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December 18, 1998

REMARKS OF THE PRESIDENT IN HIV-AIDS ADVISORY COUNCIL MEETING

5:45 P.M. EST

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release December 18, 1998

REMARKS OF THE PRESIDENT
IN HIV-AIDS ADVISORY COUNCIL MEETING

The Cabinet Room

5:45 P.M. EST

MS. THURMAN: Good afternoon, everybody. I want to thank you all for joining us this afternoon. Those of us who are gathered in this room today are partners in a battle that, while we've had significant successes in recent years, has no end in sight. Our victory over AIDS will require incredible resolve, persistence, and steadfast leadership.

This is a struggle which we all know has had all too few national leaders, but has always had the support of this leader. It is my distinct honor to present to you our leader, the President.

THE PRESIDENT: I want to get right to the subject of listening to all of you, but I would like to say that, as all of you know, we had a very good couple of days when we finally made the budget last year -- we've had a lot of good increases, a lot of things that I know you care so much about. But we've got a lot of work to do, especially in prevention and in the vaccine development I think we're going to -- (inaudible) -- pretty soon.

I would prefer, I think, because we've met before and I'm trying to stay familiar with your concerns -- I think we've done

a good job of getting the money into the programs this time, but there's a lot more we can do -- (inaudible.) However you organized this -- (Laughter.)

DR. HITT: Okay, we want to start off by having Reverend Mother Altagracia Perez lead us in a short prayer.

REVEREND PEREZ: Thank you. Thank you, Mr. President, for this moment where we can gather our thoughts and especially bring to mind all those who today are in need of courage and strength, so if we could have a moment of silence.

Spirit of life and justice and power, we welcome you in our midst. We've been brought together by a desire to improve the quality of life for all the people that we serve and represent. We're especially conscious at this moment of the men and women, that right now, are in harm's way. Our thoughts are with them and their families, as we await their safe return.

We're also ever-mindful of those who are gathered here with us and, through us, all those who struggle daily with a virus that has no cure and is hard to live with. They are here with us; the people who called us to this work; those who have gone and who have left us their legacy of courage and perseverance.

We especially gather in a spirit of gratitude for our President. We remember all too well those dark years, when a meeting like this would have never happened. We are grateful for his life and for his leadership, and we pray that you sustain him through the power of your spirit. Give him strength and courage, and stamina, and wisdom, as he continues to lead us through this dark time.

There's still so much that we have to do. Let us especially remember our communities of color and those most vulnerable throughout the world who today, and every day, are living in a state of emergency. May each of us leave this encounter with our vision of what we can do together restored, and our strength renewed, to go forward and face the challenges that await us. In the name of the One who came with hope and brought us light, we pray. Amen.

DR. HITT: Mr. President, on behalf of the Council I want to thank you for meeting with us, especially so close to your recent high profile events regarding the Congressional Black Caucus HIV Initiative for communities of color and World AIDS Day spotlight on international crisis.

Six and a half years ago I was very honored to stand with you on the stage of the Palace Theater in Los Angeles, where you outlined your commitment and genuine care and concern for those living with HIV and a really good vision of how -- (inaudible.) In light of the efforts you made in securing unprecedented funding, for starting the Office of AIDS Research, Office of National AIDS Policy, convening the White House Conference on AIDS, establishing a goal of a vaccine -- which are all landmarks I think you can be very proud of -- I am just as honored to be with you here today.

THE PRESIDENT: Thank you.

DR. HITT: In addition, I want to thank you for the humbling honor of serving this Council of incredibly dedicated and committed individuals as its chair, and to tell you on behalf of all of us how honored we are to serve your administration.

Continuing with our task of offering advice to you, we recently adopted our priorities, which reflect the community realities, especially the urgent need for action in the racial and ethnic communities, and in the youth of our country. This epidemic has been full of changes and challenges and we're really at a crossroads in this epidemic. The media all the time tells us about how people are living longer and this is a chronic, manageable disease and less people are dying overall of AIDS.

What they often fail to mention is that curb-prevention efforts are not reaching the American public. Three hundred thousand Americans don't even know they're HIV positive. And contrary to your own stated goals, we are not decreasing the numbers of new people infected. And, in fact, in many communities the numbers are increasing.

In addition, thousands of HIV individuals cannot get the early treatment the public health service guidelines tell them that they should get, but, rather, they have to wait until they become disabled from the disease before becoming eligible for treatment.

Out of all our recommendations to date, there are a few items we would like to discuss with you today that need your specific presidential intervention now if we are going to achieve these goals. Before we give you these few suggestions I want to emphasize to you that none of what we're recommending to you today would be possible without the tireless efforts of several people who serve you, this Council and the people living with HIV and AIDS -- especially in the White House and across administration. It's because of them that you've had so many successes -- namely your own NAP Director, Sandy Thurman -- (applause) -- who made real your vision of a White House office that leads the national response to this epidemic, along with the Deputy Director Todd Summers and the Council's Executive Director, Dan Montoya. And we appreciate the efforts very much.

The Rabbi has a few words.

RABBI EDELHEIT: Mr. President, we're honored to be with you today, especially so soon after your recent trip to the Mideast, where you courageously engaged in the making of peace, where you brought the gift of hope to the land of the Bible.

During this week of Hanukkah, on the eve of Ramadan and one week before Christmas, we are all reminded that all these religious holidays promise us light in the darkest time of the year. As your Advisory Council, we want to help you fulfill your vision to bring the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to that bridge that crosses into the 21st century to which you have prophetically led us. We want to help you illumine the darkness that still covers the path

to that bridge. We must warn you that there are some Americans who are in danger of being unable to cross when you lead our nation to that bridge into the 21st century.

How can we be sure that the African American who has no access to clean needles, nor the newest combination of drug therapies will get to the other side? What do we need to do to make sure that the Latino youth who is not eligible for Medicaid will have access to primary care and still be able to work that he, too, can cross the bridge with other Americans?

Here is a gift, Mr. President, from my four children. It is a dreidel -- that's right. I'm impressed. (Laughter.) It is the traditional spinning top we play -- and the four letters on it, Mr. President, stand for "a great miracle happened there." But, Mr. President, we know that there will be no one great miracle that ends HIV-AIDS. So we are here to help revive your vision of zero rate of transmission and an equitable access of care to all persons battling HIV disease.

We are here with you today, Mr. President, when a terrible political darkness has fallen over this land, because we want you to know that we will do whatever it takes to cross that bridge with you into the 21st century.

DR. HITT: As I said, we fought through a lot of recommendations and tried to come up with some specific new initiatives that we wanted to bring to your attention. And to start that off, I'm going to have Mr. Tom Henderson lead with one of the new initiatives.

MR. HENDERSON: Mr. President, when I stood, with many others during the stirring speeches of Bob Latoy (phonetic) and Elizabeth Glaser at the 1992 Democratic National Convention, I truly believed it would be my last national convention. But because of the remarkable progress we've made under your leadership in fighting this disease, I'm still here today, alive and well.

That's primarily because I'm fortunate enough to be employed and adequately insured and, therefore, able to enjoy the benefits of the new combination drug therapies. For those who must rely on Medicaid, however, for their health care, the story is often much different.

On one hand, we have new public health service standard-of-care guidelines that call for early treatment of HIV prior to disability. But on the other hand, in many cases, accessing Medicaid requires individuals to be already disabled. Instead of being able to enjoy the benefits of living longer and better lives, many are still forced to wait until they're sick and unable to work before they can even begin treatment.

Not only is that inhumane, Mr. President, it's costly as well. Access to quality medical care for those living with HIV who are incarcerated is also a major problem. In most cases, there is no preparation for connecting those individuals to medical care, once they are released back into the community.

In April of 1997, the Vice President asked HCFA to

evaluate the possibility of expanding access to Medicaid for poor HIV-positive individuals, prior to becoming disabled. HCFA/HHS has concluded that can't be done in a budget-neutral manner. Now, some would suggest that the only near-term solution is to rely on the demonstration programs called for in the Jeffords/Kennedy legislation. Mr. President, we reject those conclusions. We believe there are two things that can be done now, without legislation, to solve this problem. First, OMB currently requires finding offset cost savings within Medicaid only to determine budget neutrality. Any savings generated within other federal programs can't be considered to determine budget neutrality.

