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FINANCING FOR AIDS CARE AND THE IMPACT ON THE U.S. HEALTH CARE SYSTEM

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH
FOR FAMILIES AND THE UNINSURED

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

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FINANCING FOR AIDS CARE AND ITS IMPACT ON THE U.S. HEALTH CARE SYSTEM

MONDAY, DECEMBER 14, 1992

U.S. SENATE,
SUBCOMMITTEE ON HEALTH FOR FAMILIES
AND THE UNINSURED,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:07 a.m., in room SD-106, Dirksen Senate Office Building, Hon. Donald W. Riegle, Jr. (chairman of the subcommittee) presiding.

[The press release announcing the hearing follows:]

[Press Release No. H-53, December 1, 1992]

SUBCOMMITTEE HEARING TO EXAMINE FINANCING FOR AIDS CARE, RIEGLE SEEKS INFORMATION ON IMPACT ON U.S. HEALTH CARE SYSTEM

WASHINGTON, DC—Donald W. Riegle, Jr., Chairman of the Senate Finance Subcommittee on Health for Families and the Uninsured, Monday announced a hearing on financing for AIDS care and the epidemic's impact on the U.S. health care system.

The hearing will be at *10 a.m. Monday, December 14, 1992* in Room SD-106 of the Dirksen Senate Office Building.

Riegle (D., Mich.) said the hearing will focus in particular on how the Medicare and Medicaid programs are affected.

"I am holding this hearing to examine the burden that the spreading AIDS epidemic places on our financially stressed health care system. The risk of acquiring HIV, the virus that causes AIDS, continues to grow as more and more people become infected," Riegle said.

"Witnesses will present testimony about meeting the health care needs of the growing, changing population of people with AIDS, and the financial impact this will have on our health care system," Riegle said.

OPENING STATEMENT OF HON. DONALD W. RIEGLE, JR., A U.S. SENATOR FROM MICHIGAN, CHAIRMAN OF THE SUBCOMMITTEE

Senator RIEGLE. The hearing will come to order.

Let me welcome all those in attendance this morning.

We have had to move into this rather large hearing room because the other hearing rooms in the Senate are undergoing refurnishing during this period of time when the Congress is not in formal session. And so we are making use of this room today.

And I want to welcome all those in attendance.

Today is an extremely important hearing because we are endeavoring to bring together the latest information on the status of the AIDS epidemic in this country to understand more clearly the financial implications facing people who are dealing with this problem and facing our health care system overall.

It becomes particularly relevant as well because we need and are going to move promptly on a national health insurance reform plan when the new administration is sworn in and can send their legislative package to us.

And in the context of that package, it is very important that we have a foundation of current knowledge as it relates to the HIV-AIDS issue.

Our first panel today is going to tell us about the substantial increases in reported AIDS cases in the United States since 1981.

We have known now about this terrible problem for approximately 10 years. The best estimate that we have today is that there may be as many as 1.5 million people in the United States infected with HIV, the virus that causes AIDS.

We will also hear about the implications of the growing case load on our health care system now and in the future.

Then, later this morning, financing and economic experts will present information on the cost of caring for people with HIV disease and the scope of government programs which provide coverage for people with AIDS.

In a recent speech, President-elect Bill Clinton spoke about AIDS. And he said, and I quote him, "It's everybody's problem, not only because it is spreading throughout society, but because the sheer cost and burden of dealing with the AIDS crisis may absolutely consume all the gains we hope to make in straightening cut the other problems in our health care system."

So we will use today's testimony from this hearing to make recommendations to the Clinton administration on Federal financing policy for people with AIDS and HIV.

As in other States, AIDS is a particularly concern in my own State of Michigan where more than one person with AIDS dies each day.

As of October 1992, more than 3,200 cases of AIDS had been reported in Michigan and close to 2,000 people have died from it.

As in the rest of the country, AIDS, in Michigan, is touching all segments of the population. Infection rates are climbing, particularly among women and those in minority communities.

Joining us today is a woman from Warren, MI, Tammy Boccomino, who is here who is facing not only her own illness from HIV infection, but that of one of her sons as well.

AIDS has hit close to home in my own Senate office, where a member of my staff, Susan Neeme, was lost sometime back to this disease.

Now, as a result of great efforts by our medical and scientific community, we know a great deal more about AIDS and we are able to treat people infected with HIV more effectively.

We have learned how to potentially delay the onset of AIDS for some of those infected with HIV. Yet, although medical research continues, we still do not have either a cure for or a vaccine against this disease. So early treatment and prevention are the main tools available to us right now to combat this deadly disease.

Unfortunately, for most people with AIDS, treatment is very costly and usually difficult to come by. Approximately, 29 percent of AIDS patients in the United States have no health insurance coverage.

Some 40 percent are covered by Medicaid which is now the primary payer for AIDS-related services, but, of course, to qualify, you have to have exhausted your assets. And that program is, of course, taxpayer financed.

Thousands more, in all likelihood, have inadequate coverage. So for these people, expensive treatments and prevention services are often just out of reach.

Many of us are working here in the Senate to improve health care coverage for all Americans, including people with HIV and AIDS.

The last Congress, Senators Kennedy, Rockefeller, Mitchell, and I introduced S. 1227, a health care reform bill to guarantee all Americans health care coverage and to control sky-rocketing health care costs.

And I am currently working with members of the Senate and President-elect Clinton to create a national health care plan that will meet these goals. And that is the central purpose of our hearing today, to lay the foundation that we need to move ahead.

We introduced legislation in 1991 to help people with AIDS qualify for Federal disability benefits, especially women and children.

In most States, this would also enable these individuals to qualify for Medicaid and Medicare coverage, but we must continue to encourage the Federal Government to acknowledge the disabling effects of AIDS and extend coverage to this needy population.

So I very much look forward to working with my other colleagues on the Senate Finance Committee to make sure that people with HIV have access to the comprehensive services that they need to help them fight this deadly disease and that we disseminate as widely as we can all the information that can help people avoid having this occur in their lives.

I want to say also at the outset that Senator Pryor very much wished to be here this morning but was not able to be here. And he has asked that I submit a statement in his behalf. And I do that at this point.

[The prepared statement of Senator Pryor appears in the appendix.]

Senator RIEGLE. Let me now introduce our distinguished witnesses on our first panel. And I want to thank each of them for being here today. And I will introduce them all together. And then, I will call on them in this order for their comments this morning.

First, I want to introduce Dr. June Osborn who is here from Ann Arbor, MI. Dr. Osborn is dean of the School of Public Health at the university and serves importantly as chairperson of the National Commission on AIDS.

She has given great leadership in that assignment. And every citizen of the country is grateful to her for that. She is an international expert on AIDS. And Dr. Osborn will discuss the AIDS epidemic in the United States.

Our next witness is Dr. William Haseltine who is the Chief of the Division of Human Retrovirology at the Harvard University, Dana-Farber Cancer Institute.

He also is internationally noted for his leadership. He has spent over 10 years researching viruses like HIV. He will discuss the pro-

gression of the disease and the need for effective treatment and services.

And I want to thank him as well for coming today and for his leadership efforts now over a great length of time.

And then, the third witness on this panel that will help, I think, to put this discussion today in its full context is Ms. Tammy Boccomino who is here from Warren, MI.

And, Tammy, I want to again thank you for coming.

Tammy is herself HIV positive. Her son, Michael, has AIDS. And she will tell us something about the history here in her situation and what it is that they are finding that they must deal with now being in that situation.

And so I want to especially thank you for taking the time away from your family and coming here today.

I know it is not easy to talk about these things and particularly in direct, personal terms like this, but it is so important that we do this and that you share with us and with the country exactly what you have happening in your life and to give us the insight and the lessons that we need to take and share with others.

And I know you have come to do that today. And I am very grateful that you have. So I want to welcome you especially.

So with that, Dr. Osborn, we are pleased to have you. We will make your full statement a part of the record.

[The prepared statement of Dr. Osborn appears in the appendix.]

Senator RIEGLE. And I would like for you now to take whatever time you need to bring us up to date on what you see and to give us your best observations and advice. And we are very interested in hearing from you now.

STATEMENT OF JUNE E. OSBORN, M.D., DEAN, UNIVERSITY OF MICHIGAN SCHOOL OF PUBLIC HEALTH, AND CHAIRMAN, NATIONAL COMMISSION ON AIDS, ANN ARBOR, MI

Dr. OSBORN. Thank you, Senator Riegle.

It is a great pleasure to be here and a particular pleasure to be here with Tammy who has, as you know, done a great deal within our State of Michigan to bring people to a new awareness that we are dealing with a massive, human tragedy here and one that I would like to talk about briefly.

I will not deal with the detailed statement that I have given to you, but I would like to point out that in that, I tried to make accessible a very brief set of definitions, as your staff had suggested would be helpful, because many people still have a problem understanding the difference between HIV disease and AIDS and HIV infection and so on.

That written statement, I hope, will be of some use in that regard and lays the background also for specific recommendations that the National Commission on AIDS has made about health care financing, at the back of that statement.

I can come back to that for questions, but I wanted more in the opening few minutes to give a sense of how profound the tragedy is for our Nation and how much work there is to be done, including inexpensive work that we should have done sometime back and which we must now get about.

The epidemic of HIV infection and AIDS in the United States has reached massive proportions. In the 11 years since AIDS surfaced as a newly-recognized epidemic disease, over a quarter of a million Americans have been diagnosed with AIDS itself, of whom over 160,000 have died.

That death toll is greater than the combined toll of the Vietnam and Korean wars and, indeed, of World War I. By considerable, we assume, it will approximate the death toll of World War II.

It is a massive tragedy, involving primarily young adults in the prime of what should be their talented, creative years of productivity in society.

I stress that because we oftentimes couch discussions of health care financing in terms of whether we can afford to deal with AIDS. We cannot afford not to. We must.

It is a question of how, not whether we care for the additional million or more Americans who have not yet entered those lists of numbers, but are HIV infected and will soon need care.

Even before these individuals become ill, however, AIDS has already reached the top 10 on the list of killers of Americans.

It is the leading cause of death for men and women between the ages of 25 and 44 in many, soon to be most, of our large cities, but also it kills in rural communities and in rural areas themselves.

By the end of 1993, it will become the leading cause of years of potential life lost in the United States.

Our Nation has not done well in responding to the challenges of AIDS. And nowhere is that more true than in the context of health care access and financing of care for people living with AIDS.

We have learned a lot through the good efforts of such private funding as the Robert Wood Johnson Foundation about ways to enhance not just the economy, but also the quality of care for people with AIDS, but that information has not been well mobilized. And it would serve our chronically ill and our elderly every bit as much as people living with the virus.

One hears it said that AIDS is just one disease, but it is a new disease. It is preventable. And at present, the epidemic is volatile and not under control.

Our basic biomedical and clinical science has served us very well. And dramatic progress has been made in understanding the virus of AIDS and the mechanisms whereby it causes illness.

My colleague will be saying more about that and has been a major contributor to a remarkable level of understanding.

Study improvements and treatment for AIDS and its complicating infections and tumors have increased life expectancy from months to years for those diagnosed.

Nevertheless, a genuine cure for AIDS is unlikely in the foreseeable future. There is great need for less costly and less toxic treatments. And a vaccine is generally agreed to be years away.

We have done far less well with social and behavioral research due to a lack of funding and in some instances, outright prohibition of needed studies.

There is much work to do there because that is where we know we can make a difference to the magnitude of the epidemic years hence, but it bears emphasis that were we not to have another, single infection starting tomorrow, our work is cut out for us for the

rest of the decade with people already infected and on their way to needing care.

So your hearings are particular timely and extraordinarily important.

Since HIV is transmitted virtually exclusively by sexual intercourse, by birth to an infected mother, or by injection drug use, it is amenable to prevention through education for avoidance of risky behavior.

And that, too, must be factored into the discussion of health care financing and health care access because for each case we fail to prevent, we push this terribly costly, devastating disease further into the future of our country's health care financing problems.

At present, it is estimated that at least 45,000 new infections per year occur in the United States. That number may well be unrealistically low. And in the absence of effective approaches to the twin epidemic of substance use, it could at any time jump out of the boundaries of the projections made.

Drug abuse is the wild card in what otherwise has been a series of very orderly projections, in fact, the best set of projections, I think, for any national disaster that has ever occurred.

But we do not have treatment for substance users in any of our large cities for poor people with less than 4-weeks wait on a waiting list. And we are still arguing about what to do about clean needles in the process of waiting. That, we must take care of as a Nation.

People talk about what we would condone that way. I would like to point out what we are condoning by failing to address that part of our problem.

And, of course, now, we have a tuberculosis epidemic which is threatening in many ways. It is threatening because we do not have the public health infrastructure we should to assure good treatment of people when they become infected.

Thus, we have multiple drug-resistant strains emerging which we have always known would happen in that circumstance. And we have an unfortunate situation in which the appropriate response to the TB epidemic is being taken out of the HIV budgets.

HIV is the substrate on which that epidemic is growing. And that makes no sense at all.

So we have a great deal of work to do.

We have many other points that I could bring up, but, I think, despite the uniqueness of this great pandemic in the context of health care, AIDS presents challenges characteristic of many chronic diseases, as I mentioned before. And in many respects, the only thing new is the virus.

So the intensity of your concern and the efforts paid to try and deal with financing and access of care for people with HIV stand to have broad payoffs in a context of health care that our Nation has addressed poorly while it has invested in increasingly acute and tertiary care options.

I want to point out that the National Commission on AIDS, over the course of its 3½ years worth of work, has produced one large comprehensive report which has been referred to frequently, I am pleased to say, in the campaign and in recent times, but many others as well, dealing focally with different aspects of the epidemic

in correctional institutions, the issue of substance use that I touched on, needed leadership and regulation, some aspects of clinical research, and recently, a report on housing and one on prevention of HIV disease in the health care work place.

That is an incomplete list, but I believe that the members have all received those. And the commission is very eager to work in a variety of contexts, notably health care.

The final thing I want to say is that the commission, being a citizens' commission and broadly constituted, felt particularly concerned when we addressed the issue of health care financing, since it needs a great deal of expertise in order to deal with the kind of competence that a country as rich and vast as this should bring.

So we had many witnesses speak to us. And then, when we designed that portion of our comprehensive report, we asked Dr. Karen Davis and her colleagues, then at Johns Hopkins, to help us so that the section that I have reproduced for you at the back of my written testimony represents expert input of a concentrated, consultative sort over and above the deliberations of the commission.

It starts with a recommendation for universal access to health care because we could not in conscience avoid saying that. But having said that, it is a series of graded steps that we felt would be both economical and prudent and humane in the context of the problems coming before us.

Thank you very much for the opportunity to testify.

Senator RIEGLE. Thank you.

Before we move on, is there a figure that the commission uses? I realize there is a range of costs for each individual, but do you have any kind of an average figure for treatment for someone who has HIV over the course of the time that they require treatment?

Dr. OSBORN. A single, average figure may not have too much meaning. We can point to the growing literature of opportunity to reduce the cost per person per life span in the context of continuums of care options as opposed to automatic tertiary care hospitalization.

That literature has dropped the estimated figure from over 140,000 at the outset, even though there were very few months of life expected after diagnosis.

Senator RIEGLE. Yes.

Dr. OSBORN. Into the range now of 20,000 to 30,000 which is, in fact, a comparable range for people with other severe, chronic diseases. And I think that's the take-home point I would like to stress.

We did, in fact, ask Dr. Davis and her colleagues to help us in costing out the different alternatives that are represented in our report.

And those are in the body of the text that I did not reproduce in my brief, even in my full remarks for the committee that which are in the health care financing section of the Comprehensive Report of September 1991, entitled, America Living with Aids, which we would certainly be glad to get for people who do not have it.

Senator RIEGLE. Dr. Haseltine, you have been involved now for a great length of time in trying to understand this disease and where it is going. And we have talked about that previously. I want to have you today lay out for us your observations.

And I would like for you to take whatever time you need now.

STATEMENT OF WILLIAM A. HASELTINE, PH.D., CHIEF, DIVISION OF HUMAN RETROVIROLOGY, HARVARD UNIVERSITY DANA-FARBER CANCER INSTITUTE, BOSTON, MA

Dr. HASELTINE. Thank you.

It is a pleasure and an honor to be invited to testify on the subject of the AIDS epidemic.

I thank Senator Donald Riegle, Jr., chairman of the subcommittee, for this privilege.

The AIDS epidemic is a fitting subject for consideration by this committee. The AIDS epidemic has already had a major impact on health delivery to families and to the uninsured.

The burden that the AIDS epidemic places on these groups will increase to the breaking point in the near future. The stress results both from illness directly attributable to AIDS as well as diseases, such as tuberculosis that find a fertile breeding ground in the population of immune suppressed people.

The epidemics associated with AIDS can infect the healthy as well as the sick. The threat from these diseases comes from both within our National boundaries and also from AIDS populations in the Caribbean, South America, India, Asia, and Africa.

We will be beset by multiple, new, concurrent, lethal infections as a consequence of the primary AIDS epidemic.

The issue is not only AIDS, it is also the other diseases that AIDS brings to the total population as the number of people who are susceptible to the new diseases rises.

Senator RIEGLE. Now, I want you to stop right at that point. I want to understand and have you elaborate just for a minute on that point.

As I understand what you are saying, you are saying that because of the way HIV works, it breaks down resistance, it creates a breeding ground for other diseases that in a sense become latent by and large and can now prop up.

Dr. HASELTINE. That is right.

Senator RIEGLE. And as they come back into being, they can then move out and infect people more broadly than just people who have HIV. Is that what you are saying?

Dr. HASELTINE. What we are really talking about is the ecology of disease. It is a subspecialty of ecology. Studies done in the past confirm what we are seeing today, that is when one major disease component, many factors that affect disease also change.

For example, we are witness today to a new epidemic of tuberculosis. That epidemic is fueled primarily by people with immune suppressed systems. The AIDS population. Their is tuberculosis that was suppressed is now coming back.

But as we have seen, tuberculosis is not limited to the people with AIDS, prison guards, people who live in crowded cities also contract tuberculosis.

And there have been recent studies that show that the new epidemic of tuberculosis is not just confined to our urban centers, but has moved out into the rural parts of America as well.

Whereas this country had effectively controlled tuberculosis, we now see that AIDS has changed the established equilibrium and that disease is spreading once again.

It was brought home to me very personally when my daughter, who is a student at Oberlin College, has had to be tested for TB as a result of other students at that university in the Midwest being diagnosed with active cases of tuberculosis.

I think we will see continued examples of that disease, as well as many others. The emphasis that I will place later on the worldwide numbers is important in this context. The problem we have with AIDS in this country and other diseases consequent to the infection will be magnified by new diseases coming from abroad, not related to people with AIDS, but who have caught another infectious disease as a consequence of AIDS.

And many of those diseases are not transmitted as AIDS is. They are transmitted by aerosols, by coughing.

I think that this is an argument for continued vigilance and continued support on a wide basis for research in infectious disease. We will be subject, not only to TB, but to other new epidemics of the future.

Health care costs, should be calculated not only in terms of AIDS itself, but also in terms of the cost of tuberculosis and other epidemics.

Senator RIEGLE. Well, we will get into that. You go ahead.

Dr. HASELTINE. AIDS today and tomorrow. I first testified to the U.S. Senate on the AIDS epidemic in September of 1985. At that time, most people were confident that the epidemic would remain confined to a small group of people with particular lifestyles.

Few thought that the epidemic would affect the heterosexual population. The reaction to my testimony ranged from cries of alarmist to disbelief. Sadly, the reality of this epidemic far exceeded the most dire predictions made in that testimony.

The number of people with AIDS tells a chilling story. It is estimated that between 1 and 2 million Americans—you mentioned the number one and a half which is the best estimate—are infected with the AIDS virus.

The absence of reliable data on the extent of infection complicates the calculation of the impact of AIDS. We lack this information as a consequence of the reluctance or the inability of the Centers for Disease Control to conduct appropriate studies.

This hole at the center of our knowledge of the AIDS epidemic in the United States severely compromises our ability to predict our future health care needs.

It seems incredible that 12 years into the epidemic, we are still flying blind as a consequence of the lack of appropriate studies.

The situation outside of our National boundaries is worse. It is estimated that 10 to 20 million people worldwide are now infected by the AIDS virus. It is predicted that this number will grow to 100 million people by the year 2000.

It is my personal estimate that within the first decades of the next century, well over 1 billion human beings may be infected by the AIDS virus. That is about 20 percent of the world population.

The last 5 years have witnessed a predicted rise in the number of those infected in Africa, as well as an unexpected explosive growth of infection by the AIDS virus in India and Asia.

In the city of Bombay, the number of those infected has risen from a few hundred to almost 500,000 over the last 6 years.

In Thailand, 20 percent of the young men in the northern half of the country are now infected with the AIDS virus.

As mentioned previously, this enormous population of infected people will pose a risk of new infections other than AIDS to U.S. citizens.

The vast majority, more than 85 percent of those infected by the AIDS virus worldwide, acquired their infection by heterosexual sex, specifically, by vaginal intercourse.

The earlier speculation that infection by the AIDS virus required blood to blood contact has been shown to be incorrect.

Senator RIEGLE. Let me just ask you there, on that figure you just cited, where you say that 85 percent of the worldwide HIV situations arising comes from heterosexual contact, where does that number come from? I mean, who derives that number?

Dr. HASELTINE. There are a number of studies that have been done in populations outside of the United States, mostly by the World Health Organization, but also by international cooperative research teams, say, between Sweden and Uganda or the Centers for Disease Control, working in Africa and Asia. The U.S. Army also has done surveillance in places where we have military bases.

The other way you can get at that number is to measure the sex ratio of infected people in places such as Africa or Asia?

For example, in central Africa, there are more women than men infected with the virus. The actual ratio is about 1:1. The ratio has remained the same for as long as it has been measured.

For example, in the Caribbean, the epidemic of AIDS changed from one that primarily affected homosexual men to one that affects the heterosexual population, men and women equally, over a 5-year period.

Whereas the epidemic began, as it did in the United States, primarily in the drug-abusing and homosexual populations, it has quickly broken outside of those boundaries, especially in the Caribbean, and now has an equal probability of infecting women rather than men. Women are slightly more susceptible to infection by the AIDS virus than are men.

Senator RIEGLE. So would it be fair to say when you go back to your 1985 testimony before the Senate when you had the facts at that time and you were attempting to look ahead and make a projection, now we are 7 years up the track and based on what we now know, one of the things that has become clear in that intervening 7-year period is that this is not a disease primarily centered in a homosexual community or related to drug use per se, but is now spread out in a fashion where it predominantly comes through heterosexual relationships? Would that be a fair conclusion or not?

Dr. HASELTINE. Certainly that is true worldwide. In the United States, because AIDS takes 8 to 10 years to develop from time of infection, and because the impact of the disease is mostly measured in terms of those sick with AIDS rather than those who are infected and still relatively healthy, still have a skewed view of what

is happening. That is a problem which has consistently dogged the social reaction to the epidemic which lags 10 years behind the reality.

In effect, we are now suffering the effects of infections that occurred between 1980 and 1984.

The entire population of people infected between 1982 and 1992 have not shown up, for the most part in our hospitals.

We are really 10 years behind in terms of the impact that this will have. I think that is one of the most unfortunate aspects of the virus, that it does not kill for 10 years. Consequently, society is slow to react to the true magnitude of the problem.

In Thailand and in India, people in those countries still do not believe there is a problem. Just because they have people infected, they think that those people will not get sick. In fact, they are going to be healthy for another 6 or 7 years.

Senator RIEGLE. June.

Dr. OSBORN. Yes.

Senator RIEGLE. Thank you, Dr. Haseltine.

Dr. OSBORN. I certainly agree that using AIDS cases as we dominantly have is like using a 10-year-old snapshot of a changing terrain.

Senator RIFGLE. Yes.

Dr. OSBORN. And it has its dangers. We do have some snapshots going back that give us substantial confirmation in this country of what Dr. Haseltine has been saying about the steady trend toward a more and more universal risk pattern, as I think, is most appropriate to say.

Since people are universally sexual beings, the risk becomes a universal one that we should all be addressing as if it were our family in my view.

Senator RIEGLE. Right.

