a critically important area, because the earlier people can get access to treatment the better. And that is a very important action. I hope that the house supports the Senate action in that area and provides a kind of a base for funding of those programs.

COMMISSIONER KESSLER: Well, I agree. I hope so as well.

Dr. Scitovsky, just a simple question. Who is doing the NCHS survey, do you know?

MS. SCITOVSKY: Westat got the contract, and Dr. Fred Hellinger of NCHSR is the project officer on it. Let me add, just to add to my list of what we have done, we actually designed that study. We had a contract with NCHSR a year ago to design six difference what they call protocols for studies of the cost of

AIDS, and this is the first one that they have put out as an RFP, a request for proposal, and actually awarded.

There are at least three more that they are planning to put out. One is a study of the cost effectiveness of different forms of treatment. Another is the study of the cost effectiveness of different ways of managing the disease as against medical treatment, and a fourth is a study of the cost of testing. Because let me add to what the others have said, with a trend towards early intervention we can also expect a trend towards more testing. As persons who may suspect that they are infected find that maybe they can be prevented from developing AIDS, we may expect a much more larger demand for testing than we have--for voluntary testing--than we have had so far.

COMMISSIONER ROGERS: I wanted to simply first echo what Diane Ahrens said. I thought you presented, the four of you, with exquisite clarity some of the road blocks that patients with AIDS face in getting adequate care, and the financial end of it I have never heard presented quite as well. I hope the whole Commission will listen carefully to what Phil Lee and Jesse Green said about the fact that we cannot solve the problem of the financing of care of AIDS patients at the expense of or without looking at the problems of the uninsured who are sick for any cause, or we simply are not going to succeed as a Commission.

And Jesse, I liked your comment that perhaps the carrot rather than the stick, if we could remove the financial risks for taking care of sick poor people--and I'll put it that broadly--that you might find all kinds of imaginative things being done that would suit the local needs in the area.

I wanted to make one point from Dr. Scitovsky's data, however. I think we have done this country kind of a disservice in saying we can't afford to take cares of AIDS patients. Utter nonsense. Of course we can, and I thinking, Anne, as you gave your figures, $5 billion to $15 billion, which sounds absolutely staggering, in 1991. I couldn't help but think that is from somewhere less than in 1 percent to somewhat less than 3 percent of what we will spend in health care in that particular year.

MS. SCITOVSKY: Well under 3 percent, 1.2 percent.

COMMISSIONER ROGERS: Thank you. So for this nation to say we can't take care of these people because it costs too much is utter nonsense, and I hope our Commission will emphasize that as well. I feel very indebted to you all for wonderful testimony.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: Dr. Scitovsky, you mentioned that there may be a differential cost in serving various populations, and I think that is very important in view of the fact that we have evidence that particularly racial and ethnic minorities affected or impacted by AIDS enter the care system further on into disease progression, and I would like you to expand on that.

MS. SCITOVSKY: Well, we simply don't have the data. We have no data on women, we have no data on IV drug users, or practically none. I had some from New York State but they warned me against using them because they said it was a very small response rate and was probably a biased sample. We don't know whether minorities are most costly than Whites, we just don't know.

The point is this, however. Most of the expenses--in the past at least, I can't talk, we have not done detailed studies yet of costs over time of a patient on AZT--most of the costs of a person with AIDS are incurred in the first month of diagnosis and then in the last three months before death. So even if women have a shorter life expectancy than men, the chances are that expenses are not that different. They are incurred over a shorter length of time, but with the expenses concentrated at around the three months before death.

But I certainly think there should be far more studies. The National Center for Health Services Research will do a separate study for children, and I think also for women, but on a very small sample basis. I have urged all along--but I haven't got very far with it--that when clinical trials of new drugs are carried out they should build into the clinical trial a data collection system for costs, because you have a control group and you have the experimental group and it would cost very little to link this up with a cost accounting basis.

We did a very painful lengthy study of a very small group of the nine patients who were in the AZT Phase 2 drug trial at San Francisco General, matched them with nine others who would have qualified and were not included. Retrospectively we contacted them, they were still alive and we followed them. It would be so much simpler and cheaper to do this on an ongoing basis and you would get very important data right away.

COMMISSIONER DIAZ: Dr. Arno, just one question. You really challenged my thinking this morning with the urgent need to pass on a message to our communities about early intervention and what this may do, and has the potential of extending life and extending the asymptomatic period.

However, what do you think of the ethics of doing such a thing? It was suggested by the one of the speakers yesterday also that our major educational campaign ought to be launched now doing the very thing you have advocated here today.

What do you think about doing that when we really don't have the resources available in society so that people can get into early intervention, particularly therapeutic interventions at this time, if we don't have a system set up?

DR. ARNO: I think we don't have time to sit around and have this Commission live out its life and issue another report and have another report, another Commission. By then it is going to be over. We have to act and we have to act swiftly. And this issue has been raised in New York over and over and over again, and we do very little. I mean, the ethics are--I understand the ethical dilemma. How do you advocate treatment when you don't have the treatment to advocate for?

So that what is happening right now is we have a class system. There is no question about it, people who are knowledgeable, educated and have the money are having their early intervention, their PCP prophylaxis, and they are getting it. So I think that we need an integrated approach that prevention, education and treatment can be linked together, and early intervention is the perfect way to do that. And secondly, we seed to advocate for the services. We need to deliver and advocate for those services right now, and just demand that they be delivered.

I think the Commission here can play a role in that advocacy and I think, as I mentioned, that role would bring down the price of the drugs, it would certainly make it easier to do. But the government has got to take a leadership role. We have a Mason saying in Montreal we have a moral imperative to provide treatment. We have him a month later in the Weiss testimony saying, well, it is not the federal responsibility to provide treatment. We need leadership at all levels and if the feds won't do it, then the city and states have got to do it.

COMMISSIONER DIAZ: Thank you.

DR. LEE: I think it is important that we not believe that we don't have the capacity in the system. We have a very ample supply of physicians and hospitals, both ambulatory and inpatient services. It is a matter if the financing was there the services would be provided.

So I think that the ethical issue is the policy decision that must be made at the federal level, first of all, and then at the state level, because those are the sources largely of financing of these kinds of services. And the reason we have to do it quickly is because of the time when people were infected with the HIV virus. And very, very shortly those individuals will be moving from presymptomatic to AIDS, and we have this window during the next two to three years when we have an opportunity to really render a great service to those individuals, and many of them are unaware of the potential benefits of these treatments.

CHAIRMAN OSBORN: This is such an important discussion I want everybody to be able to bring out their points, and at the same time our schedule is beginning to squeeze. I think we should go on a little bit further. Diane, Don Goldman, Scott and Roy, in that record, if you could have your interchange be fairly quick, because surely we will have to talk about this much more, but while we have this important group here I want to take advantage of them, too.

COMMISSIONER AHRENS: I just want to go back and comment, I just want to first of all have the opportunity to really thank Phil Lee, because his institute has provided resources really nationwide to help counties cope with this issue, and I think that we could not have done it without the help of you and your staff and what you provided to the National Association of Counties.

I think when we look at this issue, we have so far fairly focused on the federal role and just touched upon the state role, but that's not where people live in this country. That's not where they are born, that's not where they live their lives, that's not where they die. And for the purposes of AIDS and providing services, they live and die and are born in counties. That means that we have got to find some way to mobilize the counties across this country.

We are hearing that this is, as we move into the future, that this is going to be increasingly a primary care disease, and the primary care is given there at the local level, not in regional facilities. Also we have heard about the impact on public hospitals. Once again, those public hospitals, and their deficiencies, are funded primarily by--are picked up at the local level.

There are models out there. We know what has succeeded, and I think perhaps to capture some of those models as make use of them. I also think that--and maybe some of you would want to comment on this--that in addressing the kinds of--this is a political issue at the local level, and in addressing that political issue it seems to me that foundations can be very helpful in mobilizing those communities, and perhaps this Commission would want to make some comments and recommendations to the foundations of this country in terms of how they expend their money at the state and local level to help mobilize communities to address this issue.

If those communities are not mobilized, the people that live in little counties of 5,000 and 10,000, or maybe 100,000, their needs aren't going to be addressed. They are simply not going to be addressed unless that community decides that it is going to address them.

CHAIRMAN OSBORN: That's an important piece of future agenda I think, and we are going to be looking back and back at that county structure and its central role. Don Goldman.

COMMISSIONER GOLDMAN: Thank you. I have just a quick question. The data on Medicaid, if you age adjust it and race adjust it, does it change at all in terms of the proportions of Medicaid and private insurance?

And the second question with respect to that is, is the shift to Medicaid, even among the White population, that you explained before, or among other populations, a shift from uninsured to Medicaid, or is it a shift from private insurance to Medicaid, in terms of a percentage of the pie?

DR. GREEN: To take your second one first, the shift occurs in both directions, but very often from private insurance one moves to no insurance, losing employment, losing insurance, ending up with no insurance but still having assets means you are not eligible for Medicaid. Then comes the process that we refer to as "spending down," which means impoverishment, and finally eligibility for Medicaid and then you are insured again. So it is often a two step process.

In answer to your first question, Medicaid as a proportion is very different for Whites than it is for Blacks and Hispanics, but each at their own level is higher for AIDS patients and increasingly higher each year than for the same racial ethnic group of patients who do not have AIDS.

COMMISSIONER GOLDMAN: One more quick question. All of you, I get some mixed messages sometimes from the four of you. You talk about a system that is broken, or nonsystem, and you suggest that Band Aids won't work. And yet at the same token there is discussion of the problems with categorical programs and yet the need to do something quickly to solve some of the current problems that we have that require categorization.

To overhaul the entire system is going to take, in terms of the public policy debate to define what kind of system we have, it is going to take 5 or 10 years, or maybe more or maybe somewhere in that order at least, optimistically. And yet there seems to be some hesitation on whether or not any Band Aid can work in the meantime.

How do he deal with that dilemma? Do we go in the direction of trying some categorical things, of dealing with some specific problems while we are working on the long term problem, or do we simply say, look, none of those things are going to work and let's get to the bottom line and overhaul the system as a whole?

DR. LEE: I think I initiated that discussion, and I would say that you have to have a vision of where you want to go. You don't want to take any interim steps that aren't consistent with that long term vision. But short of achieving the long term goals, which you can't achieve within the next two to three years but you can start the process, there are I believe some incremental steps which although categorical to some extent really relate to Medicaid, which is a generic problem. The Congress has already decided that it is possible to mandate a decoupling of Medicaid from public assistance. And I think, of course, that should be done across the board for

Medicaid, it should not be associated with public assistance.

Short of that, another step can be taken, particularly because of the preventive and cost effect nature of the interventions with respect to asymptomatic individuals. It should have a very high priority. Just like prenatal care, it can be extremely cost effective downstream, and I think Peter said it quite correctly, you will be, at least in the short term, saving money, although downstream obviously until we get more effective treatments for HIV infection, we are going to incur those costs at some point downstream.

But I believe those measures should be taken in the short term, not as ultimate solutions, and I certainly agree with Anne, you should not have a Medicare benefit for HIV infected persons like end stage renal disease. That is not the way to go.

CHAIRMAN OSBORN: Through the wonders of PAHO there is coffee downstairs again, so that we want to be sure and be able to do that. But I want Scott and Representative Rowland to have a last opportunity.

COMMISSIONER ALLEN: I just have one quick question. I'm not sure if it is, at this point, something of your studies, but the economic loss in the workplace. Are the studies out on the taxation loss of people losing their jobs? Do you have some references to where we could follow that up?

MS. SCITOVSKY: In early 1986 the Centers for Disease Control asked the Institute for Health Policy Studies to do estimates of the direct and indirect costs of AIDS in the United States for 1985, 1986 and 1991. Dorothy Rice,. the former Director of the National Center for Health Statistics, and I undertook that task. I did the estimates of the direct medical care costs, she did the estimates of the indirect costs due to loss of earnings.

However, because of lack of data on the earnings of persons with AIDS, she had to assume that the earnings of say a 37 year old male who died, or who was sick, were the same as the earnings of a similar male in that age group across the country. This is a very unsatisfactory way of doing it, but we did it.

Anyway, we came out with a very high figure.

I think we estimated--and this is in 1991 prices--direct medical care costs at 8.5 billion which, incidentally, is very similar to Fred Hellinger's estimate of 5.3 in 1988 dollars. But 8.5 billion in direct medical care costs, and 55 billion in indirect costs. So the indirect costs dwarf the direct medical care costs by a factor of four, five, six.

DR. LEE: And of you take a city like San Francisco and you look at the loss of the labor force in the city of highly skilled, both professionals and technical and administrative people, it has a very significant effect at that level beyond these sort of multibillions of dollars projected nationally.\

MS. SCITOVSKY: And, of course, in the arts you have had a terrific loss. It is going to be a problem how to estimate this as the risk groups shift, and you are going to be faced with a real ethical problem.

REPRESENTATIVE ROWLAND: I just want to thank all of you for being here, and one comment about the rural areas versus the urban areas. It is a little unsettling to me to see attention focused on the urban areas to the exclusion of the rural areas. In my own State of Georgia--I represent largely a rural district--we have seen an unbelievable Increase in sexually transmitted disease tied with the drug problem. You cannot separate those two, particularly in Black women. We have seen the incidence of syphilis increase 125 percent in the past two years, and Georgia is now number five in the country in the incidence of AIDS infection; 70 percent in the metropolitan Atlanta area, but 30 percent in the rural areas.

Our present health care delivery system is somewhat a deterrent to practicing medicine in the rural areas, again going back to a restructuring of the system. But I just want to call attention to the fact that we are experiencing in the rural areas of our country now a tremendous increase in sexually transmitted disease, intricately tied to the drug problem.

MS. SCITOVSKY: The National Center for Health Services Research survey will pick two low incidence areas--at least two low incidence areas--for study, so that will include some rural areas. As far as I know, they haven't decided yet on what areas to include, but that will be taken into account.

CHAIRMAN OSBORN: Let me thank you very much. I was whispering to David that I really don't want to let any of you go because your help has been so very valuable to us, and I am sure we will be picking on you again for your expertise. But for now, thank you so much.

We'll break for a rather precise 15 minutes if you don't mind, and then come back.

[Brief recess.]

CHAIRMAN OSBORN: I think in the interest of time we had probably better proceed. There are a couple of commissioners that will be probably coming in a couple of minutes after you start, Dr. Baily, but if you will, forgive that.

We have been telling me people that we are eager to read the material that they have given us, and we are very eager to have a chance for interchange, so if you find that a convenient vehicle and want to ad lib, that would be good, or if you prefer to go from your written testimony, that is more or less your choice. But we hope to have a chance to have some good interchange with the commissioners as well.

Thank you for being with us.

STATEMENT OF MARY ANN BAILY, PH.D.
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DR. BAILY: I am Mary Ann Baily, a health economist at George Washington University, and my testimony today is based on research on the economic implications of HIV infection for the Medicaid and Medicare program that was funded by the Health Care Financing Administration. The project included a review of private insurance in the context of the epidemic, and our review led us to the following conclusions, which I will summarize for you.

First, many of those at high risk of HIV infection are also at high risk of lacking health insurance, private insurance. To explain this a little bit, about three quarters of Americans under 65 years of age had private health insurance in 1986, and almost two-thirds of these people obtained their coverage through the workplace, half as workers and the other half as dependents of workers.

Now, employer provided coverage has significant advantages. It receives the favorable tax treatment that fringe benefits get. Those who have it are insured on a group rather than an individually underwritten basis, unless they work for very small firms, and this means that they get lower group rates and no medical screening. They may, of course, be subject to a waiting period for coverage of care related to a preexisting condition.

Those who purchase insurance as individuals pay higher premiums for lesser benefits and they must usually undergo some screening for health risks. Evidence of HIV infection or high risk status is generally grounds for rejection for insurance coverage on an individual basis.

Now, in 15 states the medically uninsurable are eligible for special risk pool coverage. Benefits in risk pools are comparable to group coverage. However, the policies are too expensive for most of the target population even though the premiums are subsidized. This structure means that the unemployed are especially likely to be uninsured. However, not all employers offer insurance and not all employees offer to take it. In fact, 60 percent of uninsured adults are in fact working. Part-time workers and workers in smaller firms are especially likely to be uninsured. Low income, age under 30 and Black or Hispanic ethnic background are also highly associated with lack of private insurance.

Now, what is alarming about this pattern is the overlap between the uninsured population and the expected future incidence of HIV. The incidence of the infection in homosexuals and those who have received blood products is falling, and the disease is spreading most rapidly among intravenous drug users--who are, of course, likely to be unemployed--their sexual partners and their offspring.

To the extent that heterosexual spread accelerates it is likely to accelerate first among young adults in the low income, disproportionately minority areas in which many intravenous drug users live.

A second general conclusion. Those who have private insurance when they first become infected may lose it later in the illness. Maintaining coverage over time is not easy for those who test positive for HIV. Individual coverage already in force can usually be renewed, but an application for new coverage is likely to be rejected. Employment with a firm that offers good health benefits is the surest route to adequate coverage. Obtaining employment may be a problem, however, if risk status is known. And changing jobs raises the problem of waiting periods. As you change jobs you can go through a period when you are not covered by either job insurance. Moreover, some people have been fired or their individual insurance canceled on some pretext once their infection status became clear.

Employment related coverage also can pose problems for a person who becomes too sick to work. Traditionally, loss of employment meant loss of group insurance at a time when a worker would find it difficult to afford or qualify medically for a non-group policy. Recent legislation, the 1985 Consolidated Omnibus Budget Reconciliation Act, or COBRA to its friends, guarantees many workers the opportunity to continue insurance at group rates for at least 18 months, but this only helps if they can afford the premiums without work income, and if they are physically and mental capable of handling the application process.

Once diagnosed with AIDS and unable to work, most people don't live beyond that 18 month COBRA extension period. If they do, however, they are likely to become uninsured, since relatively few group policies can be converted to individual coverage without medical exam, and then only at a high premium.

Third, private insurance often does not provide adequate coverage for the services that HIV patients need. And Anne Scitovsky made this point this morning, that those who do have insurance and can maintain it throughout the duration of the illness still have financial worries. Private insurance policies usually have limits on coverage, especially for out-of-hospital care, drugs, mental health care and personal care. Drug coverage, of course, is especially important since expensive drugs already play a major role in the treatment of AIDS and are expected to play a growing role in the management of the earlier stages of HIV infection in the future.

Private insurance does not cover experimental treatments. Since HIV is new and its prognosis is so grim, these experimental treatments are extremely important and patients are desperate for access to them. As noted this morning, there is almost no private coverage for long term nursing home care. This will become increasingly significant if life expectancy for patients with cognitive impairment increases. Even when a service is covered by private insurance it often does not fit the needs of AIDS patients. For example, hospice benefits, which are growing and they more commonly are covered, are usually designed for a cancer patient with a stable living situation and family support. Often they have restrictions on inpatient days and types of care that create problems for AIDS patients.

When private insurance coverage is limited, it means high out-of-pocket costs which therefore increases the likelihood that patients will exhaust their resources and require public assistance.

