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[Presidential Advisory Council on HIV/AIDS Meeting with President 12/18/1998] [Folder 2]

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PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

Friday, December 18, 1998
FOR IMMEDIATE RELEASE

Contacts: R. Scott Hitt, M.D, Chair (310) 652-2562
Daniel C. Montoya, Executive Director (202) 456-2437

PRESIDENT MEETS WITH HIV/AIDS ADVISORY COUNCIL

**PRESIDENT ASKED TO CONTINUE HIS LEADERSHIP IN ADDRESSING
HIV/AIDS IN RACIAL AND ETHNIC POPULATIONS**

The Presidential Advisory Council on HIV/AIDS (Council) today met with President Clinton to discuss the severe and ongoing health crisis of HIV/AIDS, and its particular impact on racial and ethnic populations.

"For the President to spend time with the Council, particularly at this time, demonstrates his understanding of the tremendous impact that HIV/AIDS is having both in the U.S. and internationally," said Council Chair, R. Scott Hitt, M.D. of California.

The Council lauded the President's efforts, as well as his vision and understanding of the complex social and political issues surrounding AIDS. The Council thanked the President for the tremendous increases in funding in FY 1999, including funds targeting racial and ethnic populations, HIV treatment and research. The Council noted the severe toll that the epidemic continues to take, and called for a renewed commitment for the Administration to respond to the epidemic among highly impacted populations.

During the meeting, the Council focused on the following new initiatives, and called for the President's personal involvement.:

- ▶ **Increasing Access to Care for People Living with HIV.** The Council asked the President to look again at expanding access to care for people with HIV infection, including early intervention efforts, and the necessary funding in FY 2000 to implement an expansion; and to continue to work on reducing the cost of drugs.
- ▶ **National HIV Status Awareness Campaign.** The Council called for a major, national HIV counseling and testing awareness media campaign to be coordinated by the White House Office of National AIDS Policy. The Council stressed that, given the recent advances in treatment, having those who are HIV positive voluntarily test and learn their status is extremely important so that they may enter treatment at the earliest possible stage.

- ▶ **AIDS Vaccine Development.** The Council reminded the President of his goal to find a vaccine to prevent HIV infection within 10 years, and urged him to quickly fill the director's position at the AIDS Vaccine Research Center at NIH. The Council asked the President to assure that the Office of National AIDS Policy to coordinates the development of a comprehensive federal plan to achieve the goal of an AIDS vaccine of AI DS vaccine development across all relevant agencies and organizations, both federal and non-federal.
- ▶ **Expanded Investments in FY 2000 Funding.** The Council called on the President to build on the success achieved in the FY 1999 budget by ensuring necessary increases in federal funding for the Ryan White CARE Act, the AIDS Drug Assistance Program, housing, research and international efforts in FY 2000.

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Presidential Advisory Council on HIV/AIDS Meeting with the President

December 18, 1998

THEME: SUPPORT, SUPPORT, SUPPORT

WHEN PRESIDENT ENTERS, PLEASE STAND AND APPLAUD

ATTEND THIS MEETING AS A COUNCIL, NOT AS AN INDIVIDUAL

DO NOT SPEND TIME INTRODUCING EACH MEMBER -- THEY WILL HAVE NAME TAGS AND/OR NAME TENTS

Introduction of Council's Chair - Dr. Scott Hitt by Sandra L. Thurman

Introduction by Scott Hitt, M.D.

- ◆ Thank the POTUS for the opportunity to meet with him and his staff. Thank him for his leadership, commitment and genuine caring for people living with HIV and AIDS, and for his true commitment for wanting to help end the devastating impact AIDS is having both in the U.S. and the world.
- ◆ Speaking for all members, indicate how proud you have been to serve the President and his Administration.
- ◆ Thank his staff for being at this meeting, for their past support, and for their commitment to this issue.
- ◆ Thank Sandy Thurman, Todd Summers, and any other major official in the room.
- ◆ Thank the Council members present for their commitment, leadership and friendship.
- ◆ Thank Daniel Montoya for his work as executive director and for his ability to help focus the Council's efforts.
- ◆ Acknowledge and thank him for the recent White House events focusing on AIDS.

including the Congressional Black Caucus announcement, the World AIDS Day announcement of new international funding, funding to address AIDS orphans, and new funding for vaccine development. These announcements are very important, not only for the funding they provide, but also because of the focus they bring to very critical issues.

- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
- ◆ Indicate that his focus on HIV over the past several months has sent a clear message to the American public that HIV/AIDS is not over. What we need to do now is to build on the momentum he has begun and help ensure his legacy as the one and only President who was not afraid to tackle difficult, long-term issues because he knew it was necessary and because he knew it was the right and moral thing to do.
- ◆ Mr. President, over the past year, this Advisory Council has taken a long and hard look at where the epidemic is heading and what we need to be doing as a nation to address it, and we clearly understand the role that your leadership has and will continue to play.
- ◆ In June of this year, the Council adopted as its number one priority the issue of addressing HIV/AIDS in racial and ethnic. Acknowledge his recent focus on racial and ethnic communities and the additional \$156 million in funding targeted to these communities that was obtained with the strong leadership of the Congressional Black Caucus and many others **(including the special role that Erskine Bowles played)**.
- ◆ Stress that this effort has focused the attention of the African American community on this disease in a way that has not occurred to date. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color and to ensure that racial/ethnic communities have equal access to the \$4 billion that the Federal government spends on AIDS each year.
- ◆ We believe that this will take additional measures, including better coordination of efforts, not only in the area of vaccine development, but in the running of programs, both in the U.S. and internationally.

◆ **PERSPECTIVE BY RABBI EDELHEIT**

Mr. President,

We are honored to be here with you so soon 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. During the 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 forth the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to the , to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must want you that there are some who are in danger of not being able to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 Hispanic single mother with young children whose Medicaid will not cover her drugs and primary care and also allow her to work and leave the welfare rolls, will get to the other side?

Here is a gift, 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 great miracle to end HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access 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 city, because we want you to know that we will do what ever it takes to cross that bridge with you into the 21st century.

ISSUE 1: Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

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 by supporting the following budget items.

Action Items:

1. 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 because those who 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.

2. CARE Act and ADAP

The Council urges the President to request from Congress adequate 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. **(If Medicaid is an entitlement, is it mandatory spending or does funding have to be requested?)**

3. 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 and 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. **The Council ... what do you want?)**

4. 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.

5. International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In FY 1999, however, 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. **(We need to ensure that this \$10 million increase is built into the base funding.)**

ISSUE 2: *Critical Need for Expanded Access to Care for People Living with HIV*

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. The AIDS case rate for African Americans is eight times higher than that of whites.

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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

INTERNAL USE ONLY

Anticipated Schedule/Time Line

Time Allotted: 30 Minutes

Introduction of Council's Chair, Scott Hitt, M.D. by Sandra Thurman	1 minute
Welcome/Background by R. Scott Hitt, M.D.	2.5 minutes
Statement by Rabbi Joseph Edelheit	1.5 minutes
Issue 1: Future Investment in HIV/AIDS Presenter: Regina Aragon	2 minutes (5 minutes total)
Issue 2: Access to Care Presenter: Tom Henderson	2 minutes (5 minutes total)
Issue 3: National Media Campaign Presenter: Alexander Robinson	2 minutes (5 minutes total)
Issue 4: AIDS Vaccine Development Presenter: Alexandra Levine, M.D.	2 minutes (5 minutes total)
Closing by President	5 minutes
TOTAL	18 minutes (30 minutes total)

Background leading to the questions/ recommendations must be extremely tight; accomplishments should begin the issue (IE. Thank you for your recent announcement of \$200 million in AIDS vaccine funding....) Presenters should limit the contextual and background information (especially historical context unless absolutely necessary). It would be appropriate for individuals to say something like, "as a person living with AIDS," or "as someone who has lost XXX friends to AIDS...."

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING --- Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

♦ **HOLDING --- Reverend Altagracia Perez**

- ♦ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ♦ My congregation is a mirror into the future of the AIDS epidemic.
- ♦ In this time of loving, forgiveness, and recommitment to our maker and our neighbor, we must ask ourselves whether we have done enough for our fellow woman or man or whether our efforts must be increased.
- ♦ The Rabbi spoke earlier of the symbolism that the holidays offer us. He said the holidays “promise us light during the darkest time of the year.”
- ♦ I remain committed to the fact that I too can shed some light on the darkness that the AIDS epidemic has brought upon us in the United States, and in the world.
- ♦ The AIDS epidemic continues to strike hardest at those least fortunate, those with the weakest voices in our society, and those who for too many years, have been forgotten.
- ♦ It is the role of the Council to speak for those who can not speak, to push for leadership for those who have no leaders, and to open their hearts and fill it with the love of those whose lives have been and will be forever be changed by AIDS.
- ♦ It is also the Council’s role to ask that America’s leaders, especially the President, continue to push for what is needed, even when it is difficult.
- ♦ On behalf of the Council, I ask the President to continue to show that leadership, especially for racial and ethnic communities, and especially for those in far away countries that most American’s don’t even know exist.
- ♦ Ask him to continue to be that “light in the darkness” that so many of us strive to see on a daily basis.

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- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
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- ◆ Mr. President, over the past year, this Advisory Council has taken a long and hard look at where the epidemic is heading and what we need to be doing as a nation to address it, and we clearly understand the role that your leadership has and will continue to play.
- ◆ In June of this year, the Council adopted as its number one priority the issue of addressing HIV/AIDS in racial and ethnic. Acknowledge his recent focus on racial and ethnic communities and the additional \$156 million in funding targeted to these communities that was obtained with the strong leadership of the Congressional Black Caucus and many others **(including the special role that Erskine Bowles played)**.
- ◆ Stress that this effort has focused the attention of the African American community on this disease in a way that has not occurred to date. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color and to ensure that racial/ethnic communities have equal access to the \$4 billion that the Federal government spends on AIDS each year.
- ◆ We believe that this will take additional measures, including better coordination of efforts, not only in the area of vaccine development, but in the running of programs, both in the U.S. and internationally.