Also, current policy only allows looking at a five-year budget window. We believe those hurdles can be overcome, but only if you make the decision to include a broader look at cost savings, and a longer budget window, and then direct the Secretary of HHS, and the Director of the OMB, to modify current policy to account for any resulting savings.

Second is the issue of drug cost. Mr. President, the time to deal with crucial drug cost issues is while we're also dealing with expanding access to those drugs. The vastly increased market for HIV drugs that would result from early access makes simultaneously negotiating drug cost reductions both reasonable and possible. We believe that asking the Vice President to include such drug cost issues in his ongoing discussions with the pharmaceutical industry could offer substantial potential for progress. Breaking the current gridlock, Mr. President, surrounding these issues will require your personal intervention. With that intervention, however, providing Medicaid access to early intervention therapies can be accomplished.

THE PRESIDENT: Well, I'll see what I can do about that. You know, generally, this whole medical coverage problem is getting worse in America. It reminds me of that joke that the Republicans used to tell on us -- they told me if I voted for Barry Goldwater we'd get involved in Vietnam too much. And I did, and sure enough, it happened. (Laughter.) And they said when they attacked Hillary and me for our health care plan, they said that if people supported it, things would get worse. And sure enough, they did. (Laughter.)

We've had -- these coverage problems have gotten quite profound, and as a consequence, with fewer and fewer people getting medical coverage at work, what you've got is more and more people trying to find a way to get into Medicaid.

One of the things, for example, that I want to look at as a result of this is something we're doing with disabled people who get back into the workplace. I just started an initiative not very long ago to try and have people who have disabilities, including some people with HIV and AIDS when they get better -- if you have disabilities and you go back to work, it used to be automatically you lose your Medicaid. And now more and more people are working in small businesses where they don't have employer-based health insurance or they have small pools and they can't afford to take somebody with a preexisting conditions.

So we're trying to modify the rules so that when people

are on disability, then they get off of it and they go back into the work force, they can keep their Medicaid for some period of time. And I want to go back and see exactly how we did that and what else we can do here.

Tom, I want to make sure what you said. You believe that there are savings in non-Medicaid areas that would come from keeping people off -- giving people the drugs before they get sick in the first place.

MR. HENDERSON: As you know, the process right now is for states to seek waivers. We've been working closely with a number of states who have been working on those waivers for submission at the present time. They believe there are significant savings in SSI and SSDI, in other areas, that would result --

THE PRESIDENT: -- all would be counted.

Q Yes, sir. And current rules don't allow that.

THE PRESIDENT: I've got to go back and look at that. Part of it is the way the law disaggregates money into mandatory and non-mandatory spending. I'll look at it and see if we can do something about that. I know it's very important.

I presume you still -- hello, Bob.

HATTOY: Hello, Mr. President. (Laughter.) Sorry I'm late.

THE PRESIDENT: I'm glad you're here. (Laughter.)

MR. HATTOY: I'm glad you're here. (Laughter and applause.)

THE PRESIDENT: --- notwithstanding what you said, you still think we ought to pass the Kennedy-Jeffords bill. It's a good bill.

MR. HENDERSON: Absolutely. We just think that there are some things that can be done in the near-term, though, within the administration that do not require legislation, that they would move this problem forward.

THE PRESIDENT: I'll do some work on it -- what you said.

MR. ROBINSON: Mr. President, as you said in your opening statement, prevention of new infections is an area where, although we've made some progress, we still have a great deal to do. In fact, this Council, the community at large, and your administration, has struggled with the challenge of preventing new infections.

Today we want to raise two issues related to prevention with you. First, as you know, this Council supported making federal funding available for needle-exchange programs. Today, we again want to ask you for your support in this area. We've made a request of Secretary Shalala and HHS to provide us -- the Council, the Office of

National AIDS Policy, and other federal agencies -- with a summary of the scientific information that supports needle-exchange programs to prevent new infections. We believe that this would be an important first step in fulfilling the administration's commitment to assisting communities that chose to use these life-saving programs.

Second, we want to recommend to you that the White House Office of National AIDS Policy be directed to undertake a bold, national media campaign to promote voluntary HIV testing. Without a cure, preventing new infections is our best strategy. This is especially true for African-Americans and other people of color, where the severe and ongoing health crisis has created a public health emergency.

One reason why stemming the tide of new infections has been so elusive is the fact that so many people don't know that they're infected. As a person who has thrived for the past 17 years, despite the fact that I'm living with HIV, I understand the importance of knowing one's -- status. It has offered me an opportunity to seek treatment for my HIV, and made me more aware of the need of protecting myself and others from infection.

Some members of Congress and others in the community have called for misguided measures, such as mandatory HIV testing, mandatory contact tracing, and mandatory partner notification -- measures that we believe will not be effective. However, like us, they are concerned that too many people living with HIV don't know it and, therefore, risk infecting others.

We believe that this campaign would demonstrate your administration's sound public health approach to this challenge. Modeled on ONDCP's national youth anti-drug media campaign, this voluntary HIV testing campaign would raise awareness about the continuing threat of HIV while lessening the stigma of HIV testing. Working with the CDC, national advertisors and other media concerns, ONAP would develop this campaign as a public/private partnership, which we believe would build on your legacy of an activist government and enhance your efforts to end racial and ethnic health disparities.

Mr. President, we hope you seriously consider undertaking this campaign of voluntary HIV testing, because we believe it is essential to our efforts of preventing infection.

THE PRESIDENT: It sounds like a good idea. I think Sandy is going to come up with a proposal of what we should do, but I think it's a good idea.

MS. THURMAN: We'll work with you and get one done.

THE PRESIDENT: And it offers the promise of sort of getting by the divisive arguments of the past and actually doing something. I like it.

Q Proactive.

MS. MIRAMONTES: Mr. President, I came here today as a mother with a son living with AIDS, to talk to you about vaccines. But before I speak to you about the vaccine issue, I want you to know that combination therapies, although valuable for many, are also

failing some people -- some in this room -- as well as my son. So, therefore, I really want to stress the need for continuing research, both in vaccines and in therapeutics, is as important today as it ever was.

First, I want to thank you for what you have accomplished in moving the agenda on the AIDS vaccine issue and establishing the 10-year goal. But there are several critical issues that only you can address if your goal is to be reached. And I have two examples I want to give you.

The first one, it has been 19 months to the day since your announcement of the vaccine goal, and a director of the vaccine center at NIH has not yet been appointed. We know that even though the center is only about 10 or 15 percent of the funding, this appointment really is important to be made and should be made as soon as possible.

Secondly, a preliminary vaccine meeting was held more than six months ago and, to date, there has been no follow-up meeting. When President Kennedy announced that we were going to put a man on the moon, he appointed a person within the White House to oversee this endeavor. After hearing almost 100 hours of testimony, we recommended a coordinator be placed within your Office of National AIDS Policy, with adequate resources -- and I need to really stress that -- with adequate resources to coordinate the vaccine effort. This is not that we want to tell any one agency what they are to do, but rather to coordinate vaccine activities across all relevant federal agencies. And I think the next piece is especially important: developing true partnerships with the international community and the private industry.

We also recommended that a comprehensive plan be developed and implemented, and this hasn't happened, either. I think we all need to remember that the person most at risk, worldwide, is a young person of color, and that the most effective strategy for stopping this pandemic is an effective vaccine.

So what I'm asking you, Mr. President, if you're willing to use your position to really address these critical issues.

THE PRESIDENT: Well, let me make a couple comments. First of all, I think the vaccine director is about to be appointed -- (inaudible.)

Secondly, I do think that -- the new Director of the Office of AIDS Research has been doing quite a good job. We got about a 33 percent increase in funds for vaccine research in the last budget, so that's good. And we're going to try to -- I just had a brief meeting, before I came in here, with our folks, talking about how we can expand Sandy's -- this kind of work and kind of ride herd on this thing -- (Applause.) I think that's important. It does make a difference just to have a sort of sustained White House involvement on any kind of project to keep cutting through the resistance.