Dr. OSBORN. And one can get some snapshots of that. For instance, even back in 1985 when the U.S. military was screening volunteers and those volunteers, I would suggest, probably did not include people who had recognized the same sex orientation by and large because the military is notoriously hostile to such populations, nor to people who were addicted drug users.

So, in fact, it was not a representative sample of a young age group in the society, but had been skewed, if you like, toward less representation of what might be considered HIV-risk behavior.

At that time, the sex ratio, which is a good way of identifying sexually transmitted diseases as such, was not 11 to 1 as it then was in the AIDS case population, but 3 to 1. And in places where there was a lot of virus and that had been around for a long time, like the New York City area, it was 1 to 1 already. And the younger the age——

Senator RIEGLE. Now, the ratio you are referring to is men to women?

Dr. OSBORN. Male and female.

Senator RIEGLE. Yes.

Dr. OSBORN. And that was at a time when you were not seeing very much adolescent involvement with the epidemic, but those were young adults and adolescents being tested because of volunteering for the military.

The Job Corps has given us similar clues. And even in the family of hospital surveys that CDC was able to conduct, again, deleting from those populations people who had AIDS-like or AIDS illnesses that were hospitalized for other purposes and then doing anonymous testing of bloods drawn, the national ratio of men to women is 3 to 1, not 10 to 1 or 11 to 1.

I think the more obvious thing, once one gets thinking about it, is that this is a sexually-transmitted disease. We do have the background of experience with other sexually-transmitted diseases to look at. And there has never been one that focused primarily on one sex.

Senator RIEGLE. Yes.

Dr. OSBORN. In fact, the slightly greater predominance of women to men in the areas that Dr. Haseltine was talking about are characteristic of most sexually-transmitted pathogens.

So it is behaving like any other sexually-transmitted pathogen. That has been written on the wall since the second year of the epidemic.

Senator RIEGLE. Right.

Dr. OSBORN. Not only were intravenous drug users of both sexes infected, but so were their sexual partners who did not use drugs.

And so everything that one looks at, if one looks for trends and patterns, says that in due course and perhaps quite quickly if the drug epidemic fuels things, we would end up looking like the rest of the world, which is 75 or 80 percent heterosexual transmission, once blood supply transmission has been taken out of the equation.

Senator RIEGLE. The reason that I stopped here is that I think this is a very important point that is not yet generally understood by citizens across our own country, and that is the pattern of the incidence of HIV has been shifting.

And while a lot of the early thinking was that there were just some groups in the society that were likely to have HIV that that is not what we are finding.

And it is spreading out in such a way that in places now where our information is more up to date, women, for example, are as apt to contract HIV through heterosexual relationships as someone might get it either through a homosexual relationship or through drug use with needles.

And I think it is very important that people to understand that because, I think, one of the things we need to do is to help people understand what the nature of the risk is that they face or that their children face. And I want to get to that more fully in the course of the morning here.

Dr. HASELTINE. As June pointed out, it was evident in 1985 to any person skilled in epidemiology and virology and the science of sexually-transmitted diseases that AIDS would not be confined to the homosexual population.

Despite this fact, and partly in reaction to my testimony in the Senate in 1985, a book was written called, "The Myth of Heterosexual AIDS."

Many people really did not like the message. As June pointed out, the studies that were done in 1985 by the U.S. Army made it absolutely crystal clear that in America, AIDS was already by 1985 a heterosexual disease.

In 1985, if you look at young men and women in New York City, there was an equal chance that a man was infected as a woman. It was entirely clear by then.

There appears to have been great reluctance on the part of our public spokespeople to address the problem.

It is just now, in 1992, very late in the day that government pamphlets and brochures emphasize the heterosexual nature of AIDS transmission.

I believe it has been a more serious problem than a natural reluctance to admit that individuals may be at risk themselves. It seems to be a deliberate choice by the part of our government responsible for AIDS education to underplay the risk of heterosexual infections.

I think that this failure on the part of the government has resulted in possibly hundreds of thousands of young people becoming infected with the AIDS virus when they could have avoided infection had they known what the situation is.

I have, in fact, devoted a good deal of my research in past years to understanding exactly how the virus gets into the body.

It is true that infection with the AIDS virus can be transmitted by blood. However infection also is known to be transmitted by virus and virus-infected cells present in seminal and vaginal fluids.

Exposure of intact, sexual membranes to virus in sexual fluids, such as occurs during vaginal intercourse, is sufficient to initiate infection.

The idea that only homosexual men and intravenous drug users are at risk of infection is and always has been incorrect.

In fact, there is a certain type of cell that serves as a sentinel for the immune system. Such cells are present at the surface of our mucous membranes, including the sexual membranes as well as other mucous membranes. The virus preferentially infects such cells.

The virus enters these cells. The cells migrate into the body. Studies have shown that infection can be transmitted across an intact membrane. The immune sentinel cells, called dexdrilic cells, are the most likely carriers of the virus.

The most dramatic demonstration of infection across intact sexual membranes came from observations made in 1983. Women who were subject to artificial insemination from a sperm donor who was infected were found to be infected themselves.

There was a study in Australia in which, I think, four or five women were infected by a single sperm donor.

Infection via contaminated semen has unfortunately been confirmed recently. People attempted to clean up sperm from AIDS patients. Unfortunately, some infections occurred.

There is now a plausible means to explain how the virus enters the body during sexual intercourse. Infections do not necessarily require blood to blood transmission. The AIDS virus can enter the body across intact mucous membranes without abrasions, small rips or tears in the membranes.

The incidence of infection of the AIDS virus in the United States is rising most rapidly in the young, heterosexual men and women who are not drug users.

Senator RIEGLE. Who are not drug users?

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Dr. HASELTINE. Not drug users.

I believe that the concept of risk groups originally used to describe populations to which the epidemic initially spread most rapidly is deeply harmful to public policy and has led to a false sense of security among heterosexuals.

I think that defining Haitians, gay men, drug abusers, as high-risk groups, population in the United States in which the infection was occurring then, was a mistake. Sexually transmitted diseases spread most rapidly in sexually permissive groups, but are not confined to those groups.

To repeat, a large faction of the heterosexual population, especially young men and women are now at risk of infection by AIDS. Over time, that risk will increase still further as more people become infected and, therefore, become carriers of infection.

It is an additional tragedy that infection of children by their mothers will create an additional population of the very young in need of care.

Prevention. The future impact of the AIDS epidemic on health care costs depends on the effectiveness of prevention and treatment of AIDS and its associated diseases.

Infection by the AIDS virus is almost entirely preventable, a point made by June Osborn. The methods of transmission of the viruses are known. Infection is transmitted sexually from women to men, from men to women, and men to men.

Infection is transmitted by contaminated blood, by use of contaminated needles, or by transfusion with contaminated blood and blood products. AIDS is transmitted from mother to child.

Sexual transmission of the virus can be almost entirely eliminated by prior testing of a potential partner. Such testing reduces the risk of infection by more than 99 percent. The remaining risk is due to the period of a few weeks immediately following initial infection during which infection is not detected.

The effectiveness of testing is affirmed by screening of blood used in transfusions. Screening has reduced the risk of infection by blood transfusion to less than one person in 200,000.

Testing of individuals to prevent infection has not been widely adopted. The test procedures commonly used are cumbersome, slow, and often frightening.

Reliable tests for AIDS virus infection, tests that require only a drop of blood or saliva, that can be done within 10 minutes and are simple enough to be done at home have been developed.

The use of such tests should be encouraged. The routine use of condoms and limiting the number of sexual partners also substantially reduce the risk of infection.

Recent studies show that the means to prevent infection are not—I repeat—not being used effectively. It is estimated that only 10 percent of those who are infected with the AIDS virus have actually been tested.

Yet, in incidences of sexually-transmitted diseases and of teen pregnancies, indirect measures of risk behavior have increased dramatically over the past 5 years in the United States. Condom use has risen only slightly in response to the AIDS epidemic.

Vaccines. An effective vaccine would have the single greatest impact on the AIDS epidemic. Several candidate vaccines are now

being readied for trial. Unfortunately, the state of scientific knowledge does not permit prediction of when or even if an effective vaccine will be developed.

We do not know how to overcome the multiple difficulties in making a vaccine: the problem of extreme variation amongst virus strains and infection across intact, sexual membranes, the ability of the virus to evade the immune response once infection occurs.

In planning for health care needs of families and the uninsured, we cannot rely upon the availability of an effective AIDS vaccine, neither can we rely upon rapid changes in sexual behavior to reduce the risk of infection.

Given current trends, it is my opinion that 2½ to 5 million Americans will be infected by the AIDS virus by the year 2000.

Treatment. At present, there is no cure for infection by the AIDS virus. Observations of infected populations indicate that all or almost all of those infected with AIDS will die of AIDS-related diseases within 10 to 15 years of the time of initial infection.

Over this period, the virus gradually destroys the immune system, leaving the infected individual prey to a variety of diseases.

Substantial progress has been made in prevention and in treatment of the diseases of the immune suppressed individual. Treatment of the immune suppressed typically involves an escalating dose of a number of antimicrobial medications.

Under ideal circumstances, life can be prolonged by 1 to 2 years. A variety of antiviral drugs are used to treat the underlying cause of the disease, that is the growth of the AIDS virus itself.

To date, such drugs, used either singly or in combination, have been only partially effective. Typically, anti-AIDS drugs reduce virus growth for a period of weeks to months. Thereafter, virus growth resumes despite continued treatment.

Treatment with anti-AIDS drugs is now begun well before the immune system of the infected person is damaged. It is hoped that such early treatment will slow disease progression, providing many additional years of disease-free life.

It is as yet too early to tell how effective early treatment will be. If early treatment proves to be effective, treatment of the infected may last 10 years or more.

Unfortunately, the state of scientific knowledge also does not permit us to predict when or even if effective treatments will be developed.

The impact of AIDS on the health care delivery system. The impact of AIDS on health care delivery is more predictable. More and more people will ask for and should receive the benefits of early treatment.

More and more people will ask for and should receive intensive treatment to control infections typical of late-stage disease. As treatment improves, more and more people will be treated longer and longer.

The cost of such treatments will also be high and will continue to increase both in terms of medical resources needed to treat this population and in the cost of the medication itself.

By the year 2000, between 2 and 5 million Americans will require treatment for infection by the AIDS virus. The cost of treat-

ing the secondary infections that arise as a consequence of the primary AIDS epidemic will also rise.

We are now witness to a new epidemic of tuberculosis both of the classic type and variants that are resistant to most drugs. The cost of such treatments will also be high and will continue to increase.

Thank you for your attention.

Senator RIEGLE. Well, several questions come to mind. I am going to save them until we get to the question period.

Tammy, you are living with this and your son is living with this. And I know you have a statement. And I want you to go ahead and tell us the things that you think we need to know, the things about the experience that you have had and you are having.

And also, if there is anything else that has come up in the course of the earlier comments that you want to make an observation about, I would like for you to do that, too. We would be pleased to hear from you now.

STATEMENT OF TAMMY BOCCOMINO, PRIVATE CITIZEN, WARREN, MI

Mrs. BOCCOMINO. Okay. I have been doing AIDS awareness work in Michigan for the last 5 years. Five years ago when I went and testified to a subcommittee, people said, "Well, she's just the exception to the rule."

And I knew 5 years ago I was not the exception to the rule because I represent anybody. And it is a shame I have to tell my story of how I got infected, but that is how people listen.

My story starts off as back when I graduated from high school in 1979. I was a B-plus student. I was a pom-pom girl. I had never done drugs.

I went out with somebody for a year. And then, at the age of 20 in 1980, I got married to a man who came from the Grove Point area, least likely where you would think you would see drug abuse.

Six months into the marriage, I found out this man was an IV-cocaine drug user which is hidden very well. People who do IV drugs, especially if it is not from the inner city, will hide it because it is not acceptable.

And so because he had money and he could do it a lot, I could not get help for him because he continually used it.

I ended up divorcing him. And I met my husband that I am now married to. We started our family together. We lived in a rented home. We started a business.

We had our first little boy, Tony, in 1985. And then, a year and a half later, we had our boy, Michael. And it was on the birth of Michael on that day only that the hospital was doing a specialized procedure for in vitro fertilization.

So they needed my umbilical cord blood. But before they were going to use that, they tested it for all diseases. And it came up positive for AIDS.

I sat there in total shock because I had already been divorced from my first husband for 5 years.

I used to think, "Thank God, I am married. Thank God, I am out of the dating scene." And here I was, in fact, the family that is what is going to happen for the future.

I feel that AIDS is no longer a gay disease. It is a family disease that is wiping out whole families because of how it is being transmitted.

So what I want to talk about is what I have to go through financially. It is not just for my family because I am in contact with people constantly, all kinds of families that have AIDS and the virus in their families. So we are all going through the same thing.

And the end result of this disease is just a financial burden that you cannot even believe. We do not just get to deal with our disease. We do not get to deal with just trying to stay healthy and keep our children healthy because in a family, usually, there is more than one person that is infected. It is your children or your partner.

And so we have to deal with all of us trying to stay healthy and the medical bills that go along with it. And let me tell you, when we first were diagnosed, we had an independent insurance company. And they canceled us within 6 months.

We tried to get help through the State, but our children had a savings account from when they were first born. I mean, it was only $2,000 in it. And we had a car that actually worked. So we did not qualify for any kind of help to help our medical bills.

We finally got assistance for my child, but not for me. And so then, my husband went back to his union. And he had to go back to work there to get covered by Blue Cross/Blue Shield insurance because it is a group policy, but we would have never gotten picked up if it was individual.

He had no choice. He had to go back to work in this one place.

Senator RIEGLE. Right.

Mrs. BOCCOMINO. He is stuck there. He has no other—he cannot make any other career opportunities because if we do, we cannot get insurance.

Senator RIEGLE. Right.

Mrs. BOCCOMINO. So from there, my husband now is unemployed. Our family, my son, Michael, is now 5 years old. My other son is 7 years old.

Even though we have insurance and you would think that we would be okay, our bills are still high because lots of times, your insurance does not pay for doctor visits.

It is $75 a doctor visit. My son has to go to the doctor's practically every week and if possible, every other week. So at the very least, it is $140 just for doctor visits.

We are a middle-class family. We are not rich. We are just middle class. My husband was at one time, he was unemployed. And I was making $40,000 a year.

We have to pay for my doctor bills. We have to pay for preventive care because most insurance does not pay for preventive care.

So if my son needs to get x-rays for pneumonia to make sure it is not forming, we have to pay for that because he does not have pneumonia, which is about $300 just for medication.

Anybody with this disease, it is a chronic illness. See, we have to have a lot more than just one medication. Our insurance pays for everything except for $10 of each medication.

My son is on 20 different medicines. That is $200. How do we afford that out of our budget? How do they expect us to pay for this and stay alive and worry about it all the time?

I do possibly what most people do. I put my children first. I will make sure that all his medicine is paid for, that all his doctor visits are paid for, but then, I skip visits myself.

If they tell me that I have to do a certain kind of test, like an x-ray or something, I will ask if it is covered by my insurance. If it is not, I do not do it because quite honestly, we cannot afford any more money out of our budget.

I do not even open our doctor bills anymore because it would be unrealistic to get me so upset that I cannot pay it.

Senator RIEGLE. Yes.

Mrs. BOCCOMINO. We have creditors calling our house constantly just from the hospitals for the medical bills. It is already on our credit report that we have not paid. So if we wanted to even get a new car, we could not. So it is constantly with us.

My husband and I, right now, he is on the COBRA Plan. And he has only a certain amount of time where we can pay into it. That is $400 a month. That is about all we can pay for right there.

Senator RIEGLE. Right.

Mrs. BOCCOMINO. And when he goes off of this, the only other option we probably would have would be to divorce each other. Then, the State will pick up myself and my son and our medical bills.

And I will not allow that to happen. I will not allow a financial situation to destroy our family.

So to me, while AIDS has taken away our family's future, yes, but the financial stress that accompanies AIDS in America has taken away our family's present. We cannot even enjoy whatever time we have left.

If I had any money coming in, I would like to use it to spend it as a family together, to be able to even just go to Disney World for my son is what is important to us. And so I ask that not for myself and not for my son, but for all the other families out there.

And we are a middle-class family. Can you imagine the people who do not have any insurance at all, what they have to go through? I cannot even imagine that. So I feel very lucky, even though we still have bills.

So I want to thank you for allowing me to testify and give you an insight of what it is like living with this disease and with the financial stress that goes along with it is.

Senator RIEGLE. Well, thank you for sharing that story. I think everybody that has heard you feels what you are dealing with here.

Now, your husband is laid off at the present time. So you have this insurance, but you have it only for a period of time because——

Mrs. BOCCOMINO. That is correct.

Senator RIEGLE. Unless he is called back to work, even at the $400 a month, which you are now paying, that time period will expire.

And unless he has another job that provides health insurance, the health insurance companies are not going to want to take your family, are they?

Mrs. BOCCOMINO. No. Nobody is going to take us.

Senator RIEGLE. And so then, that would put you in a situation where if you do not have other assets available to you, you have to spend down your assets.

Now, you mentioned, one option would be an unthinkable one, and that is to get divorced so that you would be in a situation where you were impoverished enough that you could qualify for Medicaid and then the State, in effect, would start to pay the bills.

But if one thinks about it, I mean, you are struggling under the weight of the disease anyway and your son is, to have our whole system put together in such a way that it makes your problem worse and worse and worse on top of the disease, it is sort of an unthinkable way to have it, but that is the way it is. And that is happening right now to you.

I mean, you are in that situation. And there are lots and lots of other people like you in Michigan and across the country that are in an equivalent situation. And as you say, you feel fortunate that you are as well off as you are right now, but that can vanish.

I mean, you are in a situation right now where, because your husband is laid off, you have it for the moment, but that does not mean you are going to have it later when you really need it.

Mrs. BOCCOMINO. That is correct.

And I know many friends of mine who have this disease and their family works, especially when more than two people in their family have it, they actually had to file bankruptcy because of their medical bills, just because of medical bills.

And I think that it is not fair in our country that if you have a chronic illness or a life-threatening illness that you would have to worry about medical bills because in reality, I am just unlucky. Anybody could be my family. And so for them not to have medical bills is just by luck really.

Senator RIEGLE. What would you say, Tammy, is the cost of all of the different medical treatment that you and your son have needed, say, over the course of a year? I mean, if you were to try to add it up, is it——

Mrs. BOCCOMINO. I would say that mine possibly is around, I would say, $20,000 because I am HIV positive and I just have preventive care to see a doctor every 3 months.

Senator RIEGLE. Right.

Mrs. BOCCOMINO. They take blood from me every month, and blood cultures and stuff. That is really the extent of my care and my medicine.

My son has full-blown AIDS. And he is hospitalized at least three times a year. I would say last year alone, his cost was about $150,000, I would say, because he was hospitalized for 5 weeks at one time.

And that is another thing, too, is that people with AIDS, this is something that we are going to sick. We are going to get better. We are going to sick. We are going to get better.

And for my son to spend 5 weeks in a hospital is a sin because he could be home. I can take care of him the same way.

Senator RIEGLE. Right.

Mrs. BOCCOMINO. But nobody will pay for home care. And that is not fair.

There was a little boy in the hospital who was in there for 3 months. And all he wanted to do was squirt his super-soaker squirt gun. They would not allow that in the hospital. He could not go outside. And if he would have just been able to go home and have home health care——

Senator RIEGLE. Right.

Mrs. BOCCOMINO. I mean, it is the quality of life that matters. And we just want to go home. We can be taken care of at home.

Senator RIEGLE. Dr. Haseltine, you said to me another time when we spoke that the progression of this disease through the society—and you have touched on it today—that another way to look at it is, it is becoming sort of a middle-class disease. And the profile of the incidence of the disease is showing up in places where 5 years ago or 7 years ago or even some of the stereotypical thinking now, you would not think that that is where the problem is.

The fact is, based on what you have told me, that the patterns indicate that there are more and more families and people exactly like Tammy that are right in the center of the bulls eye where this is happening. Is that an accurate statement?

Dr. HASELTINE. It is a little more complicated than that. If you look at the middle class, it is true that that is the area, the group in which the epidemic is rising most rapidly, but that is also because it is the group which has had previously the lowest incidence of AIDS.

So if you look at overall in the society where you see the major impact hitting, it is in poor populations.

Interestingly, regardless of ethnic group, where the population is most impoverished, whether it is a totally white population in a Northeastern city, predominantly Hispanic population in the South, or a black urban situation in other cities in the North, it is in the poor population that AIDS has made the greatest impact.

So it is independent of ethnic group, but very much dependent on income in terms of the total impact. However, the group in which the epidemic is spreading most rapidly now is in the young, heterosexual, non-drug using population.

We have major foci of infection in our population. The epidemic spreads by heterosexual contact from those foci.

If you look at a typical profile of, say, a young woman who now comes into a hospital, it may be that her sexual partner was not a drug user, but two partners back, there was a drug user or a bisexual man.

The AIDS epidemic has spread well beyond the initial confines. And that was fully predictable many years ago from the behavior of other venereal diseases.

People will often ask the question, "Why did it look first like it was a disease associated with homosexuals?"

And that turns out that, as in the case for any venereal infection, it spreads most rapidly where there is a more promiscuous population. The homosexual male population as a group had more sex partners than, on the average, the other populations.

That is why the AIDS epidemic spread most rapidly in male homosexual populations, not because of any intrinsic property of the virus, not because of a particular sensitivity of homosexual men to

the virus or any particular sex practice. It was simply the number of partners.

Senator RIEGLE. Correct me if I am wrong. In terms of what we are beginning to see on college campuses, just to take one other sort of subset within our society, what is happening there, say, versus what we thought was the case 5 years ago?

Or what is the case now, and especially because you have this business where you can get the virus and not know it for a long period of time unless you happen to get tested.

Dr. HASELTINE. Right.

Senator RIEGLE. You can be in that status and not know it. So insofar as what we know appears to be happening, what is the profile in that setting?

Dr. HASELTINE. Well, there have been some studies. I do not believe personally those studies have been adequate, but there have been some studies looking at several different colleges and universities.

A couple of years ago, I believe studies showed that 1 of 100 college men and 1 out of 300 college women were infected. And June may have more up-to-date numbers.

Dr. OSBORN. I think that is the same.

Dr. HASELTINE. So that there is a significant population. And that survey was completed 2 years ago. And as I say, I think there were methodological problems with the study. I think that represents the lower limit of infection.

To give you a number that is likely to stick in your mind, and that is, in New York City, 1 out of 53 people of all ages is infected.

In Washington, DC, that number is about 1 out of 40 people. One out of 40 people in this city is infected with HIV. There is a tremendous impact of the AIDS epidemic already here in this population.

Senator RIEGLE. I do not dispute that figure, but, Dr. Osborn, do you concur that that is the kind of number we are looking at in terms of the incidence of disease now?

Dr. OSBORN. Yes. I do concur. And I think the point that Bill has made tangentially a couple of times is important to stress, that this is a moving target.

And it is a study from the American College Health Association which is the one, I think, he is quoting. It was published 2 years ago. That looked at the 2 years before that and so forth.

Dr. HASELTINE. Right.

Dr. OSBORN. And this epidemic has been increasing rapidly. I think the central focus I would like to have is a little bit different, that is—or at least the take-home message is a little bit different, and that is that we should always have seen a universal risk.

Reading gay people out of our society, reading people who use intravenous drugs as throw-away people that we do not want to deal with anymore and therefore won't has been a tremendous intrinsic error in the entire response to the epidemic.

Bill talked about the fact that only 10 percent of people, maybe, who are infected know that. I do not agree with him about the next step which would be to make it easier for them to know that without access to anything else.

And it is one of the reasons the studies are inadequate is because the extent of discrimination, the extent of hostility in the society has led us exactly away from what we should be doing.

I fully agree with him that we should have created a climate in which people who are at risk can know their risk and know their circumstances. Testing should have been made much more accessible, always in the context of counseling because a disembodied test is at best neutral and, in fact, can be a very negative public health force.

Somebody who has had risk behavior, lots of sexual partners, for instance, tests negative on a home finger stick is reinforced in risk behavior if there is no additional counseling and work done to establish general knowledge about the magnitude of this epidemic.