◆ **PERSPECTIVE BY RABBI EDELHEIT**

Mr. President,

We are honored to be here with you so soon 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. During the 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 forth the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to the , to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must want you that there are some who are in danger of not being able to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 Hispanic single mother with young children whose Medicaid will not cover her drugs and primary care and also allow her to work and leave the welfare rolls, will get to the other side?

Here is a gift, 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 great miracle to end HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access 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 city, because we want you to know that we will do what ever it takes to cross that bridge with you into the 21st century.

ISSUE 1: Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

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 by supporting the following budget items.

Action Items:

1. 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 because those who 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.

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The Council urges the President to request from Congress adequate 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

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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 and 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. **The Council ... what do you want?)**

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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.

5. International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In FY 1999, however, 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. **(We need to ensure that this \$10 million increase is built into the base funding.)**

ISSUE 2: Critical Need for Expanded Access to Care for People Living with HIV

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. The AIDS case rate for African Americans is eight times higher than that of whites.

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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

INTERNAL USE ONLY

Anticipated Schedule/Time Line

Time Allotted: 30 Minutes

Introduction of Council's Chair, Scott Hitt, M.D. by Sandra Thurman	1 minute
Welcome/Background by R. Scott Hitt, M.D.	2.5 minutes
Statement by Rabbi Joseph Edelheit	1.5 minutes
Issue 1: Future Investment in HIV/AIDS Presenter: Regina Aragon	2 minutes (5 minutes total)
Issue 2: Access to Care Presenter: Tom Henderson	2 minutes (5 minutes total)
Issue 3: National Media Campaign Presenter: Alexander Robinson	2 minutes (5 minutes total)
Issue 4: AIDS Vaccine Development Presenter: Alexandra Levine, M.D.	2 minutes (5 minutes total)
Closing by President	5 minutes
TOTAL	18 minutes (30 minutes total)

Background leading to the questions/ recommendations must be extremely tight; accomplishments should begin the issue (IE. Thank you for your recent announcement of \$200 million in AIDS vaccine funding....) Presenters should limit the contextual and background information (especially historical context unless absolutely necessary). It would be appropriate for individuals to say something like, "as a person living with AIDS," or "as someone who has lost XXX friends to AIDS...."

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING — Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

◆ **HOLDING --- Reverend Altagracia Perez**

- ◆ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ◆ My congregation is a mirror into the future of the AIDS epidemic.
- ◆ In this time of loving, forgiveness, and recommitment to our maker and our neighbor, we must ask ourselves whether we have done enough for our fellow woman or man or whether our efforts must be increased.
- ◆ The Rabbi spoke earlier of the symbolism that the holidays offer us. He said the holidays “promise us light during the darkest time of the year.”
- ◆ I remain committed to the fact that I too can shed some light on the darkness that the AIDS epidemic has brought upon us in the United States, and in the world.
- ◆ The AIDS epidemic continues to strike hardest at those least fortunate, those with the weakest voices in our society, and those who for too many years, have been forgotten.
- ◆ It is the role of the Council to speak for those who can not speak, to push for leadership for those who have no leaders, and to open their hearts and fill it with the love of those whose lives have been and will be forever be changed by AIDS.
- ◆ It is also the Council’s role to ask that America’s leaders, especially the President, continue to push for what is needed, even when it is difficult.
- ◆ On behalf of the Council, I ask the President to continue to show that leadership, especially for racial and ethnic communities, and especially for those in far away countries that most American’s don’t even know exist.
- ◆ Ask him to continue to be that “light in the darkness” that so many of us strive to see on a daily basis.

**Presidential Advisory Council on HIV/AIDS
Meeting with the President**

December 18, 1998

THEME: SUPPORT, SUPPORT, SUPPORT

WHEN PRESIDENT ENTERS, PLEASE STAND AND APPLAUD

ATTEND THIS MEETING AS A COUNCIL, NOT AS AN INDIVIDUAL

DO NOT SPEND TIME INTRODUCING EACH MEMBER -- THEY WILL HAVE NAME TAGS AND/OR NAME TENTS

Introduction of Council's Chair - Dr. Scott Hitt by Sandra L. Thurman

Introduction by Scott Hitt, M.D.