MR. ROBINSON: Thank you very much.

MS. ARAGAN: Mr. President, the next issue we would like to discuss is the need for your FY 2000 budget to include meaningful and substantial increases in HIV funding. The Council is very grateful to you for your strong and public support for the record

increases in funding in FY 1999. At the local level, these increases will really make a difference in the real lives of the people who are struggling to live with this disease, and those who are at risk for infection.

In particular, we want to thank you for the active role that you and your staff played in successful efforts to secure $156 million for the Congressional Black Caucus Initiative. As you know, that initiative is designed to address the severe and ongoing health crisis affecting African Americans, Latinos and other communities of color in the United States.

But as you know, Mr. President, the emergency conditions that led to the need for the CBC Initiative require a sustained and expanded federal response. As you finalize your FY 2000 budget, we ask that you use this opportunity to build upon the momentum of FY'99. Specifically, we are asking that full funding for the CBC initiative be included in your base budget. As you know, some of it was one-time funded -- and that this funding be expanded in FY 2000. It is also critical that the distribution of these new funds be expedited, to reflect the fact that this is a response to a crisis situation.

As my colleagues have discussed, we are also requesting that you propose a bold funding for a bold national testing awareness media campaign, and that access to HIV treatments be expanded both through the Ryan White CARE Act and through Medicaid.

Finally, Mr. President, we ask that your budget reflect the leadership role the U.S. must play in efforts to address the global pandemic, and my colleague, Mike Isbell, will say a little bit more about that in a minute. This Council certainly understands the political dynamics of the budget process, in which you must consider what the Congress itself will fund in setting your own numbers. But the reality is that your budget really sets the stage for all future deliberations in FY 2000. We really need your initial budget request to include these AIDS funding increases so that congressional action can build upon the strongest base possible. In short, we need you to raise the bar.

Thank you.

MR. ISBELL: Mr. President, six million people become infected with HIV each year around the world, half of them under the age of 25. More than 90 percent of the infections in the world happen in the developing world where there is little or no access to the drugs that have made such a big difference to people in this country.

We were extremely impressed and heartened by your use of World AIDS Day to highlight the need for American leadership in the global fight against HIV. We strongly support the $10 million program that you announced to address the needs of women and orphans of AIDS. And we would strongly support you making this one-time funding a permanent part of USAID.

Despite this initiative, Mr. President, U.S. funding for global AIDS activities has declined in real dollar terms since 1993. Just last year the administration proposed a 10 percent cut in

federal support for funding for infectious disease programs throughout the world. We believe that we cannot turn the tide against HIV throughout the world without the aggressive, bold, energetic leadership of the United States. And we would strongly encourage in your next budget, Mr. President, that you're about to send to the Hill, that you include substantial increases for international AIDS programs at USAID and the CDC.

Just also to close, we'd also strongly support an improved coordination of the many federal programs that happen all across the government that have a role to play in the international AIDS efforts. Secretary Albright has announced, as you know, a plan to draft a U.S. international AIDS strategy, and we would hope that you would look to this as a first step toward making sure that all the federal agencies are reading off the same page and that they're part of the same team -- because it's an urgent problem and it requires an urgency of the entire U.S. government.

THE PRESIDENT: Well, in general, let me say I think the budget should reflect better attention both to prevention at home and to the communities of color. And I've been trying to get more money for the USAID mission and we'll put some more money in there. I think I'd like to make two points.

One is that this budget year will be more difficult than the last one because we got such big increases in everything last time and because of the global economy kind of slowing down, we don't expect the same amount of revenues to come in this time. And we have to fund all the big increases we got last time again. But we'll do the best we can.

The second thing I would like to say is I think that it would be very helpful to have all of you using your, whatever influence you have, with members of Congress in both parties to support more global efforts, because eventually all this is going to a menace to the United States. So it's not only a moral imperative, it's also very practical over the long run.

One of the things that has kind of bothered me is that in the aftermath of the Cold War we were able for several years to reduce our defense budget, and that was a good thing and everyone --and even the Pentagon wanted to do it. There reduced like by about 300,000 the number of civilian employees. And they plan for further reductions there.

But during that time, we actually needed to make a larger commitment on the diplomatic front or in the non-defense security areas, if you will. And with the exception of the special efforts we made in the former Soviet Union to dismantle and destroy nuclear weapons, basically there's been a wholesale effort to cut back on our diplomatic budget, even though, contrary to popular wisdom, the United States spends a smaller percentage of our income on international affairs than any other major country.

And one of the things that I have seen -- almost no one knows this, but it's true -- one of the things that I have -- now, to be fair, we also spend more on defense and a lot of our defense goes to protect other countries, as you see in the last couple of days. But, still, for the numbers -- are so much more modest, not only for

-- if you just look at the USAID program, the health programs, the empowerment of women and children, especially young girls, initiative, the small scale microeconomic development -- all that stuff that doesn't cost much money and it has a huge impact. And especially a lot of the things we can do in public heath.

And, interestingly enough, a lot of the preventive activities that we would engage in with regard to AIDS, for example, would go quite well with other things we need to be doing out there with these large populations anyway in a lot of countries that have severe public health problems.

So we've been sitting here meeting in our -- I've been having each of the last three or four days rather long, detailed budget sessions, trying to figure out how to get more blood out of that turnip. And one of the things that I'm trying to do is to figure out how to make the case to the Congress in an effective way that the United States has enormous interest, as well as obligations, in making these kinds of investments beyond our borders.

And I think anything you can do to help that, I would appreciate it. I mean, there is this sort of general awareness in Congress that the world is becoming more interdependent. There's a much more sophisticated understanding of the economics, for example. But it's not just economics. It's the environment, it's the public health, it's all these other things where we are becoming more and more caught up with each other.

Our major military mission in the last six months, before the operation in Iran, has been to send several thousand of our uniformed personnel to Central America to help them rebuild after Hurricane Mitch. It's not only the right thing to do from a humanitarian point of view, it is in our national interest. Because if those countries don't rebuild they will become highly vulnerable to all the drug traffickers. And if they don't rebuild then all their people will have to come here. And if they can't get here legally will try to come illegally. So there's all these things that we need to begin to see our relationships beyond our borders, as more of an extension of our relationships with one another, rather than as something totally different and apart from our relations with one another.

And, anyway, I don't mean to give you a speech on that; I know you believe that. But the point I want to make is, most people who run for Congress never have to think about these things unless they have a large immigrant population within their district from a particular place. So it doesn't -- this kind of discussion we're having, because you understand the HIV/AIDS issue -- I'm preaching to the choir here. But anything you can do to sort of just sit down and walk through this with congressional delegations, or their chiefs of staff, or whoever the appropriate people are from around the country, I would really appreciate.

Because I think there is a lot of support. For example, you can always get good support in Congress, bipartisan, for a big increase in the Ryan White Act. And now, we've finally got pretty good support in Congress, this whopping increase we had to help people purchase the drugs, the medicines. But it drops off markedly when you try to talk about the connection between what we're doing

here at home and beyond our borders. And I really think you could help, because this is one example of a more general challenge the country will have to face -- more every year for the next 20 years. Maybe forever, but certainly for the next 20 years.

DR. HITT: Mr. President, we really have made -- probably hundreds of recommendations in the past few years, I mean -- (Laughter.) We've tried our best to narrow down --

THE PRESIDENT: This is the most energetic -- (Laughter.)

DR. HITT: But we have narrowed down a few specific initiatives we brought to your attention today and the reason is clear, that we've talked to many administration officials and this is where we feel that there's a logjam that you can really help and get involved in, and take it to heart.

THE PRESIDENT: I will.

DR. HITT: And thank you, again, for meeting with us.

THE PRESIDENT: Thank you for the dreidel, the book, the letters. Thank you very much. (Applause.)