I think we need almost to start over because we have been going backwards in terms of reinforcing stereotypical thinking, ignoring the enormous price the society is paying for an irrational homophobia that is really punishing to people, of families of all sorts.

Everybody is part of a family. And the people who hear us talk about, "Oh, now that it is moving into another community, maybe we should care." have been punished dreadfully during this time.

So I think we as a Nation have simply got to look at ourselves and say, "Hey, this is not right. We are not dealing with people as people."

We say we care about each individual life, but we have taken whole large categories of people and said, "Well, I don't care as much about them."

When Bill did his testimony and that book came out, "The Myth of Heterosexual AIDS," the real core word was whether it was rampant in the heterosexual community.

And I think we probably made similar speeches around the country. And my punch line always was, I do not want anybody to wait around until it is rampant before I warn my twin daughters.

It is rampant enough now because the risk is there and it is something that we know to prevent and we should be doing do it.

I think the only way we can do it is as a human family, recognizing that all of us are part of that.

We have very irrational prison policies right now, for instance, that do deal with people at enormously high risk of HIV infection as if they were throw-away people.

In fact, you hear the phrase quite often, "Lock them up and throw away the key," but the average prisoner stays in a State prison for 19 months or less. That is the average length of stay.

That is not locking them up and throwing away the key. That is putting them in a place where health care is terrible. If it is not terrible, it is discontinuous with their return to the community.

They are two to three times crowded over what the prisons were designed for. And it is a perfect breeding ground for everything we worry about in public health.

So we really have to get back a little further than some of these details to rethinking what is public health? No. It is not mandatory testing.

Yes. It is letting our population be educated to the fact that there is a universal risk element out there that they can protect them-

selves and their loved ones about, rationalizing the use of the test, for instance, so that people who are concerned can quietly and confidentially find out, learn what they need to know to protect their loved ones.

And if their risk behavior has not gotten them in the past with the virus so far, they actually can become a cordon sanitaire around an epidemic that otherwise is out of control.

It is like I said about drugs before, too. People who are using drugs who are not yet infected cannot even access treatment if they hear our message right now. That makes no sense. So I would back up a little bit.

I could quite agree with an awful lot of the points that have been made, but I think in order to address the epidemic effectively from a public health and health care financing point of view, we have to first embrace that it is a universal problem for us all and that we must care for people who are infected, care for the loved ones of those people, assure universal access to health care, and get a floor on this dreadfully poor health care system.

That safety net phrase is an evil one when you look at how it functions. And then, we work as hard as we can as a Nation, as a set of very diverse communities to prevent further spread of the virus.

Senator RIEGLE. Now, I want to pick up on that. And I want to try to make it as plain and simple as I can because I think the public really needs to understand what is being said here.

And it seems to me that what we are saying is is that whatever people thought about this 5 years ago or 10 years ago or even more recently than that, there is a general public health threat here.

And people have to understand that that threat can hit them, can hit members of their family because the nature of this problem is maybe different than they thought it was and because this can move down the track from one person to another.

And you now have this second problem, too, and that is you have other diseases that people can be more susceptible to because their immune level goes down, whether it is TB, which we are now seeing a rise in TB and other kinds of infectious diseases.

So that, for the moment, let's leave that out, but that has to brought back in, too, because that is a newer part of the profile. And again, from a public health point of view, it carries a substantial risk to us. And we have figure out how to cope with that.

But it seems to me, Tammy illustrates the kind of person that can get infected here through no fault of hers.

I mean, in this case, it was her previous husband who was infected. But in the hypothetical that was mentioned earlier, if someone has had multiple sex partners, somewhere along the line, one can acquire the virus from somebody else and not even necessarily know who it was, but then, is in a position to pass it on still to somebody else.

So in terms of the advice that we should be giving people today, in other words to boil it down to the best advice that we can give a parent today or a young person in or out of college who is sexually active, what is the latest intelligent advice and counsel that we can give somebody that helps them understand the risk on the one

side and what they can do on the other side to effectively protect themselves and to protect others?

Yes.

Dr. HASELTINE. I have several comments on what you said and what June has said. I think a way of phrasing it rather than homophobia or throw-away people is even deeper than that because there are many people who are not homophobic, who deeply care about society in its multiple ramifications that still do not believe that they are at risk.

I think there is a deeper force at work, not to deny that homophobia exists or that various attitudes exist. It is an attitude of denial. People simply do not want more bad news.

Senator RIEGLE. Right.

Dr. HASELTINE. We are in a economic recession. Many people are out of jobs. People never want bad news. AIDS is the very worst of news.

I think the deeper forces that underlie the reaction to this epidemic is the denial that it can happen to me and me personally whoever that me happens to be.

I think that personal awareness of risk is a matter of education and leadership. I think—and I have advocated it at the highest levels of our government—we need national leadership to convince people that AIDS is a risk for everyone in society.

I agree with June. We cannot afford not to treat various populations, but the bulk of public policy is made by consensus opinion across this land in every single State.

And in many States and in many parts of this country, people still deny their risk. Even though it is not rationale to do so, they deny it.

And I think there have been some very serious errors made, defining risk groups, over emphasize in many ways on the technical details of how homosexual men get infected, which turn out not to be relevant at all.

I have devoted a lot of my research to pointing out how the virus can get into a normal, healthy adult, male or female.

So there is no scientific basis for the notion that you have to have unusual sex practices. Vaginal sex of the normal type will cause infection.

And I know that June is concerned about the populations that are most seriously affected, but average men and women make public policy.

We spend dollars by the average voter. And it is that target for education, the average person, who must understand that he or she can no longer deny that they and their families are at risk of infection. That message has to go out. That is the message, I believe, that we all agree has not been adequately transmitted.

Senator RIEGLE. Tammy, what do you think needs to be said here?

Mrs. BOCCOMINO. I would like to say that I do over 100 talks a year, and especially this year alone, even more than that. And the same questions I still get 5 years later.

Let me remind you that I found out 5 years ago I was infected. I have really been infected for probably around 10 years. So 5 years ago was when I first found out.

Five years later, I am doing these talks, people are still asking me, "What is HIV? What is AIDS?" They do not know the difference. If you do not know that from 5 years ago, we are in a sad state.

Let me tell you, when I go to high schools, kids ask me, "Well, okay. Is it okay? Then, I just won't have sex, but I will do other things."

They do not understand every type of sex puts them at risk. They do not understand that.

And so when I thought we were on a good step, I think, it was like 4 or 5 years ago when the Surgeon General passed around—every home had that pamphlet that was sent out to them, but that was 4 to 5 years ago.

We should have had a new pamphlet sent out every year to update, to keep reaffirming the facts, to keep showing people.

And so I feel I would like to see something passed out every year to each home in America so that people can read about this disease because most people say, well, they do not understand the facts that are given to them by maybe a medical person or most people in the newspapers and the media.

They only cover a certain point each time. They do not cover all the facts all at once. So they do not get all their questions answered all at once.

And so I would like to see every year something, some kind of a booklet passed out like we did 4 or 5 years ago.

Senator RIEGLE. June, do you want to make a point? And then, I have a couple of other questions I want to ask you before we finish and go to the next panel.

Dr. OSBORN. Yes. I would like to talk a little bit about, in response to your question, what one should be telling the people to get them more involved.

And a side comment on Tammy's point just made. I agree with that, although one of the things that has been learned in the last few years in health education and health behavior research that has been done despite poor funding is that we need to do multiple things.

A pamphlet can help some people. It cannot help people who cannot read. A pamphlet in English cannot help somebody in Spanish. Those two languages were accounted for in the earlier Surgeon General's mailing, but very few others were and so on.

We need as a Nation to pull together and, keeping our diversity in mind, develop a set of what are almost certain to become flex-strategies to develop an adequate national response.

The commission has been calling for a national prevention conference strongly supported by the President which would allow us to pull into the same discussion a lot that has been learned about what is effective in prevention and what is ineffective in prevention.

Each of those things has been learned in one or another place around the country in one or another study. That needs to be pulled together and given enough visibility and common thinking amongst ethnically and culturally diverse people that a country of our complexity can make an adequate response.

It will not be any one thing. It will be many things. And it will be many things targeted with a great deal of sensitivity to the listeners to whom we are trying to speak.

For instance, one of the audiences that I think we all want to speak to is adolescents, but those of us who are parents of adolescents know that most adolescents know that if you learn an adolescent's language, they will change it on you.

So that in point of fact, we need to learn how to communicate very difficult material to people who, as Bill says, are denying it, who do not want to hear it.

That is not going to be easy and it is not going to be straightforward, but it must be done.

Senator RIEGLE. Yes. I agree with you. Have we had a comparable public health threat, in whatever form, that in a sense is similar to this? Isn't this a unique enough situation that having a public information effort, perhaps through some kind of a national symposium, maybe a part of it is on MTV and done in the fashion that it is in young people's language, is needed? It sounds to me like this particular problem is so outside the bounds of other problems that we have had to deal with that an extraordinary effort is truly required and necessary here.

And the longer we wait to do that, the worse off we are because you are going to have a larger number of people who are going to find themselves learning by accident that they have this problem as you did.

I mean, it was only when that test was done after your baby was born, for another purpose, that this information came to light in your case. You would not have known otherwise presumably.

Mrs. BOCCOMINO. The only way I would have found out was when my child died or got too sick. And that is how I would have found out. And that is how most families are finding out that the mother is infected when their child gets real sick.

Dr. OSBORN. No. In answer to your question, in a focused way, we have not had this kind of a public health emergency in the past.

One could argue that in retrospect, we have, but we certainly have not responded. We have not had the responses at hand that we do here.

One of the tragedies of this epidemic is that we have known for most of the 11 years that we have known about it, we have known a lot of the things that we needed to know to let people avoid it. And we have never had that opportunity before.

It is interesting to point out that when polio was at its most frightening in the early and middle 1950's, for those old enough to remember——

Senator RIEGLE. Right. I remember that.

Dr. OSBORN [continuing]. The maximum number of paralytic cases—and, of course, most of those people recovered; some did not; and very few died—the maximum number in any one epidemic season was about 45,000 or 50,000. We had 45,000 AIDS diagnoses made last year and reported to CDC.

So we do have a massive public health crisis of the century on our hands. We know enough about it to know that we have to be thoughtful, that doing some things that seem obvious can work exactly backwards.

Senator RIEGLE. Right.

Dr. OSBORN. So as a Nation, we have to pull together.

Senator RIEGLE. Yes.

Dr. OSBORN. Because the commission has been trying over the last 3½ years systematically to lay out blueprints of what could be done if the national will were there. And there is lots that can be done that is not expensive.

I keep coming back to the central sense of involvement that must be there to get past the denial.

Senator RIEGLE. Right.

Dr. OSBORN. To get past some of the categorical thinking that has so characterized prior discourse. And in particular, the silence at the center, we are not used to having the bully pulpit be silent on an issue of massive national concern.

And I, too, have given a lot of talks around the country and sometimes feel when I wake up in the morning, they must think I am making up these numbers because it sounds so unreal that we could have so many Americans, young Americans in the prime of their lives, whose lives are threatened, whose productivity is threatened, and have silence at the center.

So I think we will have a new voice that will help enormously. There is much that we can do. And I think oftentimes when people ask me what else can they do, if they develop a sense of involvement during a talk or something, that they must recognize how politically difficult this issue is.

I congratulate you for holding hearings because even at this stage, it has been very hard for people in political life to grasp all of the difficult-to-discuss elements of this epidemic and face it squarely, but I think we must now. The scope of the epidemic is enormous.

Senator RIEGLE. Well, you have the human cost. You have this growing human toll. And there is this engulfing financial cost.

I mean, there is this tremendous financial cost. You just described it in personal terms, but you can multiply that out for everyone who needs care and care over a period of years.

Our health care system now is so expensive anyway. It is sort of breaking down.

You want to make a point, Dr. Haseltine?

Dr. HASELTINE. You asked a question, what can people do? I would like to rephrase that and say, what should families do to help their younger children, their children who are moving into their teens and young adulthood?

The first thing a family should do is know what the facts are. They should have the access. They should know that it is a matter of heterosexual sex.

Second, they should have an idea of what the risk of any venereal infection is in the population.

For example, there are some venereal infections or sexually transmitted diseases, as they are now called, that affect up to 20 percent of the population, the unapparent infections.

So that if you look overall, a disease like chlamydia, a very large fraction of Americans can be subject to sexually-transmitted diseases.

The numbers for sexually transmitted herpes diseases are similar. We have to have forgotten about the herpes epidemic in light of the AIDS epidemic, but it does teach us that a sexually-transmitted disease, like chlamydia that is inapparent, like herpes, really affects a very large fraction of the population across the entire spectrum of the population.

The second thing that, I think, families should do is teach individual responsibility. We are here to inform the government about what we think. But when it comes to changing behavior, it is the individual that is the center.

Every individual has to have the understanding of what this problem is and that there are certain behaviors that put them at risk of death.

I think there are other points that a family should stress. There is no such thing as safe sex. And that is what we have heard. There is safer sex. If you are going to be promiscuous, you must use condoms for all contacts.

But there is a way, which I mentioned earlier, of dramatically reducing the probable risk, and that is to know the health status of your potential partner.

Now, there are many public health implications of that. And June will be the first one to tell you that that is a difficult thing to do.

However, if there is a single thing that an individual can do to reduce their risk of infection, it is to know whether or not a potential sex partner is infected.

Regardless of the social implications of which there are many, testing of potential partners is the most important single thing a person can do to reduce their risk of infection from a news partner.

Senator RIEGLE. June, let me ask you this. You have mentioned that the National Commission on AIDS has made recommendations for financing care for people with HIV and with full-blown AIDS.

Would you just touch on some of those recommendations in a little more detail?

Dr. OSBORN. Yes. Maybe what I could do in the interest of time is to read you the parts of my written testimony that you have which are the recommendations themselves. I have filled in some but not all of the commentary. And as I mentioned, a full development of that thinking is in the larger report.

Senator RIEGLE. I understand. If you can just hit the highlights.

Dr. OSBORN. I will hit the highlights, the bold type, as it were.

Senator RIEGLE. Good.

Dr. OSBORN. And then, commend people to my written testimony in the report.

First of all, universal health care coverage should be provided for all persons living in the United States to ensure access to quality health care services.

As I mentioned, while we recognize that is a goal, it is long term. We felt we could not in good conscious omit it from the beginning of our discussion, but the remainder we worked out with great care with Dr. Davis and her colleagues.

Medicaid should cover all low-income people with HIV disease. Medicaid payment rates for providers should be increased sufficiently to ensure adequate participation in the Medicaid program.

Congress and the administration should work together to adequately raise the Medicaid cap on funds directed to the Commonwealth of Puerto Rico which has the second highest per capita incidence of AIDS itself of the U.S. citizenry and has an extraordinary cap of 79 million on all Medicaid funds.

So that, we felt was important enough to pull out as a separate statement.

States and/or the Federal Government should pay the COBRA premiums for low-income people with HIV disease who have left their jobs and cannot afford to pay the health insurance premiums.

Social Security disability insurance or SSDI beneficiaries who are disabled and have HIV disease or another serious, chronic health condition should have the option of purchasing Medicare during the current 2-year waiting period.

And finally, the Federal Government should fund the Ryan White Care Act at the fully authorized level. And I would add, since we wrote that over a year ago, that is an urgent need now, since it was not done then, as are several of these others.

In addition, I would urge that we reassess the needs in the light of current numbers because what would have been full funding of the Ryan White Care Act back when it started is now again going to be disaster relief in need of additional filling out because of the enormous increase in numbers, even since we wrote this report.

Those are the highlights of our health care financing recommendations.

Senator RIEGLE. Now, let me ask you this. You run the commission on AIDS. You are the person in charge. The commission made formal recommendations in September of last year?

Dr. OSBORN. We have throughout our time, but we made the largest set of 30 recommendations, which I just read to you seven, in September of 1991, yes.

Senator RIEGLE. With respect to the actions that were needed to implement your recommendations, what has happened in that area?

I mean, where are we in terms of actually getting done the things that you and your colleagues and the experts decided after all the work that focused on this? Where are we in terms of implementing those recommendations?

Dr. OSBORN. Senator, it has been somewhat discouraging to be Chairman of the U.S. National Commission on AIDS. I can only say that, I think, we laid out a good blueprint. I think it can be useful. Very few of our recommendations have been adopted.

I think there has been increased attention in the research sphere to diversification of research populations so that we can learn more about women and children and the way that advances in biomedical science can help them. That was one of our earlier recommendations that has seen progress.

There have been other pieces of progress like that, but such obvious things, as I mentioned earlier, like a national prevention planning conference to try and coordinate what we know and bring it to the benefit of people around the country, even that sort of thing which costs almost nothing in Federal terms has not been implemented.

As you may know, we met with the Secretary of Health and Human Services 9 months after we issued this report.

Senator RIEGLE. Right.

Dr. OSBORN. When we issued it, we had been told that we would get a quick response. When we finally got a slow response in the later spring of 1992, it was in a tabular form in which the major points we brought forth were sort of checked off with, "We are doing that. We do not agree with this. We are doing that."

And in that context, we requested a meeting and had a meeting with the Secretary in which, from our recommendations, we pulled out eight that we thought were both fairly cost neutral and well within the Secretary's power to implement quite quickly.

The result of that meeting was very unsatisfactory. And that was perhaps, those who watched TV the next night will recognize that that was the first time that we as a commission, which is bipartisan, were strongly critical.

Senator RIEGLE. Right.

Dr. OSBORN. We are charged by Congress to try and advise both branches of government. That was the first time that we, if you like, sighed or moaned or screamed out loud that we felt that our recommendations were not being heeded. I am afraid very little change from there has happened.

I must stress that throughout all levels of government, there have been hard working and heroic people so that I always hesitate to be as sweepingly condemnatory as that.

Senator RIEGLE. Right.

Dr. OSBORN. There has been enormous progress made and some very committed people working in the face of an inertia that is difficult to even believe.

Senator RIEGLE. Now, with respect to the eight, sort of recommendations that you chose to highlight that in effect were budget neutral and that you felt really had to be emphasized, not just you but your entire commission, how many of those eight have been carried out? Any of them?

Dr. OSBORN. Not to my knowledge.

Senator RIEGLE. Not a single one?

Dr. OSBORN. Not as a response in any coordinated way. We actually had pulled them out with some pain because we felt that we were already down to minimums with 30.

Senator RIEGLE. Yes.

Dr. OSBORN. And we pointed that out in our discussions, but suggested that there could be the sense of a revitalized Federal response to the epidemic if all of them were mobilized at the same time. That absolutely did not happen.

And I have not gone back to look at the list of eight lately, but to my knowledge, very little has happened.

Senator RIEGLE. Have you had a chance previously, prior to her destination, to talk to the newly-designated Secretary of Health and Human Services?

Dr. OSBORN. No. I do not know Dr. Shalala.

Senator RIEGLE. Well, I would like to undertake with the help others to see that you have the chance to meet and talk with her at the earliest time so that you can go over the list, not just the eight, but the entire list.

Now, the commission is bipartisan. So you have people there across the spectrum. Were the recommendations unanimous?

Dr. OSBORN. These were all consensus recommendations. And in our meeting with Secretary Sullivan in June, one of the people appointed by the Senate Republican appointing authority took the opportunity to speak last and point out that that was his status and that he concurred with everything that was being said.

I think there may be cavils with the one or two of the perhaps altogether 60 recommendations or so that we have made over the course of our tenure, but by and large, the commission, I am proud to say, has operated as a consensus commission and has some of its strength coming from the fact that literally half of the voting members were appointed by Democrats and half by Republicans.

And the balance, as I think you know, that even the neutrality of the commission, Congress tried to assure that in the legislation by having the commissioners elect their Chairman.

Senator RIEGLE. Yes.

Dr. OSBORN. So I, as you know, happen to be a Senate appointee, a Senate Democratic appointee, but was elected to chair the commission.

So in every kind of way, we have tried to maintain our bipartisanship because I, for one, do not feel this should be a political issue. It is a human issue and should never have been caught in any political dynamics.

And the commission itself, I think, has functioned that way to an extent which I am very proud.

Senator RIEGLE. Have you had a chance yet along the way to talk with President-elect Clinton, either prior to the campaign or since?

Dr. OSBORN. No. I have not.

Senator RIEGLE. I am going to undertake to try to encourage that such a discussion happens so that he has an opportunity to hear directly from you because you can present, if you will, on behalf on the commission all the work of the commission, its conclusions, and the urgency of the situation.

I am certainly going to take this committee record and forward that to the appropriate officials that will be coming into place because I think it is very important that we get this up-to-date informational summary and foundation ready for new people who are coming and who, I have reason to believe, will accord this a top priority as it clearly needs to receive.

If I may, I am going to thank you all. We have other witnesses that are going testify. I want to thank you all very much for coming.

Tammy, I particular want to say to you, I appreciate the outreach that you continue to do, the fact that you are out meeting and talking with people, despite all the other responsibilities and difficulties that your family is struggling with right now. We want to try to help you in every way we can. And we will undertake to do that.

Mrs. BOCCOMINO. Thank you very much.

Senator RIEGLE. Thank you all.

Let me now in excusing these witnesses introduce our next and final panel of witnesses.

Our second panel is going to include Dr. Hellinger who is the Director of the Division of Cost and Financing at the U.S. Public Health Service Agency for Health Care Policy and Research. Dr. Hellinger will discuss with us the cost of health care services for people with HIV.

Our second witness is Dr. Peter Arno who is an Associate Professor with the Department of Epidemiology and Social Medicine at the Albert Einstein College of Medicine in the Bronx, New York. And he will discuss the different sources of payments for AIDS care.

And then finally, our third witness will be Ms. Christine Nye who has appeared before this committee before. Ms. Nye is the Director of the Medicaid Bureau at the Health Care Financing Administration, known as HCFA.

She also chairs the Working Group on AIDS in that agency. And she will be discussing the roles of Medicare and Medicaid in providing payment and services for HIV-related illnesses.

So with that, Dr. Hellinger, why don't we start with you. And we will make your full statements a part of the record. And we would like your summary comments at this time.

[The prepared statements of Dr. Hellinger, Dr. Arno, and Ms. Nye appear in the appendix.]

STATEMENT OF FRED J. HELLINGER, PH.D., DIRECTOR, DIVISION OF COST AND FINANCING, AGENCY FOR HEALTH CARE POLICY AND RESEARCH, U.S. PUBLIC HEALTH SERVICE, ROCKVILLE, MD

Dr. HELLINGER. Good morning. Thank you for the opportunity to speak here.

My name is Fred Hellinger. I am the Director of the Division of Cost and Financing, the Agency for Health Care Policy and Research. I am here this morning to speak about the cost of treating a person with HIV.

Research findings presented today by myself will be based on a large part on a survey conducted by our agency of 2,000 persons with HIV around the country in 10 cities. And in these 10 cities, we collected information at a total of 27 sites.

In addition to tracking the economic impact of HIV, our agency is involved in funding research, analyzing access to care, quality of care, and methods of improving the treatment of persons with HIV.

Our agency is also funding an evaluation and development of a clinical practice guideline for initial evaluation and early treatment of persons with HIV.

I will begin by presenting the conclusions. I will then discuss some of the current implications of my findings and end with a discussion of implications for the future.

I want to first give you an idea, without getting into too much detail, of some of the difficulty in developing and forecasting estimates of treating persons with HIV because I think many people think that you get estimates of treating persons with HIV by going to a central source, looking at the number of people with HIV, looking at their bills, and multiplying the numbers of persons by the average cost of the bill. This is entirely false.

Trying to forecast the cost of HIV is like taking aim at a moving target with a bow and arrow.

HIV treatment patterns change rapidly. The treatment patterns have dramatic impact on the cost of treatment. Our data sets are generally 2 to 3 years old.

So the rapid changes in treatment and data sets which are generally 1988 and 1990 and probably as late as 1990, it is very difficult to estimate the cost of HIV.

Just one example, during the year 1988, the drug costs incurred by the Medicare program tripled.

From the year 1990 to 1991, the drug cost of treating persons with HIV in New York City increased 42 percent between those 2 years.

The rapid changes in treatment have rapid effects on the cost of treating a person with HIV.