- ◆ Thank the POTUS for the opportunity to meet with him and his staff. Thank him for his leadership, commitment and genuine caring for people living with HIV and AIDS, and for his true commitment for wanting to help end the devastating impact AIDS is having both in the U.S. and the world.
- ◆ Speaking for all members, indicate how proud you have been to serve the President and his Administration.
- ◆ Thank his staff for being at this meeting, for their past support, and for their commitment to this issue.
- ◆ Thank Sandy Thurman, Todd Summers, and any other major official in the room.
- ◆ Thank the Council members present for their commitment, leadership and friendship.
- ◆ Thank Daniel Montoya for his work as executive director and for his ability to help focus the Council's efforts.
- ◆ Acknowledge and thank him for the recent White House events focusing on AIDS.

including the Congressional Black Caucus announcement, the World AIDS Day announcement of new international funding, funding to address AIDS orphans, and new funding for vaccine development. These announcements are very important, not only for the funding they provide, but also because of the focus they bring to very critical issues.

- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
- ◆ Indicate that his focus on HIV over the past several months has sent a clear message to the American public that HIV/AIDS is not over. What we need to do now is to build on the momentum he has begun and help ensure his legacy as the one and only President who was not afraid to tackle difficult, long-term issues because he knew it was necessary and because he knew it was the right and moral thing to do.
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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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

INTERNAL USE ONLY

Anticipated Schedule/Time Line

Time Allotted: 30 Minutes

Introduction of Council's Chair, Scott Hitt, M.D. by Sandra Thurman	1 minute
Welcome/Background by R. Scott Hitt, M.D.	2.5 minutes
Statement by Rabbi Joseph Edelheit	1.5 minutes
Issue 1: Future Investment in HIV/AIDS Presenter: Regina Aragon	2 minutes (5 minutes total)
Issue 2: Access to Care Presenter: Tom Henderson	2 minutes (5 minutes total)
Issue 3: National Media Campaign Presenter: Alexander Robinson	2 minutes (5 minutes total)
Issue 4: AIDS Vaccine Development Presenter: Alexandra Levine, M.D.	2 minutes (5 minutes total)
Closing by President	5 minutes
TOTAL	18 minutes (30 minutes total)

Background leading to the questions/ recommendations must be extremely tight; accomplishments should begin the issue (IE. Thank you for your recent announcement of \$200 million in AIDS vaccine funding....) Presenters should limit the contextual and background information (especially historical context unless absolutely necessary). It would be appropriate for individuals to say something like, "as a person living with AIDS," or "as someone who has lost XXX friends to AIDS...."

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING — Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

♦ **HOLDING --- Reverend Altagracia Perez**

- ♦ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ♦ My congregation is a mirror into the future of the AIDS epidemic.
- ♦ In this time of loving, forgiveness, and recommitment to our maker and our neighbor, we must ask ourselves whether we have done enough for our fellow woman or man or whether our efforts must be increased.
- ♦ The Rabbi spoke earlier of the symbolism that the holidays offer us. He said the holidays “promise us light during the darkest time of the year.”
- ♦ I remain committed to the fact that I too can shed some light on the darkness that the AIDS epidemic has brought upon us in the United States, and in the world.
- ♦ The AIDS epidemic continues to strike hardest at those least fortunate, those with the weakest voices in our society, and those who for too many years, have been forgotten.
- ♦ It is the role of the Council to speak for those who can not speak, to push for leadership for those who have no leaders, and to open their hearts and fill it with the love of those whose lives have been and will be forever be changed by AIDS.
- ♦ It is also the Council’s role to ask that America’s leaders, especially the President, continue to push for what is needed, even when it is difficult.
- ♦ On behalf of the Council, I ask the President to continue to show that leadership, especially for racial and ethnic communities, and especially for those in far away countries that most American’s don’t even know exist.
- ♦ Ask him to continue to be that “light in the darkness” that so many of us strive to see on a daily basis.

**Presidential Advisory Council on HIV/AIDS
Meeting with the President**

December 18, 1998

THEME: SUPPORT, SUPPORT, SUPPORT

WHEN PRESIDENT ENTERS, PLEASE STAND AND APPLAUD

ATTEND THIS MEETING AS A COUNCIL, NOT AS AN INDIVIDUAL

DO NOT SPEND TIME INTRODUCING EACH MEMBER -- THEY WILL HAVE NAME TAGS AND/OR NAME TENTS

Introduction of Council's Chair - Dr. Scott Hitt by Sandra L. Thurman

Introduction by Scott Hitt, M.D.

- ◆ Thank the POTUS for the opportunity to meet with him and his staff. Thank him for his leadership, commitment and genuine caring for people living with HIV and AIDS, and for his true commitment for wanting to help end the devastating impact AIDS is having both in the U.S. and the world.
- ◆ Speaking for all members, indicate how proud you have been to serve the President and his Administration.
- ◆ Thank his staff for being at this meeting, for their past support, and for their commitment to this issue.
- ◆ Thank Sandy Thurman, Todd Summers, and any other major official in the room.
- ◆ Thank the Council members present for their commitment, leadership and friendship.
- ◆ Thank Daniel Montoya for his work as executive director and for his ability to help focus the Council's efforts.
- ◆ Acknowledge and thank him for the recent White House events focusing on AIDS.

including the Congressional Black Caucus announcement, the World AIDS Day announcement of new international funding, funding to address AIDS orphans, and new funding for vaccine development. These announcements are very important, not only for the funding they provide, but also because of the focus they bring to very critical issues.

- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
- ◆ Indicate that his focus on HIV over the past several months has sent a clear message to the American public that HIV/AIDS is not over. What we need to do now is to build on the momentum he has begun and help ensure his legacy as the one and only President who was not afraid to tackle difficult, long-term issues because he knew it was necessary and because he knew it was the right and moral thing to do.
- ◆ Mr. President, over the past year, this Advisory Council has taken a long and hard look at where the epidemic is heading and what we need to be doing as a nation to address it, and we clearly understand the role that your leadership has and will continue to play.
- ◆ In June of this year, the Council adopted as its number one priority the issue of addressing HIV/AIDS in racial and ethnic. Acknowledge his recent focus on racial and ethnic communities and the additional \$156 million in funding targeted to these communities that was obtained with the strong leadership of the Congressional Black Caucus and many others (**including the special role that Erskine Bowles played**).
- ◆ Stress that this effort has focused the attention of the African American community on this disease in a way that has not occurred to date. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color and to ensure that racial/ethnic communities have equal access to the \$4 billion that the Federal government spends on AIDS each year.
- ◆ We believe that this will take additional measures, including better coordination of efforts, not only in the area of vaccine development, but in the running of programs, both in the U.S. and internationally.

◆ **PERSPECTIVE BY RABBI EDELHEIT**

Mr. President,

We are honored to be here with you so soon 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. During the 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 forth the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to the , to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must want you that there are some who are in danger of not being able to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 Hispanic single mother with young children whose Medicaid will not cover her drugs and primary care and also allow her to work and leave the welfare rolls, will get to the other side?

Here is a gift, 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 great miracle to end HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access 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 city, because we want you to know that we will do what ever it takes to cross that bridge with you into the 21st century.

ISSUE 1: Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

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 by supporting the following budget items.

Action Items:

1. 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 because those who 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.

2. CARE Act and ADAP

The Council urges the President to request from Congress adequate 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. **(If Medicaid is an entitlement, is it mandatory spending or does funding have to be requested?)**

3. 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 and 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. **The Council ... what do you want?)**

4. 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.

5. International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In FY 1999, however, 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. **(We need to ensure that this \$10 million increase is built into the base funding.)**

ISSUE 2: *Critical Need for Expanded Access to Care for People Living with HIV*

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. The AIDS case rate for African Americans is eight times higher than that of whites.

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-- 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.

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Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

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more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

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

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING — Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

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- ♦ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ♦ My congregation is a mirror into the future of the AIDS epidemic.
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Presidential Advisory Council on HIV/AIDS Meeting with the President

December 18, 1998

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Introduction of Council's Chair - Dr. Scott Hitt by Sandra L. Thurman

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- ◆ Thank the POTUS for the opportunity to meet with him and his staff. Thank him for his leadership, commitment and genuine caring for people living with HIV and AIDS, and for his true commitment for wanting to help end the devastating impact AIDS is having both in the U.S. and the world.
- ◆ Speaking for all members, indicate how proud you have been to serve the President and his Administration.
- ◆ Thank his staff for being at this meeting, for their past support, and for their commitment to this issue.
- ◆ Thank Sandy Thurman, Todd Summers, and any other major official in the room.
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including the Congressional Black Caucus announcement, the World AIDS Day announcement of new international funding, funding to address AIDS orphans, and new funding for vaccine development. These announcements are very important, not only for the funding they provide, but also because of the focus they bring to very critical issues.

- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
- ◆ Indicate that his focus on HIV over the past several months has sent a clear message to the American public that HIV/AIDS is not over. What we need to do now is to build on the momentum he has begun and help ensure his legacy as the one and only President who was not afraid to tackle difficult, long-term issues because he knew it was necessary and because he knew it was the right and moral thing to do.
- ◆ Mr. President, over the past year, this Advisory Council has taken a long and hard look at where the epidemic is heading and what we need to be doing as a nation to address it, and we clearly understand the role that your leadership has and will continue to play.
- ◆ In June of this year, the Council adopted as its number one priority the issue of addressing HIV/AIDS in racial and ethnic. Acknowledge his recent focus on racial and ethnic communities and the additional \$156 million in funding targeted to these communities that was obtained with the strong leadership of the Congressional Black Caucus and many others (**including the special role that Erskine Bowles played**).
- ◆ Stress that this effort has focused the attention of the African American community on this disease in a way that has not occurred to date. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color and to ensure that racial/ethnic communities have equal access to the \$4 billion that the Federal government spends on AIDS each year.
- ◆ We believe that this will take additional measures, including better coordination of efforts, not only in the area of vaccine development, but in the running of programs, both in the U.S. and internationally.