END 6:40 P.M. EST

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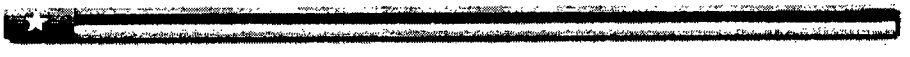

DRAFT
R. SCOTT HITT STATEMENT
INTRODUCTION TO MEETING OF PACHA WITH THE PRESIDENT
DECEMBER 18, 1998

On behalf of the Council I want to thank you for meeting with us, especially so close to your recent high profile events regarding the Congressional Black Caucus initiative for communities of color and spotlighting the increasing international AIDS crisis.

6 ½ years ago I was proud to stand with you on the stage at the Palace Theater where you outlined your vision, commitment and genuine care for people living with HIV disease to end the epidemic.

In light of the efforts you have made in securing unprecedented funding increases for AIDS programs, forming the Office of AIDS Research and Office of National AIDS Policy, convening the White House conference on AIDS and setting the goal of having a vaccine within a decade, which are landmarks you can be very proud of, I am just as proud to be here with you today.

In addition, I want to thank you for the humbling honor to serve this council as its chair and to tell you, on behalf of all of us, how proud we are to serve your administration.

Continuing with our task of offering advise we recently adopted our priorities which reflect the community realities, especially the urgency in racial and ethnic communities as well as the youth of our country.

This epidemic has been full of changes and challenges and we are at major crossroads on some key issues now. The media remind us often that HIV is manageable and that death rates are down.

What they often fail to mention is that that the current prevention efforts are not reaching the American public and are not reducing the number of new infections and that 300,000 people in this country don't know that they are infected. In addition thousands of HIV individuals cannot get the early treatment the Public Health Service guidelines have recommended but must wait until they become disabled from the disease before being eligible for treatment.

Out of all our recommendations to date, there are a few items that need ***your*** specific Presidential intervention that we would like to discuss with you today.

None of what we recommend to you, especially today, would be possible without the tireless efforts of several people who serve you, this council and all people living with HIV/AIDS.... your Director - Sandy Thurman, and Deputy Director - Todd Summers, and the Council's Executive Director Daniel Montoya....your Office of National AIDS Policy has made this meeting and our goals worthy of your time and effort.

♦ PERSPECTIVE BY RABBI JOSEPH EDELHEIT

Mr. President,

We are honored to be here with you so soon after you have returned from the Mid East, where you courageously engaged in the making of peace, where you brought the gift of hope to the Land of the Bible. During this week of Hannukah and one week before Christmas, we are all reminded that both religious holidays promise us "light" during the darkest time of the year. As your Advisory Council we want to help you, fulfill your vision, to bring the light of hope, to all those living with HIV/AIDS.

HIV/AIDS still darkens the path to that bridge into the 21st century , to which you have prophetically led us. We want to help you illuminate the darkness which hides the path. We must warn you that there are some Americans who are in danger of being unable to follow when you lead us across that bridge into the 21st century. How can we be sure that the African American homeless IV drug user who has no access to clean needles or the newest combination of drug therapies will get to the other side? What do we have to do that will insure that the Latino youth who is not eligible for Medicaid will have access to primary care and still be able to work so he too can cross the bridge with other Americans?

Here is a gift from my four children, a Dreidel, the traditional spinning top we play during Hannukah; the four Hebrew letters stand for the statement, Nes Gadol Haya Sham - "A Great Miracle Happened There." Mr. President, we know there will be no one great miracle to end, HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access to care for all persons battling HIV disease. We are here with you especially on this day, when a terrible political darkness has fallen over this land, because we want you to know that we will do whatever it takes to cross that bridge with you into the 21st century.

Tom Henderson Statement

Mr. President, since you took office, the HIV/AIDS epidemic has changed dramatically. New therapies to treat HIV have made a huge difference and have offered hope for many. Many more people are now *living* with HIV as a chronic disease, and that number is growing.

But, unfortunately, that good news does not apply to all groups. As you are aware, the face of the epidemic is changing rapidly. Today, people with HIV are increasingly likely to be young, uninsured, impoverished, abusing substances, female and members of racial or ethnic minorities. Mr. President, Denise, who was infected at age 16, is now much more typical of those living with HIV than older gay, white men like me.

The new face of the epidemic also brings into clear focus a major policy disconnect regarding how we care for people with HIV. On one hand, we have new HHS standard-of-care guidelines that call for early treatment of HIV with combination drug therapies prior to disability.

On the other hand, in many cases, accessing Medicaid and Medicare, the principal HIV care coverage programs for at least 50% of HIV+ individuals, still requires persons to be *already disabled.*

As a result, unlike those of us fortunate enough to be employed and adequately insured, those who must rely on Medicaid and Medicare for health care are basically unable to access the new therapies. Instead of being able to enjoy the benefits of living longer and better lives, they are still forced to wait until they become sick and unable to work before they can even *begin* treatment. Not only is that inhumane, but it is costly, as well.

Access to quality medical care has also become an alarmingly widespread problem for those who are incarcerated. And, in most cases, there is no preparation for connecting those individuals into medical care once they are released back into the community.

In April, 1997, the Vice President asked HCFA to evaluate the possibility of expanding access to Medicaid for poor HIV+ individuals prior to their becoming disabled. In response, HCFA/HHS has concluded that, on a national basis at least, earlier access cannot be done in a budget neutral manner. Some suggest that the only near-term solution is to rely on the demonstration programs called for in the Jeffords-Kennedy legislation.

Mr. President, we reject that conclusion. We believe that with the requisite will and some relatively minor innovation, such access to care can be provided *now*. However, we do believe that if the current gridlock is to be broken, your *personal* intervention will be necessary.

Specifically, there are three areas which need your attention.

First, it is our understanding that OMB requires finding offsetting cost savings for budget neutrality purposes in Medicaid *only*. Even if reforming Medicaid rules to cover asymptomatic HIV+ individuals actually results in savings in *other* federal entitlement or discretionary programs, OMB does not consider those savings in its analysis of budget neutrality.

Also, current policy limits States to considering only a five-year budget window. Several States believe that considering a longer time frame would make it more likely that they could achieve budget neutrality.

Your personal direction to the Secretary of HHS and to the Director of OMB to change their current policies to include a broader range of programs and a longer budget window for determining budget neutrality would go a long way toward resolving this problelm.

Second, is the overriding issue of drug costs. While reducing the cost of HIV drugs should not be the only mechanism for reducing costs, the significantly increased market for HIV drugs that will result from earlier treatment makes accompanying, negotiated drug cost reductions clearly both reasonable and essential. Mr. President, the time to deal with drug cost issues is while we are also dealing with expanding the access to those drugs.

One potentially productive approach to resolving this issue would for the Vice President to expand his ongoing discussions with the pharmaceutical industry to include the cost of drugs to the government. Those discussions should also be broadened to include all relevant Departments, particularly Justice and State, to ensure that anti-trust and international concerns are appropriately addressed.

And third, provisions for necessary *start-up* costs of Medicaid reform should be included in your FY 2000 budget request.

Mr. President, when I stood with many others during the stirring speeches of Bob Hattoy and Elizabeth Glazer at the 1992 Democratic National Convention, it was a very emotional moment for me. I truly believed that would be my last National Convention . Because of the remarkable progress we have made under your leadership in fighting this disease, I am still here, alive and well today. Now I believe we have a unique opportunity to help make sure that many others living with HIV are also able to enjoy that gift of life.

Alexander Robinson Statement

Comments for 12/18 Meeting with President Clinton

Mr. President, this Council, members of the community at large and indeed your Administration has struggled with the challenge of preventing new HIV infections. Reaching agreement on the most effective ways of preventing new HIV infections has been very difficult.

We have made progress in our efforts to include local community members in shaping our prevention programs, but there is much more to do. Today we want to raise two issues with you. One of them you will immediately recognize. The other is new and we believe offers and exciting opportunity.

First, on the issue of needle exchange programs. Without rehashing the history which we are sure you are familiar with, we want to ask for your support of a request we have made of Secretary Shalala. We have asked that HHS provide the Council, ONAP and other important agencies of the federal government with a summary of the scientific information that supports the need for these important programs. This would be an important first step in fulfilling the Administration's commitment to assist communities that want to institute these programs locally.