My estimates are derived by calculating an estimate of the number of persons with HIV that are receiving care and, by calculating an estimated number of persons with AIDS and multiplying these estimates by their average cost.

I look at three different groups. Persons with AIDS, persons without AIDS with T-cell counts below 200, which are persons which are relatively impaired compared to those above 200, and persons with T-cell counts above 200. The intensity of care varies dramatically as the person's immune system deteriorates through time.

So a person with AIDS would be expected to have higher costs. And a person with T-cell counts below 200 would be, in turn, expected to have higher costs than one above 200.

I will not discuss in any detail the models that are used to estimate the number of future cases. They are relatively standard. The data that is used are data on the number of cases reported to the Centers for Disease Control.

The estimates that are provided in my testimony were calculated on the cases reported between January 1984 and November 1991.

The individual cost of treating a person with AIDS is derived by the addition of two factors: the inpatient costs and the outpatient costs.

Inpatient costs are derived by estimating the average of length of stay of a person with AIDS times the average hospital charge times the number of admissions.

Now, the average length of the stay of a person with AIDS varies dramatically across the United States. There are large geographic differences.

For example, the average length of stay is about 11 days in California, about 12 in Texas, 14 in Maryland, 15 in Florida, about 17 in Hawaii, and maybe closer to 18 in New York State.

An interesting point to note is that there are also large intrastate variations in average length of stay. For example, in Brooklyn, the average length of stay approaches 22 days. And in upstate New York, the average length of stay is about 15 days.

The average charge per day is relatively homogeneous across the country. It varies from about a high of $1,250 in Washington to a low of about $900 in Texas. These are average charges, not average costs.

The estimate that I used in my analysis is $1,100 for the hospital charge per day.

The number of admissions of a person alive with AIDS during any part of the year is calculated to be 1.6. This number has remained constant through the years as compared with all other figures.

In fact, in New York State, we have evidence from 1989, 1990, and 1991, the number of hospitalizations for a person with AIDS has remained at 1.6.

A national study conducted by Dennis Andrulis and the National Pubic Health and Hospitals Institute also calculated this number to be 1.6.

So multiplying the average length of stay by the average charge per day by the number of hospitalizations the average person with AIDS incurs during a year comes out to $28,700 a year.

Outpatient costs are derived by looking at total cost and developing an estimate of their percentage as total cost.

In most cases, outpatient costs have ranged in prior years from about 20 to 30 percent. In California, they are 27 percent. The latest year we have data is 1989.

In New York in 1991, outpatient costs were 26 percent. It is interesting to note that in the prior year 1990, they were 18 percent and jumped to about 26 percent in 1 year.

In Florida, outpatient costs are about 24 percent.

As an average I use 25 percent of total cost attributable to outpatient cost. And from the estimate from inpatient cost of $28,700, I derive the estimate of $9,600 for outpatient costs. Therefore, the estimated total cost of treating a person with AIDS alive during any part of the year is $38,300.

Now, the cost per month is a little more complicated to derive because persons with AIDS that are included in these data bases are not alive the entire 12 months of the year.

The average person with AIDS is alive about 7½ months during that year because many people are diagnosed with AIDS during the year and many people die during that year.

This estimate is calculated by assuming an average survival from the time of the diagnosis of AIDS until death of 20 months.

Thus, at $38,300, the average person with AIDS is alive about 7½ months, and the cost per month is about $5,100 for a person with AIDS alive during a month.

The lifetime cost is estimated to be $102,000 and lifetime in this context is time from diagnosis of AIDS until death. This is generally the definition of lifetime costs for many illnesses.

And it is not particularly useful because there are large costs incurred prior to the diagnosis of AIDS. But just looking at the costs from a diagnosis of AIDS to death, which is about 20 months, at $5,100, it yields an estimate of $102,000.

Lest you think that these estimates are set in concrete, I have to note that these estimates are for 1992. In 1991, I estimated about 85; in 1990, 75; and back in 1988, 57.

So they have changed dramatically through the years due to the increased length of stay, higher drug costs, and larger amounts of money charged per day.

It is estimated that the number of persons with HIV receiving care without AIDS is equal to about twice the number of persons with AIDS.

This is a critical estimate in order to determine the total amount of money spent on persons with HIV. Today about 80,000 persons with AIDS are alive.

Since we have about 230,000 AIDS cases reported through October and 150,000 deaths, we estimate there are 80,000 persons with AIDS alive today, that there will be about 160,000 persons without AIDS with HIV receiving care at any given moment. So adding the two——

Senator RIEGLE. Let me just stop you there because as I understand it, the length of time that you can have the virus before you get so-called full-blown AIDS can last for a period of several years.

But I guess you are assuming that either that is not known by that person or there is not a pattern of care associated with the fact that they have the virus.

So when you pick the multiplier figure that you do for the length of time that they get care—well, they have the virus—but before they have AIDS in the full sense, you are only taking like a 2-year period?

Dr. HELLINGER. Well, let me backtrack a minute and get a little bit clearer. There are certainly a large number of individuals with HIV who are unaware they are HIV positive. And certainly many of those are not receiving care. Many may be receiving care, but they are not receiving it for HIV.

Now, the estimates of twice the amount a person with HIV without AIDS receiving care comes from studies of clinics.

Actually, the Centers for Disease Control conducted a study. It was published in 1991 and showed 7,500 people in nine cities were HIV positive and about 2,500 of them, one-third, had AIDS.

Now, if there are, indeed, a million people infected with HIV, this would imply that a very large percentage, about 760,000, are not receiving care for HIV.

It is likely that the vast majority of these individuals are unaware of the status.

Senator RIEGLE. So they do not even know they have it?

Dr. HELLINGER. No. They do not know they have it. In fact, they may be receiving care, but we would not be able to pick it up unless the HIV illness were noted as a diagnostic code in a hospital bill or an outpatient physician bill.

Senator RIEGLE. I see.

Dr. HELLINGER. So these people may be getting it. We cannot calculate the cost at this point.

Senator RIEGLE. Might I just ask? I just want to understand one other thing here, and that is, if somebody is receiving treatment, and has not been diagnosed as having the virus, but, in fact, has the virus, I am just wondering where in the normal course of treatment it becomes standard practice for a medical provider to do a screening test on the AIDS virus so that we would know how early in time we are trying to pick up that identification if it is there?

Or does a doctor normally wait until there is a profile of activity that suggests an AIDS virus problem before they would actually go ahead and run a test to check for that?

Dr. HELLINGER. I cannot answer that with any degree of certainty, but the individual will have a lot to say about their desire to be tested. It is the decision of the individual with the advice of the physician.

Indeed, there are many illnesses which strike persons with HIV as well as the general public, the kinds of infections that people with suppressed immune systems suffer many people do.

So if there is not a distinct reason for the physician to suggest that they be tested or if the person does not desire to be tested, then, they will not be tested.

Senator RIEGLE. Right.

Dr. HELLINGER. It is getting, I guess, to sort of a final question. A series of them would be: we cannot really determine how many people with HIV are receiving some kind of care without an HIV test being taken and a code for HIV or some kind of manifestation which is specific to HIV. There are some diseases which are incurred almost entirely by persons with HIV.

It is a very difficult question to get a handle on until there is an HIV test taken and individuals are aware and they are coded in the hospital or outpatient event.

I want to stress that my estimates of costs in this study are only of personal, direct medical care costs, and personal costs as opposed to education, prevention, and testing activities conducted by the Centers for Disease Control, personal medical costs as opposed to housing costs, benefits and counseling, transportation and so forth, and direct costs as opposed to indirect costs.

Indirect costs of the illness would be lost productivity attributable to mortality and morbidity of individuals with HIV. And these costs can be substantial.

So mine are really the kinds of medical care costs for which a bill is generated and some individual or insurer pays. They also do not include volunteer costs for medical services, any services which are provided without a charge.

My estimates of costs for treating all persons with AIDS during the year 1992 was $7.3 billion. For all persons with HIV, it is $10.2 billion, expected to rise from $10.3 to $15.2 by the year 1995. So it is a 48 percent increase between 1992 and 1995.

Senator RIEGLE. Now, let me understand the two numbers. You are saying the AIDS figure for 1992, $7.3 billion. The virus figure for 1992, did I understand you to say $10.5 million?

Dr. HELLINGER. 10.3.

Senator RIEGLE. 10.3. So if you add those two together, you are talking about 17.6. Is that——

Dr. HELLINGER. No. 10.3 is the estimate for the total cost, direct personal medical care costs of treating all persons with HIV, including those with HIV with AIDS.

Senator RIEGLE. I see. All right.

Dr. HELLINGER. Those are just with AIDS, the 7.3.

Senator RIEGLE. So the total is 10.3, using your calculations for the year 1992?

Dr. HELLINGER. That is correct.

Senator RIEGLE. Okay.

Dr. HELLINGER. I expect it to rise to 15.2 in 1995.

By way of comparison, the estimated cost of treating end stage renal disease is about $5.4 billion a year; leukemia, about 13.2; cerebral vascular disease, primarily stroke, about $64 billion a year.

Senator RIEGLE. Stroke was what?

Dr. HELLINGER. $64 billion a year.

The treatment costs for all persons with HIV of $10.3 billion is a relatively small portion of the total medical care cost of $817 billion, estimated for 1992, in fact, about 1.3 percent.

It is important to note, however, the large estimated increases in prior years and the fact that almost all projections of cost have turned out to be under-estimates of the actual costs.

One of the primary factors that has been moving the cost of AIDS has been the rapid shift from inpatient to outpatient care costs.

In fact, we found in New York State that inpatient care costs dropped by 6 percent, from 82 to 76 percent between 1991 and 1992.

A second factor which is affecting HIV costs is a rapid increase in drug costs. And I might note that my data estimates presented today are primarily using data that has been collected through 1990.

And as I mentioned earlier in my discussion, the cost of HIV changes rapidly as treatment patterns change. It is becoming clear that the cost of drugs is becoming a much, much larger part of the cost of treating persons with AIDS.

This occurs because few HIV-approved drugs replace existing drugs. For example, just going over the past couple of months and looking at the past two drugs approved for HIV, Mepran, which is a drug approved to treat persons with PCP, is approved for persons who are intolerant to using TMP-SMX, Septra, or Bactrim.

Persons who are intolerant to using these drugs will go on to Mepron. Mepron costs about $25 a day.

Sporanox is a drug used to treat histoplasmosis and blastomycosis. Prior to this, there have been no drugs that have been effective against these diseases that are approved by the Food and Drug Administration. The cost of this drug will probably approach $10 a day.

In June of this year, DDC or HIVID, another antiviral, was approved, costing about $9 to $10 a day. This is used in combination with AZT. This adds about another $9 to $10 a day to the cost of AZT which is $7.50 a day.

For these reasons, information coming out in the past few months is indicating that the cost of drugs is playing a much greater part in the cost of treating persons with HIV.

The estimates I present today, as I said, it is somewhat lagged because they are based necessarily on data a year or two ago.

Our current survey, the AIDS Cost and Service Utilization Survey, is providing very useful information on these trends. And the fact is that much of the data we are getting now from our survey—and our survey was conducted between the spring of 1991 through November of 1992—is from 1992 and late 1991.

So we are really getting what I call a real-time estimate of the cost of treating HIV rather than an academic estimate which is based on published articles in journals.

Well, taking out my crystal ball and discussing future implications, the future implications of my study are that outpatient costs are likely to increase as a proportion of total cost in future years as the use of outpatient services increases, as evidenced by the rapid rise in drug expenses in California in 1988 and New York in 1991, and as evidenced by preliminary data in our survey.

Second, there will be a greater portion of people receiving care, HIV without AIDS, in the future years than are receiving care today.

This occurs because many of the prophylactic agents, AZT, Pentamidine, DDC, and ddI have been relatively effective in reducing the progression to serious HIV infections. So we are getting more and more people with HIV without AIDS receiving care.

And this should lend pause to individuals who are looking at the CDC estimates of the numbers of reported cases this year, which will probably hold steady around 43,500 as it was last year.

Although the numbers of persons with HIV with AIDS reported to CDC is remaining relatively constant, we expect the cost to go up dramatically because of this group of people whose progression towards AIDS has been slowed by the prophylactic drugs.

And preliminary data from our ACSUS survey is indicating that the cost of treating this group of individuals is almost 75 percent of the cost of treating persons with AIDS.

This is in contradistinction to almost all the information that is provided to date. And in particular, my studies have shown that it cost about $38,300 treating a person with AIDS and about $13,000 treating somebody with a T-cell count below 200.

This number will increase dramatically in future years with the wide array of drugs that are becoming available and increased aggressive, prophylactic care.

Senator RIEGLE. Can you tell from your data—I do not say that you are necessarily the best one to answer this question, but in terms of the application of these newer drugs to stretch out the onset of AIDS, how much time have we been able to pick up on average when we are applying those new therapies?

Dr. HELLINGER. Well, being an economist, I am not an expert in the progression rates of HIV, but information presented at Amsterdam by individuals from CDC showed that in the San Francisco's Men Health Survey, rates of progression were dropping from about 40, 50 percent due to the use of prophylactic drugs.

So people are going from HIV to AIDS at a much slower rate, probably close to 40 to 50 percent than they were in prior years. These people would still need care and will be treated.

Senator RIEGLE. Yes. I understand.

Dr. HELLINGER. They will not be defined as persons with AIDS.

Senator RIEGLE. But it is helpful in terms of extending the time period for people, but it also means, as you say, the cost numbers change in terms of how that is going to look as a series over time because presumably you are still going to have at some later time, the cost of a full-blown AIDS episode, although the time prior to that now is being stretched out by virtue of these——

Dr. HELLINGER. These individuals without AIDS with T-cell counts below 200, besides increasing in number, are using many drugs.

Senator RIEGLE. Yes.

Dr. HELLINGER. In fact, on average, they are using more drugs, in our latest wave of information than persons with AIDS.

Senator RIEGLE. Right.

Dr. HELLINGER. So they are using costly drugs which they are going to continue to use to help delay serious symptoms. They use slightly less hospital care.

But I think in future years, we are going to see the cost of this group rise dramatically as the overall cost of treating persons with HIV continues to do so.

That concludes my testimony.

Senator RIEGLE. Thank you very much. That is helpful. I appreciate all the time and the effort that has gone into crafting a financing model. I know that it is not easy to do. And I appreciate the work that you have done.

Dr. Arno, we would like to hear from you now.

STATEMENT OF PETER S. ARNO, PH.D., DEPARTMENT OF EPIDEMIOLOGY AND SOCIAL MEDICINE, ALBERT EINSTEIN COLLEGE OF MEDICINE, BRONX, NY

Dr. ARNO. Good morning, Mr. Chairman.

My name is Peter Arno. I am a health economist at Montefiore Medical Center and Albert Einstein College of Medicine in the Bronx.

It is a privilege to be invited to testify before this committee. I want to thank you personally for calling this hearing which hopefully will help refocus much needed attention by the Federal and executive branches of our government to the AIDS crisis.

Since the earliest days of the AIDS epidemic, concerns have been raised about the catastrophic costs associated with AIDS treatment. Some have even suggested that AIDS would bankrupt our health care system.

These fears have proven largely unfounded. AIDS is an expensive illness, as we just heard from Dr. Hellinger, but not dramatically more so than other life-threatening diseases.

In narrow economic terms, the total direct costs of AIDS are likely to represent between 1 and 2 percent of the Nation's health care bill. This is true now and into the foreseeable future.

This is not to minimize the incalculable suffering and loss of human life associated with this epidemic—or as we heard so eloquently this morning from Mrs. Tammy Boccomino—the personal, financial tragedy that befalls so many, nor is it to downplay the importance of AIDS as a public health disaster.

AIDS, perhaps more than any other issue of the last decade, has exposed disturbing inequities in our health care system, many of which are now the focus of reform efforts. These include access to care, quality of care, control of exploding health care costs, and the control of pharmaceutical prices.

I would like to highlight two dimensions of the economic impact of AIDS: one, financing trends over time; and two, the rising cost of care.

My colleague, Jesse Green, and I have analyzed trends in the financing of AIDS care in a number of States and metropolitan areas around the country.

We have found strong and convincing evidence that Medicaid's share of financing has increased dramatically over the past few years. At the same time, the private sector's contribution to financing has declined, in some areas precipitously.

At least three factors can help explain the trend towards increasing Medicaid coverage for AIDS care: first, the shifting demographics of the epidemic; second, discriminatory underwriting practices by the private insurance industry and employers; and third and perhaps most importantly, the high rate of job loss and subsequent impoverishment after one is infected with HIV.

Medicaid's growing responsibility for the financing of AIDS care prompts concern for a number of reasons. First, it represents an increasing financial burden on inner-city health care systems. And this cannot be made clearer than in the case of tuberculosis.

In fact, I would argue that our failure to adequately deal with the AIDS epidemic has, in part, led to the resurgence of tuberculosis.

In New York City, which is the epi center of the resurgent TB epidemic and is a preview of what is to come around the country, nearly one-half of all persons with TB are co-infected with HIV. In 1990, just the hospital costs alone of treating TB patients in New York City was approximately $200 million.

Second, while Medicaid is better than no insurance at all, it does not provide the same access to care as private insurance.

Medicaid pays much lower rates to physicians than private insurance. As a result, most office-based private physicians avoid or limit their acceptance of Medicaid recipients. This has frustrated efforts to involve more primary care providers in AIDS treatment.

As HIV disease progresses, the use of health care services increases. This is true for inpatient and outpatient care, even at the earliest stages of HIV infection. However, because of barriers to Medicaid coverage, thousands of persons in need of these services do not receive them.

Even with the new CDC definition of AIDS, there is guarantee of access to these essential services because of the obstacles to Medicaid eligibility.

This underscores an urgent call for reform in our health care system so that the provision of health care is not based on arbitrary definitions nor on one's position in the socioeconomic hierarchy, but rather on meeting the personal and public health needs of our citizens.

Let me now turn briefly to the issue of the rising cost of care. During the epidemic's first few years, many of us believed that providing community-based AIDS services would reduce the rate of hospitalization and lower costs as a result.

Ten years later, we find that, indeed, hospitalizations have declined somewhat, but outpatient costs have soared. This is in large measure because we have improved the way we treat this disease outside the hospital—at home, in the clinic, or in the doctor's office.

Empire Blue Cross and Blue Shield, probably the largest private insurer for persons with AIDS in the United States, says the cost of outpatient services now exceeds inpatient costs for people with HIV disease.

Why? There are three likely reasons. One, we now treat many conditions on an outpatient basis that could formerly be done only within a hospital. Two, new and more expensive drugs have become available. And three, high-technology, high-cost home care is more widely used.

Let me focus first and quite briefly on the rising price of drugs. With more than half of all prescription drugs paid for out-of-pocket, this problem transcends AIDS and should not be left out of the debates on national health care reform.

The Burroughs Wellcome Co. paved the way for exorbitant pricing of AIDS drugs. This began with AZT, the first antiviral treatment for AIDS and a drug which the Federal Government played a major role in developing. It is also a drug which has generated more than $1.4 billion in sales.

Although most people think of Medicaid as public health insurance for the poor, it is also the largest, single drug purchaser in the country. Not surprisingly, it is the largest single buyer of AZT in the entire world.

It is my best estimate that the States and Federal Government combined pay for nearly 70 percent of the AZT in the United States.

And now, other drug companies have followed suit. In 1991, at least seven new drugs were approved by the FDA and are now being used to treat AIDS-related conditions. And the average annual price for these drugs exceeds $20,000 per person.

Senator RIEGLE. Now, that 20,000 per person, is that for all the drugs in combination or just to use a single drug?

Dr. ARNO. It is the average price for one drug per patient per year.

Finally, just a word on the proliferation of high-tech home care because this may be the fastest growing component of AIDS treatment costs.

By high-tech home care, I refer mainly to the privately owned and operated home infusion therapy market.

Senator RIEGLE. Can I just stop you for a minute?

Dr. ARNO. Yes.

Senator RIEGLE. Because I want to just try to cross-relate two statistics. And maybe I have them confused in my own mind. But when we were using Dr. Hellinger's statistics earlier as to the annual cost of outpatient treatment or hospitalization treatment, the figure that he developed would not have been large enough even to accommodate that drug cost that you have just cited for somebody that is going through receiving one of those drugs.

I mean, if one drug alone costs $20,000 a year roughly and somebody—did I understand you correctly?

Dr. ARNO. That is correct.

Senator RIEGLE. And if somebody is using more than one, I mean, that is driving those numbers way up there, isn't it? Isn't there a contradiction between those numbers and the numbers that Dr. Hellinger used?

Dr. ARNO. Well, I have to tell you, the numbers that I used to arrive at the $20,000 estimate were derived by Dr. Hellinger.

They reflect the retail costs in 1991 for those seven drugs that were approved by FDA. And there is a discontinuity in the figures, but this often happens when you get two economists in a room.

Senator RIEGLE. Right.

Dr. ARNO. I think we could iron them out at some point.

Senator RIEGLE. I just want to make sure that I have a clear understanding. So if there are quite different estimates here, at least we have them in the light of day and we can understand them.

Dr. ARNO. I think it also speaks to the point that Dr. Hellinger made over and over again which is that most of the costs he was referring to were derived from earlier data. And the costs that I am talking about are current costs and, therefore, reflect the higher prices that are in place right now.

Let me just go back to the proliferation of high-tech home care for a moment because this may well be even the fastest growing component of treatment costs. By high-tech home care, I refer mainly to the privately owned and operated home infusion therapy market which provides total parenteral nutrition or TPN, antibiotics, and other drugs.

There are two fundamental areas which demand immediate attention: price and efficacy. The prices are unreasonably high.

For example, Empire Blue Cross and Blue Shield has seen its TPN expenditures for AIDS patients—estimated at about $700 per day—grow dramatically from less than 1 percent of its major medical policies in 1986 to an estimated 19 percent by 1992.

Yet, the effectiveness of TPN in the treatment of AIDS and for many other illnesses is not well documented.

Senator RIEGLE. Now, that drug cost $700 a day?

Dr. ARNO. TPN is not a drug. It is a combination of fluids and nutrients that are used to try to meet an individual's nutritional needs.

Senator RIEGLE. I see. I beg your pardon.

Dr. ARNO. There have been numerous reports in the literature about the fact that the price of these services, such as TPN, in no way reflects the cost of the service.

Senator RIEGLE. Yes. I am familiar with that. I have seen that therapy used in other kinds of treatments for people with other problems.

Dr. ARNO. It is not true across the board. There may well be very important uses for it, but they have been very limited and they are very poorly documented. Yet, as the figures from Blue Cross indicate, there has been dramatic infiltration of the market, at least in New York, for the use of TPN.

In summary, we have seen substantial cost shifting take place in the financing of AIDS care from the private to the public sector.

And let nobody be fooled, cost shifting does not reduce the cost of care. It merely transfers the burden from one sector of society to another.

We have seen bureaucratic rigidities which have kept people from accessing needed health and preventive services.

We have seen uncontrolled profiteering in the pharmaceutical and home care industries. And this is a disgrace that affects all Americans and deserves immediate redress.

And finally, we have seen all these factors conspire together to harm the public health.

I call upon this committee which has played only a marginal role in dealing with AIDS over the past few years to exert some desperately needed leadership to work with the new administration and above all to provide hope, the hope born of a government that cares about its citizens.

Thank you.

[The prepared statement of Dr. Arno appears in the appendix.]

Senator RIEGLE. Thank you, Dr. Arno.

Ms. Nye.

STATEMENT OF CHRISTINE NYE, DIRECTOR, MEDICAID BUREAU, HEALTH CARE FINANCING ADMINISTRATION, WASHINGTON, DC

Ms. NYE. Good morning, Mr. Chairman.

I am Christine Nye, director of the Medicaid Bureau in the Health Care Financing Administration. I am here to testify on the impact of AIDS on the Medicare and Medicaid programs.

The impact of HIV and AIDS upon our citizens has been alarming and tragic. We estimate that the Medicaid program provides for financing of health care for at least 40 percent of all persons with AIDS and up to 90 percent of children with AIDS.

With the incidence of AIDS increasing in the high-risk injection drug-using population and in women and children, more and more persons are going to find themselves served by the Medicaid Program.