◆ **PERSPECTIVE BY RABBI EDELHEIT**

Mr. President,

We are honored to be here with you so soon 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. During the 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 forth the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to the , to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must want you that there are some who are in danger of not being able to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 Hispanic single mother with young children whose Medicaid will not cover her drugs and primary care and also allow her to work and leave the welfare rolls, will get to the other side?

Here is a gift, 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 great miracle to end HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access 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 city, because we want you to know that we will do what ever it takes to cross that bridge with you into the 21st century.

ISSUE 1: Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

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 by supporting the following budget items.

Action Items:

1. 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 because those who 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.

2. CARE Act and ADAP

The Council urges the President to request from Congress adequate 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. **(If Medicaid is an entitlement, is it mandatory spending or does funding have to be requested?)**

3. 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 and 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. **The Council ... what do you want?)**

4. 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.

5. International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In FY 1999, however, 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. **(We need to ensure that this \$10 million increase is built into the base funding.)**

ISSUE 2: *Critical Need for Expanded Access to Care for People Living with HIV*

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. The AIDS case rate for African Americans is eight times higher than that of whites.

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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

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- ◆ Mr. President, over the past year, this Advisory Council has taken a long and hard look at where the epidemic is heading and what we need to be doing as a nation to address it, and we clearly understand the role that your leadership has and will continue to play.
- ◆ In June of this year, the Council adopted as its number one priority the issue of addressing HIV/AIDS in racial and ethnic. Acknowledge his recent focus on racial and ethnic communities and the additional \$156 million in funding targeted to these communities that was obtained with the strong leadership of the Congressional Black Caucus and many others (**including the special role that Erskine Bowles played**).
- ◆ Stress that this effort has focused the attention of the African American community on this disease in a way that has not occurred to date. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color and to ensure that racial/ethnic communities have equal access to the \$4 billion that the Federal government spends on AIDS each year.
- ◆ We believe that this will take additional measures, including better coordination of efforts, not only in the area of vaccine development, but in the running of programs, both in the U.S. and internationally.

◆ **PERSPECTIVE BY RABBI EDELHEIT**

Mr. President,

We are honored to be here with you so soon 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. During the 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 forth the light of hope to those living with HIV/AIDS.

HIV/AIDS still darkens the path to the , to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must want you that there are some who are in danger of not being able to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 Hispanic single mother with young children whose Medicaid will not cover her drugs and primary care and also allow her to work and leave the welfare rolls, will get to the other side?

Here is a gift, 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 great miracle to end HIV/AIDS, so we are here to help revive your vision of zero rate of transmission and equitable access 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 city, because we want you to know that we will do what ever it takes to cross that bridge with you into the 21st century.

ISSUE 1: Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000

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 by supporting the following budget items.

Action Items:

1. 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 because those who 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.

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The Council urges the President to request from Congress adequate 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

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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 and 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. **The Council ... what do you want?)**

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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.

5. International HIV Efforts

The Council appreciates the President's World AIDS Day announcements related to new global AIDS efforts. In FY 1999, however, 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. **(We need to ensure that this \$10 million increase is built into the base funding.)**

ISSUE 2: *Critical Need for Expanded Access to Care for People Living with HIV*

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. The AIDS case rate for African Americans is eight times higher than that of whites.

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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

INTERNAL USE ONLY

Anticipated Schedule/Time Line

Time Allotted: 30 Minutes

Introduction of Council's Chair, Scott Hitt, M.D. by Sandra Thurman	1 minute
Welcome/Background by R. Scott Hitt, M.D.	2.5 minutes
Statement by Rabbi Joseph Edelheit	1.5 minutes
Issue 1: Future Investment in HIV/AIDS Presenter: Regina Aragon	2 minutes (5 minutes total)
Issue 2: Access to Care Presenter: Tom Henderson	2 minutes (5 minutes total)
Issue 3: National Media Campaign Presenter: Alexander Robinson	2 minutes (5 minutes total)
Issue 4: AIDS Vaccine Development Presenter: Alexandra Levine, M.D.	2 minutes (5 minutes total)
Closing by President	5 minutes
TOTAL	18 minutes (30 minutes total)

Background leading to the questions/ recommendations must be extremely tight; accomplishments should begin the issue (IE. Thank you for your recent announcement of \$200 million in AIDS vaccine funding,...) Presenters should limit the contextual and background information (especially historical context unless absolutely necessary). It would be appropriate for individuals to say something like, "as a person living with AIDS," or "as someone who has lost XXX friends to AIDS...."