Comprehensiveness of insurance tends to increase with income, so again low income people are more likely to be inadequately insured, even when they do have insurance. The structure of private insurance policies may also distort the pattern of care toward high cost services such as inpatient hospital care, since such services are often covered and lower cost alternatives are not.

Now, some insurers have been turning to case management in recent years as a partial remedy for this, often stimulated to some extent by the presence of an AIDS patient within their subscribers. The case manager identifies potentially high cost patients and works with them to develop an individualized care plan with permission the bend the contractual rules if doing so can save money. Testimony by insurers before the former AIDS Commission suggested that savings from case management can be significant, and patient satisfaction even increased. The data to support this are limited, however, and more recently there has been some concern among people who work with AIDS patients that case management will save money at the expense of quality of care.

In sum, private insurance has severe limitations as a source of financing for health care for those infected by HIV, as well as for those with other conditions that create similar needs. This is not a problem only of AIDS patients, it is a problem for anyone with a chronic disease with acute flare-ups that has the characteristics of AIDS.

These limitations are inherent in the structure of the system and they exist even in the absence of any attempts by insurers to protect themselves from the impact of the epidemic. This is a point I think that has been made this morning and probably yesterday, but it cannot be made often enough. The system itself is inherently limited in its ability to handle this disease, even for the fairly well privately insured person.

Fourth, there are a number of methods that private insurers may use to avoid bearing HIV related expenses. Now, this is a concern that has been expressed, that as the epidemic proceeds private insurers will find ways to avoid the cost of HIV related health care. We identified a number of possible responses that insurers can take. Some of these are legal, some of them are illegal. But the possible responses include screening infected people out of the risk pool, withdrawing altogether from markets with high HIV incidence, ceasing to sell individual health insurance policies, excluding HIV related conditions from coverage, restructuring benefit packages to limit coverage for services that are important to those infected by HIV, tightening the administration of rules on preexisting conditions, and dropping employment related health benefits altogether.

Fifth conclusion, so far there is limited evidence of such avoidance, but insurers have only just begun to react. To study the extent to which insurers and employers are adopting these measures, we reviewed published surveys of insurance companies, employers and persons with AIDS, testimony before the former AIDS Commission, as less systematic reports of private insurance responses in the academic and business literature and in newspapers. Usually these were examples of individual insurers or employers.

To supplement this information we also talked informally with selected insurers and employers and other knowledgeable sources. We found that while individual examples of every response mentioned above--individual examples of every response mentioned above--can be found, so far on the whole employers and insurers are treating AIDS as they would treat over serious illnesses. Insurers are attempting to screen applicants for individual insurance policies for HIV infection by a variety of direct and indirect means. And this screening has attracted a great deal of attention.

It is important to emphasize though that in this part of the market insurers have always attempted to screen out people at higher than average risk, as diabetics and recovered cancer patients would be happy to attest--or unhappy to attest. This causes severe hardship for those infected by HIV, and for other persons at higher than average risk of illness who lack access to group insurance.

Nevertheless, from a quantitative point of view, the group insurance situation is much more important. Here it seems to be largely business as usual, as nearly as we could determine. There have been scattered attempts to exclude HIV related conditions, but they have usually provoked a public outcry and been rescinded. But I must emphasize strongly that employers and insurers are only just beginning to react. Most have only had limited claims experience so far. Because of the way insurance data is collected, it does not immediately appear to them from their data to what extent they have HIV claims.

Responses to surveys indicate that if and when insurers and employers find that HIV related care is a significant factor in health costs, they are likely to take action, by restructuring benefits, increasing employee cost sharing and so on. These actions may be stimulated by the desire to cut HIV related costs, but in our judgment we suspect that they will probably be designed to appear nondiscriminatory to the extent possible.

It is important to remember that the HIV epidemic is occurring at a time when major structural change in private health insurance is already underway in response to rising costs. For many firms concern about HIV costs is likely to accelerate and shape the changes that are already in progress.

Also, I would like to emphasize that responses are likely to differ by size of firm, with smaller firms feeling greater pressure to react. These firms already have severe problems obtaining affordable health insurance coverage for their employees. Of particular importance is the possibility of employment discrimination against sero positive individuals. This has the greatest potential for decreasing access to private insurance for those infected. There is considerable evidence that some employment discrimination already occurs. There is not, however, and unfortunately, rigorous evidence on how extensive employment discrimination is.

Sixth, as the epidemic continues the private insurance share of HIV related expenditures is likely to decrease relative to the public share, as Dr. Green discussed earlier. This is apparently happening and he has got data to show it.

The epidemic is expected to spread in

populations with lower than average rates of private insurance coverage. Increases in life expectancy after severe disability sets in increase the likelihood of losing private insurance, because you lose your job. Treatment patterns seem to be changing away from care that is well covered by private insurance.

All of this means that in the absence of major new initiatives to extend private insurance coverage, the burden on public sources of financing will probably increase. Such an increase is even more likely if private insurers and employers take steps to avoid HIV related expenditures in the populations whose care has traditionally been covered by private insurance. These responses can be diminished by regulation and the pressure of public opinion, but only to a certain extent. Most of them are perfectly legal and a natural result of the normal behavior of the insurance industry.

In conclusion, I would like to emphasize a few things for the Commission. I think the Commission should give attention to seeing to it that the existing rules of private insurance are applied to the HIV infected in an even-handed manner, and the powers of state insurance regulators, the courts and publicity ought to be used to the extent possible.

The conclusion that we came to that on the whole it is business as usual by private insurers should not obscure cure the very real hardship that occurs for those who are discriminated against. Horror stories do exist and they really are horrible and they should not happen. And to the extent that HIV infected people are treated differently by private insurers in ways that are not justified by their risk status and so on, this should not be allowed to happen.

I would also like to emphasize here the lack of empirical evidence. I get all awfully tired of testifying and giving speeches in which I say, as a social science, we need more data, we just don't know anything, we need more data, and so on. But we do need more data. We especially need more information on financing from the individual patient point of view.

It makes be a little uneasy to say that I don't think there is a lot of discrimination or a lot of treating AIDS patients very differently when I realize that the sources that I have used are inherently biased to come up with that result. It would be extremely desirable if we could have better information from--and I suggested in another forums that tapping insurance counselors in AIDS action committees, people who work directly with AIDS patients in trying to get them through the financing maze, might be an important source of information and possibly surveys could be developed through those people.

Second, I want to emphasize the importance of employment discrimination to the financing of care. Now, losing one's job, or having one's job opportunities restricted as a result of HIV infection is a hardship in itself. It is bad enough to have a disease that is probably going to kill you, but to have for lose your job as well is very painful. What I would like to emphasize though is the consequences for financing your care, and if we don't prevent AIDS patients from being discriminated in the labor market we will have a much bigger financing problem on our hands. And note that the incentive for employment discrimination and the ability to find out in advance who is HIV infected has now gone up dramatically with the discovery that asymptomatic AIDS is worth treating.

It will be much easier to know that a worker has AIDS, or that worker will have a very nasty choice, should I go and find out that I have HIV and get treated, when it will then become apparent to my employer that I am in fact a liability.

Third, it would be very nice if the private insurers would respond in a positive way rather than a negative way. There are ways of restructuring benefits that actually help a person with a disease like AIDS. There are many things that private insurers can do that do not necessarily make things worse, and there are things they can do that are perfectly legal that would make things worse, and if there is anything the Commission can do to ensure a positive rather than a negative response by insurers, they should do it.

But finally, it is very important--and I think the point has been made but I will make it again--it is important to recognize that the private insurance system, which is based on a market system of distributing insurance, it is inherently limited in its ability to deal with HIV infection in a humane, cost effective manner. Business as usual in the private insurance sector is very unsatisfactory, in many cases, for persons with health conditions that are like AIDS. And it is not just AIDS patients that have these problems.

And finally, it is important to recognize the incredible stress and hardship that the patchwork financing system imposes on anyone at high risk of serious illness to manage their way through it. When I reread over my prepared remarks they seemed rather anemic, they didn't seem to have much heart. I would like to emphasize that it is extremely scary to find out that you are at very high risk for a disease that down the pike is going to create major medical care needs and kill you, and then realize that every decision you make from that day on must constantly take into account, how am I going to make sure that I have health insurance?

Deciding to get married, to get divorced, to go to work, to change jobs, all of those decisions are overshadowed, and the difference between one patient and another with very similar finance circumstances, very similar in every way except a job decision, can make all the difference in the world to whether they die a good, humane, reasonably well cared for death or a very horrible and unpleasant death.

CHAIRMAN OSBORN: Thank you very much. Let me ask the commissioners to take advantage of Dr. Baily's presence to ask questions, make comments.

Don Goldman.

COMMISSIONER GOLDMAN: I have three questions, if I may. The first question is, the last issue that you dealt with, namely the fact that we ought not lose site of the fact of the issue that one has to make life decisions based upon the availability of health insurance is not something that is unique to AIDS or HIV infection, but it is something that any person with a chronic disease has to deal with throughout their entire lives. Not to diminish it, but it is a fact.

One of the questions that I had in terms of your analysis of private health insurance costs with respect to AIDS and HIV care, I know that in the context of the hemophilia community we have developed systems and institutionalized, for example in New Jersey, where probably around 20 percent of our patients have private health insurance, but it is funded by the--the premiums are funded by the State of New Jersey through a program, and in other parts of the country where the health care providers in fact have figured out that it is cheaper to pay $1,500 or $2,000 a year per patient to pay for their health insurance, or to supplement it in some way, than it is to absorb the losses involved in the cost of care, and in some cases even providers such as pharmaceutical companies, who would ultimately be the beneficiaries of the payments under those systems, and home health care agencies who might also be the beneficiaries of such systems, in fact end up paying the premium for care to make sure their patients are insured so that they continue to get paid, and it turns out to be cheaper that way.

And I am just curious as to whether or not that is done elsewhere and if anybody has any ideas as to the extent to which it is done?

DR. BAILY: It is certainly worth looking into, the arrangements that people suffering from other chronic diseases have made to get around this problem. It sounds like a typical example of an American patchwork approach to a problem it seems would be so much easier to solve in a different way, but certainly it would be worth looking into.

COMMISSIONER GOLDMAN: The last question I have is, do the health insurers understand that to the extent that the costs of the uninsured and of being born by the insurer, that they end up paying the freight to a large extent, one way or the other?

DR. BAILY: Well, I don't think they do. I think they end up paying some of it. Certainly uncompensated care has to be shifted somewhere, and traditionally it did tend to get shifted--some of it was shifted to private insurers. But on the whole, the cost of the insured are borne by Medicaid, they are borne by state and local governments, and they are borne by the hospitals in uncompensated care. So I would say that the private insurers are not in fact bearing as much of the cost of the uninsured as all that.

CHAIRMAN OSBORN: Dave Newhall.

MR. NEWHALL: Dr. Baily, you alluded to the practice of some private insurers not to pay for investigation or experimental drugs. That's true of some public programs as well.

Could you expand a little bit on that as to what your finding has been? Are an increasing number of private insurers, as we look at AZT, for example, and some other things coming on which have not followed the traditional FDA routes, what percentage of private insurers are willing to pay for that kind of therapy, in your experience?

DR. BAILY: Well, I think that is a number that one couldn't come up with it. Let me just expand a little bit on the logic of the situation. First of all, it only applies if they do pay for prescription drugs in the first place. But if they do, then the problem exists for any investigational treatment, and has always been handled in a rather ad hoc manner in the past. And many of the things that happen in private insurance happen on a surprisingly ad hoc basis, and increasingly what has happened, I think, with AIDS is that it has put pressure on some of these ad hoc adjustments, as have certain new and quite expensive cancer treatments.

So the problem is arising both for unusual uses of approved cancer drugs and for AIDS drugs, and it is being handled in a very ad hoc manner from one insurance company to the other, depending to a considerable extent--on can't help suspecting--on how much public pressure they are getting as to what they should do.

I think there is a real and complex social issue here, which is should private insurers be paying for experimental treatments? It is not at all obvious to me that as a society we want, when we buy our private insurance, to be guaranteed access to treatments for which there is no true evidence that they work. Whether we do or we don't is a difficult question that needs to be addressed.

CHAIRMAN OSBORN: Scott Allen.

COMMISSIONER ALLEN: Could you describe somewhat of the ERISA and the policies there, exclusion policies and the dynamics of--is it the employer or is it the insurance company that decides that type of policy, or they just point the finger at each other, or how does that work? Is there some type of regulation in ERISA, for instance?

DR. BAILY: Well, the significance of ERISA, which is the Employment, Retirement, and Income Security Act--I hope I got those words right--is that it regulates fringe benefits, and it means--because of the way it was constructed--it means that employers who self-insure, who provide insurance, who self-insure their health benefit plans are exempt from certain state regulations. Which means that they do not have to meet mandated benefit laws. And so that means that there are somewhat different rules of the game for the self-insured and those who are not insured. It means that state insurance regulators don't have the same handle over the provisions of health benefit plans of the self-insured companies. Is that what you are getting at?

CHAIRMAN OSBORN: And also how to define the decision process for exclusions in that whole process.

Is it the business?

DR. BAILY: What do you mean by exclusions? Do you mean excluding AIDS people?

COMMISSIONER ALLEN: Yes. As we look at the future and the possibility of more companies looking at excluding HIV, how does that dynamic work?

DR. BAILY: Well, the states can regulate that part of health benefit programs much more easily for companies that do not self-insure, and probably it would require a federal regulation or some kind of change in the ERISA law, which I understand is not likely to happen immediately.

I do not think--now, this is one of those going out on a limb statements--but I do not think that the wave of the future is to exclude AIDS in the kind companies that self-insure. The companies that self-insure tend to be large corporations, and I think that the cost of excluding AIDS in publicity--and simply it is not that--the disease itself is not that much more expensive, or it is less expensive than a lot of things they already cover. So I don't think that the big problem of exclusion will be in the large, self-insure sector. But nevertheless, it is a problem to control it if it does become a problem.

CHAIRMAN OSBORN: Eunice Diaz.

COMMISSIONER DIAZ: Do you think there is any future in the concept of risk pools that could be shared across the industry where the private insurers would be taking more responsibility for individuals that perhaps are going to be at high risk and applying for benefits?

DR. BAILY: Well, risk pools look attractive if some ways, but there are a couple of problems. One problem is that to fund risk pools in the natural way, which is to tax insurance companies, runs into a problem with the ERISA rules. Now, Gail Walinsky, testifying before on the previous Commission, said that that could easily be gotten around. There are ways that you can fund such plans that get around that problem. A more difficult problem is the fact that in order to make risk pools work, currently risk pools charge premiums that are much too high. People simply can't afford them.

To make a risk pool work, remember you are insuring people who are going to be very sick. The reason why the insurance companies don't want them is because they can't insure them profitably. That means that it is going to cost a lot of money. So the risk pool must be heavily subsidized out of general revenues in order to make them work. And so far states have generally not been willing to subsidize them at the level where they could really be of some use.

CHAIRMAN OSBORN: Susan Neeme.

MS. NEEME: Being a PWA and planning on outliving my 18 months of COBRA, I would like to know a little bit more clearly what my options are according to converting to an individual policy. And I know in some states that Medicaid is picking up the premium of the private insurance so that they are saving money. Is that something that is state by state, and do certain states require that I be offered, after the COBRA, an individual policy, or is that something that the insurance company offers out of the goodness of their heart?

DR. BAILY: Well, I am not sure I can answer that definitively, because it is awfully difficult to keep track of what all the states require and don't require. But the simple answer to your question is, in general it isn't so much a question of state regulation as it is of corporation policy, nor is it a question of the insurance company.

If the corporation has a health benefit plan that allows you to convert to an individual policy, sometimes that provision will extend past the 18 month period, and then at the end of the 18 months you can convert. But my guess is that this is not that common. In other words, that the ability to convert to an individual policy from a group insurance policy at the end of the 18 month COBRA extension is not very common. Most people are probably not in a position to do that.

If they are in a position to do it, without medical screening, in other words, it would be at a rather high premium. The simple answer to your question is there is going to be a serious problem at the end of the 18 months, because even if person loses a job because of disability, then there is a 29 month waiting period before they become eligible for Medicare, and the gap between COBRA and the end of that

29 months is another 11 months. And as I read the system, there is nothing formal to take care of that, unless you happen to be able to convert. You certainly wouldn't be able to get a new insurance policy.

The idea of the states paying the premiums, as I understand it, the best example of that is Michigan where they have instituted a program where Medicaid will pay the premiums for someone who is in the COBRA period and is too poor to afford the premiums. And they have decided that it is probably cost effective--at least they are trying it as an experiment--to pay the premiums for the COBRA extension and then, in addition, pay, if it is a convertible policy, to pay the premiums after the conversion. But that is an experimental program and the only state I know of is Michigan. Some other states may be picking that up, too. I don't know if that answers the question.

MS. NEEME: Yes.

CHAIRMAN OSBORN: Dr. Baily, thank you very much for some very lucid testimony. We appreciate your time and I think we will probably have to hear more about this as time goes on too, because it is clearly a very central facet of the problems people are going to be facing. We appreciate your attendance.

Our next panel,. dealing with state and community issues, or beginning to deal with that, Robert Hummel, Si-hoi Lam and John Holloman. I wonder if you could come to the table.

As we have been doing, I think we will ask if each of you would speak in turn and try to allow opportunity at the end of the three presentations for the commissioners to pursue points of special interest.

COMMISSIONER ROGERS: June, could I just add to that. I have been so impressed with the interchange, and I am sure those of you who have been sitting here, those of you who are now testifying, have been too, that it would be my fond hope you would keep your own comments fairly brief and bring out your points in interchange with commissioners. We are privileged to have you all here.

STATEMENT OF ROBERT F. HUMMEL

NEW JERSEY STATE DEPARTMENT OF HEALTH

DIVISION OF AIDS PREVENTION AND CONTROL

MR. HUMMEL: Good morning. I am Robert Hummel, Assistant Commissioner for AIDS Prevention and Control in the New Jersey Department of Health. Prior to this I was the Deputy Director for the New York State AIDS Institute.

Having been involved in the public health strategy since the early days of this epidemic, I view this opportunity as a distinct honor and want to thank the Commission for the invitation to present my thoughts to you.

In addition to my comments this morning, I have submitted a package of resource materials to the staff.

New Jersey is unique in its epidemic profile because the majority of our cases are related to drug abuse. Females compromise 21 percent of over 7,000 reported AIDS cases. Compared to the United States, New Jersey has consistently had more than twice the percentage of female AIDS cases since 1982 and is currently nearly tripling the national percentage.

Due to the critical connection to drug abuse, we also have 206 reported cases of children with AIDS, 107 of whom have already died. An additional 475 HIV positive children are under case management at the state's five pediatric regional HIV centers.

I believe at this point in history we are facing a challenge that is as significant and major as the one which we faced in the early days of the epidemic. Without going into the chronology of events, this country was confronted with a public health threat characterized more by Unanswered questions than answers. Early efforts to provide these answers and develop preventive strategies were hampered by lack of resources, fear, ignorance, and even hatred against those who first exhibited signs of this disease.