Our second recommendation relates to prevention. Despite the new therapies and the efforts to find a vaccine, a cure is not in sight, and preventing new infections is the only real answer. This problem is especially critical for African Americans and other people of color, where the severe and ongoing HIV health crisis has created a public health emergency.

One reason why stemming the tide of new infections has been so elusive is the fact that so many people living with HIV do not know it. As a person who has thrived for the past 17 years despite the fact that I am living with HIV, I understand the importance of knowing one's status. It has

offered me the opportunity to seek treatment for HIV early, and it has made me more aware of protecting myself and others from HIV infection.

That is why your Council is recommending that the White House Office of National AIDS Policy be directed to undertake a bold national media campaign to promote voluntary HIV testing.

We are very excited about this recommendation. The CDC has begun to develop a strategy to determine how to get the message to young people at risk for HIV infection. With the leadership of the White House, a campaign modeled on ONDCP's National Youth Anti-Drug Media Campaign would raise awareness about the continuing threat that HIV poses, while lessening the stigma of testing. Since the media messages can be targeted to populations at risk, it will encourage those individuals to seek testing.

Our recommendation is that ONAP work with the CDC, national advertisers and media concerns to develop this public-private partnership. We think this is the kind of effort consistent with your legacy of an activist government that leverages private sector resources to achieve important national goals. It would also enhance your commitment to ending racial and ethnic disparities in health.

Finally, we think this campaign will demonstrate important leadership on a central and sometimes controversial issue. Some members of Congress and others in the community have called for misguided measures such as mandatory HIV testing, mandatory contact tracing and mandatory partner notification. Like us, they are concerned that too many people living with HIV don't know it and are at risk of unknowingly infecting others. The proposed campaign will demonstrate your Administration's sound public health approach to this challenge.

Mr. President, we hope you will seriously consider undertaking this campaign.

Helen Miramontes Statement

Mr. President --- I came here today as a Mother with a son living with AIDS to talk to you about vaccines ---- but before I speak to you about the vaccine issue, I want you to know that combination therapies are only a stop gap measure -- and these therapies are failing many people -- some in this room -- as well as my son --- therefore the need for continuing research is as important today as it has ever been ---

First -- I want to thank you for what you have accomplished in moving the agenda on AIDS vaccines and in establishing a 10 year goal to achieve an effective vaccine. ---

But there are several critical issues that ONLY you can address if your goal is to be reached --- Let me give you two examples:

First -- it has been 19 months since your announcement of the vaccine goal -- and a Director of the Vaccine Center at NIH has not yet been appointed --- Even though this Center is only 10-15% of the funding -- this appointment needs to be made ----

Secondly --- a preliminary vaccine meeting was held more than 6 months ago and to date there has been no follow up meeting ----- When

President Kennedy announced that we were going to put a man on the moon, he appointed a person WITHIN the White House---not NASA --- to coordinate this endeavor. ------ After hearing almost a hundred hours of testimony, we recommended a Coordinator be placed within YOUR Office of National AIDS Policy -- with adequate resources -- to coordinate the vaccine effort. -------

This is not to tell any one agency what to do -- but rather to coordinate vaccine activities across all relevant federal agencies -- developing true partnerships with the international community and private industry. ----
We also recommended that a comprehensive plan be developed and implemented. --- this hasn't happened either. --
We all need to remember that the person most at risk - worldwide - is a young person of color and that the most effective strategy for stopping this pandemic -- is an effective vaccine ----

Mr. President -- we urge you to give these critical vaccine issues your personal attention. ---- Thank you.

Mr. President, I am Regina Aragón from San Francisco.

The last issue we would like to discuss is the need for your FY 2000 budget to include substantial and meaningful increases for federal AIDS programs.

The Council is grateful for your strong and public support for the record overall increase in HIV funding in FY 1999. At the local level, these increases will have a real impact on the lives of thousands of people who are struggling to live with this disease and those at risk for infection.

In particular, we want to thank you and your staff for the White House's active role in securing $156 million for the Congressional Black Caucus HIV Initiative, which is designed to address the severe and ongoing health crisis among African Americans and other communities of color.

But as you know, Mr. President, the emergency conditions that led to the CBC Initiative require a sustained and expanded federal response. As you finalize your FY 2000 budget, we ask that you use this opportunity to build upon the momentum of last year.

Specifically, we are asking that full funding for the CBC Initiative is included in your base budget, and that this funding is expanded in FY 2000 in order to bring targeted resources to the crisis of AIDS among communities of color. (It is also critical that distribution of these new funds be expedited, to reflect the fact that this is a crisis response, and not business as usual.)

As my colleagues have discussed, we also request that you propose funding for a major, national counseling and testing awareness campaign, and that access to care and HIV treatments be expanded through the Ryan White CARE Act and Medicaid.

Finally, Mr. President, we ask that your budget reflect the leadership role the United States must play in efforts to address this global pandemic. Mike Isbell will speak to this issue in greater detail in just a moment.

While the Council understands the political dynamics of the budget process in which you must consider what the Congress will itself fund when setting your budget numbers, the fact is that your budget sets the standard for all future deliberations. We need for your initial budget request to include meaningful increases in AIDS funding so that Congressional action can build upon the strongest possible foundation.

In short, Mr. President, we need you to raise the bar.

This will help us ensure that all persons living with HIV disease – and not just those who are either lucky enough to have private health insurance, or wealthy enough to pay – have access to the new, life-saving therapies and essential support services, and so that those most at risk for infection can stay uninfected.

PACHA/POTUS Meeting

December 4, 1998

MEMORANDUM FOR THE PRESIDENT

TO: Sandra L. Thurman

Through: Daniel C. Montoya, Executive Director

FROM: Scott Hitt, M.D.

RE: Presidential Briefing Memorandum

This is the draft Presidential Briefing Memorandum for our upcoming December 18 meeting. We would appreciate your forwarding this Memorandum to the President and others whom you feel appropriate.

Introduction (by Rabbi Joseph Edelheit)

Rabbi Edelhiet will place the issue of HIV/AIDS into the context of the legacy that the President will want to leave as it relates to HIV. He will ask that the President do all that he can to ensure that his legacy includes addressing HIV to his fullest extent and that he carries even the most vulnerable of Americans into the 21st century.

Anticipated Narrative:

We gather here with you shortly after you have returned from Israel, where you prophetically engaged in the making of peace, where you brought the gift of hope to the Land of the Bible. It is not coincidental that we are here during the week of Hanukkah and one week before Christmas, religious holidays, whose origins are in the land from which you have just returned, religious holidays which promise us "light" during the darkest time of the year. We have come here today asking for you to help us fulfill your vision, to bring forth light to the still dark and too often terrified lives of those living with HIV/AIDS.

You have less than 400 days left in your presidency, 400 days left to lead us across the bridge to the 21st century, who are you taking with you across that bridge into the 21st century? Will you make sure that the homeless IV drug user who has no access to clean needles or to the newest combination of drug therapies will get to the other side? Will you make sure that the Hispanic woman with her young children whose Medicaid

will not cover her drugs and primary care and allow her to work and leave the welfare rolls, will this honest family get to the other side? Will you make sure that representatives of the devastated countries of Africa and Asia whose infrastructures are unable to withstand the death and dying of more than 20% of their adult populations, will any of the survivors get across the bridge?

HIV/AIDS is still darkening the path to the bridge, to which you prophetically led us during your second term, now we are asking for you to illuminate the path of darkness, help us in our despair to see the light of hope here in our own country, hope that your own Advisory Council needs to continue the fight. We are aware that the pandemic continues even as the number of deaths decrease. We are aware that more than a decade into this social tragedy, we are living through a dangerous period of religious vigilantism. What kind of Hanukkah will Dr. Barnett Slepian's family observe? What kind of Christmas blessing can Matt Shepard's parents receive? Those we represent, the persons living with HIV/AIDS are still vulnerable to the cruelty of their fellow Americans, a cruelty that is as lethal as the virus. I give you this personal gift of a Dreidel, the traditional spinning top we play during Hanukkah, the four Hebrew letters stand for the statement, *Nes Gadol Haya Sham* -"A Great Miracle Happened There." Mr. President, we know there will be no great miracle to end HIV/AIDS, what will you do now to help revive your vision of zero rate of transmission and equitable access to care for all persons battling HIV disease? Will you make sure that we are crossing that bridge with you into the 21st century?

