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NATIONAL COMMISSION ON AIDS NEWS CONFERENCE
 Topic: A commission final report
 Location: National Press Club, 14th and F streets NW
 Time: 10 a.m.
 June 28, 1993

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The editor of the report is Steve Ginsburg. Tim Ahmann, Eric Beech, Melissa Bland, Peter Ramjug and Paul Schomer also are available to help you. If you have questions, please call 202-898-8345. For service problems call 1-800-435-0101.

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TOM BRANDT (Commission associate director): Good morning and thank you very much for attending the release of the final report of the National Commission on AIDS. I'm Tom Brandt on the commission's staff, and I'll introduce the chairman of the commission, Dr. June Osborn, in just a moment.

We're going to proceed this morning--most of the members of the commission will--each will be speaking to you for two or three, or four minutes. They're identified by name in the materials that you picked up at the table.

And when everyone has had a chance to make some comments, then we'll have a period for some general questions. And I expect it'll take an hour or less.

And now here's Dr. June Osborn, the chairman of the National Commission on AIDS.

DR. JUNE OSBORN (Chairman, National Commission on AIDS): Good morning. I'm glad to be able to share with you the final comments of the National Commission on AIDS which is completing nearly four years of its, of work as mandated by the congressional act that created us.

We, by the same token, our authorization expires, we need to finish our work, and of course the epidemic is badly unfinished.

So we have tried in our final report to aim some comments and directions that we think there's urgent need for action and we'll get to that as each of the commissioners speak.

I'm going to sort of moderate things and before I get started with the real business, let me thank Dr. Roy Widdis (phonetic), the executive director of the National Commission on AIDS who has done a marvelous job of helping all of us and keeping, putting together, keeping together a wonderful staff; Tom Brandt, the associate director whom you just heard from, has likewise done a marvelous job.

And without taking the time to name them all, I'll point out to you in the book that has the final report in it, the names of the wonderful staff who have worked with the commission throughout the years. We're much in their debt.

My--I want--I'm going to be introducing the commissioners one by one, among the voting members of the commission. I want to mention how

proud and pleased we are to have with us the three representatives of the three cabinet departments who were in fact the cabinet departments who were designated in the authorizing law to be represented on the commission in nonvoting capacity.

That we've been blessed with exceptionally dedicated and consistent advice and sometimes very wise counsel from Irwin Pernik (phonetic) from the Department of Veterans Affairs; Dr. Valerie Setlow (phonetic) from the Department of Health and Human Services; and Mike Peterson, Dr. Mike Peterson from the Department of Defense. And I want to make sure that I say how much the commissioners have appreciated their very important input throughout our work.

Congressman Rowland can't be with us today; he's been a very important member of the commission.

Former Commissioner Harlon Dalton had to step down in the winter, but was good enough to wait until after we were put together and released our communities of color report in which he played a very important role, as he did throughout the life of the commissioner before that.

Commissioner Earvin Johnson of course stepped down some time back. While he was a member of the commission he was very effective and he left awfully big shoes, which as you know Mary Fisher has filled with extraordinary ability. That's an astonishment, that she's done it wonderfully, and we will hear from her later.

And my last comment that I want to make before getting things started is to say how much we miss Commissioner Belinda Mason who died just before our two-year report in September of 1991. It's not part of this report, it was part of that report, but I think I want to remind everybody that Belinda told us all, just before she died, that people in America won't--this is a paraphrase--but people in America won't quite get it right or recognize that the reason--until they recognize that the reason AIDS looks just like us is because it is us.

So with Belinda's important thought, I'd like to start the opportunity for various members of the commission to make a few--give a few words. Dr. Rogers, do you want to talk now or do you want to wait until the end?

DR. DAVID ROGERS (Commissioner): I think I'll wait.

OSBORN: Okay. We'll let David do the wrap-up as he does so wonderfully. Diane Ahrens is right here.

I'm going to ask the members of the commission to say a little bit about themselves as they start to speak rather than my dominating the mike.

DIANE AHRENS (Commissioner, St. Paul, Minnesota): Good morning. I'm Diane Ahrens. I'm a commissioner, county commissioner from Ramsey County, St. Paul, Minnesota.

It was 9:30 p.m. on a Saturday night, January 18, 1936, and Americans circled their radios to listen to their president. It was President Roosevelt's address to the nation about the most-feared epidemic about the century: infantile paralysis. In that address, the president asked every man, woman and child to take out an envelope, to insert a dime, and to send it to the White House, to help him fight polio. Many of us remember doing that, although we were just small children.

President Roosevelt, in a brief symbolic request, marshalled a nation to fight an epidemic. In a brief public statement, he turned a people permeated by fear and hopelessness into a nation of action and hope.

His was a leadership of hope.

Today we have another, even more deadly epidemic, endangering enormous fear. For those infected, there is no cure, no vaccine and a certain death. For those without the infection, there is weary queariness (sic) and uncertainty. But there need not be hopelessness if our leaders step up and step out. There need not be a fatalness and hopelessness if our leaders say yes, we will devote the resources necessary for research to find a cure and a vaccine. Yes, we will provide appropriate treatment and care for those infected and yes, we will develop a plan at every level of government to prevent this disease from spreading. Then we shall have that leadership of hope that we deserve.