We are also faced with a critical lack of scientifically based knowledge upon which to base our education and program development. The most significant change which brings us here today is that hopeful developments in research and clinical interventions provide us with an opportunity to intervene with care and treatment for HIV infected individuals in a manner not previously possible.

Past education and prevention efforts primarily centered on protecting the uninfected through messages to avoid the high risk behaviors associated with HIV transmission and to encourage those individuals who are at risk to find out whether or not they were infected.

Prior to the recent developments in early intervention, there was very little that could be done to offer effective medical intervention. Theoretically, from a public health perspective learning HIV status could lead to behavioral change which could slow down the rate of transmission. This was and is difficult to measure, but even in these efforts were successful there was very little that could be done for the individual. Even social support services--buddies, entitlements, housing--are in short supply for people who have developed a full disease spectrum.

These services remain almost unattainable to those who are HIV positive and do not fit the definition of AIDS. Aside from some heroic efforts on the part of volunteers, all of the HIV positive individuals have not been considered as part of the public health responsibility.

From a care and treatment perspective we have never really considered this epidemic to be an HIV epidemic. While many HIV infected people were receiving some form of treatment in clinical trials, or more commonly, through individual practitioners who are aware through the medical literature, professional meetings, et cetera, there were and are very few community programs offering prophylaxis to HIV infected people, and certainly no programs involving a city or a whole state.

Our education efforts have been directed at preventing infection, but we still lack a national strategy for the care and treatment of HIV infected individuals. Research has brought us now to the point when we urgently need to have in place such a strategy. This must be a national strategy for a number of reasons: Under even the most conservative estimates, the number of infected individuals is overwhelming, the

CDC currently estimates that between a million and a million and a half people are presently infected with HIV; the recent federal recommendations outlining prophylaxis were released with no additional resources or recommendations for altering existing entitlement programs from other federal agencies; the health care system is already near collapse in many parts of this country; the disproportionate impact of HIV on disenfranchised populations--Gays, the poor, racial and sexual minorities, women and adolescents and drug users--populations already having less than optimal access to quality health care; the total inability, from a fiscal and resource perspective, for high incidence states to pay for the levels of care and treatment needed for their HIV infected populations.

We as a nation are totally unprepared to deal with the impact of these recent developments and until we make HIV care and treatment a national priority, HIV will continue to kill off our population as effectively as any war, past,present or future.

In addition to our current educational efforts, the national strategy must, I believe, be two pronged. First, it must deal with the issues of reimbursement and resources, and secondly, it must provide for the development of care and treatment models and guidelines. I would like to deal with the second first since this is the easier issue, if one can speak of an easy issue in this epidemic.

The development of a national care and treatment strategy will require a rethinking of our past efforts. We are now faced with the responsibility to extend our previous education and prevention efforts. As I alluded to earlier, the majority of our funding and resources has until this point been directed to research in a variety of prevention and education strategies. Even these efforts, as one reviews the history, demonstrate a tragic story of resistance to funding, agency ineptitude, misdirected in targeting--and saddest of all--using this epidemic and the lives of individuals to further political and value laden agendas.

There is strong medical and scientific basis for the development of a national treatment strategy. While one may differ on the particulars, there is overwhelming evidence that early intervention will provide for a higher quality of life and a longer, even though indeterminate, period of functioning prior to the onset of disease. HIV is fast moving to become a chronic condition requiring years of outpatient monitoring and drug therapy. In addition to the already present costs associated with AIDS treatment, estimates are that it will cost anywhere from $7 billion to $9.6 billion to prophylactically treat those individuals that CDC indicates are already HIV infected.

The critical elements that compose the basis for a national strategy are, I believe, basically three--enhanced education and outreach, a well developed and well financed system of outpatient care located in traditional health care access points, and a managed care approach that ensures the delivery of integrated services and the collection of adequate data to insure proper utilization, review and quality of care.

Enhanced education and outreach should be designed to provide clinical treatment, and secondly, to establish a regular schedule of reinforcement to communicate the prevention message in order to reduce the danger of infection to others. Additionally, we need to reexamine our public health messages. It will be necessary to change attitudes about counseling and testing. It is no longer a service that is simply educational or research oriented, but rather assumes the role as the primary entry point to care and treatment. Therefore, we need to move to a point where it is available at every single health care access point and the clinical and social services personnel are fully trained.

While we now have an excellent counseling and testing system in place, it was not designed to provide the broad clinical linkage nor to handle the anticipated volume as word of treatment potential gets on the street.

Secondly, the managed care approach. The development of a managed care approach must be designed to provide services to people with multiple needs. One of the major difficulties we have had at the local service level is providing funding and services not traditionally thought of as health care--housing, home care support, non-acute inpatient care. This has led to the inappropriate utilization of expensive inpatient services. Almost every study done, either formally or informally, points to the fact that 20 to 30 percent of the patients in hospitals do not clinically need to be there and are there because of a lack of community support or outpatient care system.

Some of the critical elements for such a managed care approach are formal linkages between assessment and care programs, CD4 and biological monitoring capability, counseling and behavior modification, psychosocial support for clients and families, routine case management for client substance abuse, STD and family planning services, and access to clinical drugs as part of a prophylaxis and early treatment program.

In New Jersey we have initiated on October 1st of this year an early intervention program that we have termed the Treatment Assessment Program, or TAP. I would like to take a very few minutes to outline what has been developed, because it provides a model for care. While certainly not the only model, it is, as far as I know, the first attempt on a state wide basis to implement the recent federal recommendations.

The TAP program provides access to comprehensive HIV outpatient clinic and ambulatory care for HIV infected individuals throughout regions of the state and requires the development of appropriate management organizational elements at the local level for prophylaxis implementation. Specifically, the program seeks to establish up to four regional HIV outpatient clinic ambulatory care assessment centers in both high and medium incidence areas.

These centers are clusters of--

COMMISSIONER ROGERS: Bob, let me interject for a moment. I am concerned--we do have your written testimony. I think you would be well advised to kind of move briskly to your recommendations and so that we would have a chance to interact a bit toward the end.

MR. HUMMEL: Okay. Let me summarize then. Basically we are setting up four centers. We have one in place, a demonstration program. We have 115 clients enrolled over the last three weeks. We have a very sophisticated data management collection system, and we have applications for three more centers which we hope to award in about the next to two to three weeks.

In terms of reimbursement, I think what we--clearly Dr. Lee and the previous panel outlined the major reimbursement issues. I think that the most critical element that came out of that is, number one, we are not dealing with a population that has the reimbursement health care strengths that we ordinarily think of. We have a system that is in disarray, and we have an ambulatory care system that is already, for general health care, totally underfinanced.

I think if one takes the projections of HIV positive individuals, 680,000 people, and multiplies that by the cost of prophylaxis, which averages about $7,000 per year, we are talking billions of dollars each year of prophylaxis care. I have come up with some recommendations respectfully offered to the Commission for their consideration.

The first is that all future funding for HIV related prevention, research, care and treatment and education must be tied to the development of a state coordinated strategy plan. Secondly, that the federal government develop a treatment models demonstration program with funding for three years of at least $10 million to $15 million per year and target it to high incidence states.

Third, that there be developed a separate HIV unified funding stream not dependent on the grant process and with the flexibility to answer the multidimensional needs of HIV positive people. And finally, that there be developed a demonstration clinical care program targeted to dying families, especially targeted to drug using and minority populations.

Finally, I would like to extend an invitation and invite the members of the Commission to do a site visit to the first demonstration program at Jersey City Medical Center. The Medical Center would be very happy to conduct such a site visit for you, and I believe that it would offer a fairly concrete example of what one institution is attempting to do to reach this population.

And I apologize for going so long. Thank you.

CHAIRMAN OSBORN: Well, we are especially grateful for your careful testimony you have written. We have been trying to remember to tell people that we are eager to have a chance to read the full testimony as well. But the interaction has proved so useful that we appreciate your willingness to flex a bit there. Thank you also for the invitation. New Jersey is distinguishing itself in a number of ways as a forward looking set of things that we need to learn a lot about.

Let's proceed for the moment with the next witness. Dr. Lam.

STATEMENT OF SI-HOI LAM, M.D.

HILL HEALTH CENTER, NEW HAVEN, CONNECTICUT

DR. LAM: Ms. Chair, Mr. Vice Chair, Mr. Congressman and all Commissioners, my name is Dr. Si-hoi Lam and I am the chief of internal medicine immediate at Hill Health Center in New Haven, Connecticut.

Today I am pleased and honored to share my experience as a front line physician. Every day I see the casualties from three wars, the war on AIDS, the war on drugs, and the war on poverty. And they have claimed as victims the most helpless in our society. In New Haven, the 7th poorest city, AIDS has a per capita rate comparable to that of the Bronx in New York City. In the inner city where I work the impact is even more devastating. We haven't gone one day without seeing HIV patients in our clinic. A third and up to a half of our hospital patients are AIDS or HIV related. Up to now we have seen over 260 HIV cases, and the demographics are gruesome; 90 percent are minorities, almost 90 percent are IV drug users, and 36 percent are women.

Our patients are dying of AIDS because they are poor, uneducated and therefore vulnerable to drug use. They keep coming to us because they trust us. We were there for 21 years. We were there when many of them were kids. We were there before AIDS and AIDS funding. Providing AIDS care with our meager means has not been very easy.

First, many of our co-workers were afraid of AIDS. More so, they are angry about the drug addicts. No community could be proud of drug addicts, who usually victimized their own neighborhoods in the community. Some workers said, refer them out to Yale, we can't handle them. Others said, they are going to scare away other patients. But most had the decency to accept the responsibility.

We spent many meetings talking about AIDS transmission and occupational risk. we talked about our fear and frustrations. We did not mandate, but came to a consensus about our responsibility. We taught universal precautions and we discussed risk and disability coverage. All these are time consuming and it is hard to put a price tag on, but it is very important to mobilize the staff, and this is the cornerstone of our AIDS care. After treating patients for more than three years our health center is now financially ready to address disability coverage. This coverage may cost us between $50,000 to $90,000 and it only covers one-third of the staff.

We were among the first to provide HIV testing on-site at the clinic. The test costs about $180 at Yale and our Medicare reimbursement was only $45. Apparently the Yale lab was rich and generous enough to absorb the difference. Counseling was vital, but we found the standard counseling too wordy, too long, and quite incomprehensible to our patients. Also, our patients didn't come to us for HIV testing per se. They usually came in crisis, a skin abscess from drug use, a fever or pneumonia. They would not stay for an hour-long counseling anyway, they were too sick, even if we had the time. So we created our own counseling pamphlet. It was brief, simply worded, pictorial and bilingual. It was also easy to carry or easy to hide. It was also in a cheap stencil form.

Next, we needed to order the T-4 lymphocyte cell testing to manage our patients. The state could not reimburse this because they did not have a billing code, and that was two years ago. We had to negotiate the test be billed as flow cytometry, for which the state paid $73 against a charge of $170. The lucky private lab swallowed the difference.

We have yet to provide p-24 antigen testing, again because of the reimbursement issue. AZT, and now since August, aerosol pentamidine, were made available. They can both be provided in a clinical setting and are lifesaving treatments. Because of the state reimbursement change recently, we lost 34 cents out of a dollar every time we prescribed these medications. We are in the process of renegotiating with the state to exempt AZT and pentamidine from our other bulk rate discounts. We will not be able to continue absorbing the loss for long because these are expensive medications. Nowadays, in health care in America it is a chilling fact that money speaks the loudest.

There are other hidden costs. To provider aerosol pentamidine one afternoon a week, a nurse is pulled from her usual duties. This is significant, given our staffing level in a clinic what has always been too busy. Her nursing time has not been reimbursable. HIV patients require more visits, especially when they are taking AZT, and frequently their visits are lengthier because of counseling, monitoring of early signs of and many co-existing diseases. Again, this is significant because, as you know, most community health centers are understaffed and overworked to begin with.

Universal precautions and infection control are very important, but also expensive. Gloves cost an extra $5,000 per year. Disposal of biomedical wastes costs $12,000 per year. Our dental clinic, one of the few that takes HIV patients, estimates an additional $6 per patient visit due to infection control. These are not small sums for a clinic of our size.

Again, as mentioned before, disability insurance comes up to $50,000 to $90,000 per year. It is going to be internally absorbed, and it is one of the many hidden cost of our AIDS care.

To make a long story short, we had to jump many hurdles. For every step we took we had to first clear our path. We had to be pioneers, less we abandoned our patients. And obviously, we did not fight the battle alone. We are blessed to have linkage with many dedicated local agencies, be they voluntarily, religious and governmental.

There are many unsung heroes in this battle against AIDS. There are a number of lessons that we draw from. First, we believe we have done the right thing. Once we started HIV testing we were overtaken by an avalanche of positive cases, and the crucial data can help to plan and allocate resources.
Unfortunately, this trend of high infection rate has not slowed after three years. Here our experience is distinctly different from the health departments. The tests sites see mostly worried well, and it is a small fraction of positive findings. Alarmingly, inner cities are now the new front of AIDS epidemics. Women in inner cities are now recognized to be high risk only by virtue of their geographic location.
Strategically located in the same areas, community health centers ought to be providing the full spectrum of AIDS care--HIV testing, counseling, early detection

and treatment, or post-discharge care.

These health centers also are community based, trusted, and share the same cultural and ethnic identities. Of course, to take on this monumental task, community health centers need better funding, more doctors and nurses, and better support services and resources.

Second, AIDS in the inner city is different from AIDS in the middle class. Half of our AIDS patients are already dead, but no quilt, not a single quilt was made for them. The families are too often overrun with the demands of basic survival. Make no mistake though, that the degree of grief and resilience is no less. In fact, the degree of sharing and resolve, especially among the Black women, often surpasses that of the middle class families.

AIDS in the inner city cannot be divorced from drug use, but even if drug treatment were available on demand, patients are prone to relapse if they return to the same appalling conditions. After years of working with the disenfranchised, I began to understand why some of the them would choose not to be sober lest they would be left with facing the grim reality. It is a vicious cycle. The more rejected they are the more hostile till they have become.

Doctors and nurses typically don't like drug addicts, and thus the addicts always wait to the last minute and seek help in a crisis situation. It is also not difficult to see why in their predicament they do not always use condoms to protect others and themselves. Apathy, despair and denial evidently prevail.

Recently I was reading the American Cancer Society's report on "Cancer in the Poor," released this July, and I was dumbfounded by its message. Quote, "Poverty is a proxy for other elements of living, including lack of education, unemployment, substandard housing, poor nutrition, risk-promoting lifestyle and behavior, and diminished access to health care."

Again quote, "Within one race, economic status is the major determinant of cancer outcome. Therefore, the target for correction is poverty, regardless of race."

This is a cancer report. But if you changed the word "AIDS" for "cancer," it rings the same hollow truth. AIDS policy in the inner city cannot be taken out of its contest. AIDS is part and parcel of the urban health care crisis, a crisis that also encompasses alcoholism, polysubstance abuse, homelessness, tuberculosis, mental illness, homicide, teenage pregnancy, infant mortality and hunger.

Traditional medicine, more apt to deal with the middle class practice, fails to cope with such a situation. But in other innovative arena, like geriatric medicine and occupational medicine, others have successfully redefined their approach and come up with refreshing solutions. The time is now ripe to develop and urban health care initiative to retrain our health care professionals and students about the inner city phenomenon, about its symptoms and causes, its psychology and remedies.

Dealing with the poor and AIDS should not be seen as a passing bootcamp experience during residency training. AIDS should and can lead the way to reprioritize urban health care in our American agenda, and only then can we hope to see and end to AIDS in our inner cities.

Lastly, I want to point out that the word "crisis" in Chinese is made of two characters meaning danger and opportunity. AIDS, capturing our nation's attention, fear, and imagination, has the potential to revamp our system into a saner, healthier and more humane one.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much, Dr. Lam. With all of the lack of fortune that you described for your patients, they clearly are very fortunate to have you, and we appreciate your passion and your data and suggestions. Thank you.

Dr. Holloman.

STATEMENT OF JOHN L.S. HOLLOMAN, JR., M.D.

WILLIAM F. RYAN COMMUNITY HEALTH CENTER, NEW YORK

NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

WASHINGTON, D.C.

DR. HOLLOMAN: Thank you. I am John L.S. Holloman, Jr. I am the Medical Director at the William F. Ryan Community Health Center in New York City. I am called many things by many people. My friends call me Mike. So I say that just so that you will know that the long name has a formal connotation, but the Mike tells you where it is really at.

Madam Chairman, I certainly thank you for the opportunity to testify today. I certainly do appreciate the attention that you and all the panel members have given all of us who have testified up until now and will continue to do during the future.

I have been asked to address access issues concerning HIV related care for the indigent. I really don't know where to start, but I did want to say a few remarks about the center and about some of the things that I do, and then I hope to be able to respond in more intimate details during a question and answer period.

At my center every week we hold clinic in the 369th Regimental Armory at 143rd and 5th Avenue, which is now a shelter in the nighttime for some 600 homeless men. And we don't really have a clinic there since there is one bathroom, and once a week we sort of take over that bathroom for about four hours. And those who have to use the facility have to go elsewhere in order to do it, because during that four hours we are trying to afford some measure of health care, certainly not in particularly dignified manner, not in the manner that I would have my family treated in, but that's what we are doing at the 369th Armory in our homeless program in New York City, and that's in Harlem.

We have, I guess, many, many barriers to care in our community, and some of the barriers include education, which has been sort of a long-standing national problem, and I don't think the problem has been solved. Certainly the high school dropouts in our city, the uneducated, or undereducated in our city are very legend. The work force has certainly far too many educated people.

We do have some particular problems with educating people with reference to HIV infection. I think it is primarily because not a lot is known, but in our particular population even that which is known is sometimes a wee bit late in arriving. Community health centers though are found all across our nation, and we do find some 600 are associated with our national association. And we truly are front line fighters. The Hill Health Center in New Haven certainly is one of our centers. And our centers are to be found in every major urban years. We have rural centers, and we also have migratory centers, and we are concerned, as people who do provide primary care, with HIV infection.

I think that we do see it probably first. We have all the problems that are abroad in the arena,. and we have it only more so because all of the factors which lead to poor health care, to poor treatment, are combined in our centers.

As a nation, despite the efforts of the community, of CDC and other public and private funded programs, I think we are mounting far to little community education concerning awareness of, support for those affected by, and the resolute determination to stop the spread and threat of AIDS. There is pathetically little local government endorsement, and as a nation health policy we seen to be condoning discrimination. Fewer than 15 percent of corporations have developed written policies protecting employees from the virus.

Rather than making a heroic national war-time like effort to provide funding for outreach and encouraging all at risk to see their doctor, we have let the very dilemma of privacy and rights surmount the effort to fund both programs sufficient to meet the need and to protect those who are not yet in need. And I think that if we really go at it right we can do both, but I don't think we really have the national will yet to do what is necessary.