ISSUE 1: ***How Can Access to Care for People Living with HIV Be Expanded?***

Presenter:

Background

Accessing the principal HIV care coverage programs, (Medicaid and Medicare) in most cases requires that HIV+ persons be ***already disabled,*** even though new treatments offer real hope of delaying or even preventing disability.

-- Current Resource Commitment: For FY '98, the public sector devoted about $7 billion to provision of HIV-related primary care and related services, covering everything from prescription drugs and doctors' visits to case management and housing. With Medicaid and Medicare often unavailable to cover initial care for uninsured HIV+, the burden falls increasingly on relatively smaller programs like Ryan White, HOPWA and ADAP, where disability is not a pre-condition to access.

-- Changed Circumstances: Three factors have refocused attention on the existing HIV care financing and delivery system:

-- New Standard of Care: In 1997, HHS issued new treatment guidelines for HIV, including treatment with combination drug therapy prior to development of symptoms and before substantial deterioration of the immune system resulting in disability.

-- Changing Demographics: CDC estimates that 650,000 – 900,000 Americans have HIV infection. 500,000 know their status. Only 350,000 are in care. Half of all new HIV infections are related to injection-drug use.

Achieving the President's stated national goal of reducing health care disparities among racial and ethnic groups is further complicated by the changing demographics of the HIV/AIDS epidemic. People with HIV are increasingly likely to be uninsured, impoverished, abusing substances, female and members of racial or ethnic minorities - populations historically underserved by the health care system and requiring culturally appropriate and sensitive care.

-- Declines in Mortality: AIDS-related deaths have declined (44% during first half of '97 compared to '96). AIDS diagnoses are down (12%). ***But the number of people living with HIV is increasing***. Demands on the health care system have changed, from a need for more intense end-stage care, to a need for services associated with a chronic condition. Additional costs of caring for more HIV + with expensive drugs, however, are often offset by reducing or, at least deferring, the dramatically higher costs associated with the later stages of HIV-disease. As a result, lowered inpatient costs may well compensate for increased outpatient costs.

Status: In April, 1997, Vice President Gore asked HCFA to evaluate the possibility of expanding access to Medicaid for poor HIV+ individuals prior to their becoming disabled. In response, HCFA/HHS has concluded that, on a national basis, Medicaid expansion cannot be done in a budget neutral manner.

However, the cost-estimate currently being used by HCFA/HHS of $27,000 for annual AIDS-related costs to Medicaid is ***dramatically*** higher than the average cost of care experienced in private HMOs or in the VA (the largest single direct provider of health care for HIV+), which are estimated at $10,000 - $12,000 per year.

Between the first quarter of FY '91 and the fourth quarter of FY '97, the percentage of the Medicaid budget spent on HIV drugs increased from 0.57% to 5.25%, an almost ***tenfold*** increase. Actual HIV drug expenditures grew from under $20 million in the first quarter of FY '94 to almost $120 million in the second quarter of FY '97. ***HIV drug costs are the single largest component of HIV treatment and care and that segment is growing rapidly.***

HCFA/HHS has suggested that individual states submit 1115 Medicaid waiver requests proposing expanded HIV+ care and treatment, as an alternative to a national solution. Several states are currently preparing such waiver request proposals. However, three

policy issues seriously hamper the ability of states to achieve budget neutrality:

Current Administration policy requires finding offsetting cost savings in Medicaid ***only.*** Under that policy, even if expansion results in savings in other federal entitlement (*e.g.,* Medicare, SSI and SSDI) or discretionary programs (*e.g.,* HOPWA and CARE Act), those cannot be counted toward achieving budget neutrality.

Current Administration policy limits states to considering only a five-year budget window. A longer time frame, if permitted, might make it more likely that states could achieve budget neutrality.

Given the centrality of prescription drugs in the new treatment standard, any successful attempt to develop a cost-neutral strategy must include a reduction in drug prices. In fact, Massachusetts health officials indicate that an additional reduction of approximately 15%, on top of their existing 26% discount, would be necessary to achieve budget neutrality in their waiver program. While drug pricing should not be the only mechanism for achieving expanded-access cost neutrality, the resulting increased volume of federal, state and local governmental drug purchases makes accompanying drug cost reductions clearly both reasonable and essential. Unfortunately, to date no one in the federal government has been willing even to attempt to deal with the issue of drug pricing.

Anticipated Question/Request:

The President should direct the Secretary of HHS and the Director of OMB to use a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame to determine budget neutrality for the purpose of the 1115 waiver applications.

The President should direct the Vice President to expand his discussions with the pharmaceutical industry to include the cost of HIV-related drugs. All relevant departments should also participate, including Justice and State, to ensure that anti-trust and international concerns are appropriately addressed.

The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

Issue 2: International Commitment to HIV/AIDS

Presenter:

Background

Need some stats here on the international HIV problem, including total number of HIV and AIDS cases, number of AIDS orphans, etc. Should discuss lack of medications, lack of infrastructure to address HIV, and lack of resources. Should also include something about how Secretary Albright called HIV an international security issue.

Recent Activities:

During World AIDS Day activities on December 1, the President announced an additional $10 million to address the issue of AIDS orphans in the developing world. He also directed ONAP director Sandy Thurman to go to South Africa and provide him with recommendations on what more needs to be done.

Anticipated Question/Request:

Over the last five years, your budget proposals have not sought increased funding for global health programs, and the last budget actually proposed a decrease in infectious disease program funding. Nevertheless, a Republican Congress provided a $4.0 million dollar increase to the USAID's global health budget. Given your public statements regarding the global AIDS pandemic and the indisputable statistics so clearly and widely known in the Department of
State, HHS, Commerce, Defense, the Peace Corps, U.S. Information Agency, National Intelligence Council, the CIA, USAID, as well as NIH and the CDC, why haven't you sought to increase the global health budget - which is currently $250 million and which should at least be doubled to $500 million? I must assume that the facts must not have been brought to your attention.

Issue 3: Need for a National HIV Media Awareness Campaign Targeting Young People to be Administered out of the White House Office of National AIDS Policy

Presenter:

Background

Despite the advances in HIV/AIDS care we have made little progress in developing and sustaining HIV prevention efforts that effectively reach individuals and populations most at risk for HIV infection. The Prevention Subcommittee has met with and reviewed the recommendations of the leading national HIV and AIDS organizations. There is widespread support for a national effort to promote HIV testing and knowledge of sero-status. We will only stop the spread of HIV if we have an effective effort to minimize the opportunities for HIV transmission.

According to estimates by the Centers for Disease Control and Prevention nearly fifty percent of individuals living with HIV do not know that they are HIV-positive. Research indicates that knowledge of HIV status has a positive long-term impact on the risky behaviors of people living with HIV.

A national media campaign can be effectively undertaken because it 1) may be targeted to reach populations at greatest risk; 2) would receive widespread and bipartisan support; 3) provides for a public private partnership.

Strategy and Funding

As stated earlier this effort would be model on the current ONDCP youth drug prevention campaign. ONAP would work with community and private industry partners who would provide matching funds (and in-kind media buys) to mount the campaign.

PACHA proposes new funding in FY '99 to enable ONAP to begin planning for the campaign including identification of potential partners for the campaign. In addition, PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.

PACHA recommends that the Department of Health and Human Services (Centers for Disease Control) be directed to review its current capacity to provide adequate funds for HIV testing and counseling. Based on the available information, if necessary the CDC should receive an increase in FY '99 funding to ensure the success of this outreach effort.