Our president has made a good beginning. His must be a leadership of hope, promising a coordinated national response to HIV, but there's a lot of hate out there. He needs our support and that of the Congress.

It is not just the White House. Leadership must come from the Congress, from the governors, from the legislators, from the mayors and from the county commissioners around this great land. They, too, must provide a leadership of hope.

The dime in the envelope was the symbol. It was a symbol of a committed nation and a committed leader. A leadership of hope calls for the best in each of us. The call is not complex. We have done it before, and we must do it again.

We need to hear it from every state capital and every county seat across our land, beginning, of course, from both ends of Pennsylvania Avenue.

OSBORN: Thank you very much, Diane. Now I'd like to ask Scott Allen to speak.

K. SCOTT ALLEN (University of Texas, Dallas, Texas): I'm Scott Allen and I work with the University of Texas Southwestern Medical Center in Dallas, and as Harlon called me, our resident mystic. So I'd like to begin my comments.

The human face of AIDS is easily lost in the political agenda of this epidemic. We get caught up in the politics of AIDS and lose touch with the lives consumed by the anguish of daily deterioration. We must not forget the faces of an epidemic begin one face at a time.

Education is one person at a time understanding the risk of certain behaviors. Drug treatment is one person at a time finding the solution to their addiction and support to live in freedom each day. Medical treatment is one person at a time receiving the proper care through our frazzled medical system and drugs necessary to survive. My hope is that somewhere in the process of battling an epidemic, we do no harm to the wounded.

My fear is that the hatred and judgmental attitudes in our society will suffocate the compassion and care necessary for any effort to alleviate the HIV epidemic. I have seen firsthand the countless scars left by hatred and disgust for those living with HIV by self-professed moral people.

When people learn about the deaths of my first wife and our eight-month-old baby caused by AIDS, there is sympathy and sadness. When I tell them how my 10-year-old son lives courageously with his HIV infection, there is usually an outpouring of love and support. But when I get to the portion of our plight where I speak of my gay brother and his HIV infection, there is noticeable difference in the reaction of some, not all

gratefully, but some. The illusion of innocence and guilt still pervade the very fabric of our response and as long as we still frame our efforts in this epidemic by the deserving and the undeserving, we will never succeed in stopping its march into the devastation of the collective soul.

I fear our society has not grasped the unfolding demise of our health care system. I hear talk of what is it going to cost me if we do, rather than what is it going to cost us if we don't. We have little sense of what it means to be a community. I again have seen firsthand the consequences of our neglected health care system. I work at a medical school with an HIV clinic in a county hospital. I have insurance. My son gets his care in a private hospital adjacent to the county hospital in which I work. His care is fast and convenient.

My brother does not have insurance. He gets his care in the county hospital. He waits with the other, over 2,500 patients, for one of four docs in the clinic. While lives hang in the balance, the imbalance becomes more pronounced.

I fear the numbness of pain where the weariness takes such a toll that feelings cannot be felt. Can a human being run out of tears? No. The feelings always seem to return and the tears once flow again. But can a society run out of compassion and feeling for the thousands of deaths caused by AIDS?

Have we reached a point where an unacceptable epidemic becomes acceptable, and we become willing to live with a certain number of deaths?

Have we become numb to the tragedy of AIDS? I fear the callousness of our policies will take its toll on us and we will lose the feelings that sustain us.

Answers will not come from Washington but from the heart and soul of people who care, and at times when I grow weary of the political inertia, I remind myself of people I have around our country through the work of this commission, and the people in my own life that know how to love and care for the wounds of those of us caught in the tragedy of AIDS.

I cannot forget the best humanity has to offer comes from people who give of themselves to alleviate the suffering of another, one at a time.

OSBORN: Thank you, Scott. Don Dejarlais.

DONALD DEJARLAIS (director of research, Chemical Dependency Institute, Beth Israel Medical Center, New York): Hi. I'm Don Dejarlais. I'm the director of research at the Chemical Dependency Institute of Beth Israel Medical Center in New York. We're now in the second decade of the AIDS epidemic, with about 50,000 cases newly diagnosed each year, and 40- to 80,000 new HIV infections each year.

I think the greatest fear of members of this commission is that at the third decade of the epidemic, there will be still 50,000 new cases of AIDS diagnosed each year, and still 40 to 80, perhaps even more, thousands of cases of diagnosed--of new HIV infections per year.

Simply, that does not have to be. We actually know what needs to be done to prevent new HIV infections. Our prevention programs are not perfect, but they can be quite effective. In developing countries, the World Health Organization estimates we could cut the rate of new HIV infections in half.

In a country with the resources of the United States, we should be able to cut the rate of new HIV infections by three-quarters or even more.

I want to specifically address a couple comments to where we've

probably done the worst job of HIV prevention. That's with people who share equipment for injecting drugs, and also with the sexual and perinatal transmission that follows the transmission from sharing drug injection equipment.

The previous presidential commission made recommendations that we need to have drug abuse treatment readily available to everyone who has a drug abuse problem. That particular recommendation has been repeated by this commission in every report we've made on prevention.

We have also made a strong recommendation that we need legal access to sterile injection equipment for people who have drug problems.