Let me speak for a moment on the subject of behavior change which is so necessary in our communities. There are strong, acknowledged barriers to behavior change in any culture, primarily due to the confidential, taboo ridden nature of the area of sex and the variety of views on proscriptions against substance abuse, depending on one's perspective in the community. To address the scale of change needed, given this degree of entrenchment in present ways, we will require massive, highly labor intensive infusions of counseling. The cost are staggering but must be calculated and sought after. The programs must be novel and yet acceptable. Barriers to working with the meek and the aggressive alike, with those rife with denial that they could be at risk and with many more women than ever before now driven to prostitution in search of money for drugs, all this must be taken into account.

There is simply no other way. We will not be able to get the job done if we merely debate pilot demonstration programs or research studies. There just isn't time. Such studies have been conducted and they must be brought to the light of day and fully funded nationwide.

Screening. Beyond prevention and education comes identification of those at risk. Community health centers and other publicly funded providers of care have a unique opportunity to screen patients that they see for other purposes for HIV risks. It is one thing to educate the public, it is another for a person to use the knowledge obtained to make a decision to be tested.

A doctor can help. Whole campaigns of screening for medically indicated treatment are needed since risk factors that warrant testing are now widely found in the low income and minority populations due largely to the explosive proliferation of risk behaviors around drug abuse.

In the community health center program, the cost of screening all of our patients would necessitate adding about 20 percent--that is, 120 million--to our present federal funding per year due to the relative high cost of staff needed for pre and post test counseling of each patient, negative or positive.

We cannot take on that cost on our own. Federal program managers, to permit this new focus without funds, would have to allow massive cuts in our other work. Congress could raise our funding by a corresponding amount, but seems ill inclined to do so for this one need alone. After all, our ability to expand to meet more than one sixth of the need for health care for the uninsured we have been addressing for over 10 years and that shows no sign of improving at this fiscal junction.

So our centers find themselves pressured to out-refer primarily, or assume HIV prevalence is not growing so greatly in their service populations. And I ask you a hypothetical, what if it were growing? And I think we know the answer to that hypothetical.

The consequences of this fiscally induced myopia are massive. I am not speaking solely of community health centers now, but I will agree to use them as an example to make several points. Denial makes it difficult to encourage physicians to obtain training in HIV treatments or to participate in clinical trials, difficult the justify seeking funds for programs to educated minority and low income high risk populations about the value of testing and, if positive, the various drugs that they should be learning more about which can keep them alive longer. And difficult to mount efforts to work in a powerful way with other agencies and service organizations where links are required because of the sweep of impact of HIV on communities.

Consider the number of programs or coalitions we know of which actively pursue provision of housing for persons of color with AIDS or ARC. I don't believe there are very many. Yet the shelter needs of low income ARC and AIDS patient are most likely acute, and we may be talking about 15,000 to 25,000 low income minority symptomatic homeless persons in need of shelter assistance as of this very month, and winter is nearly upon us. Health organizations, minority advocates in housing, homeless groups have yet to build bonds needed desperately to being bringing such problems into reality.

Alternate test sites and testing. Now, let's go back to the medical care. As a subset of the whole issue of screening, getting those tested and cared for who should be. Let me say a word or two about the only form of screening that has been widespread to date, and that's self-referral. Voluntary testing among the poor, aside from the major issues about confidentiality, protection, means access to free and private testing, counseling and if needed, subsequent care. We have not yet set up a system for this. In New York City people wait an average of two months after a positive test for a medical work up with no caregiver during that time to provide counseling that is needed, answer technical questions as they come up, and assist in learning the body's cues as to the commencement of symptoms. All we have set up is the testing function through CDC funded state and local health departments operating alternate test sites.

There are few trained social workers, especially bilingual ones, at the alternate test sites which the nation has become dependent on for HIV testing. At least we do not think that there are. There is no national oversight of this program despite its national importance as a beachhead against undetected spread of the virus among the indigent and others. For example, we cannot say that all states operating a program have requirements that counselors be provided, although it is a clear ethical requirement. CDC's assistance of the immigration service in developing an HIV screening program in 1987 resulted in a physician form that explicitly stated that counseling was not required.

COMMISSIONER ROGERS: John, let me interject that we are so anxious to interact with you, could you sort of from your vast experience tell this Commission what you would like to have from us to try and deal with some of the dreadful problems you are recounting and then let us have at you a bit?

DR. HOLLOMAN: Surely. I think that there are several things that are necessary. Certainly we must recognize that the community health centers do exist. They are there. They have been there for 20 years. They are federally funded. They are linked to other existing programs. I think that we need, one, to recognize their existence, and to fund them to do a job that no one else can do as well. Certainly we do not need to attempt to create another alternate health care delivery system. We have in many areas substance abuse programs that are far too isolated. They have been put off in a corner. They have been sort of hidden from view, "not in my neighborhood."

We have that kind of concerns. We need to provide an extension of our community health center network through linkages, through on-site provisions of primary care, so that this particular population can be brought in concert, can be brought in step. We should not wait until they are extremist before they get the care that they need. They should not be done a disservice, as some of our local health officials would do.

In other words, we cannot write off the substance abuser. We cannot give him, as we say, sterile needles on city hall steps so that he can shoot illegal drugs--not only illegal but contaminated drugs--into his already tortured veins, I think that there is something absolutely immoral about that. I think we do recognize the fact that there continues to be both segregation and discrimination, color based as well as economic based, in this country and in our health care delivery system.

Our health care delivery system is doomed to fail basically unless we recognize that the duality has to be ended. We see signs when we visit hospitals that say, "Clinic This Way," "Private This Way." And that gives a message that means that the poor are somehow less worthy. Its means that we really are willing to discount them, and when it comes to a substance abuser our contempt for the poor is even greater. We subliminally learn that in medical school because we are taught on clinic patients and we find that that is perfectly acceptable. And once we have gotten our skills together, we can then move to the north shore of Long Island, or move down to the east side of Park Avenue and become contiguous with the other providers because that's where the money is. We are really going to have to do something about where the need is. And the need is where I have indicated. The need is there on the front line. The need is among the 37 million who have no insurance. The need is among the poor.

So it is important that we recognize that if the poor go down, that the rest of us will be pulled down. If we are trying to stop the spread of AIDS, we don't kill off the addicts just because it is an isolated group. We are doing to have to have drug free programs. We are going to have to have not just methadone car wash maintenance. We are going to have to do something about the conditions that drive people to the drugs. We are going to have to recognize that these are our citizens and these are the citizens that we need to take care of, not just the more privileged few, but all of them.

I could go on, but I will stop. We have need to recognize that a health policy is necessary and that we need to fund community health centers to do a job that they are already doing without funding. We need to have the teams put together and put in place on the front line. We don't need to stay in the Ivory Tower and test. We don't need to stay home and make demonstrations. We need to continue the work of Dr. Lam and the rest of those in Newark and other places who are really out there fighting and fighting hard. Thank you.

CHAIRMAN OSBORN: Thank you very much, Dr. Holloman. That is a most eloquent and moving as well.

I think we will take some time for the commissioners to interact. We are running late, but I think we have some leeway in the afternoon and it is an important panel to get a chance to learn from.

Larry Kessler.

COMMISSIONER KESSLER: I really appreciate the dilemma that health centers have, but I guess I am concerned that you may be generalizing, too, that the health centers want to do this job. I know they are not equipped in some cases to do it because of underfunding and poor staffing. But my experience has also been that many of them do not want to get into the field. Of the 24 health centers in Boston we have four that are doing an exemplary job, and another 20 or 21 who are trying to avoid the problem. And even if funding was available they wouldn't go after it.

There is also I think a growing issue. As health centers get into the field the siting is revisited. We had a problem siting health centers years ago for environmental reasons and for property value reasons and for parking issues and all that. But now what I see happening is, wait a minute, this health center is going to draw the addicted people, it is going to draw AIDS, and the community based neighborhood groups are saying "no" to that.

How are we going to get around this issue and what can your organization on a national level do to help us at the local level and help this Commission understand that tension that I think may be understated in your testimony?

DR. HOLLOMAN: I think it is very important to recognize that community people have been struggling hard many times to lift themselves out of poverty, to gain some handle on the health care delivery system, particularly primary care, which has been particularly inaccessible. To some degree they have done that, that is part of their 21 years experience. So why should they have to go back to go, go back to become a center which has a big sign up, "AIDS," which is like saying quarantine, this is out? Why lose all of the primary care that they have developed over the years?

I can understand that. So one of the things that we have done in the Ryan Health Center--and I would like to take this opportunity to invite you to see the Ryan Center--we do have a center in New York City, which is at the upper educe of, quote, "Yuppieville," and it is a nice center, one which we have put together with federal assistance and private financing.

It is such a nice center that some people in lower Manhattan have suggested that it is too good for those people. Now also, out of that good looking center, we take care of people in the homeless program that we have. We take care of people in single-room occupancy hotels. We take of the recently deinstitutionalized individuals, some of whom are barricaded inside. That what we are doing it.

But how are we doing it? We are doing it by trying to avoid the designation of AIDS, just as we tried to avoid the knowledge that we would take care of Hansen's disease, or any other leprous type condition, because we believe in comprehensive care. I'm trying to knock a hole in categorical approaches that seem to be so popular among certain agencies within the federal establishment. So what I am trying to suggest to you, that we want to strengthen our comprehensive care and to try to include the care of the HIV infected individual. Because the good portion of their lives--and we hope that their lives will be extremely long--they will be essentially well, and we want to be able to afford them the continuing confidentiality, the continuing dignity, and we recognize that it requires education to do this.

The first thing that we did when we decided we wanted to go after funding for leprosy was to educate our board, and in turn educate the community, then our staff so that we would be supported. We took that same approach to AIDS, that we also recognize that AIDS was already around us and that the only thing that we did not need was to wave a red flag against a community and a society that didn't want to accept the reality of the AIDS epidemic. And we think we need help in that.

And I would certainly agree with you that there are some centers that certainly reflect the community biases against the poor, even. But certainly a community biases against certain diseases, and particularly substance abusers, although I can assure you that cocaine and crack is closer related to Wall Street and insider trading.

We have also have significant numbers of crack babies all around us, so that we have problems that are societal and broad. So that we have a job. Every community health center does not want it, and I don't think it should be forced necessarily upon them. But I think we should have the opportunity and we should have the rewards, not the penalties. I am trying to make sure that people who do provide comprehensive care among the health centers will get the assistance and funding.

I don't think we need to really be competing, because those who are left out who have a problem are just as bad off or even worse than they were before they recognized it and began to compete for it. But we can do it in our health center movement and we have a head start on those who have no expertise. I would suggest that when the medical schools start a new program they reach around and where there is money they are instant experts, some of whom have never seen the community. I looked at your family practice and community medicine programs, and now I look at your AIDS programs. We are bringing a bunch of book-learned

Ivory Tower people into communities that need all the help they can get, but they are not necessarily the only experts that are around.

Thank you.

CHAIRMAN OSBORN: Don.

COMMISSIONER GOLDMAN: Mr. Hummel, just two or three questions regarding financing of care.

As your case loads have increased and as the recommendations of CDC regarding use of preventive measures to deal with HIV infection and its complications, what has happened in terms of federal funding as those demands have increased, both in terms of scope of services required as well as the number of patients?

MR. HUMMEL: Your question I think goes directly to the issue that we are facing this morning. To have put out recommendations with no allocation of resources has put high incidence states in a very, very significant bind. There was an Article in the paper this morning--and it is certainly no news--but it is constantly reinforced that the New York City health care system is near collapse. And in New Jersey we estimate that by 1992 the inpatient costs--that is excluding what we are talking about this morning--the HIV cost is going to be a billion dollars. That's twice what the whole state budget for uncompensated care is. And that's the population of medically underinsured or non-insured that Dr. Lee talked about this morning is going to be twice the whole budget of $500 million for this year, just for AIDS alone.

HIV we are talking about jumping from 7,000 people in terms of public health responsibility, to 70,000 people. And I only use New Jersey as an example. I think that it is incumbent and morally and ethically responsible for the Federal Government to begin to look at the cost of HIV treatment. And no other disease that I know of do we say, we are not going to treat you until you are near death. we treat people for diabetes, for hypertension. We don't wait for somebody to go into insulin shock to provide them some kind of treatment.

That same analogy applies to AIDS. We have got to stop talking about AIDS and start talking about our public health responsibility for HIV. We are facing a major catastrophe and I think that it is amazing to me that we can talk about $10 billion, $20 billion, and people just are immobilized. We are not talking 20 years, we are talking two or three years down the road. And I would hope that this Commission very, very strongly recommends and does all in its power to get some financing out there, because states are dying.

COMMISSIONER ROGERS: Bob, let me just add, I would say there are two diseases where we permit that to go on. One is IV drug use, the other is AIDS.

MR. HUMMEL: Yes, that's true, and they are interrelated. And that says something about the populations that are affected.

CHAIRMAN OSBORN: Larry Kessler.

COMMISSIONER KESSLER: Do you have some cost figures on your program in New Jersey?

MR. HUMMEL: Yes, they are included in your packet.

COMMISSIONER KESSLER: Okay. And in terms of your legislature, how difficult was it to sell them in terms of the funding, or did you just construct that out of the DPH budget?

MR. HUMMEL: Well, frankly, the way state budgets work and the way governments work, when we put together the spending plan for this year it was certainly not anticipated that there would be the need for a major prophylaxis program. We have to plan for 1991 and 1992 in submitting our legislative budgets. Basically what we have done to get the demonstration program up with the informing the legislature of our intents was redirect funding away from some education and research programs to get those programs up.

We basically internally redirected within the division $500,000 to get the demonstration program up. We asked the legislature for and got approval, in a special carry-over appropriation language, for $800,000 to get the other three or four treatment centers up. But right now we are going to go before the rate setting Commission, ask for an increase in rates for outpatient services, but the program is running on a string, I'll be very honest.

CHAIRMAN OSBORN: Diane Ahrens.

COMMISSIONER AHRENS: Thank you.

Mr. Hummel, I wanted say first of all how much I appreciate, I believe it is page three of your testimony, which seems to encapsulate so well for us really the issues that are out there that we need to address. I heard Dr. Coy speak recently in terms of your pilot project, and perhaps this has changed in the last 10 days, but one of her concerns was the underutilization of that. People were not coming in, and I am wondering if you have any sense of why that is so?

And my second question really relates to testing and reporting. What do you do in New Jersey in terms of testing and reporting, and is it done on an identifiable basis and so forth?

MR. HUMMEL: Let me answer that in two parts, as briefly as possible. As of yesterday morning--or as of this morning, I was handed a card that I asked for--in the last three and a half weeks we now have 119 people enrolled in the one demonstration program. That is by word of mouth without advertising. Monday of this week billboards went up all over the State of northern New Jersey telling people that something can be done for them, they need to be tested. We have done a massive physician campaign over the last two weeks. We have also given T-shirts out to drug addicts in the hopes that they will wear them into shooting galleries and reach people where we can't reach them.

We have done 5,000 T-shirts. About half of them are on the streets as of this week. So without all of that publicity it was understandable why we didn't get a further increase. There is now a three week waiting period for scheduled appointments as of this morning. The 119 people that are scheduled are going to fill up the next three weeks. Ninety-two of the patients are known referrals from drug treatment centers. We have another 500 patients that we will expect to have enrolled by December. And we are getting some preliminary data that I hope will prove very valuable on cost utilization, referral patterns, compliance issues, and we would have that in the next two months I would expect.

So the reason is it takes time to get people in place and stuff, but it looks like--I am scared actually. If this continues, if this rate continues we are going to be breaking the system by the end of this year, beginning of next year.

In terms of reporting, actually Monday I am--a week from Monday I am going before the Public Health Council to ask for a change in reporting regulations. At this point, because New Jersey does not have confidentiality legislation, we are going to require reporting, without identifiers, of HIV. That reflects a philosophical and public policy change that we must deal with HIV as the epidemic and the disease and we can no longer be limited to AIDS.

When we have confidentiality in, we will more than likely at least look at the presence of or the need for identifiers. This to me is critical for the children. We have an estimated infection rate of .5 percent in some of our major cities, and .5, a half a percent, and that averages out to about 200 HIV infected really and truly infected children a year. And that turns into major figures in terms of the number of positive kids, and we need to reach them and intervene with both their mothers and the kids.

CHAIRMAN OSBORN: I want to thank the panel very much for their important testimony. You added to our sense of gloom, I guess, in some ways, but the commitment with which you have presented directions and pointed out existing institutions that can be strengthened is very helpful as well. So thank you very much.

I know Dr. Jellinek and Dr. Matheny are both here. Obviously we are running late. If we could try and be back briskly at 10 of 2:00, a little bit less than an hour for lunch, but that way I hope that will work out all right with your schedules and we can proceed with our discussions.

Thank you again.

[Luncheon recess from 12:55 to 1:55 p.m.]

AFTERNOON SESSION

1:55 p.m.

CHAIRMAN OSBORN: I appreciate very much the patience of our afternoon's witnesses. We had a fascinating morning. I think you got a taste of that as you came in, but we ran late. So thank you so much for being here and for your patience.

We'll be hearing now from Dr. Paul Jellinek from the Robert Wood Johnson Foundation and Dr. Sam Matheny from HRSA. We have been encouraging people who had material to present to us to the extent possible to be fairly brief in summary in their presentations because the interactions with the commissioners have turned out to be a particular valuable way of finding out exactly what you want us to know and think about.

So with that as a hope, why don't you go ahead and lead off, Paul.

STATEMENT OF PAUL JELLINEK, PH.D.

ROBERT WOOD JOHNSON FOUNDATION

PRINCETON, NEW JERSEY

DR. JELLINEK: Thank you, Dr. Osborn, Dr. Rogers, members of the Commission. I very much appreciate the opportunity to appear before the committee today to talk a little bit about the role of private foundations in the HIV epidemic.

Earlier this week I checked with the Foundation Center in New York, which is an independent organization that provides information about foundations, and I was told that so far somewhere between 150 to 200 private foundations in this country have made AIDS related grants. This includes small community foundations, small family foundations, all the way up through the big national philanthropies such as the Ford Foundation, Pew Memorial Trust.

Not surprisingly, these grants are incredibly diverse, ranging all the way from basic biomedical research in the laboratory to front line outreach education services in the streets. And I think to summarize this broad range of activities would simply take a lot more time than we have at our disposal today.

Instead, I am going to focus my comments on the activities of a singe institution, the Robert Wood Johnson Foundation, where I am employed as a senior program officer. The Robert Wood Johnson Foundation is based in Princeton, New Jersey and is the largest private foundation in this country dedicated exclusively to health care. The Foundation is active in a large number of health related issues in addition to AIDS, such as child and adolescent health, long term care, drug and alcohol abuse, mental health, health care for the homeless, and the organization and financing of care, although I must tell you that as each year goes by AIDS becomes more and more a factor in everything that we do. Our total annual payout for all program areas right now is about $100 million.

The Robert Wood Johnson Foundation made its first AIDS related grant in December of 1985 and since that time has made over 110 grants in the area totaling approximately $50 million. Between January 1986 and December 1988 AIDS grants accounted for approximately

15 percent of the Foundation's total grant making across all of its program areas.