Political Assessment

HIV testing is being promoted by both liberal and conservative members of Congress and the community. Some of these ideas run contrary to sound public health strategy, which is non coercive and voluntary. This campaign would allow the President and the Administration to offer a proactive agenda that is moderate, has a high probability of success and has the potential to receive bipartisan support.

If successful this effort will identify a number of individuals who are HIV positive who will need to have access to care. Despite the fact that there is a need for expanded access to HIV care for those individuals who are currently know to be living with HIV, this effort should be undertaken. It will be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Question/Request

The PACHA recommends that the President direct the White House Office of National AIDS Policy develop and oversee a national media campaign to more individual

knowledge of HIV status. This initiative would be administered by ONAP and modeled on the National Youth Anti-Drug Media Campaign currently coordinated by the White House Office of National Drug Control Policy. Through public services announcements and other targeted media messages this broad national campaign would promote the value of HIV testing and counseling and would especially address the severe and ongoing HIV-related health crisis in minority communities.

Issue 4: Prisons Improved HIV prevention, treatment for currently incarcerated, and continuum of care for those being released.

Presenter: Jeremy (?)

Background

There are currently over 1,083 inmates with HIV/AIDS in 94 federal prisons throughout the United States. Approximately 10 to 15 of these inmates are in each facility spread throughout the system. Some of these facilities have access to state-of-the-art medicine, as witnessed during the site visit to the Cumberland federal Corrections facility in Maryland by the Subcommittee on Prison Issues of the Council. Others, have minimal, infirmary level health care, often inadequate for the very specialized problems of inmates living with HIV/AIDS. Within the correctional system, individuals with HIV/AIDS account for just under 10% of the prison population in the United States. In some sites, this number expands to even 16%.
[Attach NIJ Report for stats, if relevant???]

Of key concern is the need to address and respond to the issues of (1) improved HIV prevention for those who are HIV negative or at-risk for re-exposure, (2) access to high quality treatment and supportive care while incarcerated, and (3) continuum of care in the transition from prison or transitional facility to community-based health and service programs upon discharge from prison or transitional care facility.

The disparity in access and quality of care issues raises a serious health and human rights situation which has been affecting inmates with HIV and other serious medical conditions who are being discharged from our federal correctional institutions.

Inmates are being asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program, a program which allows them transitional entry back into the community where they live in a half-way house for a period of 3-12 months.
[Attach CRCP form???.]

During this period they are ineligible for any Federal subsidies such as Medicaid,

Medicare or ADAP because they are technically still under the auspices of the Federal Correctional System. This calls into question the very nature of informed consent which is at the heart of the patients bill of rights we need so much and which you are calling for. Essentially, these individuals are responsible for the entire cost of their medical treatment and associated pharmaceuticals. Because the waiver they have signed financially relinquishes the Bureau of Prisons from these costs (a waiver which the Bureau of Prisons admits is done as a cost saving measure), hundreds , if not thousands of individuals find themselves in these half-way houses with no means to adequately cover their health care costs.

The implications of this are grave not just for these ex-offenders but for the public-at large. The potential for treatment failure with the development of drug-resistant strains of HIV is real and poses a disastrous consequence to the patient and to the health of the public who can conceivably be exposed to these dangerous strains. The only alternative available to these ex-offenders is to voluntarily re-enter the prison system, giving up rehabilitation, employment, and freedom.

There appears to be a stalemate on this public health issue; an issue which has been discussed among those at ONAP, HHS and the BOP but which seems to be stalled and which certainly strikes us as an issue which could be corrected in a relatively short period of time.

Anticipated Question/Request:

SOMETHING DEALING WITH THE PARAGRAPH IMMEDIATELY ABOVE???

Issue 5: Racial and Ethnic Populations -- Capitalize on Recent Successes

Presenter: Ms. Debra Frazer Howze

Background/Concerns:

Despite comprising less than 25 percent of the U.S. populations, racial and ethnic minority communities comprise more than 50 percent of all AIDS cases. In youth, more than 65 percent of all HIV cases in young people under the age of 25 are in Black and Hispanic youth. More than 75 percent of all AIDS cases in women are in minority women. The infrastructure necessary to provide HIV prevention and services is extremely limited in minority communities.

In March 1998, the Council adopted at its priority the call for a State of Emergency in AIDS and Public Health that exists in Communities of Color. The Council was very encouraged by the Administration's work (especially that of the CBC and ONAP) to make possible the $156 million of targeted dollars in response to the severe and ongoing health crisis in communities

of color. The Council understood this to be a critical first step in addressing the disparities in health outcomes in minority communities, specifically around HIV/AIDS treatment, care and prevention services.

The Council expects that the President and his administration will capitalize on the momentum that has been created by members of Congress and community advocates. New dollars are needed to target these communities with the services, treatment and interventions necessary to equalize outcomes with other communities that are enjoying decreases in new infections and death rates. It is also important that HHS review its planning priorities and all of its initiatives to insure that the current resources are directed to those communities in greatest need. Letters have been sent to the Secretary, Assistant Secretary for Health/Surgeon General and the head of CDC with specific questions and concerns regarding how their work impacts these communities that are disproportionately impacted. We hope that your administration will act on these concerns as soon as possible.

We also hope that you will continue to address the critical nature of the health crisis in HIV/AIDS whenever you meet with the Congressional Black and Hispanic Caucuses to develop and implement a strategy to respond to the urgent HIV prevention and HIV/AIDS health care needs of these communities. Your leadership in this matter can greatly impact the quality of life of these constituencies that have supported your Presidency. As we look to the new millennium, it is our hope that the Democratic leadership will be proactive in responding to the needs of these communities and insuring that all Americans share equally in the best health care available in the world. It will be critical that meetings with key civil rights, social justice, youth and children's advocates, and health care leaders in communities of color, to encourage a community-wide effort to respond to this public health emergency (need a verb here -- be held/take place/be convened by the POTUS?). As members of the HIV/AIDS "community " we will do everything in our power to encourage these leaders to take a more active role in ending the devastation occurring in their communities. It will take everyone, with all their talents and resources to stem the tide of this pandemic. We know that working together we can make a significant impact on behalf of those in greatest need.

Anticipated Questions/Request:

Request that the President capitalize on the success of the CBC Initiative and move rapidly to secure additional funding, including funding targeting other minority communities; that the President include HIV in his discussions with the Congressional Black and Hispanic Caucuses; and that the President convene a series of meeting with minority leadership to impress upon them the urgency of the situation. **(???? -- is this what they want -- I summarized above?)**

Issue 6: AIDS Vaccine Development Progress

Presenter: **?????**

Background

In May, 1997, the President declared a goal of development of an effective AIDS vaccine within one decade. This announcement had a greater impact than ever imagined, serving to inspire the effort around the world, and also serving to invigorate the scientific community within the United States. The Council expresses their thanks for your courage and vision.

The Council believes that significant progress has been made since the declaration, and applaud the President for his time and sincere effort in the endeavor, and for his commitment of additional funds.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached; 18 months have already passed.

In July 1995 and March, 1998, the Council passed the following recommendations:

1. Substantive involvement, coordination, and collaboration among all relevant federal agencies, the private sector, and the international community are critical to the development of an effective AIDS vaccine.

2. Federal leadership at the highest level will be required, through the Office of National AIDS Policy, ensuring that adequate resources are provided for the coordination process necessary to achieve the goal of an effective AIDS vaccine.

3. The Office of National AIDS Policy should ensure the development and implementation of a comprehensive federal plan to achieve the goal of an effective AIDS vaccine.

4. The process of defining the structure and mission of the proposed (AIDS) Vaccine Center at NIH, and the appointment of a director with the highest level of expertise, should proceed promptly.

5. The urgent need for an AIDS vaccine mandates the simultaneous implementation of both basic and empiric scientific approaches.

Eighteen months have passed since your declaration. However, the overall administrative mechanism by which to coordinate the efforts of all relevant Federal agencies, regulatory agencies, private industry, and the international community has not been accomplished, nor has a comprehensive Federal vaccine strategy been developed. Further, an accomplished vaccine scientist has yet to be appointed to lead the Vaccine Center at the NIH. The Council believes that development of an effective vaccine will require immediate attention to these deficiencies, especially if the goal is to be accomplished within the stated time frame.