I have been asked to discuss HCFA's role in financing health care, the populations we serve, the services we cover, the program costs of serving persons with AIDS, and specific initiatives we have undertaken to improve access to care for this population.

HCFA administers the Medicaid and Medicare programs and advances service delivery options and State initiatives to enhance access to care.

Eligible persons living with AIDS or HIV infection are included among the 35 million served by Medicare and the 30 million served by Medicaid.

The Medicaid program pays for health care services for certain low-income, poor, aged, and disabled individuals and at a State's option for medically needy persons who have high medical bills relative to their income.

Thirty-six States and the District of Columbia currently provide Medicaid benefits for the medically needy.

Those single and childless adults with AIDS or a severe HIV infection who qualify for Medicaid do so by meeting the disability criteria of the Supplemental Security Income Program (SSI), which determines program eligibility through federally applied income and resource standards. This program also establishes that an individual has a physical or mental disability.

Persons living with AIDS or HIV-related conditions in families with dependent children may become eligible for Medicaid by meeting State Aid to Families with Dependent Children (AFDC), Program income and resource requirements.

Children under age 6 and pregnant women in families with incomes at or below 133 percent of the Federal poverty level are eligible for Medicaid.

Also, children age 6 and over, born after September 30, 1983, in families with incomes at or below the Federal poverty level are eligible for Medicaid.

States also have certain options in providing Medicaid to pregnant women and children under age 1 in families with incomes between 133 percent and 185 percent of the Federal poverty level.

Once a State has determined someone to be eligible for Medicaid, an individual has access to a number of basic services, including inpatient and outpatient hospital services, clinic services, laboratory and x-ray services, nurse practitioner services, nursing facility and home health services, Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services, and physician services.

Additionally, States may provide a wide range of optional services to meet the needs of persons living with AIDS or HIV infection, including home and community-based services, prescription drugs which every State covers, targeted case management services, and hospice services.

Home and community-based services allow States to offer expanded services to persons who would otherwise require institutionalization. Currently, 15 States have targeted home and community-based services to persons living with AIDS.

Combined Federal and State spending for these services reached nearly $18 million in fiscal year 91.

Home and community-based services provide case management, private duty nursing services, personal care, home mobility aids, medical supplies, home health aide services, specialized foster care services, and other services.

As of September 1992, 42 States also offered targeted case management services. Nine States specifically targeted these services to persons with AIDS or HIV-related conditions.

Thirty-five States offer hospice care under their Medicaid program. Medicaid also provides access to appropriate drug therapies.

All States offer Medicaid drug coverage of drugs sold by manufacturers who participate in the Medicaid drug rebate program. And all State Medicaid programs cover all FDA approved prescription drugs for HIV-related conditions and AIDS.

Medicare, on the other hand, is solely a federally funded and administered health insurance program for persons aged 65 and over and certain disabled people. Disabled individuals become eligible for Medicare by first qualifying for Social Security Disability Insurance (SSDI) benefits.

An individual qualifying for SSDI must wait 24 months after receiving his first benefit payments before Medicare eligibility begins.

Medicare program services include inpatient and outpatient services, skilled nursing facility care, home health care, hospice care, and physician services.

Both Medicaid and Medicare prohibit discrimination against persons living with AIDS and HIV-related conditions. Health facilities violating this law risk revocation of their Medicare and Medicaid certification.

HCFA can also take action against a State that fails to terminate a facility that violates anti-discrimination laws.

The estimated Federal Medicare and Medicaid costs of financing care and treatment of persons living with AIDS in fiscal year 1993 will reach nearly $2 billion.

Senator RIEGLE. Will reach nearly $2 billion. That is your best estimate?

Ms. NYE. Yes. For combined Federal Medicaid and Medicare expenditures. That is correct.

Senator RIEGLE. And are you going to go on and include the State part?

Ms. NYE. The Medicaid program pays almost 25 percent of the aggregate cost of all national expenditures for medical care on behalf of these individuals.

Combined Federal and State Medicaid expenditures for AIDS care in fiscal year 1993 are estimated to be about $2.5 billion. And this is just for Medicaid. These outlays are projected to reach $3.8 billion by 1997.

Medicare pays 1 to 2 percent of the total national cost of direct medical care for persons living with AIDS. The program will spend a projected $385 million in Federal funds in 1993.

Medicare's share of treatment costs is expected to increase in the future as new medical technologies and drugs enable persons living with AIDS and HIV-related conditions to meet statutorily required 24-month waiting periods for Medicare coverage under the SSDI program.

Coordination between HCFA and other entities, both inside and outside of the Federal Government, is extensive. We work closely with many groups in this endeavor.

Since States, however, have primary responsibility for the administration of the Medicaid program, HCFA works very closely with State Medicaid staff to improve access to care and financing.

For example, we have recently conducted targeted program reviews of many of the States with major problems in this area.

Another issue of growing concern, particularly among the at-risk HIV population, is the recent increase in drug-resistant TB.

Because TB disproportionately affects people with HIV infection and AIDS, we anticipate that the Medicaid program will become increasingly involved in the financing of care for those with TB.

We recently sent guidelines to all States, which describe what Medicaid can cover for this population.

HCFA's goal is to continue to work closely with States to strengthen existing programs and expand coverage of optional benefits for the care and treatment of persons living with AIDS and HIV-related conditions.

As we move to resolve problems in the current health care delivery system, we are hopeful that many of the access issues affecting uninsured and underinsured Americans will be addressed. This particularly impacts the population we are addressing today.

We look forward to working with you to meet the challenges that confront us in providing health care to all Medicaid and Medicare beneficiaries, both now and in the future.

Thank you for giving me the opportunity to speak today.

[The prepared statement of Ms. Nye appears in the appendix.]

Senator RIEGLE. Ms. Nye and Dr. Arno particularly, you probably heard the testimony of our first panel. And you are certainly familiar with the TB problem that has grown up around the country. And I am sure in New York, you are seeing that in a major way.

The first panelists were making the point that because of the nature of the way the HIV virus works that in suppressing the immune system, can, in effect, have an indirect effect of causing the fostering of other diseases to get going more broadly than they might otherwise do. And as they get loose, they can go out and infect other people.

Is that an accurate to view that problem, Dr. Arno? And if so, what——

Dr. ARNO. I could speak to it directly in terms of the resurgence of TB in New York. I think in part the data shows a dramatic increase in co-infection between TB and HIV.

From 1984 through 1990, the co-infection rates of people with TB went from somewhere like 11 percent to 46 percent.

However, I think it is unfair probably to blame the resurgence of TB on AIDS and I think more firmly, the blame——

Senator RIEGLE. I do not want to sound as if I am doing that.

Dr. ARNO. Right.

Senator RIEGLE. I am not doing that. I am really raising the question from the first panelists as to whether or not by lowering resistance to——

Dr. ARNO. Absolutely. What happens when you lower resistance for people that are exposed to TB is that you facilitate the progression from passive infection with TB to active disease. And that has been documented strongly in the literature. And that is, in fact, what is going on.

But the convergence of AIDS and TB, just to make a point, has more to do with the politics of Reaganomics and the Bush administration over the last 10 years that have led to increased poverty in their inner cities, increased homelessness, increased drug abuse, the convergence of all of these things that are conspiring to build the resurgence of TB.

Senator RIEGLE. Well, I would agree with that. And I certainly have seen that as well. And we have taken a lot of steps to try to prevent that and turn that around. And hopefully, we are going to see some major changes in policy that can help us there.

But I want to understand this question of whether there is a second level threat that starts to develop here that is hard to see, that has public health implications and, in turn, very substantial financial implications, and that is I was understanding one of our first panelists to say that if you have a situation where the nature of the HIV virus and AIDS itself in terms of lowering immune protection allows other diseases to take hold that we, in effect, suppressed previously, like TB and so forth, if that happens, can an incidence of a rise in TB, then, end up moving out into the population in a different way, in a different way than the problems of transmitting the AIDS virus directly?

Dr. ARNO. Well, TB is already moving out of the population. In New York, we have had at least 100 health care workers that were exposed to TB in the hospital. This is multiple drug-resistant TB, TB for which there is very poor prognosis.

Senator RIEGLE. I see.

Dr. ARNO. At least half the people die with it. And if they are HIV infected, the fatality rate is over 80 percent.

So it is already going on. It has happened in the prisons. It has happened in the homeless shelters. It has happened in our health care facilities. And it affects the entire public at large because we all need to access some of the facilities, such as the hospital.

Senator RIEGLE. Sure. Right. Is there anything in addition to TB that is sort of coming on the radar screen like this that we have seen? Or is TB——

Dr. ARNO. Not to my knowledge, nothing like TB. TB is a very, very serious public health threat.

Senator RIEGLE. You see, the reason that I am taking the time to press the point is that we are not doing enough to really talk to ourselves as a country and address this issue.

We are not giving people good enough information. We are not stressing the importance of it. We are not forcing it into focus and onto the radar screen.

We are not getting the kind of national leadership behind this that we should have been getting. The National Commission on AIDS has said that over and over and over again.

But I think what we are now seeing is, I think, if the public understands that they can be at risk here through a series of a chain of events in ways that they perhaps had not understood before that that creates, if you will, some very important public pressure and pressure on even our political leadership to really confront this issue, confront it much more directly in terms of all the information that we have. What methods of prevention work?

What can people can do? What knowledge do people have to have? What knowledge do children need to have?

I mean, in other words, I think in order to be able to be an informed citizenry, we have to understand these implications. And I think there is a lot of denial that is embedded in any problem that we have.

We denied the Vietnam war for years in terms of what it was doing to us. And it took a long time to finally wake up to that. You see this across many different areas.

But I think today it would alert some of the other leaders in our government and alert the public if they understood better the nature of the threat that this poses to the society is not a simple, one dimensional threat. It is more serious than that and has to be treated that way.

I mean, that is part of what I am drawing out of what I am hearing today.

Now, I do not want to overly dramatize it or to take it out of the context in which it ought to be, but it seems to me that we have two responsibilities here: number one, to get good facts to the public so that they are informed and they know what is going on and they know how they can sort of condition their own behavior in order to protect themselves and to not, in fact, either become a public health risk or what have you.

And secondly, if we have a problem here that is a burgeoning problem for all the different reasons we have talked about, higher drug prices and a lot of other things, and most of these costs now

are being shifted back through the system onto the Medicaid system, and the private insurance system, it looks to me as if they are sort of edging away as much as they can and dumping this cost off on the government and onto the citizenry, there is a huge cost problem here that also has to be faced.

There is obviously, too, just a basic equity question. I mean, I do not want people out there dying of TB or AIDS or anything else that we can somehow prevent or in some other way. If there is some other aspect of this where treatment is going to work, I want to make sure that we are on the track of seeing to it that people are getting the services they need.

So that is the spirit in which I am raising the point and trying to make sure that we have a current understanding and that we take it out of the technical language and into language that citizens might be able to understand and make some sense out of.

Dr. ARNO. Let me just make one more comment about TB, reflecting what you just said. I think denial is going on about TB across the country because like many other things, they say, "That's an epidemic. That's New York. That is not affecting us."

That is the major form of denial I see going on across the country. And that is totally illusory because TB rates are going up across the entire United States and, in fact, in countries around the world. So, number one, that is false.

Senator RIEGLE. Just from the point of view of TB being an infectious disease, how does one get TB from another person? Do we know?

Dr. ARNO. We do know. Thank you for reminding me of what I forgot and was going to mention.

Like one of the challenges that June Osborn mentioned earlier, we have a lot of difficulty. And we need a lot of creative energy and thought and resources to understand better how to improve behaviors and changes in behaviors to prevent transmission of HIV.

We do not have to do any of that with TB. We know it has been around for hundreds of years. We know very well how it is transmitted. And there is very little mystery to it.

In fact, we know how to deal with it. And the tragedy and disgrace is that we are not committing the resources to doing it.

Senator RIEGLE. Explain that. Tell us.

Dr. ARNO. Well, I am not a clinician, but TB is a lot more easy to transmit than HIV. It is spread through the air, through a drop of nuclei of TB germs that are transmitted through the air, but it requires very, very long exposure in confined quarters for one person to transmit it to another.

But that is the reason why in hospitals, there is a very serious problem since we have all forgotten about TB, the whole medical profession over the last several decades.

There has been a shut down of isolation beds. There has been a shut down of negative air pressure rooms where the TB is vented to the outside environment where it poses no danger.

We have seen the tracking of infectious multi-drug resistance TB within our congregant facilities, such as hospitals and day care centers and so forth. It requires confined exposure.

And it is not easy, but what we need to do is provide the public health infrastructure which is minimal resources for health depart-

ments around the country to provide the therapies that people need.

And if people are homeless or unable to complete their therapies, we need to be able to facilitate that. And that is where the money needs to go because without that, we will evolve more and more strains of multi-drug resistance. If that occurs, that is serious for everyone because there is no cure right now.

Senator RIEGLE. Let me ask you, Ms. Nye, one of today's witnesses indicated there may be a problem with inadequate access to certain services under Medicaid and that that may be due in part to under reimbursement, particular for physician office visits.

Can you tell us what the Medicaid program is doing to try to address that problem? Is that a real problem? I mean, just laying the cards on the table.

Ms. NYE. To say that it is not a problem would be not laying the cards on the table. It is definitely a problem, but it varies very much by State.

States can establish the reimbursement rates they provide for every provider group. And, in the non-institutional service area States have even greater flexibility.

So I could point to one State that pays $12 for a physician office visit and another State that pays $60 for a physician office visit. So it does vary greatly.

I can say though that States' responses to this particular problem as it affects persons living with AIDS have in many cases, been encouraging. There are over 20 States providing enhanced and increased reimbursement for certain services for persons living with AIDS.

I will also add that, as we examine the AIDS epidemic, and the problems of access to health care, particularly in the Medicaid population, it provides a microcosm of what changes need to be made with in the broader context of health care reform.

The situation of rates varying from State to State is a good example of how access problems correlate to States with lower reimbursement.

Senator RIEGLE. Dr. Arno, from your advantage point, let me ask you this. Most AIDS patients receiving Medicaid qualify only after they meet the strict definition of disabled under Social Security. And, of course, these individuals have to impoverish themselves in order to qualify, don't they?

Dr. ARNO. Yes.

Senator RIEGLE. And is there evidence to show that had they received treatment in the earlier stages of their disease that maybe their current health care needs would have been less severe and maybe less costly in the long run?

Dr. ARNO. Let me try to answer that in three ways—or at least two. I think the evidence is fairly clear that early intervention, which is really what you are talking about, does enhance the quality of life and does proiong survival.

Senator RIEGLE. Yes.

Dr. ARNO. I think that in terms of the cost effectiveness of early intervention, per se, we have no firm answer on that yet.

We are looking at that. We are looking at that, in fact, in the Multi-Center AIDS Cohort Study to see whether, in fact, we can measure that.

But I would say that there is two ways that it may be cost-effective. One, if we can as a society or as the government come to some understanding of what reasonable drug prices might be and have some way of enforcing that, we would go a long way towards reducing the cost. It is largely the pharmaceuticals.

And secondly, if we put up a public health perspective spin on early intervention, which I think is well warranted, which means to say that it is not just dispensing medicines, but it is really talking about an integration of primary medical care that includes treatment, monitoring, risk reduction counseling, and the whole package of services, and we call that early intervention.

Then, I think one can easily make the argument that by doing that, by putting people into a care system, we will prevent future HIV transmission.

You do not have to prevent a lot of new incidences of transmission to save an awful lot of money. As Fred said, we are talking $100,000 for lifetime cost. Blue Cross is talking $150,000 lifetime cost.

So if you can prevent future transmissions: (a) you can accomplish your public health goal of stemming the epidemic; and (b) you can make this cost-effective modality.

Senator RIEGLE. Let me thank you all for coming today and for your testimony.

We are going to take this testimony and share it, not only with the full committee, but with other committees in the Senate that have authority in this area because there are other committees that can take steps beyond the cost issues that, I think, need taking. And I want to encourage them to do that.

Thank you very much.

The committee stands in recess.

[Whereupon, the hearing was concluded at 12:40 p.m.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED

PREPARED STATEMENT OF PETER S. ARNO

Since the earliest days of the AIDS epidemic concerns have been raised about the catastrophic costs associated with AIDS treatment. Some have even suggested that AIDS would bankrupt our health care system. These fears have proven largely unfounded. AIDS is an expensive illness but not dramatically more than other life-threatening diseases. In narrow economic terms, the total direct costs of AIDS, are likely to represent between one and two percent of the nation's health care bill. This is true now and into the foreseeable future.

This is not to minimize the incalculable suffering and loss of human life associated with this epidemic. Nor is it to downplay the importance of AIDS as a public health disaster. AIDS, perhaps more than any other single issue of the last decade has exposed disturbing inequities in the health care system. Many of these are now the focus of reform efforts. These include access to care, quality of care, control of exploding health care costs and control of pharmaceutical prices.

I would like to discuss two dimensions of the economic impact of AIDS. First, financing trends and their implications both for patient care and for stemming future HIV transmission. Secondly, the rising costs of this care.

TRENDS IN THE FINANCING OF CARE: THE "MEDICAIDIZATION" OF AIDS

My colleague Jesse Green, from New York University Medical Center, and I analyzed trends in the financing of AIDS-related inpatient care in five states—California, Massachusetts, New Jersey, New York and Washington. We also looked at the 13 metropolitan areas within those states that had the greatest number of reported AIDS cases.[1,2] With the exception of Washington, all of the states increased Medicaid's share of funding for AIDS-related inpatient care (Table 1). We have called this the "Medicaidization" of AIDS. Likewise, the proportion of hospitalizations covered by private insurance declined significantly in California, Massachusetts and New York and in nine of the metropolitan areas (Table 2).

These are a few of our other findings:

- In most cases, these financing trends are not fully accounted for by demographic changes in the AIDS population. In other words, increased AIDS incidence among poor and largely minority populations, who are more likely to be covered by Medicaid, do not completely explain the shift in financing (Tables 3 and 4).
- People with AIDS are more likely to be covered by Medicaid than patients with other illnesses, even after adjusting for age, sex, and ethnic mix (Table 5).
- Patients who receive Medicaid are much more likely to be admitted to the hospital from the emergency room than people who are privately insured. For example, in California, Medicaid recipients with AIDS are more than twice as likely (55% vs. 23%) to be admitted via the emergency room than AIDS patients with private insurance (Table 6).
- Physicians are paid much less for services they provide to AIDS patients with Medicaid than those covered by private insurance. For example, a physician who receives $100 from a private insurer would receive on average $33 from Medicaid in San Francisco and $15 in New York (Table 7).

At least three factors can help explain the trend towards increasing Medicaid coverage of AIDS care.

First, the shifting demographics of the epidemic. In recent years the incidence of AIDS has grown more rapidly among poor people who are more likely to be covered

by Medicaid. This includes drug users, women and children.[3] However, as noted earlier, this does not fully account for the "Medicaidization" of AIDS.

Second, discriminatory underwriting practices by the private insurance industry and employers has led to a drop in coverage for people with AIDS or those deemed at high risk of AIDS.[4,5]

Third, and perhaps most importantly, the high rate of job loss and subsequent impoverishment qualifies many people for Medicaid.[6,7] This may become more true as survival time after diagnosis increases.

Medicaid's growing responsibility for the financing of AIDS care prompts concern for a number of reasons. First, it represents an increasing financial burden on inner-city public health care systems. Second, while Medicaid is better than no insurance at all, it does not provide the same access to care as private insurance.[8,9] As I mentioned before, Medicaid pays much lower rates to physicians than private insurance. As a result most office-based private physicians avoid or limit their acceptance of Medicaid recipients. In fact, many physicians do not include AIDS patients in their practices because of their perceived link with Medicaid. This has frustrated efforts to involve more primary care providers in AIDS treatment.

As HIV disease progresses, the use of health care services increases. This has been clearly demonstrated by Sharon Zucconi at the University of Pittsburgh and her colleagues in the Multi-center AIDS Cohort Study (MACS).[10] It is particularly true on the outpatient side even at the earliest stages of HIV infection, when CD4 counts are above 500. However, because of barriers to Medicaid coverage, thousands of persons in need of these services do not receive them. Therapeutic advances available in the outpatient setting both prolong survival and improve the quality of life. Moreover, the link between outpatient primary care, health education and risk reduction counseling affords an ideal opportunity to stem the transmission of new HIV infection.[11] Yet even with the proposed new CDC definition of AIDS there will be no guarantee of access to these essential services because of the obstacles to Medicaid eligibility that are likely to remain. This underscores an urgent call for reform in our health care system so that the provision of health care services is not based on arbitrary definition nor on one's position in the socioeconomic hierarchy but rather on meeting the personal and public health needs of our citizens.

RISING COSTS OF CARE

Let me now turn briefly to the issue of the rising costs of care. In the early days of the epidemic, many of us believed that providing community-based AIDS services would reduce the rate of hospitalization and lower costs as a result. Ten years later we find that indeed hospitalization rates have declined but outpatient costs have soared. This is in large measure because we have improved the way we treat this disease outside the hospital—at home, in the clinic or in the doctor's office. Empire Blue Cross and Blue Shield, probably the largest private insurer for persons with AIDS in the country, says the cost of outpatient services now exceeds inpatient costs for people with HIV disease (Figure 1). Why? There are three likely reasons:

First, we now treat many conditions on an outpatient basis that could formerly be done only within the confines of a hospital. Second, new and more expensive drugs have become available. Third, high-technology, high-cost home care is more widely used.

Another cost-related issue of great urgency is the rising price of drugs. With more than half of all prescription drugs paid for out-of-pocket, this problem transcends AIDS alone and should not be left out of the debates on health care reform. The Burroughs Wellcome Company paved the way for the exorbitant pricing of AIDS drugs. This began with AZT, the first antiviral treatment for AIDS, and a drug which the federal government played a major role in developing (Figure 2).[12] Other drug companies have followed suit. In 1991, at least seven drugs were approved by the FDA and are now being used to treat AIDS-related conditions (Azithromycin, Clarithromycin, ddI, EPO, Foscarnet, G-CSF, GM-CSF). The average annual price for these drugs exceeds $20,000 per person (Figure 3). Consumers, government and the private sector are all impacted by these kinds of prices. Although most people think of Medicaid as public health insurance for the poor, it is also the largest single drug purchaser in the country. Not surprisingly, it is the largest single buyer of AZT in the world. It is my best estimate that the states and federal government combined pay for nearly 70% of the AZT in the United States.

Finally, just a word on the proliferation of high-tech home care, because this may be the fastest growing component of AIDS treatment costs, at least in New York. By high-tech home care I refer mainly to the privately owned and operated home infusion therapy market, which provides total parenteral nutrition (TPN), antibiotics and other drugs. Two fundamental areas demand immediate attention—price

and efficacy. The prices are unreasonably high. For example, Empire Blue Cross and Blue Shield has seen its TPN expenditures for AIDS patients (estimated at $700 per day) grow dramatically from less than one percent of its major medical policies in 1986 to an estimated 19% by 1992.[13] Yet the effectiveness of TPN in the treatment of AIDS and many other illnesses is not well documented.

In conclusion, we have seen substantial cost shifting take place in the financing of AIDS care from the private to the public sector. Let nobody be fooled—cost shifting does not reduce the cost of care, it merely transfers the burden from one sector of society to another. We have also seen uncontrolled profiteering in the pharmaceutical and home care industries. This is a disgrace that affects all Americans and deserves immediate redress.