Again, according to the staff at the Foundation Center, the Robert Wood Johnson Foundation's grants account for over half of all private foundation funding for AIDS to date. The Foundation has focused its AIDS funding or four principal areas. First of all, health services delivery; second prevention; the third is policy research; and the fourth is public information.

Today, in view of the focus of these hearings, I'm going to concentrate on our experience in the area of health service delivery, which is where we so far have the most experience and where we have put most of the money. In particular, I want to focus on the AIDS Health Services program, which was our first major initiative in this area.

The AIDS Health Services program was authorized by our board of trustees in 1985 and was funded in 1986. It is a $17.2 million, four year competitive national program that provides support to 11 cities around the country to assist them in developing comprehensive community based systems of care for persons with AIDS and AIDS related illnesses. The program was stimulated originally by the apparent success of the community based system that had emerged in San Francisco in the mid-1980s. It is currently in its third year of operation, and that means that these 11 cities have approximately one year of funding left from the Foundation.

The purpose of the AIDS Health Services program is to show that by organizing its resources into a comprehensive system of in-hospital and out-of-hospital community based care, the community can provide the full range of services that people with AIDS need in their home communities while at the same time reducing some of the pressure on the community's hospitals, especially the public hospitals, which you heard about yesterday.

Although the program drew on the San Francisco model, we made it clear from the start that every community had its own set of needs and resources and therefore our program would not be "Kentucky fried San Francisco."

What have we learned after three years in the field with this program? Well, I would say the good news is that the community based model of providing care seems to work. The 11 projects funded under the program have served over 12,000 people with AIDS and over 20,000 what we call collaterals, which includes people with AIDS-related illnesses, people who are still asymptomatic, and family, lovers and friends.

Hospital stays are getting shorter, although that also seems to be happening in cities that don't have our grants and seems to be partly attributable to general improvements in treatment. Perhaps most important is the fact that the community based approach seems to work in very diverse kinds of communities with very different kinds of case loads, not just San Francisco, but Dallas, New Orleans, Seattle, Nassau County, Miami, Atlanta, and even places like Jersey City, Newark, the South Bronx, and Belle Glade, places with large numbers of drug related cases.

It is a especially important, given the recent shifts in the epidemic. Not only are we seeing more cases among intravenous drug users, their sexual partners and their children, but now crack is coming into the picture. So the impact on our inner cities may be even worse than we had originally expected. Also, more and more adolescents are now beginning to show up at the clinics.

The fact that our projects have been able to serve even these very difficult to reach populations with very complex problems and needs underscores for us the resilience and potential value of the community based model of care, not only for AIDS, incidentally, but possibly for other chronic degenerative diseases as well. The not so good news is that these projects are now stretched dangerously thin, with case managers in some communities already carrying case loads of almost 200. As things currently stand, it's not at all clear how they will even maintain their current levels of operation, let alone expand their services to meet the rapidly growing need.

As I said, our grants are scheduled to end next year, and HRSA's total funding of programs--which Dr. Matheny will discuss--has remained essentially flat since 1986, despite the growing number of cities eligible for their demonstration grants. Meanwhile, as you have heard repeatedly, the numbers continue to increase very rapidly. Just looking at a few of our AIDS Health Services sites, we see that in Atlanta the case load has gone up about 230 percent since we started in 1986; In Palm Beach County, which includes Belle Glade, about 280 percent; in Newark 310 percent; and in Seattle 360 percent.

In New York City, where we have our biggest AIDS grant under the AIDS Health Services program, AIDS patients accounted for 1 out of 12 beds two years ago, and now, two years from now in 1991, the case load is expected to be three times that number. That is almost incomprehensible. And it brings us right back to the question of financing, which is, of course, the main subject of today's hearing.

Let me say now that I believe that the financing of care for persons with AIDS and HIV infection is simply beyond the reach of private philanthropy. That's not to say that private philanthropy hasn't and won't continue to have an important role, but actually paying for the volume of care that is needed is on a totally different order of magnitude from what foundations, even big foundations, can handle.

We got some sense of this last year when the Foundation issued an unusually open ended call for innovative AIDS prevention and service projects. We received over 1,000 proposals from almost every state and territory requesting in excess of half a billion dollars. It was far and away the biggest response to any call for proposals the Foundation has ever sent out.

The $500 million is over five times the Foundation's total annual payout for all of its program areas. After a very intensive review process, the Foundation ultimately awarded 54 grants under this program totaling$16.7 million. While this was clearly a major commitment, it left over nine hundred proposals, many of them very good ones, unfunded.

The problem becomes even more obvious when you compare private foundation spending with what the federal government is already spending and is projected to spend. I mentioned earlier that the Robert Wood

Johnson Foundation has committed $50 million to AIDS since 1985, and that this constitutes over half of all private philanthropic spending for AIDS to date.

By contrast, the Federal Government--and this does not include considerable resources from state and local government--has already spent $5.5 on AIDS since 1982, and by 1992 is expected to spend at least $4 billion per year. That is 40 times the Robert Wood Johnson Foundation's payout for all of its program areas. Now, not all of that $4 billion is for services, but neither is all of our $50 million.

The point is that when one looks at the real levels of need that are out there in the community, foundations are a drop in the bucket. Although a lot of people have received services under the Robert Wood Johnson Foundation's programs, the real purpose of these programs is to test the viability of new ways of delivering care and to find out how doable it is. Once it is clear that this can be done, that community based systems can effectively serve people with AIDS and HIV infection, no matter where they live or no matter how they got sick, then the question of whether or not these systems become a permanent reality in our nation's health care system is up to those responsible for the financing of the health care system.

Thank you members of the Commission. I appreciate it.

CHAIRMAN OSBORN: Thanks very much, Paul.

Sam, why don't we just go ahead with your testimony too, and then we'll have a chance for the commissioners to interact with both of you.

STATEMENT OF SAMUEL C. MATHENY, M.D., M.P.H.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

DEPARTMENT OF HEALTH AND HUMAN SERVICES

WASHINGTON, D.C.

DR. MATHENY: Thank you Dr. Osborn. I am delighted to be here to have a chance to present to you, and I'm also delighted to share the time with Paul Jellinek, because for the last three years our programs have been developed in tandem. We have, I think, developed a very close relationship between the Foundation and between our agency, and we have attempted even to hold joint site visits and to, as much as possible, coordinate the services, the types of programs that we have developed. And I think that a lot of the things that we would probably say will probably reflect each other's comments and we probably don't have very great difference of opinion about how that these programs have developed and worked.

I was asked to comment specifically on several of our programs in HRSA, but the service demonstration grants, which are quite similar to the Robert Wood Johnson Foundation grants, the pediatric demonstration grants, and our drug reimbursement program.

In the interest of time and because that I think that much of the material on the drug reimbursement grant is in the testimony, I would like to just answer questions concerning that, as well as some of the pediatric demonstration grants, because they are fairly new, and give you a little bit more data which has not been presented before about some of the conclusions that we have found and some of the information that we have available on the service demonstration grant program.

As of this year we have funded over $52 million to 25 cities and a number of states, the District of Columbia, and Puerto Rico. And as a result of these programs I would just like to emphasize that we, as did the RWJ Foundation, make a strong attempt in these programs to attempt for the establishment of the coalition. And the very process of developing these grants I think has done a great deal, as did the RWJ Foundation, in pulling together a very diverse community of providers of concerned people and of health systems that heretofore probably had not had a lot in common, nor any reason to work together very much. The process, in some cases successful and in other cases unsuccessful, of applying for both our funds and that of RWJ has I think in the long run been one of the more--although it cannot be measured very well in an evaluation scheme--it has been one of the more successful aspects of the grant program. And even programs which didn't receive the money the first or second time around, with technical assistance, with the understanding of what true coalitions have meant, have come back and I think have been the stronger for this in the long run.

The programs then were to attempt to develop the coalition to assess the needs in the particular community, determine where the priorities should be set, and try to come to some agreement within this geographical area--we determined these at the beginning to be standard metropolitan statistical areas--to at least address the concerns in each of these areas and then to establish these priorities and to propose how that both the Robert Wood Johnson Foundation money and our own would help to alleviate some of the concerns, some of the issues, and some of the service needs in the area.

This was coupled, as Paul has mentioned, with a strong emphasis on the case management, on the community based service model, which we encouraged in all the programs. Particularly in these programs too, we asked that the grantees, and requested that they demonstrate how that they would meet the needs of minorities in the programs that we had funded. And so some of our concerns and interests are on how successful that they were in meeting some of these minority needs.

The program in general--and I'll ask Shelley if she could just put up the first overhead. In social support services--and I'll come back to some of this in a minute--there are a number of different services that the programs provided. We had very little priorities structuring. We really requested that the programs establish what the priorities should be on the funding, and we think that probably some of our feedback in the evaluation--which has just ended and which I'll mention--this has been one of the more successful aspects, is that the programs were not cornered into trying to respond to us. In other words, they were allowed to respond to what their own local needs were and to have, as it were, 25 variations on a theme. As you can see, the services were numerous in the social support area.

In the service categories--and this was before the last four programs were funded--virtually all the programs did provide, and we have supported, inpatient services, ambulatory care, drug abuse and counseling, counseling and testing, and case management. I am emphasizing this and pointing it out because in many cases what we asked them to do was to utilize our funds as the way to fund programs and services that could not be provided in any other manner. So in some cases what you are seeing--in most cases--it is reflecting what the local needs are, where the gaps were that we have attempted to fill, and I probably would think that this has been, in the cases where--virtually all of our programs were also funded by Robert Wood Johnson, and then we had a number of additional programs--that these reflect in many cases where the most needed services were identified in those particularly communities.

Next. And again, most of them felt and requested funds for providing support for home health, mental health, in-home support, prevention--of which up to 20 percent of the total grant funds could be for education and prevention as well--and provided support for sub-acute skilled nursing and residential care.

In looking at some of the statistics on who we served in the report, I would might add as well is that we had a larger number than the number of cases in the country of women that were served by these programs. I think it also reflected a significantly larger number of Blacks and Hispanics that were served through this program than the numbers would reflect in the national statistics of numbers in each of the groups. In addition, most of the programs did request funds and were supporting hospice care, transportation, and the development of hotlines in their communities. And to continue, housing, dental and legal services were provided in most cases as well.

In general then--next overhead--just to summarize this and show where the monies went through these programs, these were demonstration programs but you can see that the service needs were identified by the community and being the most significant, and most of the funds did go for services, in some cases for administrative coordination, for general administration of the program, and then some for education and prevention, although there were other funding sources that most of the programs had to provide this.

But I think it points out that the service need was significant in almost all of the sites, as well as some of the coordinative services. And when we term coordinative services, we are talking about services which were housing coordination, food services coordination, that were very difficult for programs to fund or were non-reimbursable, and in which we have provided--and again, when I am saying "we," the Robert Wood Johnson Foundation as well--the only way that some of these services would probably have been supported in those particular communities.

Next overhead. If we look at what kinds of services that we were actually paying for, as again you can see the majority of this were services for case management of patients. Now, that is also part of our own emphasis, so this may be skewed, but in many cases these services were probably not reimbursable in any other format, or if they were reimbursable, were not uniformly reimbursable because of differences in state Medicaid waivers. Medical Services were funded to some extent, as well as home health, and then the others tend to fall in smaller proportions.

COMMISSIONER ROGERS: Could you hold that one for just a minute, put that other one back.

Sam, I think the answer to this is probably no, but does this give us any sort of proxy as to how the AIDS patients should be taken care of, or is it a forced distribution kind of thing?

I ask because we have said 80, 90 percent of the care probably ought to be out of the hospital, some of it should be in the home, and I'm interested, your slide kind of looks that way. I mean, medical services, you have 20 percent.

DR. MATHENY: I think this reflects where that there are needs to be filled that the programs did not have any other source to get those needs. And so in some case our money is the desperation factor, or the last resort factor. But in addition, I think it also may reflect the fact that this was probably the stage in which the programs were being developed at this point.

And we found that this--which I'll get into a little bit later--is that programs did enter into sort of a set number of stages in the development of where communities were going and how that they were impacted by the epidemic. And in the early stages the emphasis was on inpatient services and on the development of acute care, and as the epidemic increased, the numbers increased, the emphasis and the funding requests tended to be more in the direction of ambulatory services, and then in home and community based services, and then in the development and the concentration even increasingly on ambulatory, and then early prevention, which is I think a new phase that we are entering and seeing now.

Just an example of some of the types of activities, and this is really just picking and choosing, but just showing that the activities that programs selected and that we have helped support are things that were really quite diverse and all over the board, anywhere from free-standing centers, which were needed for aerosolized pentamidine in Boston, to residential support, as in the case of Bailey House in New York City, training for home care companions, in some cases specific training for the development of some of the experimental programs, for buddy programs, actually, with IV drug abusers and within the minority communities.

I would just like to mention a couple of things about the findings. We will be very shortly publishing a much more extensive report, but I wanted to share with you some of the preliminary aspects of this particular report, which was developed by Systemetrics and was presented to our agency just several weeks ago.

Basically, as I said, some populations still we found--and this was an evaluation only, I might add, on the first four programs that we funded, which was San Francisco, Los Angeles, Miami and New York City, and it only reflected what had occurred through the summer of 1988. So in some cases this does not reflect the standards today, or I am certainly not talking about all 25 sites.

But be that as it may, some programs really had been still inadequately reached or served, and those particularly, in most cases--and I am not talking about just for the drug treatment, but services needed for IV drug abusers were deficient still at this time and had not been completely met, those needs, in all four cities. And especially the concerns, it was very--we found that most of the programs, even in areas in which the minority communities were a significant proportion of the numbers of AIDS patients, that the development of services to the minority communities has continued to be a difficult task. It is not that the programs weren't addressing these, that they weren't attempting to do it, but that it has been more difficult to establish because the development of volunteer groups in the minority communities, the development of adequate outreach services that are culturally significant for the minority communities still presents problems and are ones in which I think we are going to have to concentrate even more effort.

Help though, on the other hand, is still needed for financing a lot of basic services for the Gay and bisexual populations, and we can't ignore the fact that in many of our communities the White, Hispanic or Black Gay designated populations are still by and away the majority of the patients who are at risk and are being affected by the epidemic, and that the case load and growth of the case load has been extremely significant, as Paul pointed out. The reimbursement gaps have really not significantly changed since 1986 at the time this study was instigated, except perhaps for the inclusion of AZT under Medicaid in all 50 states at this time.

There are inadequate local resources available, and this particularly is a concern in the case of social services, and if there is any one area in which that the gaps probably are most significant, it is in the area of the social services such as the case management and housing. And we find that the housing issue continues to be one which plagues almost every community in the United States.

Again, I jumped ahead of myself. The shortage of key services and long term care, residential and housing, and again in drug treatment, but that we have probably achieved fairly substantial progress, as Paul said, in development of comprehensive case management systems, that public hospitals, with some glaring exceptions, have tended to be able to meet these needs. That obviously has not been the case in cities that are already suffered acute hospital shortages, such as a number on the east coast, New York in particular. But it does not seen to be as an acute concern in other parts of the country at this point about their adequacy of having a sufficient number of beds. The reimbursement issues are a completely different story. And that many model programs like the ones that I gave the examples have been developed that I think can be prototypes that can be shared by numbers of other people throughout the country, and that we also--I just mentioned earlier that we found that there were sort of patterns of development that communities have gone through, and it helps, I think, in looking at the communities and where they stand at the time in the phase of the epidemic to realize that they may be in an earlier stage and that then therefore they could tailor the money and target program dollars to the development of that particular phase of the epidemic as it is affecting and targeting that community.

That is the sum of what I would like to tell you about the service demonstration programs. I would also just like to say that we have initiated another, for us I think an exciting program, of transfer of some $9 million from the Alcohol, Drug Abuse, and Mental Health Administration to establish ties between primary care and substance abuse. These programs have only been funded within the last couple of weeks. There are 22 sites throughout the country that have been funded, and I look with great anticipation to the development of these programs as particular models for the integration of care for the IV drug user and where that we are going with this throughout the United States.

In summary, I would say that looking at where we are going in AIDS in the '90s is that HIV I think we have to view in the future, as we probably have had many people say, as a continuum of care. It is not any long an AIDS issue, it is an issue of an infection with the virus, and that therefore our services I think really should increasingly be concerned with the capability of the system to provide help for early intervention and that therefore that the cost in the future, probably around early intervention, are going to maybe perhaps shift from the cost that we are looking at now of inpatient care to within a very short period of time being the majority of the cost being outpatient care and that very likely could result in being the cost for the use of drugs in either the treatment or the prophylaxis of HIV infection.

There is going to be an increased need to look at how that we can do a better job of integrating the treatment of IV drug use into the treatment of HIV infection and the prevention. And this in turn I think means, because of the numbers of people we are seeing, that AIDS really has to be viewed as a family disease in that if you want to do adequate prevention, education, prophylaxis, early intervention, it has to be done in a setting where that the family as a whole can receive care, because we are going to see more women infected, more children who are infected, and the sexual partners of the women who infected them are their IV needle sharing partners, and we need to have a setting in which that can occur in an easy atmosphere fear.

It is very difficult to imagine how that we could develop and respond to the epidemic unless that the system, the primary care system of the United States, is geared up to be able to adequately handle this, provide the needed prophylaxis and the early intervention. It is our opinion that only through this integration we will be able to achieve that. HIV infection, asymptomatic infection, is not a very complicated disease at this time to treat. It is one that the average primary care provider in the United States should be able to handle, should be able to recognize, and should be able to respond to adequately. And unless what we take that on and provide that this is the responsibility of all primary care providers, I don't think we'll be adequately able to meet the challenge of meeting the needs of over a million people that may need to have some form of intervention, prevention, or therapeutics within the very near future, and that's the way our agency intends to tailor its programs in the years to come, particularly through coordination and integration with other agencies that are providing research, mental health services, and prevention and education.

CHAIRMAN OSBORN: Thank you very much, Dr. Matheny and Dr. Jellinek.

Commissioners, have at it. Eunice Diaz.

COMMISSIONER DIAZ: I would like to ask Dr. Matheny about one of the programs that you are responsible for. Many of us had really looked forward with anticipation to excellent results coming forth in creating more access points to health care through the training of physicians through your AIDS educational and training centers, because there is such a priority that some of us feel in the reaching or training of minority health professionals. Can you give us a feeling as to whether these AIDS ETCs have really done the job for us in the communities where it is really going to make a difference then?

DR. MATHENY: Well, that's a real particular concern, and as you may know, Eunice, or at least it will be announced very shortly, that the training and education of physicians who are working with minority communities or who are minority health providers will be fending preferences and have to be addressed by these education and training centers.

So this is obviously a strong concern of ours. It meets the specifications of the section under the legislation under which these programs now are dually authorized. So that will be a strong area of interest.

We have an ongoing evaluation plan and program, and one of the aspects of that evaluation is to assess its impact on both minority providers and the minority community, and we'll have some more results forthcoming from that shortly.

CHAIRMAN OSBORN: Mr. Konigsberg.

COMMISSIONER KONIGSBERG: Dr. Jellinek, I think the Robert Wood Johnson Foundation and HRSA both have done an outstanding job in these demonstration projects, and I would certainly like to commend both organizations.