Anticipated Question/Request:

1. Urge the President you to use the authority of your Office to help recruit an accomplished

and vigorous vaccine scientist to lead the AIDS Vaccine Research Center at the NIH.

2. Asks the President to assure that the Office of National AIDS Policy works to coordinate the development a comprehensive federal plan to achieve the goal of an AIDS vaccine.

3. Ask the President to mandate the development of a mechanism to assure the full and on-going coordination of all relevant Federal agencies, regulatory agencies, private industry and the international community, allowing the process of vaccine development to proceed efficiently, and as rapidly as possible. **(WHY ISN'T THIS PART OF #2?????)**

Issue 7: The Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

Presenter: **???????**

Background

As the President finalizes his FY 2000 budget in the coming weeks, the Council urges that he include in his request to Congress meaningful increases for the complete HIV/AIDS portfolio, including HIV prevention, care and treatment, housing, research and international programs.
Together, these five major areas represent a comprehensive approach to ending the pandemic and caring for those living with HIV disease. As the number of persons living with HIV/AIDS in the United States continues to grow, these critical programs require additional funding if we are to
successfully achieve the important goal of eliminating racial and ethnic disparities in health outcomes by the year 2010.

The Council is grateful to the President and other Administration officials for their strong and public support for substantial increases in HIV/AIDS funding in FY 1999. Central to this success was the leadership of the Congressional Black Caucus in proposing and advocating adoption of its HIV/AIDS Initiative. The CBC Initiative has focused important attention on the disproportionate impact of HIV disease on African Americans, Latinos and other communities of color. The Council urges the President to use his FY 2000 budget request as an opportunity
to maintain and build upon the important momentum established in FY 1999.

The severe and ongoing health crisis HIV in communities of color requires a sustained effort and increased resources in each of the following areas:

- Prevention

The Council continues to be concerned by the Administration's historic lack of support for increased funding for HIV prevention efforts. In FY 2000, the Council calls upon the Office of National AIDS Policy to initiate a well-targeted, national HIV testing initiative, in order to reach an estimated 30% of persons living with HIV who, because they are unaware of their HIV-status, are at increased risk for passing the virus on to others and are missing out on early care and treatment opportunities. With 50% of new HIV infections currently related to injection drug use, the Council also urges the Administration to continue to expand substance abuse treatment services, and to support other, scientifically sound prevention programs for injection drug users and their partners.

- CARE Act and ADAP

The Council urges the President to request from Congress adequate and full funding for the AIDS Drug Assistance Program (ADAP) and all other titles of the Ryan White CARE Act, which provide important medical and support services that stabilize the health and lives of individuals with HIV disease and facilitate access to HIV treatment. The Council also requests that the President request increased funding for the Health Care Financing Administration to cover start-up costs related to expanding Medicaid coverage to low-income individuals with HIV disease, and to avoid forcing disabled individuals - including those with AIDS - to choose between entering the labor force and continued Medicaid or Medicare coverage.

- Housing

Federal housing programs play a critical role in efforts to stabilize the health of individuals living with HIV. The lack of stable housing - provided through key HUD programs such as the Housing Opportunities for People with AIDS (HOPWA), Sec. 8 other supportive housing programs - makes it more difficult for homeless persons with HIV/AIDS and those at imminent risk for homelessness to engage in the health care system and adhere to complex HIV treatments.

- Research

The substantial federal investment in HIV research, to date, has resulted in remarkable treatment breakthroughs that are prolonging the lives and health of thousands of persons with HIV/AIDS. The Council is grateful for the Administration's strong commitment to vaccine research and urges full funding of this global health imperative. The Council reiterates its strong support for research on microbicides.

- International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In contrast to such efforts, FY 1999, the President actually proposed a reduction in USAID funding. It is our hope that the President's FY 2000 budget will reflect the renewed importance of U.S. contributions towards the twin goals of ending this worldwide pandemic and mitigating the health and economic costs associated with it. The Congress' $4 million increase for US AIDS in FY 1999 represents a small, but important step towards a full and appropriate role for the U.S. in global AIDS efforts, and should be expanded upon in FY 2000.

Anticipated Questions/Request:

??????

Members, Presidential Advisory Council on HIV and AIDS

Stephen N. Abel, DDS
Mr. Terce Anderson
Ms. Regina Aragon
Ms. Judith Billings
Mr. Charles Blackwell
Mr. Nicholas Bellman
Jerry Cads, MD
Lynne M. Cooper, D. Min.
Rabbi Joseph Edelheit
Mr. Robert Fogel
Ms. Debra Fraser-Howze
Ms. Kathleen Gerus
Ms. Phyllis Greenberger
Nilsa Gutierrez, MD
Mr. Bob Hattoy
Mr. B. Thomas Henderson
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Michael Isbell, JD
Mr. Ronald Johnson
Mr. Jeremy Landau
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Mr. Steve Lew
Mr. Miguel Milanes
Ms. Helen Miramontes
Rev. Altagracia Perez
Michael Rankin, MD
Mr. H. Alexander Robinson
Ms. Debbie Runions
Mr. Sean Sasser
Mr. Benjamin Schatz
Mr. Richard W. Stafford
Ms. Denise Stokes
Rep. Charles Quincy Troupe
Bruce Weniger, MD

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Potential Questions (11)

1) Access to Care

The President should direct the Secretary of HHS and the Director of OMB to use a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame to determine budget neutrality for the purpose of the 1115 waiver applications.

The President should direct the Vice President to expand his discussions with the pharmaceutical industry to include the cost of HIV-related drugs. All relevant departments should also participate, including Justice and State, to ensure that anti-trust and international concerns are appropriately addressed.

The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

2) International

Over the last five years, your budget proposals have not sought increased funding for global health programs, and the last budget actually proposed a decrease in infectious disease program funding. Nevertheless, a Republican Congress provided a $4.0 million dollar increase to the USAID's global health budget. Given your public statements regarding the global AIDS pandemic and the indisputable statistics so clearly and widely known in the Department of
State, HHS, Commerce, Defense, the Peace Corps, U.S. Information Agency, National Intelligence Council, the CIA, USAID, as well as NIH and the CDC, why haven't you sought to increase the global health budget - which is currently $250 million and which should at least be doubled to $500 million? I must assume that the facts must not have been brought to your attention.

3) National Media Campaign

The PACHA recommends that the President direct the White House Office of National AIDS Policy develop and oversee a national media campaign to more individual knowledge of HIV status. This initiative would be administered by ONAP and modeled on the National Youth Anti-Drug Media Campaign currently coordinated by the White House Office of National Drug Control Policy. Through public services announcements and other targeted media messages this broad national campaign would promote the value of HIV testing and counseling and would especially address the severe and ongoing HIV-related health crisis in minority communities.

4) Prisons

There appears to be a stalemate on this public health issue; an issue which has been discussed among those at ONAP, HHS and the BOP but which seems to be stalled and which certainly strikes us as an issue which could be corrected in a relatively short period of time.

5) Racial Ethnic Populations

Request that the President capitalize on the success of the CBC Initiative and move rapidly to secure additional funding, including funding targeting other minority communities; that the President include HIV in his discussions with the Congressional Black and Hispanic Caucuses; and that the President convene a series of meeting with minority leadership to impress upon them the urgency of the situation. **(???? -- I summarized the above from the narrative -- I believe this is what is requested.)**

6) Research

1. Urge the President you to use the authority of your Office to help recruit an accomplished and vigorous vaccine scientist to lead the AIDS Vaccine Research Center at the NIH.

2. Asks the President to assure that the Office of National AIDS Policy works to coordinate the development a comprehensive federal plan to achieve the goal of an AIDS vaccine.

3. Ask the President to mandate the development of a mechanism to assure the full and on-going coordination of all relevant Federal agencies, regulatory agencies, private industry and the international community, allowing the process of vaccine development to proceed efficiently, and as rapidly as possible. **(WHY ISN'T THIS PART OF #2?????)**

7) Appropriations

Unknown