We basically know what we can do. We know that those type of prevention programs work. It is really no excuse for our failure to act. Within the next month the commission will be issuing an additional report on behavioral prevention of HIV infection.

We're really at a point where our failure to prevent HIV infection is not a failure of lack of funds to reduce HIV infections. Rather, it's a failure of political will to carry out and implement effective prevention programs.

OSBORN: Thank you, on. Now I'd like to Enice Diaz to speak.

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NATIONAL COMMISSION ON AIDS NEWS CONFERENCE

June 28, 1993

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EUNICE DIAZ (Commissioner): Friends and colleagues, what you see here before you today are individuals. Many of us like yourselves are four years older, and hopefully wiser than when we first were appointed or met as a commission. These have been four difficult years and yet very memorable and rewarding.

As a family, each member on this commission has contributed unique experiences, individuality and a strong mind. We've learned to work together, disagree when necessary, and come together on major concerns and issues. The dedication and integrity of my fellow commissioners I will always remember with great pride.

We have shared accomplishments, sorrows and frustrations throughout these years, yet I believe today we also share hope. Some of the major accomplishments of this commission, as I would like to remember, are the fact that we have not been afraid of tackling some very difficult issues, controversial issues surrounding this epidemic. From recommending the careful implementation of needle exchange programs to tackling the issues of sex education for adolescents, this commission has certainly not been shy.

However, as the only ethnic minority member left on the commission after the departure of my fellow commissioners Harlon Dalton and Earvin Johnson, I feel compelled today to mention, on our last press conference, the fact that AIDS continues to severely and disproportionately affect communities of color in this nation. Over 50 percent of the total reported cases of AIDS in this country are among African Americans and Latinos. Other communities, like Native Americans and Asian Pacific Islanders, although may not be disproportionately affected, have some serious and unique problems when facing this epidemic.

The commission took the bold step of recognizing this problem and posing solutions with the help of many of you in this room through our challenges of HIV among communities of color, even though we knew that this could further stigmatize already stigmatized and disenfranchised communities. We recognize that we were in a unique position to give credible analysis of many problems and put forth some thoughtful recommendations. I also, with pride, remember the bold steps we took of addressing the HIV epidemic in Puerto Rico, and that was a very unprecedented step. Many times Puerto Rico is forgotten by federal policymakers.

I do not think that there are many other commissions that have met from individuals who came from as far as Guam and the territories and attempted to deal with their issues, as well.

The challenges are still there, unresolved issues. And with a sense of accomplishment, because of the opportunity we have been able to provide to open the dialogue to many groups on discussion of HIV, that broad spectrum of community that needed to be heard, greater involvement of people at the local and regional level.

We also shared some sorrows. Continuing to see the devastation and the number of deaths of people infected and dying. I have kept log of friends and colleagues that have died during my tenure on this commission, and it outnumbers 300 individuals. We also have shared some very real frustrations. And at this time, when we share those frustrations, we do so with a sense of hope for a new day that is dawning in this country.

There are many unresolved issues 12 years into this epidemic. We have posed many of the questions but certainly not all of them, and certainly have not offered all of the solutions or the answers through our work of four years.

We are frustrated at the lack of mobilization that needs to occur in short order and the development of leadership in this country at all levels that has taken too long, and we are most frustrated and angered to see that a decade into this epidemic, there is still intolerance and inhumanity reflected in the response of many of us to those that are afflicted by HIV, but our hope is great for the future. A new day is ahead in our being bale to organize a coordinated response to HIV.

We heard this morning from the representatives from the Department of Health and Human Services and the newly appointed AIDS coordinator that there will, in short order, be a response in this country to this epidemic. We applaud the appointment of Dr. Gebbie to this position. We do not have the luxury of starting anew, but building on what is there, and in that order, be able to move with a very forceful agenda.

We need to now concentrate on the building of structure and organization on which the commission has left a legacy and a blueprint for some thoughtful action. The will and resolve of federal, state and local individuals will prevail towards graded and accelerated accomplishments in prevention, treatment, research and advocacy for AIDS.

Whereas many of you have picked up our report, and the front page says that in fact, this job may prove to be uncomplicated and easier than we think, I, for one, think it is a difficult job. But with God's help and the resolve of the American people and this new administration, I am confident that it must be done and that as a nation, we are ready to do it. And with the leadership of the president and the administration, we can and must do it.

OSBORN: Thank you, Eunice. Mary Fisher.

MARY FISHER: I'm Mary Fisher. I'm founder of the Family AIDS Network, an artist, a mother, an HIV-infected woman with two healthy sons.

My tenure on the commission has been brief. It ends when the commission adjourns just before my eighth month in office. I want to use my last opportunity on this stage to make a few personal appeals.

To President and Mrs. Clinton and those working with them to reform our nation's health policies, I promise every support, constant prayer and urgent vigilance.

Though the commission is adjourning, the commissioners live on in hope and concern, and we are frankly desperate for national leadership in the arena of AIDS. Where once there was hope perhaps too great or expectations perhaps too high, now there is suspicion, perhaps too deep. The air in the AIDS community is thick with the fear of broken promises.