I guess my question to you, Dr. Jellinek, with the grants running out--and perhaps I don't feel that as acutely since I left Fort Lauderdale as I would if I were still there--but it raises a real serious question though that if the evaluation of these projects proves that they were successful, which I am sure that it will, how are we going to continue the systems that were started, the raised expectations, the chances that people took in setting up these projects, not knowing whether they would be supported by the states or by the communities?

What would you recommend to this Commission that we do and say that would bring some continuity to the process to the process and to the funding?

DR. JELLINEK: I think my appearance in front of the Commission is a part of our strategy, as well as my appearance in front of various committees and so forth, to alert people who are in a position either to finance care or to influence those who finance care to the success of these programs so far, and at the same time alert them to the very severe shortage of resources in some of these communities.

So that is one part of it. But beyond that, we have been working quite actively with many of the sites to try to uncover for them whatever local, state and private resources may be available in their communities.

At the same time, I must tell you that this program has precipitated something of a crisis for us at the Foundation. The Foundation historically does not continue any of its national program grants once those grants are over, but recognizing the severity of the problem right now in many of these communities and the absence of funding, it is something that we have at least had to talk about.

It is a very serious problem, and I am not sure exactly how each site is going to resolve it. Certainly some sites have made some progress in working with their states and working with local foundations and so forth. My guess is that some of the pieces of some of these systems will certainly go under unless additional funding is brought in, and certainly they will not be able to continue to meet the expanding need for services unless additional resources are forthcoming.

My sense is that the Commission can play a very important role to two senses. One, by keeping a spotlight on the problem, and secondly, by keeping the heat on the system. And I think that's what these hearings about are about, and I think they have been very effective in that respect.

COMMISSIONER KONIGSBERG: Just, if I may, a quick follow-up.

The projects, of course, were targeted to high incidence areas, major urban areas. What do both of you--I guess what thought has been given to the care and treatment in the rest of the United States--which is where I live now, in the middle of the rest of the United States--because the same issues are beginning to arise, the same systems of care may apply but in a very different way. In other words, smaller, medium sized cities, and even rural areas, has any thought been given, either by HRSA or the Foundation, to that?

DR. MATHENY: This year for the first time we did develop planning grants for HIV infection which were geared really at lower incidence states and areas, and in fact we even encouraged regions of states that were more populous, but they themselves had not experienced the same phase of development as--West Texas being one--to apply and did and were successful. And we funded about 22 of these, if I am not mistaken, this past cycle.

Unfortunately, it doesn't look as if there will be any money in the budget for next year to continue those planning grants or to carry them forth for the next phase in development. We have been very interested in this as a problem, because the epidemic is moving into areas other than the first four cities.

Other activities we are trying to encourage and develop are such as holding a national workshop on AIDS and HIV infection in rural areas, which we plan on doing in early January, to try to understand a little bit more about the issues of health care delivery and services and what we should be doing to try to meet these needs.

CHAIRMAN OSBORN: Dave Rogers.

COMMISSIONER ROGERS: Paul, as your former president--oh, excuse me, you had something you wanted to add.

DR. JELLINEK: Well, in response to Dr. Konigsberg's question, which I think is a very important one, first of all, right from the beginning in the development of the AIDS Health Services program, our thinking was that we should include communities that at that point did not have a large number of AIDS cases, and indeed a number of the 11 grants went to places--they had to have at least a hundred AIDS cases, but many of them were just over that level. So that was part of our strategy from the beginning because we recognized that the earlier a community could begin to develop an infrastructure, the more effectively it could respond once the numbers starting increasing.

Beyond that, as part of our AIDS prevention and service grants, we have made grants to a lot of low incidence places, partly for prevention, but also for development of systems of care. So we are in Utah and rural Oklahoma and Alabama, Grant County, ,Wisconsin, rural Georgia, in a lot of places where people now are clearly very concerned about this issue and where they need the resources to get started.

COMMISSIONER ROGERS: Paul, I'll continue. I will give you a short lecture you don't need, but in response to Chuck's question about continuation of funds, you are correct, certainly, that the Foundation has traditionally said, let's us be the seed money and let's get things started, let's get it moving, let's let people kick the fender, slam the door, see if it works, and then move it into the mainstream of funding.

I would also, however, point out that that has not invariably been the case for the Foundation, and here is a situation where you, we and others are screaming crisis. I would, as a piece of gratuitous advice, would hope very much that the Foundation continues--if it is going to send that message, it damn well better continue to put some dough into this area. And you can carry that message back to your colleagues from me.

DR. JELLINEK: Your advice is much appreciated.

COMMISSIONER GOLDMAN: This question is really directed to both of you. There are a series of questions, but they all related, and the order in which you answer them is really not important.

One is, could you define what you mean by "community based program"?

The second question that I have is, Dr. Matheny's comment about the treatment of chronic HIV disease is not complex. I have never known anyone with a chronic disease lasting a lifetime who has been happy being the only patient with that chronic disease being treated by a physician in the community, that people with chronic diseases, in my experience, are much better treated by physicians who at least have a handful of such patients so that they have the resources necessary to keep up to date on what is going on and have some kind of relationship with some other institutions that make some sense in terms economically. And if a physician just has one patient who has a particular problem, then it is often rare that those kinds of incentives exist.

All of which relate to the third question that I have, which is the primary question. That is, we have heard from a lot of the witnesses today that really one of the things that I think that they are looking for in terms of people from the community, and what I hear is, is there some concept of an idealized system of a goal of structure of care from both a regional, national, local, state basis, and a continuum of care from the physician in the community to the major medical teaching center, and how a system of care for HIV infection could and should be developed, based on the kind of models that you are funding? And is there some way that we can put those kinds of models together, at least have some idealized programs, understand what kind of staffing is required to produce at what levels of patient care, you know?

What kind of professional expertise is necessary? Do you need and immunologist? You know, what kind of medical expertise do you need? What kind of nursing expertise do you need? What kind of social services are essential and necessary? And then how that kind of system can be structured, or some models as to how that can be done, in a very clear and defined way so at least we have a goal and an ideal to shoot for and so that we understand what a proper program is and then we can more effectively, it seems to me, use our resources to meet that.

DR. MATHENY: Quite a question.

CHAIRMAN OSBORN: Twenty-five words or less.

DR. MATHENY: Well, when I said that HIV infection is a chronic disease, I think that we have to look upon chronic diseases in the context of other chronic diseases in the country. And there are at least three levels that have been recognized as how that the medical care system manages and works with any disease entity. And chronic diseases have been successfully dealt with by primary providers for many, many years and done quite well. And this goes from anything from diabetes to congestive heart failure to myocardial infarctions to the management of chronically ill children.

The question and the issue I think is that knowing that the system requires at least several levels of care, and that at one level, which is the level of entry into the system--and I'm talking here may be perhaps about the asymptomatic level. With a million people there is no way to devise a system, design a system, which would only deal with this problem and set up a separate health care system to handle the needs of these people. And it is not that complicated, it is not that difficult to do, to know and to train people to adequately recognize those in the practice that are at risk, to assess their status at that time, to appropriately test when it should be done, to counsel other members of the family, to make a diagnosis, if that's the diagnosis, based on laboratory exams, and to begin prophylaxis if necessary.

Depending upon the provider's interest--and I'll use the term "physician," but it could cool very easily as well be a nurse practitioner or a dentist or a nurse. The provider then at the second level of concern may--there are certain conditions, certain instances in which that person may wish to have consultation to continue the management of that patient. That will depend upon both the interest of the provider as well as the skill level as well as the number of people. It is a cost effective way of dealing with that particular patient problem?

In areas where that the provider will have 10 or 15 patients, he may very well wish to achieve consultation when he has someone which he doesn't see things that frequently. But he still functions as the ombudsman, he still functions as the gate keeper, he still functions as the primary provider of medical care.

At the third level or the tertiary level, this is a level in which that the patient would be referred into a specialist for the majority of the management of that care. And again, this is not a standard thing. If you look at where that the medical care has been provided in the AIDS community, many of the AIDS specialists that we have today started as primary care providers who may have been Gay, may have been dealing with heavy numbers of Gay patients, who have developed themselves into an area of expertise.

So I think it is a complicated question and it is no different than the way that we take care of diabetes or, actually hemophilia, for that matter. In a number of cases we have referral centers, as you well know, but in many cases for many problems the primary concern or the primary care may be provided by a well trained primary provider.

And I think that is the system and the model that we are encouraging. It is the model that makes sense, it is the most cost effective, it uses the services already in place and provides local care, and particularly important when we are concerned about the care for minorities and inner city populations. If one devices a system which depends upon tertiary, specialized care, we will not be providing adequate family care to the people that need it, and providing early intervention, and providing the prophylaxis that may be needed at the locale, and hitting the family as an issue. And that's why I think we are going in that direction.

DR. JELLINEK: I would like to underscore Sam's point about keeping this in the mainstream system to the extent that it is at all possible. I think that is incredibly important, particularly on an issue as sensitive as HIV infection. In terms of an idealized model, I think we are moving in that direction. I don't think we can point at any specific community and say they have got it. Some people thought we could do that with San Francisco, but it became clear very quickly that Jersey City was not San Francisco and that and indeed you would have to do things quite differently, although some basic principles could apply.

Those principles I think are that you would want to have a range of in and out of hospital health and support services available. You want to have come case management or care coordination to help somebody negotiate that system of services. You want to have sufficient funding for those services. You want to eliminate categorical funding barriers that exist across those services so that the services can be used flexibly to respond to the actual needs of the patient. You want to have clear links to other agencies and support services that aren't necessarily directly related to AIDS.

I mentioned earlier that AIDS is becoming more and more a part of all the problem areas that the Robert Wood Johnson Foundation works in. They are becoming more and more a part people's problems across the board. So this whole notion of trying to coordinate not just AIDS services but other services with AIDS services I think is becoming increasingly important.

And last, but I think very importantly, flexibility has to be a very important part of the model, not just flexibility across communities because of different circumstances, but also flexibility over time. Because the epidemic is evolving, the needs of patients are changing over time, so flexibility is very much a hallmark of any kind of a model in this case.

CHAIRMAN OSBORN: Diane Ahrens.

COMMISSIONER AHRENS: I have a question just in terms of what I'm hearing here, and that really has to do with I guess what I call it is mainstreaming. But when we talk about using the primary care provider over the long run to provide the service, I don't know whether you heard Peter Arno this morning, but he gave us some rather dramatic information in terms of reimbursements. And we are really looking at this point I think at the Medicaid system, because that's the primary funding mechanism, public funding mechanism for reimbursement.

And I feel a little as though we are at the epicenter and the department that you represent is sort of moving in one direction and funding mechanisms are either stationary or moving in the other direction. And I am wondering what the Public Health Service will be doing--and I realize that the funding is not your responsibility--but since you are moving in one direction and these figures are moving in another, what will you be doing to try to address this issue?

It just seems that a physician is not going to accept a patient with reimbursement at $7 when Medicaid is paying $80 and Blue Cross is paying $78.

DR. MATHENY: Well, this question really should be one directed I think more at the Health Care Financing Administration and I would certainly encourage their input and comments on that particular issue.

As you know, the Public Health Service's prime mission is really in prevention, education and research. Our agency, because it is the Health Resources and Services Administration, has been one that has addressed the people that I would say have fallen through the cracks, or have the potential to, whether it is maternal and child health or AIDS.

We have limited capability to respond to that. What we have been trying to do is to develop to the best extent that we can--and I think that we are going to see a lot more of that from our agency, NIH, CDC and Alcohol, Drug Abuse and Mental Health Administration in the next year, are cooperative ventures where that we can stretch to the fullest extent possible the integration of the clinical trials, the research with health provision, with the mental health interests, with the drug abuse demonstration projects, and tying this in in models to primary care.

It is an issue that is beyond us to be able to solve, to be frank about it. It is one, obviously, that we are concerned about, but it is a little beyond the purview of the Public Health Service itself except to continue to provide leadership and to work in these demonstration projects to achieve that.

DR. JELLINEK: If I could just add a brief note, we have talked to HCFA about this repeatedly. One of HCFA's staff sits on our National Advisory

Committee and is very much aware of HCFA's policies in this area. HCFA also has problems in terms of what it can do. HCFA, of course, is accountable to the Congress in turn. And Congress in turn is accountable to the American people.

So I think the issue goes beyond the staff a HCFA. The question of how AIDS will be financed in the long term is not just a bureaucratic question, it is a political question. It is a question of political will, and I think until the political will exists in the American public and in the Congress, it will be difficult for HCFA to respond too.

CHAIRMAN OSBORN: I'm going to have David ask the next question in just a second, but the staff--just for members of the Commission as an aside--Larry Kessler was good enough to go out and get cards for both Belinda Mason and for Harlon Dalton, who couldn't be with us at this meeting, and staff will come around and that's what the bustle in the back of the room is so everybody doesn't misunderstand our level of interest.

David Rogers.

COMMISSIONER ROGERS: This is to Dr. Matheny, though you may want to boot this one, but this is down your alley more than the one that Diane asked you.

I think all of us really applauded your decision to try and tie primary care to substance abuse, all of us who were concerned with AIDS. But there are three of us in this room--Dr. Des Jarlais, Mr. Goldman and I--who come from New York and New Jersey where they have 5 percent of the IV drug users that have got AIDS, and from that 9 million bucks only 7 percent of it went that direction.

That seems to me a gross miscarriage of what you have just been articulating, namely, we are going to get to the people who need it the most, and here are two states that are absolutely desperate and they got none of your dough for precisely the people you said this was designed for.

Am I taking unfair advantage of you, Sam, In putting this question to you?

DR. MATHENY: Yes, sir.

[Laughter.]

DR. MATHENY: As you know, these were awarded on competitive grant cycles, and unfortunately that was sort of the way that that particular cycle went. We are certainly hopeful that not only can that program continue but can expand, and I would certainly feel that everybody is quite concerned that we have some successful models going on in New York.

CHAIRMAN OSBORN: Scott Allen.

COMMISSIONER ALLEN: Sam, I have a question. First off, I have been part of the RWJ and HRSA's help in Dallas with the AIDS Arms, and case management has been enormously helpful and I appreciate all that you have done in my city.

I have a question though, you talked about cooperative ventures, and I know the DDI for the pediatrics is out of NIH, and it is also a demonstration grant in Houston. And one of the issues that was presented to me was that the transportation is not available to the Houston site for pediatrics throughout the region, but it is to Washington. And so it is more cost effective to the child PWAs to go from say San Antonio all the way to Washington, because it is paid for, but they can't get from San Antonio to

Houston or from New Orleans to Houston.

I noticed you had transportation on there, and I don't think that's probably what you are talking about in that respect. But what can be done in that case? It causes tremendous amount of energy to get a child on a plane for a three hour flight. It costs far more than need be since there is a site in Houston.

So can you help and try to figure out who do you talk, to how do you get that done, and is there some type of cooperative venture to make this a lot easier?

DR. MATHENY: Well, we have been looking at what we could do to assist--and we will be working on that more--of looking at the clinical trials units and how that we can interdigitate some of where we have service demonstration grants to help facilitate that.

As far as the issues on the clinical trials, it is out of another pocket of money that we don't have any control over, which is NIH. And I am not doing trying to dodge the question, it is just that I don't have as much information on it as I should because of it being a different agency.

DR. JELLINEK: It sounds like they have been using our travel coordinator from the Foundation.

CHAIRMAN OSBORN: Are there other comments or questions from the commissioners? Am I missing anybody? Don Des Jarlais.

COMMISSIONER DES JARLAIS: Sam, you talked in terms of the chronic disease and integrating HIV treatment into sort of regular ongoing health care. For many people, particular minorities in this country, that primary health care doesn't exist. What are your thoughts of how you might provide chronic disease care for HIV infection for people who use the emergency room as their primary source of health care?

DR. MATHENY: Well, it is a real issue, and it is an issue whether it's AIDS or, again, whether it is hypertension or diabetes or what it is, and I am not sure we are any closer to solving it for one than we are the other. One thing that we are trying to do though particularly is to this year we will have an additional $10 million as seed money to supplement community health centers that are in areas that can provide a lot of that primary care service.

Particularly, a lot of these are at ground zero in New Jersey and New York, and those will be targeted to receive both--already we have started with three to receive CDC money for direct prevention and education activity, and also for direct money to provide better services for HIV infection in those centers.

They are ones that are dealing with a lot of poor people. About 64 percent of their population is under poverty level that has no insurance, and about 60 some percent of this population are also minorities in inner cities. So this is an area where we can do some things and we do have some control over of trying to earmark some funds. The difficulty of working with a system where there is no continuity of care is one that is a big problem whether it is from whatever concern it is, and I am not sure we are going to be able to solve that through this particular issue.

DR. JELLINEK: I think another model that we have been experimenting with a little bit is to actually move the site of primary care, for example, to a drug treatment clinic, in the case of Asbury Park. They have a major drug treatment clinic and they have now located primary care services there as well. And that can also be done with STD clinics, sometimes with family planning centers, where those services can be strengthened and enhanced to actually provide ongoing chronic and primary care.

DR. MATHENY: I will add, Don, that it is what the intent is of the new programs that we are funding with the Alcohol, Drug Abuse and Mental Health Administration, is to increase both the drug treatment capacity and the primary care capacity.

CHAIRMAN OSBORN: Well, thank you both very much for your input. We value it and the programs that you have contributed. We have heard a lot of very distressing things over the last couple of days, but the efforts of the Foundation and the HRSA demonstration projects have been cited repeatedly as sources of insight and at least incipient optimism. Thank you.

Now we turn to a summary of the Hispanic/Latino Teleconference, and Eunice Diaz will lead us with and Patricia Mendoza.

SUMMARY OF THE HISPANIC/LATINO TELECONFERENCE

BY EUNICE DIAZ AND PATRICIA MENDOZA

MS. MENDOZA: Good afternoon. Thank you for the Commission and the invitation to come before you and provide you with some information about just a very recently delivered teleconference project last Friday, October 27th. Eunice and I have been involved with that project and we are here to tell you a little bit about I guess the background of the project and its formation, and then also to have an opportunity to show you some filmed material that we did get today.

My name is Patricia Mendoza and I work at the University of California Los Angeles with the Continuing Education Division there. And in that capacity I am responsible for Hispanic programs, and working with the Health Sciences Division, this is a proposal that we wrote. It is an interesting joint venture on our own campus with the Chicano Studies Research Center, our Continuing Education branch, and also with some national organizations.

The project idea came to UCLA in an interesting way, and it points out our third joint venture, which was Congressman Roybal's office here in Washington, D.C. The Congressman had been very interested and, of course, he has been very involved with the AIDS issue for a number of years, even before it was popular, I think, to go after funding for this kind of support. And he was very interested in our finding some mechanism to reach community leaders in the Latino community. For some reason or other that level of support from Hispanic leadership had been missing, and it was an idea that he brought forth.