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TABLE 1: PERCENTAGE OF AIDS HOSPITALIZATIONS FINANCED BY MEDICAID BY STATE AND MSA

STATE/MSA	TOTAL CASES	% WITH MEDICAID BY YEAR 1983	1984	1985	1986	1987	1988	1989	TREND*
CALIFORNIA	65,905	15.8%	18.1%	27.7%	31.2%	32.8%	34.9%	34.2%	+
San Francisco	17,946	18.5%	22.5%	33.0%	33.3%	32.5%	34.9%	34.1%	+
Los Angeles	26,614	10.4%	10.3%	21.9%	29.0%	31.4%	33.2%	31.5%	+
Anaheim	2,598	15.0%	27.4%	21.3%	25.5%	28.3%	30.2%	27.9%	
San Diego	3,923	0.0%	5.4%	32.3%	34.9%	39.5%	46.9%	41.1%	+
Oakland	3,471	40.0%	38.3%	33.2%	26.6%	23.3%	36.6%	39.6%	+
Riverside	1,912	12.5%	31.4%	31.2%	31.2%	35.4%	33.0%	36.4%	
NEW YORK	67,393	35.9%	40.5%	45.0%	48.5%	51.3%	52.6%	...	+
New York City	56,919	39.1%	41.9%	47.2%	50.4%	53.0%	54.6%	...	+
Nassau/Suffolk	3,714	26.2%	16.2%	20.8%	28.1%	40.4%	42.1%	...	+
NEW JERSEY	17,564	...	...	27.3%	31.1%	29.7%	32.1%	...	+
Newark	8,099	...	...	29.2%	34.3%	32.3%	34.7%	...	+
Jersey City	2,583	...	...	19.5%	23.3%	27.8%	31.4%	...	+
Bergen/Passaic	2,446	...	...	27.3%	31.8%	32.6%	32.4%	...	
WASHINGTON	4,302	...	...	31.9%	28.0%	29.4%	26.8%	31.7%	
Seattle	3,404	...	...	30.4%	23.4%	26.3%	23.0%	28.4%	
MASSACHUSETTS	8,149	10.3%	13.9%	21.4%	24.1%	27.2%	33.1%	35.4%	+
Boston	6,191	10.0%	13.1%	19.4%	23.2%	23.9%	30.1%	31.1%	+

* + or − signifies, respectively, significant upward or downward trends ($p \leq .05$)
MSA signifies Metropolitan Statistical Area

Green & Arno, 1991

TABLE 2: PERCENTAGE OF AIDS HOSPITALIZATIONS FINANCED BY PRIVATE INSURANCE, BY STATE AND MSA

STATE/MSA	TOTAL CASES	% WITH PRIVATE INSURANCE BY YEAR							TREND*
		1983	1984	1985	1986	1987	1988	1989	
CALIFORNIA	65,905	56.0%	50.7%	43.0%	40.3%	34.8%	30.4%	29.0%	-
San Francisco	17,946	55.0%	46.3%	40.3%	38.3%	28.9%	25.8%	26.2%	-
Los Angeles	26,614	70.6%	63.1%	52.5%	47.4%	43.0%	38.3%	37.2%	-
Anaheim	2,598	20.0%	35.7%	42.0%	34.8%	37.6%	31.3%	29.8%	-
San Diego	3,923	33.3%	67.6%	40.7%	38.0%	30.5%	21.5%	17.2%	-
Oakland	3,471	0.0%	13.6%	26.9%	32.5%	34.4%	24.0%	22.5%	-
Riverside	1,912	50.0%	31.4%	36.2%	33.2%	30.8%	30.0%	24.6%	-
NEW YORK	67,393	42.9%	41.8%	36.8%	33.0%	31.9%	30.8%	...	-
New York City	56,919	44.1%	42.2%	36.3%	33.2%	32.1%	31.1%	...	-
Nassau/Suffolk	3,714	49.2%	61.1%	59.9%	45.4%	44.5%	43.6%	...	-
NEW JERSEY	17,564	...	...	28.4%	25.5%	26.6%	26.1%	...	
Newark	8,099	...	...	29.7%	24.0%	25.0%	25.7%	...	
Jersey City	2,583	...	...	31.6%	34.2%	30.0%	23.4%	...	-
Bergen/Passaic	2,446	...	...	30.1%	28.9%	31.8%	32.7%	...	
WASHINGTON	4,302	...	...	36.8%	33.2%	44.0%	47.2%	42.4%	+
Seattle	3,404	...	...	38.0%	35.0%	48.0%	52.1%	46.3%	+
MASSACHUSETTS	8,149	48.3%	52.3%	43.9%	44.0%	41.8%	36.4%	32.1%	-
Boston	6,191	52.0%	55.1%	47.5%	45.9%	46.2%	39.7%	37.6%	-

* + or - signifies, respectively, significanc upward or downward trends ($p \leq .05$)

Green and Arno, 1991

TABLE 3: YEARLY TRENDS IN PERCENTAGE OF AIDS HOSPITALIZATIONS FINANCED BY MEDICAID DEPENDING ON RACE/ETHNICITY

STATE/MSA	TOTAL CASES	% WITH MEDICAID BY YEAR 1983	1984	1985	1986	1987	1988	1989	TREND*
CALIFORNIA									
White	49,882	14.6%	17.3%	25.1%	27.4%	28.5%	29.8%	28.2%	+
Black/Hispanic	14,355	27.4%	25.0%	24.4%	47.9%	48.7%	51.2%	51.4%	+
San Francisco									
White	14,901	19.2%	21.6%	31.0%	31.8%	30.6%	32.2%	29.5%	+
Black/Hispanic	2,559	14.3%	33.3%	49.8%	48.5%	44.9%	50.2%	53.5%	+
Los Angeles									
White	18,287	8.2%	9.5%	17.7%	22.0%	23.8%	24.3%	23.1%	+
Black/Hispanic	7,717	26.9%	16.0%	37.5%	47.4%	49.9%	51.9%	48.9%	+
Anaheim									
White	2,238	15.4%	28.4%	23.5%	24.7%	27.9%	25.9%	24.2%	
Black/Hispanic	318	16.7%	0.0%	5.9%	30.4%	35.3%	60.3%	47.3%	+
San Diego									
White	3,160	0.0%	5.7%	27.5%	31.9%	38.3%	42.5%	35.5%	+
Black/Hispanic	646	0.0%	0.0%	54.6%	53.6%	50.5%	66.7%	64.4%	+
Oakland									
White	2,251	45.5%	39.7%	25.5%	18.8%	15.9%	29.1%	25.4%	
Black/Hispanic	1,118	33.3%	36.4%	59.6%	49.3%	46.7%	48.3%	59.5%	+
Riverside									
White	1,522	14.3%	32.0%	32.2%	30.1%	35.0%	32.9%	34.2%	
Black/Hispanic	368	0.0%	30.0%	26.1%	36.2%	35.0%	34.5%	44.1%	+
NEW YORK									
White	25,950	16.1%	19.3%	24.1%	25.9%	28.8%	31.1%		+
Black/Hispanic	37,265	56.3%	58.4%	59.8%	64.3%	65.6%	66.3%		+

(continued)

Green and Arno, 1991

TABLE 3 CONTINUED

STATE/MSA	TOTAL CASES	1983	1984	1985	1986	1987	1988	1989	TREND*
		% WITH MEDICAID BY YEAR							
New York City									
White	22,547	16.9%	18.7%	24.2%	24.6%	27.6%	29.8%		+
Black/Hispanic	33,086	59.2%	59.7%	61.5%	66.1%	67.0%	67.8%		+
Nassau/Suffolk									
White	2,555	22.4%	10.2%	20.6%	23.8%	31.7%	37.7%		+
Black/Hispanic	1,004	41.7%	34.1%	22.3%	44.6%	61.3%	54.1%		+
NEW JERSEY									
White	5,670			18.0%	17.7%	20.1%	21.6%		+
Black/Hispanic	11,443			33.3%	37.9%	34.9%	37.2%		
Newark									
White	1,771			17.2%	20.3%	21.3%	22.8%		
Black/Hispanic	6,236			34.1%	38.7%	35.3%	38.0%		
Jersey City									
White	992			17.9%	14.4%	24.0%	25.1%		+
Black/Hispanic	1,460			20.6%	29.9%	30.7%	36.5%		+
Bergen/Passaic									
White	991			24.8%	17.0%	20.4%	17.5%		
Black/Hispanic	1,370			30.7%	45.1%	43.1%	42.4%		
MASSACHUSETTS									
White	5,747	10.9%	10.3%	18.0%	19.2%	22.5%	27.1%	28.6%	+
Black/Hispanic	1,618	20.0%	17.9%	31.1%	39.5%	36.4%	49.5%	52.3%	+
Boston									
White	4,562	9.8%	8.1%	15.9%	20.1%	20.7%	25.1%	25.8%	+
Black/Hispanic	1,148	20.0%	18.5%	29.6%	37.8%	37.4%	48.5%	56.3%	+

* + or - signifies, respectively, significant upward or downward trends ($p \leq .05$)

Green and Arno, 1991

TABLE 4 : YEARLY TRENDS IN PERCENTAGE OF AIDS HOSPITALIZATIONS FINANCED BY PRIVATE INSURANCE DEPENDING ON RACE/ETHNICITY

STATE/MSA		TOTAL CASES	% WITH PRIVATE INSURANCE BY YEAR 1983	1984	1985	1986	1987	1988	1989	TREND*
CALIFORNIA										
	White	49,882	58.3%	53.5%	45.8%	44.2%	38.5%	34.8%	33.6%	-
	Black/Hispanic	14,355	41.9%	29.0%	27.6%	24.0%	24.5%	16.9%	15.8%	-
San Francisco										
	White	14,901	56.2%	46.9%	42.1%	39.9%	30.3%	27.8%	29.1%	-
	Black/Hispanic	2,559	57.1%	40.4%	26.3%	24.6%	20.8%	15.3%	12.1%	-
Los Angeles										
	White	18,287	72.8%	68.8%	57.4%	55.4%	51.1%	47.4%	45.9%	-
	Black/Hispanic	7,717	53.9%	31.1%	33.5%	26.1%	23.0%	19.5%	19.2%	-
Anaheim										
	White	2,238	15.4%	35.8%	43.2%	36.1%	37.1%	33.9%	31.4%	-
	Black/Hispanic	318	16.7%	50.0%	29.4%	17.4%	35.3%	11.0%	20.5%	
San Diego										
	White	3,160	25.0%	68.6%	43.5%	40.2%	33.0%	24.7%	19.5%	-
	Black/Hispanic	646	50.0%	50.0%	27.3%	25.0%	16.8%	8.1%	7.9%	-
Oakland										
	White	2,251	0.0%	19.0%	30.9%	39.5%	38.6%	29.8%	30.3%	
	Black/Hispanic	1,118	0.0%	0.0%	10.6%	11.3%	20.5%	14.0%	10.5%	
Riverside										
	White	1,522	42.9%	44.0%	43.5%	36.2%	33.3%	34.0%	27.3%	-
	Black/Hispanic	368	[illegible]%	0.0%	0.0%	19.2%	20.0%	15.5%	16.1%	
NEW YORK										
	White	25,950	64.2%	64.3%	60.6%	57.0%	56.9%	53.9%		-
	Black/Hispanic	37,265	19.3%	22.4%	18.9%	16.4%	15.9%	15.8%		-

Green and Arno, 1991

(continued)

TABLE 4 CONTINUED

STATE/MSA		TOTAL CASES	% WITH PRIVATE INSURANCE BY YEAR 1983	1984	1985	1986	1987	1988	1989	TREND*
New York City										
	White	22,547	68.7%	67.5%	63.0%	60.5%	60.2%	58.4%		-
	Black/Hispanic	33,086	21.6%	22.5%	18.6%	16.3%	16.3%	16.1%		-
Nassau/Suffolk										
	White	2,555	49.0%	64.4%	60.3%	46.1%	54.7%	49.7%		
	Black/Hispanic	1,004	50.0%	52.3%	55.3%	30.1%	21.4%	27.5%		-
NEW JERSEY										
	White	5,670			43.2%	44.4%	42.6%	44.1%		
	Black/Hispanic	11,443			19.6%	16.1%	17.6%	17.3%		
Newark										
	White	1,771			52.4%	49.6%	49.1%	52.5%		+
	Black/Hispanic	6,236			20.6%	15.2%	17.0%	16.3%		
Jersey City										
	White	992			24.4%	44.0%	35.8%	36.9%		
	Black/Hispanic	1,460			36.9%	25.8%	23.9%	14.5%		-
Bergen/Passaic										
	White	991			46.5%	46.5%	46.0%	49.3%		
	Black/Hispanic	1,370			12.3%	12.4%	19.0%	22.4%		+
MASSACHUSETTS										
	White	5,747	58.7%	56.4%	47.6%	51.6%	49.2%	44.1%	40.8%	-
	Black/Hispanic	1,618	0.0%	50.0%	37.0%	24.2%	17.8%	16.1%	11.3%	-
Boston										
	White	4,562	63.4%	60.2%	50.3%	52.4%	51.5%	46.3%	44.7%	-
	Black/Hispanic	1,148	0.0%	51.9%	42.9%	25.9%	20.3%	18.2%	15.8%	-

* + or - signifies, respectively, significant upward or downward trends ($p \leq .05$)

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TABLE 5: MEDICAID SHARE OF FINANCING FOR HOSPITAL CARE: AIDS HOSPITALIZATIONS, ALL HOSPITALIZATIONS, 1988

STATE	% MEDICAID AIDS	% MEDICAID ALL	RATIO (AIDS TO ALL)
FLORIDA	20.4%	8.9%	2.3
NEW JERSEY	32.1%	8.6%	3.7
CALIFORNIA	31.0%	17 8%	1.7
WASHINGTON	29.5%	5.5%	1.9
NEW YORK	52.6%	18.2%	2.9
MASSACHUSETTS	30.3%	9.1%	3.3
WEIGHTED AVERAGE	38.3%	14.7%	2.6

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TABLE 6 : SOURCE OF ADMISSION BY PAYER (MEDICAID VS. PRIVATE INSURANCE)

PERCENTAGE OF PATIENTS ADMITTED TO THE HOSPITAL VIA:

LOCATION	EMERGENCY ROOM MEDICAID	EMERGENCY ROOM PRIVATE	PHYSICIAN REFERRAL MEDICAID	PHYSICIAN REFERRAL PRIVATE	OTHER* MEDICAID	OTHER* PRIVATE
CALIFORNIA	54.6%	23.1%	39.6%	73.7%	5.8%	3.2%
Los Angeles	54.5%	17.3%	42.0%	80.7%	3.5%	2.0%
San Fransisco	59.4%	27.8%	35.2%	69.[illegible]%	5.4%	3.1%
Anaheim	63.2%	35.6%	34.7%	61.8%	2.1%	2.6%
San Diego	59.1%	32.3%	39.2%	65.6%	1.7%	2.2%
Oakland	46.3%	26.2%	39.6%	68.4%	14.1%	5.4%
Riverside	57.0%	36.5%	40.3%	61.5%	2.[illegible]	2.0%
NEW YORK STATE	66.2%	35.8%	15.1%	36.8%	18.8%	27.4%
New York City	68.2%	45.6%	13.7%	37.1%	18.1%	17.3%
Nassau/Suffolk	39.5%	38.7%	23.7%	24.5%	36.9%	36.8%
NEW JERSEY	56.9%	46.2%	30.8%	46.2%	12.2%	7.6%
Newark	61.5%	43.6%	22.9%	45.6%	15.7%	10.9%
Jersey City	66.1%	50.1%	21.5%	45.4%	12.4%	4.5%
Bergen/Passaic	52.9%	52.2%	43.9%	45.8%	3.2%	2.0%
MASSACHUSETTS	64.4%	54.1%	24.0%	32.9%	11.7%	13.0%
Boston	67.4%	55.6%	21.0%	31.1%	11.7%	13.3%

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(continued)

TABLE 6 CONTINUED

PERCENTAGE OF PATIENTS ADMITTED TO THE HOSPITAL VIA:

LOCATION	EMERGENCY ROOM MEDICAID	EMERGENCY ROOM PRIVATE	PHYSICIAN REFERRAL MEDICAID	PHYSICIAN REFERRAL PRIVATE	OTHER* MEDICAID	OTHER* PRIVATE
WASHINGTON	10.[illegible]	27.4%	42.8%	65.2%	46.5%	7.5%
Seattle	44.6%	27.2%	40.8%	65.0%	14.5%	7.8%
FLORIDA	56.2%	32.5%	27.0%	59.0%	16.8%	8.5%
Miami	52.6%	26.5%	20.2%	62.1%	27.2%	11.5%
Fort Lauderdale	77.8%	38.7%	17.9%	55.3%	4.3%	6.0%
West Palm Beach	59.2%	40.4%	19.1%	48.1%	21.7%	11.5%

* Other includes admissions with source such as transfers from hospitals or nursing homes.

Differences in the distribution of source across payers in each state and city are significant at $p \leq .005$ except for Nassau/Suffolk which is significant at $p \leq .05$.

NOTE: New York data are for 1986-1988 because source of admission data were first collected in 1986. California data are for 1983-1989. New Jersey data are for 1985-1988. Massachusetts data are for 1983-1989. Washington data are for 1985-1989. Florida data are for 1988 to November 1989.

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TABLE 7 -PAYMENT RATES TO PHYSICIANS FOR COMMON AIDS-RELATED SERVICES: COMPARISON OF MEDICAID AND PRIVATE INSURANCE*

SERVICE PROVIDED	NEW YORK MEDICAID RATE, $	NEW YORK PRIVATE INSURANCE RATE, $	NEW YORK MEDICAID TO PRIVATE INSURANCE RATIO	SAN FRANCISCO MEDICAID RATE, $	SAN FRANCISCO PRIVATE INSURANCE RATE, $	SAN FRANCISCO MEDICAID TO PRIVATE INSURANCE RATIO
INTERMEDIATE OFFICE VISIT NEW PATIENT	11	84	.13	46	85	.54
INTERMEDIATE OFFICE VISIT ESTABLISHED PATIENT	11	57	.19	18	49	.37
INITIAL HOSPITAL VISIT WITH HISTORY & PHYSICAL	20	120	.17	46	147	.31
SUBSEQUENT HOSPITAL VISIT	8	63	.13	28	65	.43
BRONCHOSCOPY	60	775	.08	146	329	.28
BONE MARROW BIOPSY	12	173	.07	45	76	.26
ENDOSCOPY FOR BIOPSY	20	144	.14	45	163	.28
COLONOSCOPY FOR BIOPSY	160	698	.23	290	794	.37
CHEMOTHERAPY BY INFUSION	35	71	.49	12	28	.43
SIMPLE AVERAGE	37	243	.15	74	226	.33

* Rates are rounded to the nearest whole dollar. Private insurance rates are from Empire Blue Cross/Blue Shield of New York and Blue Cross of California and rates are based on the 75th percentile of physician charges. New York rates are for Manhattan. Rates in Los Angeles (not shown) were very close to those in San Francisco.

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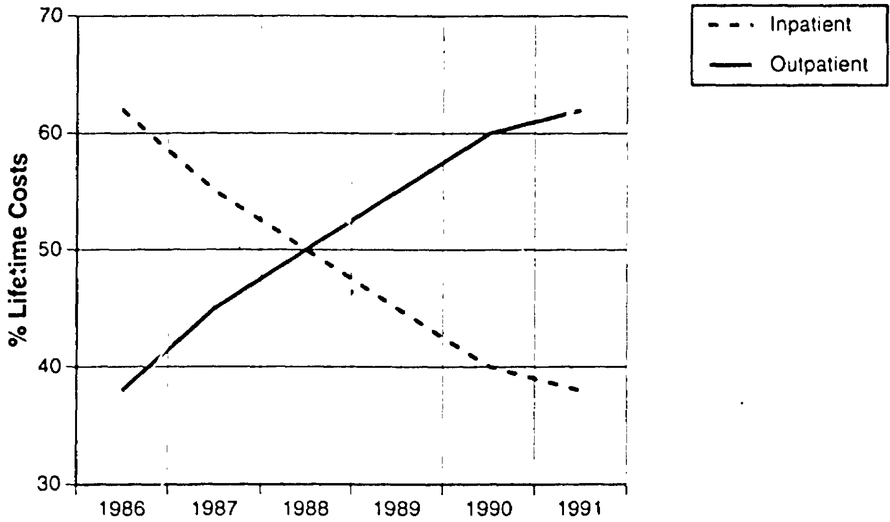
Figure 1

AIDS INPATIENT VS. OUTPATIENT LIFETIME TREATMENT COSTS, 1986–1991

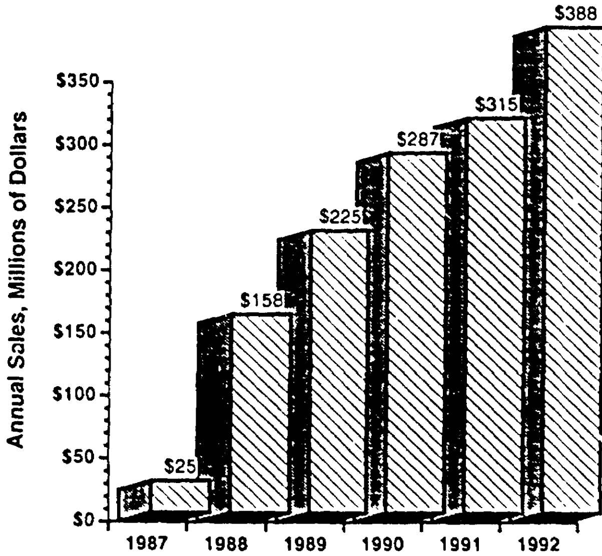


Source. Jon Eisenhandler, Ph D , Empire Blue Cross/Blue Shield

Peter S. Arno, Ph D
Montefiore Medical Center
Albert Einstein College of Medicine

Figure 2

BURROUGHS WELLCOME AZT SALES TOTAL, 1987-1992 = $1.4 BILLION



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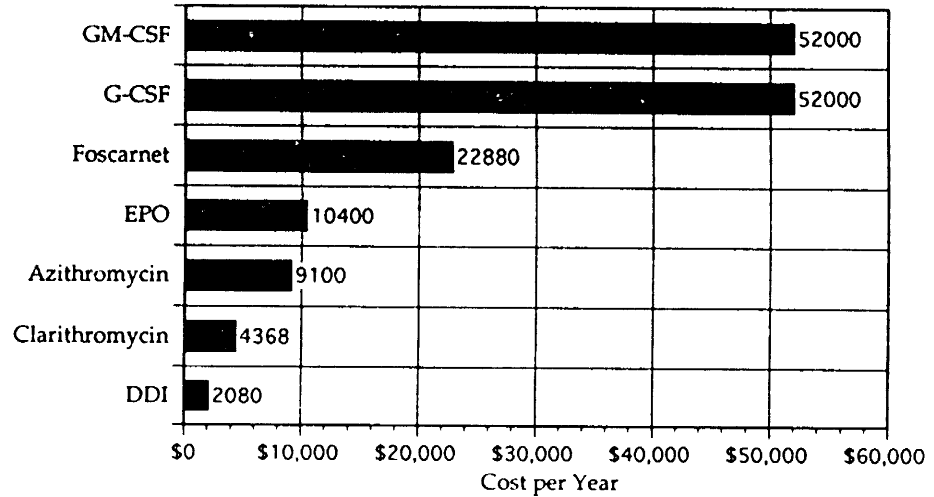
Montefiore Medical Center
Albert Einstein College of Medicine

Figure 3

Selected Drugs Used to Treat HIV Disease
Retail Cost per Year



Source: Fred Helliner, Ph D., *Inquiry* 1992,29 363

PREPARED STATEMENT OF FRED J. HELLINGER

Good morning Mr. Chairman. I am Dr. Fred Hellinger, Director of the Division of Cost and Financing in the Agency for Health Care Policy and Research (AHCPR), an agency in the Public Health Service. I am pleased to be here this morning to discuss my research on the costs of medical treatment for persons infected with human immunodeficiency virus (HIV), including those diagnosed with AIDS.

Research findings that I will present today are based in part on the AIDS Cost and Service Utilization Survey (ACSUS). This AHCPR-funded survey collects data on medical services used by persons with HIV. In addition to tracking the economic effects of AIDS and HIV, AHCPR sponsors research on the quality of care and access to services for persons with AIDS and HIV-related conditions and on the effectiveness of medical treatment. AHCPR also is sponsoring the development of a clinical practice guideline on the initial evaluation and early management of HIV-positive individuals. AHCPR's research activities on HIV are aimed at increasing understanding of the costs and delivery of medical services to infected persons and on enhancing effective and appropriate treatment for those individuals.

SUMMARY OF STUDY FINDINGS

With respect to the costs of treating HIV infected persons, data from ACSUS and other sources have shown that the cumulative or national cost of treating all persons with the HIV rose considerably over the past year, and I predict that costs will continue to rise over the next several years. I forecast that the cumulative cost of treating all persons with HIV will increase 48 percent from 1992 to 1995 (from $10.3 billion to $15.2 billion).