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING --- Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

♦ **HOLDING --- Reverend Altagracia Perez**

- ♦ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ♦ My congregation is a mirror into the future of the AIDS epidemic.
- ♦ In this time of loving, forgiveness, and recommitment to our maker and our neighbor, we must ask ourselves whether we have done enough for our fellow woman or man or whether our efforts must be increased.
- ♦ The Rabbi spoke earlier of the symbolism that the holidays offer us. He said the holidays “promise us light during the darkest time of the year.”
- ♦ I remain committed to the fact that I too can shed some light on the darkness that the AIDS epidemic has brought upon us in the United States, and in the world.
- ♦ The AIDS epidemic continues to strike hardest at those least fortunate, those with the weakest voices in our society, and those who for too many years, have been forgotten.
- ♦ It is the role of the Council to speak for those who can not speak, to push for leadership for those who have no leaders, and to open their hearts and fill it with the love of those whose lives have been and will be forever be changed by AIDS.
- ♦ It is also the Council’s role to ask that America’s leaders, especially the President, continue to push for what is needed, even when it is difficult.
- ♦ On behalf of the Council, I ask the President to continue to show that leadership, especially for racial and ethnic communities, and especially for those in far away countries that most American’s don’t even know exist.
- ♦ Ask him to continue to be that “light in the darkness” that so many of us strive to see on a daily basis.

Presidential Advisory Council on HIV/AIDS Meeting with the President

December 18, 1998

THEME: SUPPORT, SUPPORT, SUPPORT

WHEN PRESIDENT ENTERS, PLEASE STAND AND APPLAUD

ATTEND THIS MEETING AS A COUNCIL, NOT AS AN INDIVIDUAL

DO NOT SPEND TIME INTRODUCING EACH MEMBER -- THEY WILL HAVE NAME TAGS AND/OR NAME TENTS

Introduction of Council's Chair - Dr. Scott Hitt by Sandra L. Thurman

Introduction by Scott Hitt, M.D.

- ◆ Thank the POTUS for the opportunity to meet with him and his staff. Thank him for his leadership, commitment and genuine caring for people living with HIV and AIDS, and for his true commitment for wanting to help end the devastating impact AIDS is having both in the U.S. and the world.
- ◆ Speaking for all members, indicate how proud you have been to serve the President and his Administration.
- ◆ Thank his staff for being at this meeting, for their past support, and for their commitment to this issue.
- ◆ Thank Sandy Thurman, Todd Summers, and any other major official in the room.
- ◆ Thank the Council members present for their commitment, leadership and friendship.
- ◆ Thank Daniel Montoya for his work as executive director and for his ability to help focus the Council's efforts.
- ◆ Acknowledge and thank him for the recent White House events focusing on AIDS,

including the Congressional Black Caucus announcement, the World AIDS Day announcement of new international funding, funding to address AIDS orphans, and new funding for vaccine development. These announcements are very important, not only for the funding they provide, but also because of the focus they bring to very critical issues.

- ◆ Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, that many people cannot tolerate the new drugs, and that some 300,000 (?) Americans do not even know their HIV status, and thus can not benefit from the new drugs.
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-- 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. The AIDS case rate for African Americans is eight times higher than that of whites.

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 pharmaceutical 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 1,115 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.

Action Items:

1. The President should direct the Secretary of HHS and the Director of OMB to include a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame in the determination of budget neutrality for the purpose of the 1115 waiver applications.
2. 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.
3. The President should include provisions for necessary start-up costs of Medicaid expansion in his FY 2000 budget request.

ISSUE 3: Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy

Background:

Treatment guidelines issued by the Public Health Service recommend that doctors begin monitoring their HIV-positive patients and consider initiation of antiviral therapy as soon after infection as possible. The federal government's official treatment guidelines can benefit a patient only if the patient knows that he or she is infected with HIV. Unfortunately, the CDC estimates that one in every three Americans living with HIV, and 50% of all persons with non-symptomatic HIV infection, are ignorant of their HIV status. Because of such poor testing rates, far too many Americans learn that they are infected only when they become seriously ill and after HIV has already seriously damaged their immune system. Clearly, a major national initiative is needed to break through ignorance and denial so more people can take advantage of recent medical breakthroughs. 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; and 3) provides for a public private partnership.

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.

Until there is a vaccine and a cure, the most important knowledge an individual can possess regarding HIV is his/her HIV status. Knowing one's HIV status is crucial both to obtaining appropriate care and to preventing further spread of the disease. This effort, if successful, will identify a number of HIV positive individuals who will need to have access to care. Despite current limits on such access for individuals who are already known to be living with HIV, this effort should be undertaken. It will also be important to evaluate the need for expanded HIV and AIDS health care in severely underserved communities.

Action Items:

As stated earlier, this effort would be modeled on the current ONDCP youth drug prevention campaign. ONAP would work with the CDC to develop the campaign, and with the community and private industry partners to provide matching funds (public service announcements and in-kind media buys) in order to mount the campaign.

1. The PACHA recommends that the President direct and support the White House Office of National AIDS Policy in developing and overseeing a national media campaign to encourage

more individual knowledge of HIV status. Building on this “know your status” effort by the CDC, the PACHA recommends that this initiative 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 service 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.

2. The 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, the PACHA recommends that the President propose to fund this effort in his FY 2000 budget request.
3. 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.

ISSUE 4: *AIDS Vaccine Development Progress*

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 its thanks for his 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.

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.