To Kristine Gebbie, named last week as our nation's first AIDS policy coordinator, I offer publicly what I have promised her privately: my absolute support for every effort to find a cure, stop the spread, relieve the suffering and care for the afflicted.

We on the commission take our leave just as you take up the

torch. I leave wishing you courage. When I came last fall, I said that to press for better legislation without calling for greater dignity, to ask for more funds for HIV-positive citizens without challenging the immorality of the abuse they routinely suffer.

To issue brave calls for government action without equally courageous calls to our fellow citizens would call into question our own understanding of the issues. I believed it then and I still believe it now.

On November 17th, 1992, when I assumed my commission chair, this is what I said to the previous administration. I believe respectfully that it would also be my counsel to you. We must speak thoughtfully, boldly and consistently. If we are silenced, if we shade the truth for political or personal gain, if we lower our voice when we hear the distant thunder of a political storm, then we have failed not only at public policy, but worse, at public trust.

And so this is my appeal to you, Mr. President. For the sake of millions of Americans dying and grieving, but more for the sake of the nation itself, remember the promise of leadership, and lead. And therefore I offer this same appeal to you, Christine, as to the president: lead, stand up and speak for those hundreds of thousands whose voices have been stilled, speak gently of comfort to the grieving and quietly with hope for the dying, but speak boldly, loudly to the nation. Be obsessed by your conscience, hate prejudice, love compassion, teach dignity, and do not fear losing when you go to battle for those with so little left to lose.

In a word, lead.

The gavel will sound, the cameras will go off, we'll shake hands all around and go home. But for some of us, going home is an odyssey into an uncertain future. I spent last week at the bedside of the man with whom I shared two sons and eventually one virus.

(Pause while she cries.)

I have come from Brian's funeral. I spent last Saturday holding our sons at his graveside, writing our names in freshly turned dirt, drying their tears while struggling so hard to see through my own, trying to make sense out of a 5-year-old's grief and a 3-year-old's questions.

The commission is packing up and going home. And so am I. But I will not go passively or quietly. When next my children stand at a parent's grave, they may be old enough to ask whether the nation cares. God help the person who needs to answer them. I am going to ask for leadership today and again tomorrow, and I am going to raise my voice each time I ask until those who have asked for our confidence have earned it by leading.

Let me be clear. It is not the AIDS community itself which is desperate for leadership. It is the nation at large. Those who imagine that this is someone else's problem, someone else's disease, these are people who need leaders or they will surely die. The senator who compares HIV-positive immigrants with infected fruit, the preacher who regards the virus as God's idea, these justify our call for leadership.

Most of all, the nation needs moral leadership. Without it, we will perish. With it, there is hope. Morally it is no more possible to think of this as a crisis for the infected than it is to think of slavery as an African-American problem, the Holocaust as a Jewish problem, or abuse as a child's problem. When that message finds a leader to deliver it convincingly, we will begin to understand as a nation that this is our crisis. Perhaps then for the first time, we will address it with the moral persuasion need to wage and win a war.

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NATIONAL COMMISSION ON AIDS NEWS CONFERENCE

June 28, 1993

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FISHER (continuing): I need to go home and answer hard questions from two children. But someone needs to lead.

DONALD GOLDMAN (Former President and Chairman, National Hemophilia Foundation): Boy, that's a tough act to follow. My name is Don Goldman. I'm an attorney from New Jersey, former president and chairman of the National Hemophilia Foundation. You have heard perhaps from Mary and from others who have preceded me up here, one of the--one reason why my four years of service on the commission has been a pleasure and that is the wonderful colleagues and caring and loving people with whom I have had the opportunity to serve and a wonderful staff to help us, and of course those of us throughout the community with HIV disease who has kept us honest, let us know what reality is, we all are appreciative.

There are a few messages that are contained in our final report that I'd like to emphasize and speak to for a moment. One of them is that there is no cure. The idea that there will be some new technological breakthrough over the foreseeable future that will put this problem aside and that it will be a technological out for the terrible problems that we face are as realistic as the adolescent who believes that he can have or she can have sex without a condom and save himself or herself from AIDS nonetheless because they're invulnerable.

Adolescents are not invulnerable and people are not invulnerable.

On the other hand, there is good news. The good news is that prevention works. But in order for prevention to work, there has to be leadership, and I think that's one thing that you've heard here and it's one of the reasons that our final report contained but two recommendations really, one of them being leadership.

The fact of the matter is that if President Clinton spoke today and spoke effectively about AIDS and HIV disease, thousands of lives would be saved. Prevention works.

The tragedy is of the thousands of lives that would be saved, none of them would likely be saved during his term of office because if we found a cure tomorrow miraculously, and we're not, the cases of AIDS and the people that are dying from HIV disease are still there, and likewise the cases that we would be saving by prevention today are cases that are going to occur later on in this decade or maybe into the next decade.

It is very, very difficult and we do understand, how do you develop a political will to take action which is necessary to save thousands and thousands of lives when really it's going to be the next administration's term that will benefit politically. But what's important to know is that without regard to the political benefit, the fact of the matter is that people's lives will be saved, can be saved and should be saved.