Available information indicates that both the average cost of treating a person with AIDS and the average cost of treating an individual with HIV without AIDS are higher than calculated in recent studies.

I estimate that the average yearly cost of treating a person with AIDS is $38,300, and that the average yearly cost of treating an infected person without AIDS is $10,000. The lifetime cost of treating an AIDS patient is calculated to be $102,000.

For purposes of forecasting the costs of treating persons with HIV, three categories were designated for people living with HIV:

(1) those with AIDS (based on the 1987 definition by the Centers for Disease Control and Prevention (CDC));

(2) those without AIDS but who have T-cell counts below 200; and,

(3) those without AIDS but who have T-cell counts equal to or greater than 200.

Available evidence suggests that the number of persons with HIV without an AIDS defining illness receiving treatment for HIV is equal to about twice the number of persons with AIDS. In addition, I estimate that the number of people with HIV without AIDS receiving treatment for HIV is evenly divided among those who have T-cell counts below 200 and those with T-cell counts equal to or greater than 200.

I estimate that the average yearly cost of treating an infected person without AIDS with a T-cell count below 200 is $13,525, and of treating an infected person without AIDS with a T-cell count equal to or greater than 200 is $6,444.

My estimates only include what are referred to as "personal medical care costs" (hospital, physician, drug, nursing home, and home health care). "Nonpersonal medical care costs" such as testing, education, and non-medical support services (transportation, housing, employment assistance, and benefits counseling), and the indirect costs of HIV/AIDS measured by lost productivity are excluded.

DATA SOURCES

My estimates are the first to use data from the ACSUS. The ACSUS is a comprehensive examination of the health services used by approximately 2,000 persons with HIV in ten cities. The survey involved six interviews with each of approximately 2,000 respondents (500 asymptomatic, 750 symptomatic, and 750 persons with AIDS) over an eighteen month period from spring 1991 to fall 1992. Of these respondents, there were 350 women, 700 male intravenous drug users, and 950 homosexual/bisexual individuals.

Respondents in the ACSUS were enrolled at 27 sites (e.g., hospital inpatient wards, hospital outpatient clinics, private clinics, and physician offices) in ten cities (Baltimore, Chicago, Houston, Los Angeles, Miami, Newark, New York, Philadelphia, San Francisco, and Tampa). The interview data were supplemented with information from provider bills (e.g. hospital, clinic, pharmacy, home health, and nursing home bills) and medical records. Data from the first wave of ACSUS interviews (March 1991 to July 1991) were used to help construct the estimates that I present today.

Data from other sources including the Multicenter AIDS Cohort Study (MACS) sponsored by the National Institute of Allergy and Infectious Diseases, the Adult/Adolescent Spectrum of Disease Study sponsored by CDC, the New York State Department of Health, the California Department of Health Services, the Florida Medicaid Program, and the Governor's Committee on AIDS in Hawaii also were used.

PROJECTING THE NUMBER OF AIDS CASES

The number of AIDS cases was projected for the years 1992 through 1995 using two models and a data set comprised of the number of AIDS cases reported to the CDC during the 102 four-week periods from January 1984 to November 1991 (CDC, Morbidity and Mortality Weekly Report, volumes 35 to 40, issue no. 52 of each volume). Based on these models and data, the number of AIDS cases is projected to be 66,300 in 1992, 76,300 in 1993, 86,800 in 1994, and 97,800 in 1995.

PROJECTING THE NUMBER OF PEOPLE WITH HIV RECEIVING MEDICAL CARE

Based on the CDC AIDS case definition, one-third of all people with HIV receiving medical care have AIDS, one-third have T-cell counts below 200 (and do not have AIDS), and the remaining one-third have T-cell counts equal to or greater than 200 (and do not have AIDS). Evidence supporting these estimates comes from an array of sources including the Adult/Adolescent Spectrum of HIV Disease study (AASD). The AASD began active surveillance at more than 50 sites in nine cities during 1990. Medical records obtained on 7,635 HIV-infected individuals revealed that for every person with AIDS at these sites, two

additional persons with HIV were receiving medical services. (Farizo, Karen; Buehler, James; Chamberland, M.; et al. "Spectrum of Disease in Persons with Human Immunodeficiency Virus Infection in the United States" Journal of the American Medical Association, volume 267, number 13, April 1, 1992, pp. 1798-1805.)

Data presented in a recent article that I authored also showed that the number of people with HIV without AIDS receiving medical care was equal to approximately twice the number of persons with AIDS receiving medical services (Hellinger, Fred J., "Forecasting the Medical Care Costs of the HIV Epidemic: 1991-1994", Inquiry, volume 28, Fall 1991, pp. 213-225). This article presented data from ten sources including data from the state of Hawaii, the San Francisco City Clinic Hepatitis B Study, and numerous clinics and hospitals.

Data from the MACS reveal that the ratio of the number of persons with T-cell counts less than 200 without AIDS to persons with AIDS is 1.28 (Schrager, Lewis, "Cost and Utilization Issues--the MACS presented at the HIV-AIDS Health Services Research and Delivery Conference sponsored by AHCPR and HRSA, U.S. Public Health Service, Miami, Florida, December 5, 1991). This figure is an overestimate of the ratio of the number of infected persons with T-cell counts less than 200 who receive medical care for their illness to the number of persons with AIDS because some infected persons with T-cell counts less than 200 may not have become aware of their infection had they not enrolled in the MACS. For the projections being discussed today, I estimate that the ratio of persons with T-cell counts less than 200 without AIDS to persons with AIDS is equal to one.

FORECASTING INDIVIDUAL TREATMENT COSTS

Estimates of the lifetime costs of treating a person with AIDS have ranged from $27,751 to $147,000. ("Lifetime" in this context means from the time of an AIDS diagnosis until death.) Recent estimates have narrowed the range of estimates from $40,000 to $85,000 with most at the high end of this range. The "costs" of medical care in these studies represent the cost of care to the purchaser of health services and usually represent payments from insurers to health care providers.

The following method was used to estimate the treatment cost for a person with AIDS and the treatment cost for a person with HIV who has not been diagnosed with AIDS.

PERSONS WITH AIDS

The inpatient hospital cost of treating an AIDS patient during a year is derived by multiplying estimates of the average length of stay, the average charge per day, and the number of hospitalizations. An estimate of outpatient services is then added to the estimate of inpatient costs to calculate the total cost of treating a person with AIDS during a calendar year.

Average Length of Stay (ALOS)
The average length of a hospital stay for a Medicaid patient with AIDS in Florida was 15 days in 1990 (LaCrosse, James, AIDS Caseloads and Expenditures in Florida, The Florida Legislature, Joint Legislative Management Committee, Tallahassee, Florida, November 1991). In New York State, the ALOS for a person with AIDS hospitalized during 1990 was 19.2 days (New York State Department of Health, AIDS in New York State Through 1990, Albany, New York, 1991). Data from the California Department of Health Services revealed that the ALOS for a Medi-Cal

recipient hospitalized with AIDS was 11.6 days in fiscal year 1989 (Hiehle, Gene; Maxfield, William T.; and Kizer, Kenneth W., Medi-Cal Studies in AIDS Demographics and Expenditures for Per[illegible] with AIDS, 1980-1989, California Department of Health Se[illegible]es, Sacramento, California, March 1990), and data provided in a report issued by the Governor's Committee on AIDS in Hawaii indicated the ALOS for a person with AIDS was 17.4 days in early 1990 (Governors Committee on AIDS, Costs of Care Estimates for Hawaii HIV-Infected and AIDS Patients, Honolulu, Hawaii, June 5, 1990).

The only recent data from a national survey is from the ACSUS for the period from March to July 1991. The ALOS for the 677 people with AIDS in the ACSUS was 16.3 days. I use 16.3 days as my estimate for the average length of staff for a person with AIDS.

Average Hospital Charge Per Day
The average hospital charge per day for a person with AIDS in New York State rose from $921 in 1989 to $1,004 in 1990 (New York State Department of Health, op.cit. 1991). The average charge in 1989 for a hospital day of care in California for a person with AIDS was $1,150 (Hiehle [illegible] al., 1990). Based on these studies, I use $1,100 as my estimate for the average charge for a hospital day.

Number of Hospitalizations Per Calendar Year
The 1985 and 1987 National Public Health and Hospitals Institute (NPHHI) surveys found that the number of hospitalizations per AIDS patient was 1.6 (Andrulis, Dennis P.; Beers, Virginia S.; Bentley, James D.; and Gage, Larry S., "The Provision and Financing of Medical Care for AIDS in U.S. Public and Private Teaching Hospitals", Journal of the American Medical Association, volume 258, number 10, September 11, 1987, pp. 1343-1346; and Andrulis, Dennis P.; Beers, Virginia S.; and Gage, Larry S., "The 1987 U.S. Hospital AIDS Survey", Journal of the American Medical Association, volume 262, number 6, August 11, 1989, pp. 784-794). The 1988 NPHHI survey found it to be 1.7 (Andrulis and Rathbun, op.cit., 1991). Data from the New York State Department of Health indicate that the number of hospitalizations per AIDS patient was 1.6 in both 1989 and in 1990. I deduce that the average number of hospitalizations per AIDS patient during a calendar year is 1.6.

Inpatient Costs
Using the estimates presented in the preceding paragraphs implies that the inpatient cost of treating a person with AIDS alive during any part of a year is $28,700 (16.3 days x $1,100 x 1.6 hospitalizations/year). This figure is higher than recent estimates because of longer estimates for the average length of stay and increased estimates of the average hospital charge per day.

Outpatient Costs
In New York State, outpatient care constituted 12 percent of total costs in 1988, 22 percent in 1989, and 18 percent in 1990. Although the proportion of cost attributable to outpatient care fell between 1989 and 1990 in New York State, the absolute amount of outpatient costs rose from $158 million to $174 million because the amount spent on medical care costs for AIDS rose 28 percent from $768 million in 1989 to $986 million in 1990 (New York State Department of Health, op.cit. 1991).

In California, outpatient services comprised 27 percent of all Medi-Cal expenditures for persons with AIDS in fiscal year 1989, 25 percent in fiscal year 1988, and 17.5 percent in fiscal year 1987. A report issued by the Florida legislature in November 1991 found that outpatient care comprised 6 percent

of medical care costs to treat persons with AIDS on Medicaid in 1988, 19 percent in 1989, and 23 percent in 1990 (LaCrosse, op.cit.). This report predicted that this figure will rise to 24 percent in 1991 and 26 percent in 1992.

Based on these studies, outpatient care (i.e., $9,600) constitutes 25 percent of the total cost of care. Using information provided in reports from New York State and California, the cost of the components of outpatient care are estimated to be: $3,660 for outpatient hospital, clinic or physician visits; $420 for long term care costs; $1,460 for home care costs; and $4,060 for outpatient drugs.

Lifetime Treatment Costs Per Person with AIDS
The preceding analysis indicates that the cost of treating a person with AIDS alive during any part of a year is $38,300 ($28,700 for inpatient care plus $9,600 for outpatient services). It is estimated that the mean survival of a person with AIDS from the time of diagnosis of an AIDS defining illness until death is 20 months, and that the lifetime cost of treating a person with AIDS is $102,000. This is higher than recent estimates and reflects enhanced longevity, higher hospital charges per day, and slightly longer lengths of stay.

Data from the San Francisco Department of Public Health indicate that the mean survival time of 4,994 individuals diagnosed with AIDS between 1988 and 1990 was 19.24 months (Lemp, George, San Francisco Department of Public Health, personal communication, December 16, 1991). Most estimates of survival of persons with AIDS are reported as medians (the length of time below (or above) which 50 percent of persons with AIDS will survive). Mean survival estimates (the average number of months lived by a person with AIDS) are used to derive cost estimates because each month of survival involves the use of medical care resources. The ratio of the mean to the median survival for persons with AIDS was estimated to be 1.09 in San Francisco (San Francisco Department of Public Health, AIDS in San Francisco: Status Report for Fiscal Year 1987-88 and Projections of Service Needs and Costs for 1988-1993, San Francisco, California, April 22, 1988).

Recent data from the New York City Department of Health (Blum, Steve (Office of Epidemiological Research, New York City Department of Health), personal communication, December 12, 1991) indicate that the median survival for someone diagnosed with AIDS is 18 months. Assuming that the ratio of the mean to median survival is 1.09 implies that the mean survival time is 19.6 months (1.09 x 18).

If the number of people that contract AIDS during the year occurs at a constant rate and the mean survival time is 20 months, then the average number of months lived by a person with AIDS alive during any part of a year is 7.5 months (Hellinger, op.cit., 1991) My analysis estimates that the average medical care cost of treating a person with AIDS alive during any part of a year is $38,300. If the average number of months lived by a person with AIDS alive during any part of the year is 7.5, then the average cost per month of treating a person with AIDS is $5,100, and the average lifetime cost of treatment is $102,000 ($5,100/month x 20 months).

INFECTED INDIVIDUALS WITHOUT AIDS WITH T-CELL COUNTS LESS THAN 200

I estimate that the average cost of treating an infected person without AIDS with a T-cell count less than 200 is $13,525 per

year. My estimate is derived from data collected from the MACS and the ACSUS, and is the sum of inpatient care ($7,603), outpatient care ($3,001), home health care ($423) and drug costs ($2,498). This is slightly more than one-third of the cost of treating a person with AIDS ($38,300). The $13,525 estimate is higher than most existing estimates of the average cost of treating an infected person without AIDS.

INFECTED INDIVIDUALS WITHOUT AIDS WITH T-CELL COUNTS EQUAL TO OR GREATER THAN 200

I estimate that the medical care costs of treating an infected person with a T-cell count equal to or greater than 200 without AIDS is $6,444. This estimate also is derived using data from the MACS and ACSUS, and is the sum of the following components of costs: inpatient ($2,323); outpatient care ($2,635); home health care ($81); and drugs ($1,405).

FORECASTING CUMULATIVE (NATIONAL) TREATMENT COSTS

As stated earlier, I estimate the cost of treating a person with AIDS alive during any part of a calendar year to be $38,300. To obtain an estimate of the national cost of treating persons with AIDS in 1992, I multiplied $38,300 by the number of persons expected to be alive with AIDS at any time during 1992 (i.e., 176,789 persons). Using these figures, I estimate that it will cost $6.771 billion in 1992 to treat all persons with AIDS. Estimates for the national cost of treating persons with AIDS in future years were constructed in a similar fashion.

I calculated that the cost of treating a person with HIV without AIDS and with a T-cell count below 200 is $13,525 per calendar year. I also approximated that the number of persons with HIV without AIDS with a T-cell count below 200 receiving medical care equals the number of persons with AIDS. To obtain an estimate of the cumulative cost of treating people with HIV without AIDS and T-cell counts below 200, I multiplied the cost of treatment ($13,525) by the expected number of persons under treatment. Thus, the cost of treating this population is forecast to be $2.391 billion in 1992 and $3.527 billion in 1995.

The cost of treating a person with HIV without AIDS and a T-cell count equal to or greater than 200 was calculated to be $6,444 per calendar year. It is forecast that the number of people in this group that receive treatment is equal to the number of persons with AIDS. Thus, to obtain an estimate of the cumulative cost of treating persons with HIV without AIDS with T-cell counts equal to or greater than 200, the cost of treatment per person ($6,444) is multiplied by the expected number of persons under treatment. The cumulative cost of medical care for this population is estimated to be $1.139 billion in 1992 and $1.681 billion in 1995.

The following table displays the cumulative projected costs of treating all persons with HIV in 1991 dollars.

(Dollars in billions)

	1992	1993	1994	1995
Cost of treating people with AIDS	$6.771	$7.782	$8.865	$9.990
Cost of treating people with HIV without AIDS and T-cell count below 200	$2.391	$2.748	$3.131	$3.528
Cost of treating people with HIV without AIDS and T-cell count equal to or greater than 200	$1.139	$1.310	$1.492	$1.681
Cost of treating all people with HIV	**$10.301**	**$11.840**	**$13.488**	**$15.199**
Percentage increase in cost of treating all people with HIV		15.0	13.9	12.7

As shown in the table, the cost of treating all people with HIV is forecast to rise 48 percent from $10.3 billion in 1992 to $15.2 billion in 1995. The rate of increase during these years is expected to decrease from 15.0 percent in 1993, to 13.9 percent in 1994 and to 12.7 percent in 1995.

Further, the cumulative cost of treating persons with AIDS using a definition of AIDS that adds all people with HIV with a T-cell count less than 200 is about 35 percent greater than the cost of treating persons with AIDS under the current definition. The cost of treating persons with AIDS in 1992 is forecast to be $6.772 billion under the current definition and $9.163 billion ($6.772 billion + $2.391 billion) if all infected people with T-cell counts below 200 are included. It is important to note that these health care costs would be incurred regardless of one's definition of AIDS.

DISCUSSION

It is vital to obtain timely data in order to assess the cost and scope of the HIV epidemic because treatment patterns for persons with HIV change rapidly, and changes in treatment patterns affect the cost of treatment. For example, the cost paid by individuals or insurers of prescription drugs used to treat persons with AIDS more than doubled between 1988 and 1989 in New York State. Preliminary data from ACSUS now suggest that the cost of drugs used to treat an individual with AIDS has risen over the past 18 months. These increases are due to the increase in the average number of drugs taken by an individual with AIDS and an increase in the number of persons with AIDS.

In addition, preliminary data from ACSUS also suggest that hospitalization rates for persons with AIDS have fallen over the past 18 months.

Estimates of the cost of treating a person with AIDS have climbed steadily over the past few years. In 1991, I estimated that the "lifetime" (i.e., from AIDS diagnosis until death) cost of treating a person with AIDS was $57,000 in 1988, $75,000 in 1990, and $85,333 (Hellinger, op.cit.). In 1992, I estimate that the lifetime cost is now $102,000. The soaring cost of care is epitomized by the experience of Empire Blue Cross/Blue Shield, the single largest private insurer of persons with HIV, whose cost of care per person from the time of HIV infection until death increased from $75,000 in the mid-1980s to more than $150,000 in 1991.

One year ago, I estimated that the yearly cost of treating a person with AIDS was $32,000, and that the average cost of treating an individual with HIV without AIDS was $5,100 (Hellinger, op.cit., 1991). I now estimate that the yearly cost of treating a person with AIDS is $38,300, and that the average cost of treating an individual with HIV without AIDS is about $10,000.

The widespread use of expensive drugs has contributed to the high costs of treating persons with HIV. AZT was approved for use in persons with T-cell counts below 500 in March 1990, and ddI was approved in October 1991 to treat HIV in persons who cannot use AZT. Patients using AZT often experience anemia (low red blood cell count) and neutropenia (low white blood cell count). Epoetin Alfa (brand name Procrit) was approved in January 1991 to treat low red blood cell counts in patients with HIV. This drug costs about $200 a week for three 7,000 unit doses. G-CSF (granulocyte colony stimulating factor) was approved in February 1991 to treat cancer patients with neutropenia, but also is used to treat neutropenia in persons with HIV by some physicians. This drug costs about $1,000 a week.

I have approximated that the lifetime cost of treating a person with AIDS is estimated to be $102,000. This is about twice the estimated lifetime cost of treating a woman with breast cancer ($52,000), and five times the estimated lifetime cost of treating a person with lung cancer ($20,000). It is less than the estimated $175,000 lifetime cost of treating a person with end stage renal disease. However, the cost of treating all persons with HIV is estimated to be considerably more than the $5.4 billion spent to treat persons with end stage renal disease. This is due primarily to the greater number of persons with HIV receiving medical care.

Although HIV is an expensive disease, it is expected to consume only 1.3 percent of the dollars spent on health care in 1992 ($10.3 billion of an estimated $817 billion). Yet, expenditures on medical care for persons with HIV are forecast to increase 48 percent from 1992 to 1995 (from $10.3 to $15.2 billion), and the proportion of health care spending attributable to HIV is also likely to increase during this time period. All cost increases are due to the projected number of persons with HIV receiving medical care.

That concludes my testimony, Mr. Chairman. I would be happy to answer any question the Subcommittee may have.

PREPARED STATEMENT OF CHRISTINE NYE

Good morning Mr. Chairman, members of the Committee. I am Christine Nye, Director of the Medicaid Bureau in the Health Care Financing Administration (HCFA) and am here to testify on the impact of AIDS on the Medicaid and Medicare programs.

The impact of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) upon our citizens has been alarming and tragic. The Centers for Disease Control and Prevention (CDC) reports that about one million Americans are infected with HIV; that approximately a quarter million people have been diagnosed with acquired immunodeficiency syndrome (AIDS); and that over 160,000 have died of the disease.

HCFA estimates that the Medicaid program alone provides for the financing of health care to at least 40 percent of all persons with AIDS and up to 90 percent of all children with AIDS. With the incidence of AIDS increasing in the high-risk injection drug-using population, and in women and children, more and more individuals will come to be served by this Federal and State supported program.

Today I would like to define for you HCFA's role in the financing of health care, the populations we serve, the services we cover, the program costs of serving persons with AIDS, and specific initiatives being employed by HCFA to enhance care to this vulnerable population.

HCFA'S ROLE

HCFA is charged with the administration of the Medicare and Medicaid programs that provide financing of health care benefits for many elderly, low-income, blind and disabled individuals including eligible persons living with AIDS or HIV-related conditions. The agency's role is to implement its Federal programs, coordinate service delivery options, and encourage State initiatives that enhance access to care for all those eligible for its programs.

Eligible persons living with AIDS or HIV-related condition are included among the estimated 35 million served by Medicare and the estimated 30 million served by Medicaid. However, the confirmation of a specific disease or medical condition generally is not, itself, sufficient cause for establishing eligibility in these programs.

MEDICAID/MEDICARE ELIGIBILITY AND SERVICES

The Medicaid program, as you know, is a joint Federal/State program that pays for health care services for eligible low-income individuals, poor, aged, and disabled individuals, and, at the option of each State, medically needy individuals. Medically needy individuals are those with high medical bills relative to their ability to pay—including persons living with AIDS or HIV-related condition.

Medically needy individuals may "spend down" to Medicaid eligibility by incurring medical expenses that reduce their incomes to a State-specified level. Thirty-six States and the District of Columbia provided Medicaid benefits through a medically needy program.

Most single and childless adults with AIDS or a severe HIV-related condition qualify for Medicaid by meeting the disability criteria of the Supplemental Security Income (SSI) program which determines program eligibility through Federally applied income and resource standards. This determination must also establish that an individual has a physical or mental disability which will prevent him or her from engaging in substantial, gainful activity (SGA) for at least one year.

Persons living with AIDS or HIV-related conditions in families with dependent children may become eligible for Medicaid by meeting State Aid to Families with Dependent Children (AFDC) program income and resource requirements.

Children under age 6 and pregnant women in families with incomes at or below 133 percent of the Federal poverty level (FPL) are eligible for Medicaid. Children over age 6, born after September 30, 1983, in families with income at or below the Federal poverty level, are also eligible for Medicaid.

And, at a State's option, pregnant women and infants under age 1 may qualify if they are in families with incomes between 133 and 185 percent of the FPL.

Once a State has determined Medicaid eligibility, an individual will have access to a number of basic services. These mandatory services include: inpatient and outpatient hospital services; rural health clinic services; laboratory and x-ray services; nurse practitioner services; nursing facility and home health services; early and periodic screening, diagnosis and treatment (EPSDT) services; and physician services. The EPSDT program provides comprehensive health care services to children under age 21.

In addition to these basic services, States may provide a wide range of optional services to meet the needs of AIDS recipients including home and community based waiver (HCBW) services, prescription drugs, targeted case management services, and hospice services.

HCBW services allow States to offer expanded services to persons living with AIDS and, in some cases, persons with HIV-related conditions. Individuals served must be Medicaid eligible persons who would, without the waiver services, require institutionalization paid for by Medicaid.

In the past year, HCFA has streamlined the waiver application process to expedite the implementation of HCBW programs. To date, we also have approved 15 State HCBW services targeted to persons living with AIDS.

Some of the services provided under these waivers include case management, private duty nursing services, personal care, home mobility aides, medical supplies, home health aide services, and specialized foster care services.