However, the Council believes serious deficiencies remain which must be addressed if the President's goal is to be reached.

Eighteen months have passed since his 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.

Action Items:

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

INTERNAL USE ONLY

Anticipated Schedule/Time Line

Time Allotted: 30 Minutes

Introduction of Council's Chair, Scott Hitt, M.D. by Sandra Thurman	1 minute
Welcome/Background by R. Scott Hitt, M.D.	2.5 minutes
Statement by Rabbi Joseph Edelheit	1.5 minutes
Issue 1: Future Investment in HIV/AIDS Presenter: Regina Aragon	2 minutes (5 minutes total)
Issue 2: Access to Care Presenter: Tom Henderson	2 minutes (5 minutes total)
Issue 3: National Media Campaign Presenter: Alexander Robinson	2 minutes (5 minutes total)
Issue 4: AIDS Vaccine Development Presenter: Alexandra Levine, M.D.	2 minutes (5 minutes total)
Closing by President	5 minutes
TOTAL	18 minutes (30 minutes total)

Background leading to the questions/ recommendations must be extremely tight; accomplishments should begin the issue (IE. Thank you for your recent announcement of \$200 million in AIDS vaccine funding....) Presenters should limit the contextual and background information (especially historical context unless absolutely necessary). It would be appropriate for individuals to say something like, "as a person living with AIDS," or "as someone who has lost XXX friends to AIDS...."

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HOLDING --- International Issue --- Michael Isbell

Mr. President, I'd like to address an issue of great urgency -- American leadership in the fight against the global HIV pandemic. I need not repeat the well-known statistics reflecting HIV's devastation throughout the world, nor is it necessary for me to repeat the many humanitarian, economic and strategic reasons why the United States ought to work to bring the global pandemic under control. As you know, the Council has long urged you to take a global leadership role on AIDS, and we were delighted by your announcements on World AIDS Day two of which focused on additional funding for AIDS orphans and in which you directed Sandy Thurman to do a fact finding mission to South Africa in early January.

As your advisory council, we recommend that you follow up this powerful message to the world with two essential initiatives. First, we recommend that you propose and fight for a substantial increase in funding for international AIDS programs at the Agency for International Development, the CDC, and other agencies. U.S. support for international programs has essentially remained flat in real dollar terms over the last several years, and this must change if we are ever to begin to bring HIV under control in the developing world. Second, the federal programs that deal with AIDS in the developing world are scattered throughout the government. Only the President has the authority and the power to require that these many efforts be effectively coordinated, and we urge you to ensure that this happens.

HOLDING --- Improved HIV prevention, treatment, continuum of care for the incarcerated and for those being released, as well as protection of the public health

Mr. President, there are over 1,083 inmates with HIV/AIDS in federal prisons. Approximately 79% of all inmates are from Black and Latino communities, populations disproportionately affected by AIDS.

Inmates preparing for transition back into the community are asked to sign a "voluntary" treatment waiver form as a condition to participate in a work-release program. This leaves them ineligible after 30-days for subsidies such as Medicaid, Medicare or ADAP while still being under the auspices of the Federal Correctional System, for an indefinite period of time.

- This disparity in access and quality of care, poses serious health risks to the individual,
- There is a potential for treatment failure and development of drug-resistant strains of HIV. This has negative implications for our nations research effort given your 10-year goal of developing an AIDS vaccine, and
- Informed consent, at the heart of the patients bill of rights we need so much and for which you are calling, is also placed in jeopardy.

Mr. President, we need your help, to address this important public health issue.

◆ **HOLDING --- Reverend Altagracia Perez**

- ◆ I represents a predominately immigrant, underserved, culturally and linguistically mixed community in Los Angeles.
- ◆ My congregation is a mirror into the future of the AIDS epidemic.
- ◆ In this time of loving, forgiveness, and recommitment to our maker and our neighbor, we must ask ourselves whether we have done enough for our fellow woman or man or whether our efforts must be increased.
- ◆ The Rabbi spoke earlier of the symbolism that the holidays offer us. He said the holidays “promise us light during the darkest time of the year.”
- ◆ I remain committed to the fact that I too can shed some light on the darkness that the AIDS epidemic has brought upon us in the United States, and in the world.
- ◆ The AIDS epidemic continues to strike hardest at those least fortunate, those with the weakest voices in our society, and those who for too many years, have been forgotten.
- ◆ It is the role of the Council to speak for those who can not speak, to push for leadership for those who have no leaders, and to open their hearts and fill it with the love of those whose lives have been and will be forever be changed by AIDS.
- ◆ It is also the Council’s role to ask that America’s leaders, especially the President, continue to push for what is needed, even when it is difficult.
- ◆ On behalf of the Council, I ask the President to continue to show that leadership, especially for racial and ethnic communities, and especially for those in far away countries that most American’s don’t even know exist.
- ◆ Ask him to continue to be that “light in the darkness” that so many of us strive to see on a daily basis.