We are sitting here now, and I come from New Jersey, in which AIDS and HIV disease is the leading cause of death of individuals in the

prime of their lives between the ages of 25 and 44, both men and women. This is not a problem that's going to go away, that's going to get better with inaction. We need action, we are hopeful for action. We have a new administration. All of us are hopeful of the action that's potentially there, the lives that are potentially saved and savable, and worry that maybe they won't.

We hope and pray for the future, and we thank you and each of you and the American people for having given us the opportunity to have tried to do our best to serve you during the past four years. Thank you.

LARRY KESSLER (Executive Director, AIDS Action Committee): I'm Larry Kessler, the executive direction of the AIDS Action Committee in Boston. I've been doing AIDS work, frontline AIDS work for the last 10 years. And the past four have been a real privilege and a challenge because I have had the extraordinary blessing of working with a group of fellow commissioners who are without doubt committed to doing something about this epidemic. They are caring, loving, interested and committed. But they, like myself, are also frustrated because in the past four years, we have heard a lot of very trying and sad, stressful stories, we have seen many situations that we hoped we would never see again in our lives. We heard people's tales of woe and we heard challenges and calls for leadership and partnership.

Many of those have gone unanswered, and one of the frustrating things about being on the commission is that sometimes we have to leave those scenarios and those people behind and hope for the best.

We now in the last few days have seen a surge of activity and some new renewed interest in this epidemic. And like Mary Fisher, I also say to Kristine Gebbie, you don't need to go across America to find out what is happening in terms of AIDS. Read our two reports. The previous report and this report are like the Michelin guide to AIDS in America. It's all in here. I don't think you're going to find anything new that hasn't already been said. We haven't found anything new that we didn't say two years ago. All we found was more of the same and a continued decline.

Hopefully now that will change. But I also know my commissioners real well and I know myself, and even though we are going out of business and ceasing to be an organized commission, an organized body, we're all individually committed, we're all individual advocates, and we will continue to watch this administration and the secretary, and the AIDS coordinator, and the Congress, and all the other Cabinet officers as well.

And we will wait and hope for a sign of leadership that in fact does turn this epidemic around. We won't wait long. As individuals, and as individuals connected to health departments, to universities, to churches and synagogues, to the public, we will continue to be voices. We will continue to be advocates. We will continue to be critics when we need to be.

So often AIDS has been pushed to the back burner. This weekend, and today, it's back on the front burner. I hope it's still on the front burner two weeks from now, two months from now, and two years from now, until it actually deserves to be pushed behind the stove.

It's been behind the stove too long; it's been on the back burner too long. We need to keep it on the front burner; we need to pay attention. Americans deserve it, we need it, lives are at stake. Thank you.

OSBORN: Next, the penultimate speaker is Charlie Konigsberg.

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DR. CHARLES KONIGSBERG (director of public health, Delaware):
Good morning. I'm Dr. Charles Konigsberg. I'm the director of public health for the state of Delaware.

When I began my career in public health some time ago, in the late '60s, I was confident that infectious diseases would not be a major part of my career. Obviously I was wrong, as we know.

The other thing, and perhaps the most naive approach I had was that in the midst of the Great Society still in my mind, I thought that America could would, and should take care of its problems, especially its health care problems.

And seeing that communicable diseases had in fact been actually conquered, eradicated in the case of smallpox, this gave me a great sense of optimism. Well, some years later, when I was the county health director in Broward County, Florida, which is the Fort Lauderdale area, it was a sobering shock and a challenge for me as I watched the AIDS epidemic sweep across South Florida.

I learned firsthand how woefully unprepared, not only our medical care system, but also our public health system, and our social support systems were for this devastating late 20th century epidemic.

Is the roof caving in? Some of us last night at a hotel saw literally a roof cave in. Fortunately not on one of us, but it well could have been. I think a lot of people in America don't really believe that the roof is about to cave in on them. And I think they need to take a quick, take a serious look at what this epidemic is doing to our country.

I want to touch very briefly on one of the themes and principles which I was very pleased to see in our commission's final report, and that's our nation's public health system.

The president is focusing, and rightly so, I might add, a great deal of attention on fixing our medical care system in this nation. But let's not lose sight of our public health system, which is the forefront of our prevention system, particularly state and local health departments which are responsible for safeguarding the health of populations.

It was a 1988 Institute of Medicine report, "The Future of Public Health," that described our public health system as in "disarray," a very tough word.

Well, is it? Well, maybe so if we've got a resurgence of tuberculosis, we've got measles when we have a vaccine, and we've been unable to get a handle on AIDS.

So I agree with the final report of this commission, that we must have a vital and responsive public health system, because no disease in the history of the world has ever been conquered without leadership and action by public health.

The same will hold true for AIDS, I assure you.

I would like to commend President Clinton for naming a former state health official, Christine Gebbie, to the position of AIDS

coordinator.

I know Ms. Gebbie well. I know her to be a superb, dynamic, and level-headed leader who cares deeply and will serve us well in this capacity. I know she will have the support of the nation's state and local health officials.

I'd like to say a few personal words about serving on this commission. This was a position that I never sought. I was very surprised when I was nominated by the National Association of Counties and was interviewed by Senator Dole's staff.

I have found this to be an incredible experience. There's so many visions in my mind, things that I've experienced, what I've seen, the voices I've heard--yes, the cries for help, the despair. But I guess nothing haunts me more--and Larry Kessler can relate to this because he gave me the picture that he took of the armory for the homeless in New York City.