It came to the university, even though a national coalition had been formed here in Washington of, I guess, almost every important Latino/Hispanic organization from the LULAC, the GI Forum, to Mexican American Legal and Educational Defense Fund to the National Coalition of Health and Human Services Organization, National Council of La Rasa[phonetic].

I could go on. It is a large list. This Commission, this advisory group, rather, was very interested in lending support to such a project. And as in all groups, it became apparent that we would have to formulate a small working group from that larger advisory panel, and landed up working with about five major organizations--National Association for Latino Elected Officials, the Latino-Latina Lesbian and Gay Organization, Congressman Roybal's office, and one of his aides was on our advisory team, the National Council of La Rasa and COSSIMO [phonetic] were all part of a group.

And so we had the national level, all these organizations as one of our co-venturers. We wrote the proposal--I was one of the authors--at UCLA, and submitted as an unsolicited proposal to the Centers for Disease Control. And we were successful in getting the funding. The project actually began back in May when we were beginning to work together as a team at the university, and involving community based organizations, and we got funded very recently, in September, the teleconference actually taking place last Friday, as I mentioned, October 27th.

We learned a lot in this process and I am going to talk about some of those things that we did learn. I have talked a little bit about how the idea came our way, but I would like to share with you some of the things that we learned with respect to process.

You may or may not know that although the Latino/Hispanic group is bound together by a common language, Spanish, we are an incredibly heterogeneous group compromised of Puerto Ricans, Cubans, Mexican Americans, in some quarters even Mexican Americans don't respond to that term, it has to be Chicano or Chicana. We have then the Central Americans. We are a highly diverse heterogeneous community.

And as we started to work on this project it became apparent that everybody wanted to be able to have a way of being able to speak for their particular distinctive community, and so that we learned a lot about that. It was very clear that we needed to keep a national perspective. Here in Washington it was very apparent that they did not want a West Coast product, so that was a message given loud and clear. And we knew also that there are regional differences when it comes to HIV infection and AIDS in our community, and we were very sensitive to want to represent that, not only at the level of the topics that we would cover, the presenters that would ultimately be chosen, but also our main focus was to highlight promising strategies, things that had already been funded, programs that were at work, materials, educational and interventional materials that were at work in our community and were proving to be effective.

And we did not feel that this teleconference, this project, was about anything brand new, but it was to serve as a dissemination vehicle for things that were working right in our community and things that we wanted other Latino communities across our country to know about and to be able to have that as food for thought, for things that could be possible in their own communities.

That was the intent, to use existing materials, both educational print materials but also public service announcements and videos that had already been produced and funded by other grants, and also to have an opportunity to, as I mentioned, focus on those promising strategies.

Our target audience was very exclusively leadership, and it was this term that we wanted to define I think in some unique ways, because we wanted to go beyond elected leadership to also those very important influential people that we all know about in communities or in organizations that may not have the more prominent positions but are very critical in influencing their constituency. And so we defined leadership in a very broad manner, people who are actually movers and shakers within their community, and we wanted to broadly identify those sectors from the health and human service organizations, the educational sector, the religious sector, the legal sector, and just bring in a wide range of leaders to this program.

We have been on the phone canvassing since Monday trying to get a sense of how the project was received, the teleconference project was received, and we have got nothing but glowing remarks. We are using as a measure--and this is very qualitative--we do have some quantitative measures also at works, but I wanted to get a feel for the project as I came before this Commission to be able to tell you whether people in the Latino community across the country--and I am not going to go into specifics because when you see the taped comment you will see how many sites we were in and a little bit of that information.

Overwhelmingly it was a program very well received. My own feeling as being involved with the project was looking at something in the neighborhood of 54 presenters that we had, the overwhelming majority of these being Latino, may be save three, but to have the opportunity I think to view very articulate, well credential professionals from our own community talking through our own voices about our own experiences and our own issues with regard to HIV infection and AIDS was extremely powerful. .

It sent forth I think a very positive role message, and a wonderful role model example for leaders who perhaps may be very reluctant to come on board with respect to this particular issue. And they could see other physicians, psychologist, social workers, any number of things, Congress people, from our own community getting very strongly behind the issue of HIV infection and AIDS in our community. And so it was just a very powerful sort of mechanism, I think for me as well, and I wanted to share that with you.

A lot of politics around this issue. Some

I've mentioned with respect to the different Hispanic constituencies, but also with respect to our Gay community within our Latino Lesbian and Gay organizations. We'll get to some that when Eunice talks about our presenters and some of the conflict that we came face to face with these groups. I think that they particularly wanted a much stronger message, almost an exclusive message, if I can use that word, with respect to homophobia and Latino sexuality and homosexuality in specific.

I always felt like the bad guy with this project. That's not what CDC had funded us to do and we had a very specific message of education and a very broad spectrum of issues with respect to HIV infection from education and prevention, intervention, across all issues, men, women, adolescents, the pediatric issue, care and treatment issues, across the board. It was a mechanism to be able to give some very specific information, very broad based information, and increase substantially the level of awareness for our community leaders so that they could be well informed to take on that local leadership role with respect to HIV infection and AIDS.

I think we were able to deal with that effectively. I think that that community as well, as they viewed the teleconference and participated at our different sites, were pleased with the ultimate result. It was a particularly positive experience for I think anyone connected with the project. It is like anything else that happens, when you are preparing and working so strenuously with it for over a year it seems like I don't know what it is going to take up my time now, but we are already trying to think ahead of what the next steps are and what they should be now that we have raised this level of consciousness.

COMMISSIONER DIAZ: My role was simply to put together the format of the program, the speakers, and to be able to integrate this into what actually came on screen at those sites. I came to this project at the special invitation of KCET, public television in Los Angeles. We have been a consultant for KCET for the last three or four years in other media developments. Some of you might have had the opportunity to see a previous production of theirs, CIDA is AIDS [phonetic], which was a one hour telecast on public television and through the Uni De Cion [phonetic] chain. And for any of the commissioners that would like that, that can be made available, also funded by CDC.

So KCET had a number of Latino professionals that they had worked with and felt very comfortable in inviting me to join them for the last six weeks and to put together the format, the content and the speakers.

So that's basically what I did. I think Patricia has covered very well the planning aspects of this. It was just really a mammoth job. Each one of us contributed our particular skills. I guess that KCET thought that perhaps my background and knowledge of diverse programs around the nation, individuals who were involved at every level, would perhaps be the best way to make sure and ensure that we left no stone unturned and were really able to reflect on that teleconference the very best amongst us.

And it came down to some very critical decisions of if we had two people, two speakers that could deliver a message--and I will use an example--in Los Angeles we have a number of parents, mothers, who have lost children to AIDS, or young people to AIDS. But yet about six weeks ago I had met a woman in San Antonio as I spoke at a conference there that had such a powerful message to deliver in terms of her being a Latino mother of a person who had died of AIDS a few months before. The message was absolutely as so compelling and so moving that we made a choice to fly someone there from San Antonio rather than to use individuals from Los Angeles. I share that so you can begin to see the human drama behind this. It was a fascinating job, certainly a very challenging one, but one that didn't permit me to come up for air for about six weeks. And definitely actually a very moving experience, as Patricia has described it.

I think that the rest speaks for itself. We would like to have you see just a very short clip of this presentation, perhaps the opening of it and the closing. And again, I think that the one word I would like to underline is that we tried our very best to send a very powerful message to our community leaders that there is really no excuse for individuals to not be involved in some aspects of AIDS. You will see this if you are able--did you choose the psychosocial panel?

MS. MENDOZA: Just the beginning and the end.

COMMISSIONER DIAZ: The beginning and the end. There are many panels, and individuals have described to us that it is so useful to them that we can divide the content and use it in training, sensitization of staff, and work with community based groups on the basis of the information there. So KCET and CDC will have the job of cutting it up into smaller segments. The entire production was four hours and 59 minutes, and it covers the wide range of AIDS topics.

The main message we wanted to leave with the people that participated in this and the ones that were the speakers is that we need a broad spectrum of community involvement to be able to work together on an AIDS action agenda.

So with that I think we will let you experience it.

MS. MENDOZA: I just want to mention the sites, and the sites had originally been selected based on CDC data for large numbers of Latinos with HIV infection, or at risk for HIV infection. And just so that you get an idea of where we were, we were in Phoenix, Arizona, we were in Tucson, we were in California at several of the universities, at Cal State LA, Cal State San Bernardino, at UCLA. We were also in Long Beach, in Oakland, Sacramento, San Diego, San Francisco--in spite of the earthquake we were in San Francisco.

We were Colorado, in Connecticut, in Florida, in Illinois, Kansas city. We were in Massachusetts. We were in Michigan,Nevada, New Jersey, New Mexico, New York, Pennsylvania, Puerto Rico, several sites in Texas, Austin, San Antonio, Corpus Christi, Houston. We were in Utah, Wyoming, Montana. We were in Washington State and in Washington, D.C.

And we had an additional site at Clairmont College because one of our speakers was there and had undertaken funding for that, and another site that was at no cost to our project was in Tijuana, Mexico, so it was really quite varied. So maybe we can go on with the clip.

[Video presentation.]

MS. MENDOZA: I wanted to mention that we did use two site coordinators at each site that were identified for us by the national advisory team. We relied on them and their knowledge of the community based organizations across the country, so that there were two, a male/female site coordinator at each of our sites, and we did entertain questions using the panel format that the teleconference employed.

COMMISSIONER DIAZ: Although you saw primarily people you knew, elected officials to begin it, and our friend, Cabinet member, Dr. Sullivan, throughout the five hours there is participation by other politicians, the teleconference finishes with a very impressive message from Henry Cisneros, appealing to the Hispanic leadership for involvement.

We also had the participation at no charge to this project of five individuals in the entertainment business, including Vicky Carr, Ricardo Montalban, Eddie Olmos and others. And cooperation really as far as speakers from community based organizations, funding agencies, and numerous individuals that are doing fine work in Hispanic America in regard to AIDS.

We were very proud of this project because it represented the collaborative work of so many individuals, all working toward one goal, that of increasing the numbers of us that are involved in the front lines of AIDS work. And odd definitely delineating for individuals that watched it, a role that each one of us can play, whether that be in prevention and education, in service delivery, in advocacy, in networking and coalition building, and in all of the aspects that relate to involvement of different segments of the community, the religious community, the professional community, the Gay community, youth groups, prisoners and others.

MS. MENDOZA: Thank you very much.

CHAIRMAN OSBORN: Thank you very much. It is a wonderful way to end our two days in the sense that this is a most creative and constructive contribution and obviously it is an especially important one, because I know that you are leading in getting through a message that has been particularly difficult to deliver and to deliver in a way that is readily received by the intended communities. So I think for the whole Commission I want to thank you for your special efforts and for sharing them with us today. That's really very exciting work. Thank you.

COMMISSIONER DIAZ: We just need to add that the color is splendid. Something happens with this, but we were our true colors that day.

CHAIRMAN OSBORN: Do any of the commissioners want to comment or ask any questions about the teleconference?

Thank you so much. We appreciate it.

We come now to a stage in the schedule where we have some flexibility. The commissioners will be relocating to Virginia after a bit, as they know, and as was I think announced. And between now and then we want to discuss a few matters and to decide on an order of business and to take a few minutes to review some very important work that was done by the staff.

Let me see if I can remember to dispose of a few matters. One is this Commission is so new in terms of getting itself organized that some of the commissioners even probably don't know for sure that our address is now 1730 K Street, N.W. I had hoped that we could organize ourselves to go over and see the

Commission offices, and pushed that plan until more sensible heads pointed out to me that it is Friday afternoon, it is rush hour, it is Washington, we have got to go to Virginia, so I gave up on that.

But on the other hand, I think it would be good for commissioners and our guests to know that the offices are there, the staff is working very hard, and as I have commented to a few of you, has been doing the good work that put together as smoothly coordinated a session--two sessions--as we have had, although they were just barely set up to work even last week in the usual styles of work that people are accustomed to, like telephone lines and fax machines and Xerox and all that.

So I think I just want to express again my admiration for the marvelous job that made these first two sessions go off so very well and with such a rich input from well chosen and well spoken witnesses, and the good discussion that they allowed.

So for the commissioners in particular, but others too, I think I'll just simply invite you to visit the Commission offices when your schedules permit and we'll forego that adventure this afternoon in Washington rush hour traffic.

Next, we were quite enthusiastic as a Commission to have the opportunity to base our work on the important report that had been submitted by the Presidential Commission in the summer of 1988. And because of the remarkably detailed job that Commission did, with nearly 600 recommendations, this presented something of a challenge, and I think the staff have worked very, very hard to bring the recommendations into a form where we can now look at them in an efficient manner and begin to get a sense of what is happening, what is not, how to prioritize attention to capitalize on the work of that Commission and make sure their intentions were carried through on.

I asked Maureen if she would mind taking a few minutes to describe the process and the product, and then we can have a brief discussion about how to make best use of the product that I think the commissioners have received in their packets.

MS. BYRNES: I hope you have each received a packet. It was left at the desk for you when you checked in, and for those who didn't receive one at the desk, we tried to make every effort to get one available to you before I explained what our process was and you had a chance to review the product.

Essentially what the staff of the Commission did do at your request was contact the National AIDS Program Office to identify what to date had been done, both through PHS as well as any of the other agencies in the appropriate federal departments that would be called on to respond to recommendations made by the Presidential Commission.

And the National AIDS Program Office provided us with the information that they had to date, and then made an effort to provide us with updated information for those recommendations and categorization of different recommendations for the most recent developments and the most recent updates in those particular areas.

Just because I was beginning to explain to you the process, I also want to do a little show and tell. The information is provided through binders this way, which we didn't think you would each appreciate if we sent you another Federal Express package showing you what the update was in response to each recommendation. But it was done.

In December of 1988 the first review of those recommendations was done, and it was compiled through these binders. The recommendation is listed at the top, and then the categories that you have seen on our staff memo that we provided are listed and each recommendation then is put into one of those categories with a narrative response from each of the agencies, as I said, both at the Public Health Service level as well as from any of the other appropriate agencies that would be called on to respond.

Our essential findings through this task was that in fact there is no routine ongoing monitoring of these recommendations. As I said, and it was indicated in the memo, there was an initial review done in September of 1988. There was an update done in July of 1989 in a somewhat ad hoc basis. Not every recommendation that had a response in December 1988 got an update in July of 1989. We worked with the National AIDS Program Office over the last couple of weeks to see if we could get additional information past July 1989, or for some information that had not been collected on the other recommendations up to July 1989. And we will be getting some of the information from the agencies and are still awaiting an update on many, many of the other regulations.

As I said, essentially the staff report, at this stage of the game, is that the material is being collected but not on a regular basis and we would suggest not in a format that lends itself to evaluation, not in a format that would really allow this Commission to take a look at how the Public Health Service and how the other agencies in fact are responding to the recommendations of the Presidential Commission.

We would make three specific recommendations that would allow for such evaluation to take place. The first is that there should be a regular routine, ongoing evaluation with a specific period of time in which each of these recommendations are reviewed and updated. To our knowledge, that is not going on at this point in time. HHS initiates it on its own, or at our request, at the National Commission staff request. Such information was requested, but our suggestion and recommendation would be that there be a set period of time at which each of these recommendations are reviewed to see if their categories should be changed, have they moved from the "Under Consideration" category into the "Planned" category, into the "Completed/Ongoing" category, but on a regular basis, collected in a format that would allow us to look at whether or not the Commission in fact supports, agrees, disagrees with the response of the appropriate agency to that particular recommendation.

We would also recommend that the categories be looked at carefully for as much detail as possible. The thing that struck us, I think, most glaringly is that the first category in the federal response section is entitled "Completed/Ongoing," and it is difficult within that broad category to really identify in a fairly timely fashion what in fact has been completed and what in fact is still ongoing. I think more clarity within that category would be appropriate and also allow for a more detailed and effective analysis of the state of each of those recommendations.

And then the staff recommendation would be that on that regular basis the National Commission continue to review the status of the recommendations and make decisions or suggestions or recommendations about the categorization. I think once the material is put into a format that this Commission can review and analyze, my suggestion is there may be differences of opinion between how the individual agencies are responding about whether or not they recognize or agree with the Presidential Commission that it is an appropriate federal role to provide certain services or to make certain changes, or whether or not it may be appropriate in another format or at a another level of government or in the private sector for such an activity to be undertaken.

Looking at a number of categories as we were able to put the information together, there were certainly some questions that the staff had, but that kind of a detailed questioning or analysis of presentation of information was difficult for us to do since it was the Commission staff that went through these hundreds of pieces of paper, tried to compile them in a format that made some sense, but did not go any further than that in terms of the review, because to some degree a number of the recommendations were also--a number of the responses were also somewhat out of date, and it was just clear, looking at those categories, that we knew in fact HHS had done a particular response, or completed a particular response, when it perhaps was in one of those other categories.

I would be happy to answer any questions about the process, or questions you may have about where the staff should proceed from here.

COMMISSIONER DES JARLAIS: Thanks very much for not sending out a couple of more binders.

Would it be worthwhile to have some prioritization done of all those recommendations, rather than trying to tackle them all every three months or every six months or something like that?

MS. BYRNES: It strikes me that that would be a very good idea. It strikes me that it is appropriate for the Department of Health and Human Services to continue to monitor all of the recommendations and at some point in time say, we are going to just set these aside because, for whatever reasons, if you monitored them forever you are not going to really get anything that would be new or innovative. But I do think the Department of Health and Human Services should continue to monitor all the recommendations. But for the purposes of this Commission, I think it would be particularly helpful for us to identify priority areas that we would want to have that information made available on a timely basis.

I think that is a terrific suggestion and would be the most help to this Commission that--it is my understanding--is going to narrow a focus and be more detailed about the areas that it is going to choose to look at and that we might want more detail about in terms of those Presidential recommendations.

COMMISSIONER GOLDMAN: I think perhaps we will end up discussing it more tomorrow, but I would think that the monitoring of the Presidential recommendations might well be a task that was assigned to a working group that we might choose to select.

That might be one of the tasks that we are assigned and in that way engage in the prioritization as well as the overview.

I was wondering, since we have somebody from the AIDS Program Office here, if there is any expressed intention of the AIDS Program Office to provide continued updates and what their Office's viewpoint is in terms of that process?

DR. JIM ALLEN: We do have an intent to do that, and in part, probably some of the reason it hasn't been accomplished more expeditiously has to do with me personally, because the Office was planning to put that into place at the time that I was asked to come in as the acting director back in January. And at that point there was an attempt being made to monitor not only the recommendations from the Presidential Commission, but also from the Charlottesville report that had come out--or the Charlottesville Conference had been in June of 1988, the report wasn't published until I think early January of 1989.

There were the recommendations from the Pediatric Task Force, there were a whole host of other recommendations, and sort of the expectation of the Office was, we have to track everything. And I said, wait a minute, you know, you are drowning us in paper. I mean, you can see part of the response. So I asked that that all be put on hold.

In particular, I felt that there needed to be some sort of a standard or reference point, and we really didn't have any. Many of the recommendations that were contained in the Charlottesville report, for example, were very similar or duplicative in some way, although phrased differently from the recommendations that were in the Presidential Commission report. And I was very concerned about the time reporting burden on the agencies as well as on my staff.