These waiver programs are approved for an initial 3-year term and may be renewed at State option if the State meets certain requirements. Cost neutrality is an important consideration and States must provide services only to those who would otherwise need equally or more costly Medicaid institutional care. In FY 1991, Federal and State Medicaid spending for AIDS waiver programs cost nearly $18 million.

Case management services allow States to target groups of eligible people to help them gain access to needed medical, social, health educational and other services. As of September 1992, 42 States offered targeted case management services, with eight States specifically targeting persons living with AIDS or HIV-related condition.

Hospice programs, too, are important services that provide comprehensive care to the terminally ill and include extensive coverage of home care, physician services, nursing care, medical appliances and supplies, home health aide and homemaker services, therapies, medical social services and counseling. Currently 35 States offer hospice care services under their Medicaid programs.

Medicaid also provides eligible persons with AIDS or HIV infection access to appropriate drug therapies. States offering optional drug coverage under their Medicaid plans must cover all drugs of any manufacturer who has signed a rebate agreement with the Secretary of Health and Human Services. Currently, all State Medicaid programs cover all Food and Drug Administration (FDA) approved prescription drugs for HIV-related conditions and AIDS.

States can also cover experimental drugs at their discretion. HCFA, however, does not mandate that States cover these drugs because they are not approved by the FDA.

Medicare, on the other hand, is solely a Federal health care insurance program for the people age 65 and over and certain disabled people. These disabled individuals become eligible for Medicare by first qualifying for Social Security Disability Insurance (SSDI) benefits. An individual qualifying for SSDI must, then, wait 24 months after receipt of his or her first benefits payment before Medicare eligibility begins.

Medicare program services include inpatient and outpatient services, skilled nursing facility care, home health care, hospice care and physician services.

Both Medicaid and Medicare prohibit discrimination against persons living with AIDS and HIV-related conditions. Health facilities violating this law risk revocation of their Medicare and Medicaid certifications while individual practitioners can be excluded from program participation. HCFA can also take action against a State that fails to terminate a facility that violates anti-discrimination laws.

COSTS: MEDICAID/MEDICARE

The estimated *Federal* Medicare and Medicaid cost of financing care and treatment of persons living with AIDS in Fiscal Year (FY) 1993 will reach nearly $2 billion. Medicaid is the largest single payer of direct medical care services for persons living with AIDS. The Medicaid program pays almost 25 percent of the aggregate cost of *all* national expenditures for medical care on behalf of these individuals.

Combined *Federal and State* Medicaid expenditures for AIDS-related care in FY 1993 are estimated at $2.5 billion. These outlays are projected to reach $3.8 billion per year by FY 1997.

Medicare pays one to two percent of the total national cost of direct medical care for persons living with AIDS—an estimated $385 million in Federal funds in FY 93. Medicare's share of treatment costs is expected to rise in the future as new medical technologies and drugs enable persons living with AIDS and HIV-related conditions

to survive the statutorily required 24-month waiting period for Medicare coverage under the SSDI program.

HCFA/STATE INITIATIVES

HCFA seeks to better coordinate and improve the Medicaid and Medicare programs through cooperation with various entities both inside and outside the Federal government. For example, we coordinate efforts with: State administered Medicaid programs; other Federal agencies at the national level; health services research organizations; private provider organizations; foundations; advocacy groups; and private insurance companies and trade organizations.

Since States have primary responsibility for the administration of the Medicaid program, AIDS coordinators in each of HCFA's 10 regional offices exchange information and work with State Medicaid staff to make their programs as flexible and comprehensive as possible. These coordinators help States resolve obstacles that hamper access to services and financing.

For example, provider outreach activities have been conducted by all States to encourage access to care for persons living with AIDS and HIV-related conditions and most States are offering enhanced services. Several States have been cited by HCFA for exemplary practices in their HIV/AIDS related activities.

The State of New York developed an innovative curriculum for training personal care workers to be AIDS case managers and to disseminate resource materials on available services. The State of New Jersey informed contractors, providers, regional and local staff about the consequences of confidentiality and discrimination penalties and violations. And, the State of Georgia developed an excellent key contact directory of available resources in the Atlanta metropolitan area.

Another issue of growing concern, particularly among the at-risk HIV population, is the recent increase in virulent forms of drug-resistent tuberculosis (TB). Because TB disproportionately affects people with HIV infection and AIDS, the poor, minorities, the homeless, immigrants and substance abusers, we anticipate that the Medicaid program will become increasingly involved with the financing of care for people with TB.

Recently HCFA sent a report to all the States entitled "The Medicaid Program and Tuberculosis." This report, along with a "National Action Plan" which was also distributed, provides States with information on coverage for services provided in institutions for TB. Under current statutory authority, the Medicaid program allows matching funds for residential treatment in hospitals, nursing facilities, intermediate care facilities for the mentally retarded, and care in psychiatric facilities for persons under 21 years of age.

HCFA also coordinates with other Federal agencies to keep abreast of new developments in AIDS and HIV treatments, to share data on the disease, and to coordinate programs. And, HCFA has funded a variety of projects during the past several years, sponsoring health services research such as an examination of the effect of AIDS on the Medicaid population.

CONCLUSION

HCFA's goal is to continue to improve the implementation of its Federal programs, to coordinate service delivery options, and to encourage State initiatives for the care and treatment of persons living with AIDS and HIV infection. As the nation moves to resolve problems in the current health care delivery system, we expect many of the access issues affecting uninsured and underinsured Americans to be addressed.

We look forward to working with Congress to meet the challenges that confront us in providing health care to all Medicaid and Medicare beneficiaries both now and in the future.

PREPARED STATEMENT OF JUNE OSBORN

The epidemic of HIV/AIDS in the United States has attained massive proportions. With more than **one quarter of a million** Americans already diagnosed with AIDS in just the first eleven years, at least *one million additional* persons are infected with the Human Immunodeficiency Virus (HIV) and are almost sure to become ill in the next few years. Were there not another new instance of HIV infection staring tomorrow, our work would be cut out for us for the rest of this decade caring for those already caught in the path of the new epidemic virus. It is truly the public health crisis of our time!

In this testimony, I will attempt to provide some detail about these startling numbers; identify trends and anticipated elements that will affect the efficacy of national response; and then relate those themes to the specific issue of impact on the health care system which provides the focus for this hearing.

BACKGROUND AND DEFINITIONS

Before I begin my main task, let me be sure we are all staring at the same baseline of information about the epidemic itself. As you know, the illness or syndrome we now call **AIDS** was first recognized as potentially epidemic in the United States in 1981, when clusters of young adults on either coast developed unusual and lethal illnesses that reflected severe immune deficiency. These took the form of infections and/or tumors of sorts that were rarely seen except in people whose immunologic defenses had been drastically impaired (as, for example, by chemotherapy for primary cancers). Yet these were young men who had been healthy. As more and more cases appeared, always involving serious infections or tumors and crippled immune response (specifically, nearly total lack of what are called CD4 cells) the new clusters of illnesses were given the name **acquired immune deficiency syndrome** or AIDS.

To track what appeared to be a novel epidemic, the Centers for Disease Control established rigorous criteria for that diagnosis. Lists were created of infections and tumors characteristically occurring in a setting of prior health but profoundly depressed CD4 cell counts. To apply a diagnosis of AIDS to a given patient, specific illnesses on the list had to be present. [Subsequently the definition of AIDS has been altered several times, and a newly expanded definition is currently in the offing to accommodate for greater understanding gained since those early days. In particular, the early definitions were derived from experience with men, and the manifestations in women were not fully represented—a deficiency that the proposed new definition attempts to remedy. In any event, the principle still holds that the diagnosis of AIDS is rather rigidly defined; many health care financing strategies have been designed in which an AIDS diagnosis is a necessary prerequisite for eligibility—so the point is not arcane].

By 1983 it was evident that an epidemic was indeed underway; that lesser or less distinctive manifestations such as prolonged enlargement of lymph nodes, chronic diarrhea and severe tissue wasting seemed to be harbingers of AIDS; and that the numbers of Americans already affected were in the thousands. In addition, similar cases were being recognized around the world. A direct threat to the blood supply and those dependent on it (such as people with severe hemophilia) became clear.

In 1983–84, French and American investigators succeeded in isolating a previously unknown virus in these contexts, characterizing it as a member of the retrovirus group of viruses, and devising techniques to screen for its presence by identification of antibodies in the blood of infected individuals. With the exception of one or two dogged dissenters, it is now uniformly accepted within the scientific and medical communities that the new retrovirus is a necessary—and in some cases, a sufficient—condition for the development of AIDS. Those remarkable leaps forward were a dramatic payoff for decades of wise investment in "basic science" and, of course, allowed not only for screening of the blood supply (which has been dramatically successful) but also for learning quickly about the natural course of infection with what was named the **human immunodeficiency virus** or HIV.

Quickly thereafter, investigators established that HIV was transmitted exclusively by a few specific routes of infection: sex (both homosexual and heterosexual); injections of substantial quantities of blood or sharing of injection apparatus in the context of injection drug use; or birth to an infected mother. [Subsequently it was found that breast feeding could also transmit the virus from mother to infant]. No other routes of infection worked—as dramatically illustrated by searching for evidence of infection among family members who had cared for loved ones dying of AIDS. Without sexual contact, no instance of such spread was found—nor has it been subsequently. Similarly, insect transmission does not work; so that the one merciful fact about HIV is that it is constrained to routes of transmission that are potentially amenable to education for prevention.

Thus the basic groundwork was laid for understanding of the virus, the epidemic, and the probable ability to prevent infection by **avoidance** of behaviors that put people at risk. Briefly, once a person becomes infected with HIV, antibodies appear in a matter of weeks that allow recognition of the infected state. In some instances HIV-infected people experience brief illness about a month into their infection; but more commonly there are no symptoms or outward sign of illness for a number of years (although the antibodies persist). Then a series of relatively minor illnesses signals the progressive decline of CD4 cells (and associated loss of immune com-

petence); when the level has dropped to approximately 20% of normal, the hallmark infections and tumors of AIDS usually appear. The average interval between beginning of infection and full appearance of AIDS is now recognized to be very long: 10–11 years.

That describes the most characteristic course of HIV infection. In recent years it has become increasingly apparent that **HIV disease** might be a better term than AIDS—that once infection starts, even though it may be silent, on-going damage to immune cells is occurring, and that "early intervention" and careful clinical follow-up and care may be of considerable benefit to people in sustaining their good health and delaying the onset of AIDS.

What we call AIDS, then, is simply the final stage of this progression; and in fact (of significance in the context of today's discussions) many people have died of HIV disease without ever "qualifying" for a diagnosis of AIDS. While it is not yet known whether *everyone* infected with HIV will ultimately become ill, it is clear that well over 90% will do so; and while survival has been increased from a few months to several years after the AIDS diagnosis for some people (notably those who know how to access the system and can afford to), a fatal outcome is the overwhelming rule.

CURRENT STATUS OF THE AIDS EPIDEMIC, AND TRENDS IN HIV INFECTION

From the foregoing it is apparent that focusing tightly on AIDS itself as an indicator of where we are in the epidemic of HIV is unwise: it would be like using a ten-year-old snapshot to assess a changing terrain. Thus, discussion of the current status of the epidemic numbers must deal with trends in HIV infection as well as in AIDS diagnoses.

As to AIDS: as of September 30, 1992, there had been 242,000 cumulative cases of AIDS reported to CDC. Of those, over 160,000 had died. In other words, the remarkable stresses on our systems of health care delivery and financing about you will hear later this morning reflect the on-going care needs of 80,000 people still living with AIDS. (As will be noted later, an additional 600,000 HIV-infected people probably should be receiving care now).

There have been distinctive trends in AIDS diagnoses over these first eleven years: initially, in the United States, the overwhelming majority were men who had sex with other men, and another plurality were injection drug users. The initial "sex ratio" of men to women was over 11:1 With each passing year-these figures have changed: women have been the fastest increasing group and now constitute 12% of AIDS diagnoses. And heterosexual transmission has been the mechanism for a steadily increasing percentage of cases. While that **percentage** is still low, two points are of note: first, it is a percentage of an enormously large number; and second, around the world, 75% of AIDS cases have been spread by heterosexual intercourse. Thus we are steadily approximating a pattern that is well established worldwide.

A final feature of AIDS itself is its disproportionate impact on communities of color in the United States. More than 50% of all AIDS cases diagnosed thus far have been in people of color; among women the percentage is more than 70%, and among children over 80%. The terrible impact of those facts has been intensified by mistrust and denial within communities that have felt marginalized and have become disaffected for other societal reasons, making education for prevention perilously difficult to actuate.

As to HIV: The AIDS statistics are grim enough, but the trends seen there presage much worse—and more universal—trouble to come. The increasing involvement of women, of minorities, and of heterosexual spread is underscored. But in addition, the age at first infection with HIV is decreasing. Already, nearly 10,000 AIDS cases diagnosed have been in the 20–29 age group and thus are likely to represent infections acquired during adolescence. The vulnerability of teenagers is obvious to any parent who has survived those turbulent years with their kids; for adolescence is an age of experimentation—with sex, with drugs, with "life styles"—and some of those experiments have become deadly.

In recent reports from CDC and from the Guttmacher Institute, increasing sexual activity characterizes today's youth, and the percentage of teenagers who have had more than one sexual partner has risen to over 60%. Well over 75% of high school graduates are sexually active; and one must note that the inclusion of "drop outs" would surely push that statistic higher. Injection drug use has played a key and increasing role in the epidemic so far; but in the past five or six years, "crack" cocaine has intensified the threat of drugs to accelerate the HIV epidemic, since it is commonly associated with the trading of sex for drugs.

It is estimated conservatively that, beyond the 250,000 Americans already diagnosed with AIDS, an additional million are already infected and on their way to needing care. In fact, given what we have learned about so-called early intervention—provision of care and maintenance of health **before** CD4 cells drop to critical threshold levels—it has been estimated that at least two-thirds of that million *should* be under care now. Many of them do not know they are infected, but among those who do, both access to and financing of care pose daunting or insuperable problems. People with AIDS are spending into poverty and homelessness and, far too often, literally dying on the streets!

Finally, the U. S. Public Health Service has estimated that the number of **new HIV infections** per year is no less than 45,000 but may be twice as large; and that the number of new AIDS diagnoses in the year 2000 is likely to be 98,000! These projections assume that present trends will hold: however, the failure of the "war on drugs" to provide treatment for those addicted persons who want it and/or to deal in the meantime with strategies to assure clean needles (either bleach instruction or needle exchange programs) means that in most areas of the United States those numbers could jump sharply. The drugs and HIV/AIDS epidemics are truly "twins" and, in the worst case, "siamese" twins; and the country must address the vulnerability of drug users and their sexual partners with great urgency or the above projections will be low.

RECOMMENDATIONS FOR HEALTH CARE FINANCING IN THE HIV/AIDS EPIDEMIC

The National Commission on AIDS, created by Congress, with a mandate to advise both the legislative and executive branches of government on policy issues presented by the AIDS epidemic, began its work in the fall of 1989 and is now in its fourth and final year. The Act that created the Commission called for, among other things, a comprehensive report at the end of two years. The report *America living with AIDS* was carefully crafted to meet that requirement and was sent to your offices in September 1991. In that report we chose to focus on a few areas where our role as a broadly constituted "citizens' commission" would be most appropriate and useful. One of those was health care financing.

However, we felt that the gravity and complexity of the overall health care crisis in access and financing required us to seek expert assistance in order to produce recommendations that were realistic and practical. We therefore sought consultative support from Dr. Karen Davis and her colleagues at Johns Hopkins and worked closely with them to mold the following recommendations, which I will quote directly from the report:

> "(1) **Universal health care coverage should be provided for all persons living in the United States to ensure access to quality health care services.** The Commission believes universal health care coverage is a necessary step to ensuring access to quality health care . . . . In the interim, the Commission recommends a series of intermediate short-term steps to address the urgent problem of inadequate coverage for people with HIV disease.
>
> "(2) **Medicaid should cover all low-income people with HIV disease.** The commission recommends eliminating the disability requirement and raising the income level for Medicaid eligibility for people with HIV disease. By eliminating the disability requirement, low-income people with HIV infection who have not had a clinical diagnosis of AIDS could be covered by Medicaid and receive the early intervention treatments and services they need. Increasing the income eligibility requirement would prevent many people with HIV infection from having to impoverish themselves in order to qualify for basic health care services. At the same time it would relieve some of the reliance on public hospitals by the uninsured.

The Commission strongly believes these changes should be mandated; however, at the very least, states should be given the option of making these changes. In addition, the Commission believes these changes can and should lead to further changes that will include people with serious chronic conditions other than HIV disease.

> "(3) **Medicaid payment rates for providers should be increased sufficiently to ensure adequate participation in the Medicaid program.** Unrealistically low reimbursement rates under the Medicaid program serve as a serious disincentive for health care providers to care for people who rely on Medicaid. Medicaid rates should be raised to Medicare levels.

"(4) **Congress and the Administration should work together to adequately raise the Medicaid cap on funds directed to the Commonwealth of Puerto Rico to ensure equal access to care and treatment.** Because of the existing cap on Medicaid funds allocated to the Commonwealth of Puerto Rico, none of the Medicaid recommendations the commission has put forward to expand benefits for people with HIV disease would include individuals living in this part of the United States.

"(5) **States and/or the federal government should pay the COBRA premiums for low-income people with HIV disease who have left their jobs and cannot afford to pay the health insurance premium.**

"(6) **Social Security Disability Insurance (SSDI) beneficiaries who are disabled and have HIV disease or another serious chronic health condition should have the option of purchasing Medicare during the current two-year waiting period.** Medicaid should be required to purchase Medicare coverage for low-income beneficiaries.

"(7) **The federal government should fund the Ryan White CARE Act at the fully authorized level.**

"(8) **The following interim steps to improve access to expensive HIV-related drugs should be taken:**

(a) adequately reimburse for the purchase of drugs required in the prevention and treatment of HIV disease, including clotting factor for hemophilia;

(b) undertake, through the Department of Health and Human Services, a consolidated purchase and distribution of drugs used in the prevention and treatment of HIV disease;

(c) amend the Orphan Drug Act to set a maximum sales cap for covered drugs."

These recommendations are only a few of those made by the National Commission on AIDS in that and other reports; however, they are the most germane to today's hearing. I hope the urgency of the issues discussed here will pique additional interest, in which case I would urge you to request copies of the full Comprehensive Report and other Commission reports from the National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849–6003.

PREPARED STATEMENT OF SENATOR DAVID PRYOR

Mr. Chairman. I want to applaud you for calling this very important hearing on the financial impact of the cost of AIDS and HIV infection treatment on the American health care system. The distinguished panel of experts you have assembled for this morning's hearing should give us a better handle on the challenges facing our health care system as we head into our second decade with the AIDS epidemic.

While you will probably hear more updated figures here this morning, estimates made this summer by the Agency for Health Care Policy and Research are that the cost of AIDS and HIV treatment will reach $15.2 billion by 1995. These numbers illustrate an increase of almost 50 percent from the $10.3 billion that the health care system will spend in 1992. Obviously, these numbers are staggering and can be expected to increase exponentially as the AIDS and HIV patient population increases.

Much of the explosion in cost we have seen in the nation's AIDS health care bill has come, in large part, from the cost of medications used to treat HIV infection. It is very common for patients with full blown AIDS to take multiple drug regimens to treat a wide range of symptoms. Patients with HIV, who have not yet progressed to full blown AIDS, are also usually taking one or a combination of medications to slow down the progress of the disease.

According to a recent estimate by the New York State Department of Health AIDS Institute, it is typical for an AIDS patient to spend on average $4,000 a year for medications, with some spending over $10,000 a month. Why are AIDS medications so expensive? Drug manufacturers cannot realistically contend that these high prices for AIDS drugs are due to the lag in FDA approval time. Many AIDS drugs were brought to market and approved by the FDA relatively quickly, yet drug manufacturers are charging some of the highest prices for these drugs that have ever been charged. As usual, the manufacturers contend that these high prices are justified to pay for the research and development expenses for these drugs.

In my mind, however, this argument just simply does not add up. That is because there are too many unanswered questions about the federal government's role in the research, discovery, and development of these AIDS drugs. There is significant evi-

dence to suggest that the taxpayers of this nation—you and I and the AIDS patients that are using these medications—already have helped to pay for the cost of researching and developing these AIDS medications. If that is the case, then we should all be asking the very basic question: How can these high prices be justified?

Here are just a few examples:

- *AZT:* Several books and articles have provided well-detailed descriptions of the federal government's extensive role in the discovery that AZT has anti-HIV properties. In spite of this significant federal involvement, the company that manufactures the drug—Burroughs-Wellcome—has a pricing structure that results in the typical AIDS patient paying between $3,000–$4,000 a year for the product.
- *Foscavir:* According to Secretary Sullivan, the federal government invested $22 million to do clinical research on this drug, used to treat certain eye infections in AIDS patients. Astra, the company that makes this drug, is charging $22,000 a year.
- *DDC:* This drug, recently approved as an adjunct to AZT therapy, was apparently discovered in federal laboratories. The federal government was the first to apply and receive orphan drug designation on the drug. Yet a private drug manufacturer—Hoffman LaRoche—now holds the exclusive rights to the drug and can charge whatever *they* believe is a reasonable price for DDC.
- *EPO:* This biological, used to treat anemia associated with HIV infection, can cost up to $200 a week. Yet, because it was developed as an orphan drug, the American public helped to pay for much of the clinical testing on the drug. In addition, although the annual sales of the drug are in the hundreds of millions of dollars—hardly qualifying it as an orphan drug—its orphan drug status prohibits competitors from coming to market. If the Orphan Drug Act was amended so that competitors could come to market when a drug is no longer an "orphan," the competition could help drive down the price of this biological, making it more affordable to AIDS patients and the health care system.

These four drugs listed above are just a few examples. Other AIDS drugs reportedly developed with federal government support include DDI and Pentamidine. Reports are that two very promising AIDS drugs that are in development, the TAT-gene drug (which is projected to cost $2,500 a year), and the Protease Inhibitor (estimated to cost about $10,000 a year) could double the cost of AIDS patient drug maintenance to $25,000 a year.

Given that AIDS is likely to become a chronic, long-term condition that will require maintenance drug treatment for perhaps decades, it is very easy to see how the cost of AIDS drugs will continue to be a major challenge facing the health care system.

The fact is that AIDS patients and the American public may be paying many times over for the cost of AIDS drugs. First, we help to pay for the research and development of these drugs through our own multi-billion dollar investment in federal laboratories, such as the National Institutes of Health. Second, we provide lucrative tax credits to drug manufacturers to do research on these drugs, including generous orphan drug tax credits. Third, many patients pay for these high drug prices through skyrocketing insurance premiums and deductibles, and then again through out-of-pocket costs when their medical insurance is exhausted, or when they lose their insurance. Finally, we pay for a fourth time through our tax-supported federal-state Medicaid system, which bears a significant part of the cost of paying for AIDS care.

Mr. Chairman, I have said it before: taxpayers, AIDS patients, the research community, and the health care system deserve much better accountability than this. At the very least, manufacturers that market drugs which were developed with federal funds should justify their prices and price increases for these products.

We should link the awarding of a patent, license, or market exclusivity on these products to an agreement with the manufacturer that the launch price for the drug and any price increases during the period of market exclusivity are truly reasonable. A new mechanism needs to be developed to assure that fair pricing structures are established for all drugs, especially those which are developed with significant federal resources, or through Cooperative Research and Development Agreements (CRADAs).

To explore the various policy options that might be enacted to address this situation, I will hold a hearing in February in the Special Committee on Aging on the issue of federal government support for new drug research and development. Federal support for new drug R&D does not stop at AIDS drugs. It appears that pharmaceuticals in many therapeutic classes—cancer drugs, cholesterol-lowering drugs, smoking cessation products, and others have been brought to market with signifi-

cant public investment. I will ask a panel of experts both from within and outside the federal government to give us guidance on ways to assure that pricing structures for pharmaceuticals developed with federal government support are reasonable.

Mr. Chairman, I thank you for the opportunity to submit a statement for this hearing, and am looking forward to returning to the Senate in January to resume my duties.