It's a picture that will forever stay burned in my mind, that and the bowery as well. What has become of us that people must live this way? I mean, is AIDS not a direct result of this in many ways?

And finally, let me say a few words about my fellow commissioners and the staff. Never, in my experience, have I had the honor and privilege of working alongside such truly dedicated and remarkable people.

We shared the common bond about this devastating epidemic. I commend June Osborn and David Rogers for their leadership. This has not been an easy job for either one of them. They have done extremely well and kept us on track.

To the National Association of Counties which nominated me for this position, and to Senator Dole who recommended me for my appointment to this commission, I appreciate your confidence in me, but most of all, I appreciate your concern about AIDS. Thank you very much.

OSBORN: Thanks very much, Charlie. And lastly, let me ask Dr. David Rogers to sum things up.

DR. DAVID ROGERS (Commissioner): I was afraid I'd be like Queen Elizabeth in reverse here, a giraffe.

I have really nothing to add from what's been said. I think you've gotten very powerfully from this remarkable group the sorrow, the enormous amounts of suffering we've seen across the nation in our four years with this, and it obviously has changed each and every one of us. We've bonded well because of it. I'm proud of at least what we've been able to articulate.

The other theme that comes through obviously is the frustration. There are very few bright spots about AIDS, but I would mention a couple. One is we know very precisely how it is transmitted, and as Don Des Jarlais said, we know exactly what to do to slow or to break the back of this epidemic and how to take much more compassionate care of people.

Another bright spot is the kinds of people that have coalesced around this issue. In every city, in every community-based organization, you cannot help but wonder at the tenacity of the human spirit and the kinds of noble human beings that have dedicated a great deal of themselves to this.

The frustration stems obviously from what we have felt has been a singular lack of leadership and a recognition that with leadership, we can indeed turn this epidemic. I think all of us feel, over time, as a society we will, in part, be judged with how well we deal with this crisis of our times, and that we have high hopes that as we go out of business, it will

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Q: Many of you have talked about leadership. Now they tried to give a very specific example (inaudible) needle exchange (inaudible), where we haven't provided leadership. Could any of you give us a couple of more specific examples of what you mean by leadership, what you want President Clinton to do? Because if you say to the president, we want you to talk about AIDS, he'll say yes, I am talking about AIDS.

OSBORN: Well, one of the areas in which I think we all have to do a little bit better, and this gets back to the previous question a bit, is in looking at AIDS as if it were a peripheral or marginal problem, looking at the behavior that puts one in the way of infection as if it were somehow not mainstream behavior.

We need to learn as a nation that this is a sexually transmitted disease and to the greatest possible, that is a universal. Decisions about sexuality are universal; they are not marginal. The kind of decision made can be, to assort oneself one way or another. Some of them aren't decisions. Some of them are circumstantial situations. But we have made a terrible mistake as a country by looking at this as if we could--when I hear people use the phrase "let's eliminate risk behavior", I shudder because it means they don't understand. You don't eliminate risk behavior. You minimize risk, just like you do with the rest of the circumstances that go with being a biological being.

So it's as easy as facing our own biology. It's as difficult as facing the issues that come with that, but we've been paying a terrible immoral price for a long time by letting our adolescents become pregnant for lack of education about how to avoid that, for letting people think that there is nothing dangerous out there when there is, for letting--I always focus on the adolescents because I think everybody who's been involved with adolescence knows that there we're not talking lifestyle; we are talking an age of experimentation, and some of the experiments have proved deadly, and we need to say that.

If people know that, then they have an opportunity to respond thoughtfully and within the context of their own moral structures.

But if they don't know that, it is wildly immoral of us not to have shouted loud enough to say so.

Q: So you want the president himself to go on the road and talk about this? What do you want from him?

OSBORN: The president has the bully pulpit. All of us are on the road, and we know perfectly well we can't be heard, we can't shout loud enough. We need some help there. And just as if there were some other crisis that threatened one and a half million lives of young, productive Americans, the president needs to say something about that and say it often and say it different ways and in different contexts and bring it into

the--it's a sad part of the fabric of American life now, but it is a very real one. And to the extent that silence is allowed to continue, people then can continue to pretend that it isn't out there.

It's always going to be out there. It's like nuclear weapons. I'd rather they weren't there either, but they always will be. We need to live in a world with them. And so we have to be thoughtful.

The same is true here. This is a massive expanding tragedy, as the report says.

ALLEN, : One of the suggestions that we heard in our hearing on business and the work place in HIV education is for the president to have HIV education seminar in the White House for his own staff, and to move that out to all the secretaries. And that would be a wonderful example to our community if the president would take on that initiative.

OSBORN: Thank you.

Q: Since Dr. Des Jarlais and Dr. Konigsberg spoke most directly to the prevention (inaudible), I was wondering if I could direct my question to them. And that would be--any responsible (inaudible) medical professional, citizen, public official, et cetera, has suggested the basic thrust of this commission is (inaudible) pandemic is nearly totally misplaced, and that except for research and education the Federal Reserve (sic) and the federal government's role is the smaller role, that the answer is really implementing the traditional control, public health control measures at the local level, and that there's been some interference with the ability to do that, at least maybe in terms of political will. (Inaudible)?