I did not like the categories that we used in the Charlottesville report, and since that was the Public Health Service report and since it was used not only for our program but also for our budget, I felt that it was important to revise those. And one of the first things that I did with the agencies and with my office staff was to revise our budget categories.

Well, that sort of threw everything into a bit of a turmoil in terms of the process that we already had for getting updated information, and my computer program people, who had been looking at developing--or had started to develop a computer tracking system, stopped.

We are in the process now, we have picked up. That's being done at the present time. We will be going back out to the agencies in the very near future with a request to update all of the Presidential Commission recommendations. As a matter of fact, we have already notified them of that fact. The response has not been overwhelming, but we will get that done. And to the extent that you have got recommendations that would be useful to you in terms of format or whatever, we are more than happy to work with you on that.

CHAIRMAN OSBORN: David?

COMMISSIONER ROGERS: Perhaps I could couple what Maureen has told us with what Don had suggested and what Jim has just said. I will put it in the form of a question, Jim.

Would it be helpful, I would say post our discussion tomorrow, for us to ask our staff to prioritize, and probably in a fairly tough fashion to pick out the 10 or 14 that seemed most critical, to share that also with you, that that might serve also as some guidelines? Obviously, HHS is going to do what it will do, but that might help serve as a guideline for your group also to decide which ones to really focus in on.

DR. JIM ALLEN: Sure. I think that would be a very useful suggestion. And in particular, I would suggest that as you go through the materials that the Commission staff has pulled together, that you look for ones where perhaps some focused attention by the Commission would be helpful in getting a response that we might not be able to provide. For example, in terms of increased appropriations or, you know, other types of responses from other agencies that would enhance our response.

COMMISSIONER ROGERS: Very self-serving remark there Jim, but I think we could do that, too.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: My concern is that the report has so--Maureen, I didn't get a package because I came in late to that hotel last night--but certainly I am sure that the job as you have described is really well done in terms of how you are explaining it was managed. But it would be very helpful to me to see within the care and treatment and financing sections of the President's report where those are today in terms of us making either additional pronouncements or continuing to look again at recommendations in terms of care and treatment.

It would be very interesting to see, as far as I am concerned, if 50 percent of those issues that were discussed here over the last two days and we obviously felt very strongly about continuing to focus are in fact in the President's report. It would be interesting to see if there are any gaps of what was said today and what has been presented before.

So just in care, treatment and financing, I would kind of just like to take it chunks at a time. To pick let's say 14 from the entire report, I am not sure we could even deal with that, because some of the areas we have either heard from ourselves, here, or possibly planning to focus future meetings. But just what we did today, in terms of picking up what is in that report; is this a possibility?

MS. BYRNES: Of course. I have anticipated since the September 18th and 19th meeting that treatment and financing of treatment services were priorities for the Commission. To some degree it is how we put together the hearing for yesterday and today. That, of course, off the top of my head, would be almost like one in two, although that's not to suggest that three, four and five are not equally important. But I would certainly expect that we could request up to date information from HHS on the care and treatment and financing issues and be able to report on those fairly quickly.

To some degree I did that as we were going through the quick categorization, and I was really struck by something that Dr. Smith said yesterday in terms of encouraging within the community health center system and other care facilities, specialists being brought in in addition to the primary care physicians. And that's clearly a recommendation that was made by the Presidential Commission, and the response suggests that that would be appropriate--the response to that recommendation--but in the very, very cursory investigation of whether or not there was a procedure for specialists to apply for the National Health Scholarship programs and perhaps participate in that program in a way of paying back some of the loans to become an infectious disease specialist, there wasn't a policy in place for that and there were some real serious budget problems with whether or not in fact that would be a practical thing for a specialist to be able to participate in.

So there are fairly specific--597--there are some very specific recommendations, even within those treatment and financing areas, but I am sure that we would be happy to respond, because I think that that has been identified clearly as one of the priority areas.

CHAIRMAN OSBORN: As I mentioned when I introduced this, I didn't think that we could possibly pick up and dispense with the excellent work of the staff in a 10 minute discussion frame, but rather I wanted to get it on the table, and I think this bit of discussion has been quite helpful to start us all thinking about how best to take advantage of that hard work. And a number of things that are coming up are not mutually exclusive. Use as a way of focussing additional agendas, use as a spur for other kinds of activities, as well as the prodding as needed, too.

So I think maybe, unless somebody has something else at the moment that they want to say about that in a pressing way, we can just let that--just think about that now a little bit, look back at the paper that you have been given with now some deeper insight into what was intended and how it might yet be molded further to become more useful.

But I think I want to thank the staff for having taken a reduction job of major magnitude and succeeded so well on short notice.

The other thing I thought would be wise to introduce now, but not necessarily to complete our discussion in this particular venue, but rather to continue it after we go out to Virginia, some of the commissioners have felt that there were two items that were brought up in testimony at this meeting that again it would be wise to respond to quickly, because they aren't matters that one can cogitate about so much. There are deadlines and things happening that press them.

One of these has to do with the immigration situation, and Don Goldman may want to speak to that a little bit; the other having to do with a discussion initiated by Don Des Jarlais even before this meeting in the present hazard that the stance about needle exchange, which may indeed be very firm, has gotten coupled with the stance about bleach and education for the use of bleach, and that these in turn may even have been coupled with doing research on them.

And so I wondered if each of you would take just a couple of minutes to introduce the topic, because we may want to as a Commission express ourselves in some way about part or all of those issues sooner rather than later, whether we do it in the next day or whether we talk about it some, but then end up with a telephone conference. Whatever the mechanism, I thought perhaps it would be good to start the discussion before we disband in this venue.

COMMISSIONER GOLDMAN: Thank you. What I wanted to suggest was that we heard yesterday--and yesterday morning seems so long ago with the richness of the presentations that we have had on so many issues--but if you recall, the presentations began with Jonathan Mann on the international aspects of HIV disease, with Mr. Carman for the World Federation of Hemophilia, and one of the issues that seemed to be indicated in coming up there were the concerns over United States immigration policies, especially as they relate to visitors and the difficulty that that appears to be presenting with respect to the planned World Federation of Hemophilia meeting next August 1990, and from what I understand, also problems relating to an International AIDS Conference scheduled in San Francisco, I believe in June of 1990.

I know with respect to the hemophilia community that Canada, England, Ireland, Greece and a few other countries have already indicated that--and this is both patients and physicians and political leaders as well within those communities--have indicated an intent to boycott that meeting based upon the restrictive immigration policies of the United States and visitor policies requiring persons who are HIV positive to self-identify themselves as part of the immigration process, which is especially alarming.

Most people even with the most infectious of diseases can pass through Immigration and nobody knows anything. However, if you have hemophilia--and every one knows that a large percentage of the people with hemophilia have HIV disease--the question gets asked in the United States in terms of kids in school and things like that, if you have hemophilia, you know, where is the result of your HIV test?

And people with hemophilia carry clotting factor with them. That never used to be a problem, but now it is a problem only because to the extent they came to the United States it raises questions about their HIV status. And those concerns and others--and that doesn't mean that the hemophilia community is any differently affected than any other--and it seems to me that those are policies which the World Health Organization has clearly indicated have absolutely nothing to do with the prevention of the spread of HIV disease, are inappropriate, an ineffective way to do it. And if we are talking about a system, we are talking about concerns of Congress and budget and things of that nature, the elimination of those kinds of artificial restrictions would be an easy way to eliminate at least some expense on the part of whatever administrative costs are necessarily and wastefully spent in doing so.

I don't want to deal with the exact text of a resolution at this point, and my recommendation is that the Commission, however, at this time authorize staff to prepare maybe a mini-position paper and a draft recommendation of a resolution for the Commission to formally consider and adopt at some point towards that arena, And it might go beyond. There are other immigration issues which are collateral to it that staff might feel are appropriate to mention in some way, but just generally speaking in that arena, and I would so move.

CHAIRMAN OSBORN: Charles?

COMMISSIONER KONIGSBERG: I have a question.

I should know this, but I don't. Maybe somebody else does.

Those kinds of immigration policies that relate, where does that come from within the federal establishment? Jim, do you know? Is that something congressionally mandated, or is that rule making out of one of the federal agencies, or what?

DR. JIM ALLEN: It is complex. The enabling legislation, obviously, is statutory. The Division of Quarantine, which is in the Centers for Disease Control, has traditionally developed the list of what is called dangerous and contagious diseases that is then applied by the Immigration and Naturalization Service, which is part of the Department of Justice.

COMMISSIONER KONIGSBERG: That is complex.

DR. JIM ALLEN: The list of dangerous contagious diseases was amended a number of years ago to include AIDS. It was subsequently amended just at about the same time as Congress mandated through legislation that HIV infection be added. It is an interesting point, but a very important one, that HIV infection is the only disease that is on the list by statute. Everything else is on only by regulation.

The discussion on the Floor of the Congress--and I think it is very clear when you go back and read that--most of the senators clearly felt that they were adding a condition that would apply only to permanent immigrants. Immigration and Naturalization Service and foreign quarantine, or Quarantine Service, could have easily told you, however, that it applies to any traveler to the United States for whatever reason. And sometimes the rules are applied selectively.

In this instance, we ran into problems last year because although the Congressional intent was very clear that it was to have been for permanent immigrants to the United States only in terms of testing and exclusion if they were HIV positive or had AIDS, that in fact it could be applied to anyone, and as testing has become more widespread and early intervention therapies have become available, that has clearly been done.

COMMISSIONER KONIGSBERG: Well, as a follow-up, I think that as a part of any resolution that that Commission might endorse, if we don't feel that this is rational from a public health perspective we need to document that. I guess I am--I want to avoid just a kind of a knee-jerk reaction, and those kinds of measures, I think, are somewhat grounded more in history as well as perhaps prejudice, but more than public health rationale. But we ought to be able to append something that is authoritative and scientific, and I think that will lend some to our credibility.

Am I off on that, Jim, or do you think that kind of would be helpful?

DR. JIM ALLEN: I think it is a very appropriate statement, in particular when you look at the list of dangerous contagious diseases for which there is exclusion. Well, obviously, things have changed a lot, but it did not and never has included, to my knowledge, smallpox, for example. Most of the diseases that are listed on there--I think it is something like 8 of the 10, I don't remember the exact number--but the vast majority of them are sexually transmitted diseases, things like syphilis and gonorrhea. Virtually all of them are treatable, given current antibiotic therapy.

You know, clearly from a rational public health policy perspective one would want to urge that the entire list be reviewed carefully and updated, and be aware that with the HIV you obviously have to have a reversal of language in the statute as well as a change in the regulation, itself.

COMMISSIONER KONIGSBERG: Well again, and not to belabor the point, but a plea to staff and to all of us on the Commission that when we tackle these kinds of issues, let's be sure that we know not only in our hearts that we are right but in our heads that we are right, and then I don't think we'll have the credibility problems. Whether we succeed or not is another question. Enough said.

CHAIRMAN OSBORN: I think David Rogers wanted to make a comment.

COMMISSIONER ROGERS: Well, I think it has already been said. As I heard Don's recommendation, he did include both; one, that we have a clear cut statement of the absurdity of this policy, and two, that we recommend that it be gotten rid of. And I would suggest the staff go ahead and draft--I would recommend that the staff go ahead and do that. I think you moved that, Don--

COMMISSIONER GOLDMAN: Yes.

COMMISSIONER ROGERS: --and I would second your motion.

COMMISSIONER GOLDMAN: I just want to make one thing clear, and in response. I think I clearly said two items, A, a resolution, and B, a position paper, which is exactly I think what you were referring to, namely a rationale behind it. And I specifically and intentionally referred to both of those items.

CHAIRMAN OSBORN: You will find it helpful to look back to the work that the World Health Organization did on this topic in February of 1987. In February or March of 1987 there is a report on international traveler screening at that time which deals with the most acute version of this, but which deals in a brief form with the background of the issue as a whole. And there was considerable study done at that time. Jim, you and I were both involved in that.

DR. JIM ALLEN: I would also encourage you to get from, I believe it is probably Immigration and

Naturalization Service, a list of reasons why people are actually excluded, travelers are actually excluded when they apply to come to the United States. There is something like--I don't remember the numbers--it was on the order of 1.6 or--I don't know. It is well over a million travelers. I think there were a total--in a calendar year I think there were a total of something like a hundred people that in actual fact were finally excluded on the basis of a dangerous contagious disease. You know, this clearly is not a category that is highly important in our area in terms of letting people into the country.

So it is useful to get that kind of information from INS also.

COMMISSIONER GOLDMAN: And among those people that were excluded included some children who were dying of AIDS in England who were funded to go to Disneyland by the "Make a Wish" foundation but whom the INS decided that mere visiting the United States was not a sufficient basis to overcome the exclusion. And I think eventually they finally changed their minds with the kids because it was such a bad example if they would have gotten there. But if you read their own regulations literally and the statute literally, there was no way to let those kids in except to decide that the case is so silly that we are just going to break the law and avoid the regulations.

CHAIRMAN OSBORN: It has been moved and seconded that the staff be asked to help us with this and do a small background paper. I am not sure that moving and seconding was necessary, but since it has been done why don't we proceed.

All those in favor please say aye.

[A chorus of aye.].

CHAIRMAN OSBORN: Opposed?

[No response.]

CHAIRMAN OSBORN: And Don Des Jarlais, would you sketch for us the background of your--

COMMISSIONER DES JARLAIS: Yes. One of the things that John Mann brought up yesterday was the important potential for countries to learn from each other in terms of successful AIDS prevention systems, treatment systems, whatever.

In terms of the prevention of the spread of

HIV among drug users in this country, the distribution of bleach for disinfecting use in injection equipment has really been the American innovation in the field. It is really what we are known for in this particular area of prevention.

Studies are currently underway to evaluate the effectiveness of this as a prevention effort, and like all studies of AIDS prevention it will probably take three to five years before you have a sense of just how effective it is. Certainly the preliminary data is encouraging, but if you think of other things like distribution of condoms or such, you really need to track the virus for a long time before you come to anything conclusive.

Unfortunately, the present funding authorization bill for the Department of Health and Human Services contains a provision that would stop this research on the distribution of bleach. It is linked in with language on prohibiting any federal funding for syringe exchanges, but it clearly has been extended so that federal funding could not be applied to doing research on the effectiveness of bleach distribution.

And it is a Catch 22 type of wording. The wording specifically says that you can't do this research until a determination is made that the intervention with bleach distribution is safe and effective. So that basically at best it is saying, well, there may be some Europeans who might start doing it. When they do all the research, then the U.S. Government can make a decision.

But it is one of those Catch 22 situations where you can't do research until you already know the results of the research. So I would like to move that the Commission formally go on record as strongly supporting the continuation of research efforts on the safety and efficacy of bleach distribution. These have been going for the last three or four years with federal support. It is simply a matter of our going on record as saying we support continuation of research in the bleach distribution area.

CHAIRMAN OSBORN: Yes, Jim?

DR. JIM ALLEN: Can I give just a bit of background and slightly different perspective?

The language last year in the appropriations bill, or actually I guess it is in the Hope legislation, does not mention bleach disinfection programs whatsoever. It simply puts in language that indicates for needle exchange that it can be done only if the Surgeon General makes a determination that it is effective at reducing HIV infection and drug use.

While the Administration has a very clear policy on needle exchange programs, to my knowledge there has not been an actual statement or policy decision on bleach distribution programs. Again to my knowledge, the Administration is not directly funding any bleach distribution or programs of this type, but many of the community based organizations that are funded both through ADAMHA and through CDC do have as one part of a comprehensive component bleach distribution and education programs, works disinfection, if you will.

Very clearly the language that was proposed by Senator Helms this year, and adopted I think fairly overwhelmingly by the Senate, puts a very different light on things. We would be delighted to see the language that was used last year substituted for it. Procedurally it isn't clear to me exactly where things stand at the present time, and you may have more current information from your previous position on exactly what process might be followed and what might be the most useful at this point.

I am not sure that the Administration spokesmen are going to come out with a strong recommendation on this actual point one way or the another.

MS. BYRNES: As I am sure that most of you know, that language was part of the FY '90 Labor-HHS bill that was vetoed by President Bush just a couple of weeks ago. So there has been no final passage of a final spending bill by the House or the Senate that would make a final determination. So to date that issue is still open, as far as I would interpret it, since there hasn't been a final passage of that bill.

DR. JIM ALLEN: It probably will come up next week. Time is of the essence here.

CHAIRMAN OSBORN: Okay.

COMMISSIONER GOLDMAN: Again, I don't know what the procedural processes are, but if there is a second necessary for Don's motion, I will second it.

And I would like to add, not on any specific grounds relating to the merits or demerits of bleach as a disinfectant, or its appropriateness, but it just seems to me that given what we do know, but more important given what we don't know, about issues involving IV drug abuse, that the federal government, it seems to me, ought to be perfectly free to choose what projects it wishes to fund and what projects it wishes not to fund, but it ought not be able to take the position that projects that it may fund indirectly--or that projects that it may fund can't indirectly try innovative schemes that may be appropriate for their own communities to solve their communities' drug abuse problems.

We need more of this kind of research, we need more innovation, we need more kinds of experiments in differing kinds of methodologies, and not government restrictions on what kinds of methods could even be used in a research context, and I would therefore think that it would be perfectly appropriate for this

Commission to do so.

CHAIRMAN OSBORN: If I can summarize what I think is being said here, if we could have rather simple language supporting the concept that ongoing research of this sort is appropriate and necessary and urgent, that in this instance the time scale is such that that would be done much better sooner than any later. Perhaps that one we can proceed with, Don, if I could ask you to draft such language, and we may be able to carry this discussion on.

It has been moved and seconded that that process go forward. Is there any other discussion?

All those in favor please say aye. Oh, I'm sorry Diane, excuse me.

COMMISSIONER AHRENS: I am a little confused about this. I don't know anything about it, other than what I am hearing, and I am hearing Don say one thing and I thought I heard that Jim was saying something slightly different in terms of what needed to be done to correct the situation. Is that not correct?

All I want to say is that whatever we do, we need to address what needs to be fixed and that's all.

CHAIRMAN OSBORN: Right. I think that among the staff and the people that we can turn to that could be made quite precisely clear and would probably determine the language that was used, so that can be double checked. I think for the moment what we need to do is simply to add our momentum as a Commission to that project, which then does have a sense of hurry about it. I appreciate your clarification.

All those in favor please say aye.

[A chorus of aye.]

CHAIRMAN OSBORN: Opposed?

[No response.]

CHAIRMAN OSBORN: Good. In that case, this venue session of the Commission will be adjourned. There is a bus that is going to pick us up, go retrieve the luggage that needs retrieving at the Inn at Foggy Bottom and wherever, and then go on out to Virginia, and I guess pretty much directly. I think the bus is probably there, because I think it was going to be there at 4:00. So why don't we do all of that, and thank you very much, all of you, for being with us.

Maureen needs to adjourn the meeting as a federal employee.

MS. BYRNES: The meeting is adjourned.

[Whereupon, at 4:15 p.m., the meeting was adjourned.]