OSBORN: Dr. Des Jarlais?

DES JARLAIS: First, just briefly, one of the wonderful things about a multicultural country like the United States is that people don't get your name right very often. It's Des Jarlais.

Yes, Charlie and I really agree that the public health system of the United States has deteriorated and that effective prevention requires efforts at the local level. That's where you have the face-to-face contact with adolescents who are starting to experiment sexually and starting to experiment with drugs. That's where you have drug abuse treatment programs to get people to overcome addictive diseases; that's where you have condom distribution programs so that people who are sexually active can minimize the risk of a whole variety of sexually transmitted diseases; that's where you have street outreach programs to drug users, to distribute condoms, to encourage and help them to practice safer injection.

But it's very, very hard to get effective action at the local level if you've got confusion at the national level. And since this epidemic began, we've had confusion at the national level. That has not been the responsibility of any single individual, any single president, any single Cabinet member; it's been the result of our political system which does not do a very good job in dealing with sex, drugs, death, or money--and AIDS involves all of those.

We really need effective action at the political level of the neighborhood, the city, the county, the state. But as long as we have confusion at the national level, it's going to be very, very difficult to get the effective local action we need.

KONIGSBERG: I'd just like to add very briefly to Dr. Des Jarlais' point. I think when you talk about prevention measures in the public health system, we have to think much more broadly than some of the classic measures. And I can't really state that any better than Dr. Des Jarlais did. I think it goes back to the leadership question and the kind of support that state and local health officers get. Certainly we could use a lot more help from the federal establishment. It's not so much the money issue as it is getting some of the restrictions off. There's an awful lot of restrictions on what you can and cannot teach. And I think Dr. Osborn has drummed that in constantly with us.

But it still goes back to the leadership. If you look back in time to what was done in this country to get a handle on tuberculosis and look at what the public health leaders did as well as the voluntary sector, it boiled down to somebody at the local and state level putting together all the elements that it took to try to get at the control of that particular disease.

And in that sense this is no different.

Q: Question for Dr. Rogers. Mr. Kessler alluded--the administration alluded to maybe the Clinton administration hasn't been as forthcoming as many had hoped during its first six months. (Inaudible) criticism of the president, and why do you think all of a sudden there was an AIDS (inaudible) last Friday?

ROGERS: Yes, I think all of us have been deeply concerned. Splendid commitments at the outset, at the time of his--preceding his election. And we have felt it has taken too long to get at this issue. I think all of us are delighted that at long last the engines have gotten started and it looks as though they're moving in the right direction.

But your answer is correct. Obviously we are advocates about a particular disease, and the fact that the government has been slow on the uptake has disappointed us. But we have some renewed hopes now, particularly with the appointment of Kristine Gebbie and a fine group around her.

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National Commission on AIDS/news conference (fourth add)

June 28, 1993

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Q: Do you think that with the demise of this commission and the (inaudible) has on administration, that this issue, at least from the point of view of the administration, could indeed go on the back burner?

ROGERS: I hope not. We're keeping our fingers crossed. You're right, I think the main thing we've been able to do is to keep this issue on the public agenda. We've been scolds, we've been a thorn in the side of the administration. And you're absolutely right, with us disappearing, whether interest will subside--I hope not. And I think all of us are personally committed to making sure that doesn't happen.

Q: Dr. Rogers, is there any concern on your part or others (inaudible) Kristine Gebbie's position on mandatory AIDS testing. Some other groups have raised concerns that her point of view isn't consistent with theirs.

ROGERS: The--I don't really know all of her points of view as yet, and I--and having watched her in the past, I think she's a splendid listener, she's a good consensus builder. My guess is she's going to get an AIDS education like a drink of water from a fire hose. She's going to have a lot of information coming into her in the next few weeks, and I bet she will pay careful attention to it.

Q: Just to follow up, your position remains unchanged on this? This is something that you're opposed to (inaudible)?

ROGERS: Yes, and perhaps that deserves just one word of explanation. We have tied ourselves in kind of public health and epidemiologic knots that don't make at first blush great sense. And that's true on mandatory testing, it's true on a number of issues like that.

That really stems from the point that June and Mary and the rest alluded to, which is the amounts of discrimination and stigmatization are so severe, we felt that it simply shouldn't be. A colleague and I recently wrote, not only do you lose your life, you lose your job, you lose your insurance, you lose your friends, you lose your family.

And that's too expensive, and consequently I think all of us have felt mandatory testing is not the way to go.

OSBORN: One other thing about that question. In terms of how we approach health and particularly healthy behavior, with health reform coming and so on, the concept really has to be discarded that we can tell people what to do and they'll be healthy.

We really have to enlist people whose health is at issue as colleagues in a joint effort towards health so that the discrimination that's out there for somebody who has heard the message and goes and seeks

testing to know where they stand is a terrible disadvantage to good public health.

And that question, I think, stems from that. We've got to fix it at its core. We can't fix it by saying, let's do mandatory things now. What else are we going to do mandatory? Are we going to make people be treated? Are we going to make people behave 24 hours a day the way we have decided they should?

That's no way to achieve health in this behavior-related illness or in other behavior-related illnesses, so we might as well start on our health reform right now, recognizing that the informed cooperation and partnership between health care giver and the person needing that care is the critical ingredient for this and many other illnesses that this society is paying too much for now.

Q: For Dr. Osborn or Dr. Rogers, over the past four years, with all your reports, with all your recommendations, can you point to any change in policy or any action which you can look to with pride and say we had some hand in that? Are there any positive results you report from all of this work?

OSBORN: Well, I like the way you ask the question because you said we had some hand in that, and yes, I think we can point to a lot of things in which we've had a hand, maybe not as big as we'd like, but at least, as Dr. Rogers said, keeping issues on the public table, on the public agenda that otherwise sank below awareness has in a lot of ways mobilized or galvanized a lot of constructive work on the part of very committed people at all levels of government and in voluntary agencies and so on.

I think that may even be the best thing we did was to keep hope alive for people working very hard in this epidemic. Many people have come up to each of us as members of the commission and said thank you for what you do, it helps to have a voice out there saying why it is we're doing these things that we are working so hard to do.

You can point to some specific things that have moved a little bit, not enough. I think we were able to reopen the discussion of how we deal with substance misuse in this country, at least to a fresh set of hearings and the GAO report that followed that confirmed our assertion that this was a very important, top-of-the-list place to go looking.

We probably have had some effect in terms of what kinds of educational messages now get out that didn't four years ago, and you could go down the list like that. I think perhaps the fact that the commission's gone around the country has made a difference in bringing forth some response on the part of religious organizations. I think we've been able to work well with the V.J. Styles (phonetic) group and the workplace folks to try and get that higher up. Very hard and it would in fact be arrogant to take too much credit because so many other people are working hard. I think the fact that we've been able every once in a while to get attention refocused has probably been our major contribution, as practically you have to say that's all commissions can ever do anyway.

Q: (Inaudible.) Should leadership do something separate and additional, the leadership that you're calling for across the board? Is there something extra that needs to be done for communities of color?

VOICE: I think so. The question was, does something additional or extra need to be done in communities of color? For many years, early in

this epidemic, we did not hear the voices from those communities nor made any organized effort at doing such. I'm proud to say that this commission took some very bold steps at the inclusion of those voices wherever we went on many issues. And certainly those of us that represented those communities made sure that speakers and individuals who were touched by this epidemic directly had an opportunity to testify and come before us.

But now that we see this commission not there after tomorrow, we urged this morning and will continue urging and prodding the administration and also the leadership in the AIDS field to listen to these voices, help to bring individuals from the various communities of color in coalitions where it's going to make a difference for us. Many of these individuals have yet not taken public stands about issues. Our politicians and leadership within our own communities need to be moved. Our houses of worship are very important, a voice that must be heard and a coalescing place where important messages of prevention and involvement have to get out.

So yes, extra work needs to be done because we slacked off initially in this epidemic, not saying this is a problem that we are going to have in our communities of color. We didn't see those images projected for a long time and therefore we are really about three to five years behind the majority community in being able to look at this. There are some wonderful organizations, some of them represented here today, who are making a difference in this regard. Tomorrow there will be a major press conference by a coalition of all Hispanic communities getting together on this issue, and that is a first in 10 years.

So yes, something extra needs to be done. There needs to be a continued avenue of communication and involvement to mobilize those communities, within those communities, as rapidly as possible.

Q: Is there any evidence that AIDS is spreading to the heterosexual community in a more rapid fashion? Has that changed much, or is it still primarily the homosexual (inaudible)?

VOICE: How rapidly is enough? Seventy-five percent of the HIV infections in the world are heterosexually transmitted. We are the same species, and every year the fraction of American cases of AIDS related to heterosexual transmission increases. Every year--there's a snapshot of new HIV infections--we approach greater and greater sexual equality of opportunity with this virus.

I have found it very distressing to hear people wanting to wait until heterosexual spread is, the usual word is rampant before we do something about it. It's now 7, 8, 9 percent, I don't pay much attention, but that percentage is now of an awful number. Three hundred thousand Americans diagnosed with AIDS.

So those percentages are another way of denying and lulling ourselves. We Americans can get very upset about a few thousand cases of--and I don't mean to minimize the disease, but Lyme disease. We need research, we need better diagnostic tests, all that kind of stuff, a few thousand cases. We have more heterosexual AIDS than that. And if we let the rest of the world give us a signal, the rest of the world says this is a heterosexual disease. We were given an early warning by the gay community that we failed to take notice of. We reacted hatefully instead by saying it's just them, not us, so we can turn our backs. That was a terrible, tragic, historic mistake, and if we keep on making it, we will perpetuate this epidemic into the next century just that much further.

The people who are getting sick now, many of them are people who

became infected before we knew there was a virus. But every day after this that people become infected, we know there's a virus, we know how it's spread, we know it is a sexually transmitted disease and an injecting-transmitted disease, not a homosexual disease or a disease of drug users.

It's all of us, like I said at the beginning, and I think that that's the message that we would like to leave with the country as part of our four years' work, that AIDS looks just like us because it is us, and that will just get more true with time.

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National Commission on AIDS/news conference (fifth and final add)

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