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Subseries:

OA/ID Number: 19429

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Folder Title:
[Presidential Advisory Council on HIV/AIDS Meeting with President 12/18/1998] [Folder 3]

Stack:	Row:	Section:	Shelf:	Position:
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- 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 an unpopular issue because he knew it was necessary and because he knew it was the right and moral thing to do.

- Remind him that HIV has become more and more a disease of color, affecting Black and Hispanics disproportionately, and setting itself up in other minority populations to have the potential to devastate those communities as well. Overseas, HIV is endemic is some countries, having infected more than 25% of some communities with no end in sight.

- Over the past year, his 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 communities. While the Council called on the administration to declare a state of emergency, the Administration did not. The $156 in additional funding is very important, and can not be understated, but now the challenge is 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.

- There are four main areas of concern that we bring to you today, and other Council members will briefly review them for you.

- Remind him again of the Council priorities for the remainder of its term, that of focusing its efforts on racial and ethnic communities. Ask him to view the discussion from that context -- the impact of HIV/AIDS on America's and the world's most vulnerable populations.

  In general, they are:

  1) A critical need to expand access to care for people living with HIV/AIDS;

  2) The need to develop a national HIV counseling and testing campaign to make sure people know their own HIV status so that they can get into treatment at the earliest possible stage;

3) Also want to discuss what the Council believes is a lack of progress on implementing your stated goal of developing a vaccine against HIV infection within ten years; and finally,

4) A critical need to expand the Federal government's investment in addressing HIV prevention, services and research, especially for the most vulnerable populations.

- One other issue, the need to address HIV prevention and care in incarcerated populations is very important for the Council, but since we only have a limited amount of time, we will focus on the four issues discussed before.

- Suggest that the format for discussion will be a brief summary of the issue by a Council member, followed by recommendations for action. Then questions by the POTUS or other. Ask the POTUS to please interrupt with questions as necessary.

AT THE END:

- Thank the POTUS and his staff for their time and obvious concern and commitment.

- If you feel comfortable, restate any commitments or instructions to staff that were made.

- Thank the Council members present for their work.

- Thank Daniel Montoya for his work as executive director and for his ability to help focus the Council's efforts.

- Indicate how proud you have been to serve the President and the Council in your role as chair.

- Say that you look forward to expanding the relationship between the Council and the White House in the future as yet, unforseen issues affecting the lives of people living with AIDS present themselves.

--- end ---

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AGENDA FOR PACHA MEETING WITH THE PRESIDENT
DECEMBER 18, 1998

INTRODUCTION

Presenter:_____

ISSUE 1: ***Critical Need for Expanded Access to Care for People Living with HIV/AIDS***

Presenter:_____

ISSUE 2: ***Need ~~for a~~ to develop National HIV Counseling and Testing Awareness Campaign to be Directed out of the White House Office of National AIDS Policy***

Presenter:_____

ISSUE 3: ***AIDS Vaccine Initiative Development Progress and Concerns*** Lack of Progress on Implementing your stated goal of an HIV vaccine within 10 years

Presenter:_____

ISSUE 4: ***Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000***

Presenter:_____

ISSUE 5: ***~~Better~~ Improved or Enhanced Agency Coordination and Improved Global Funding for HIV/AIDS***

Presenter:_____

ISSUE 6: ***Improved HIV prevention, treatment for the incarcerated, continuum of care for those being released, and protection of the public health.***

Presenter:_____

ISSUE 7: ***"Severe and On-going Healthcare Crisis" and ~~possible minority interventions in~~ focus on Racial and Ethnic Populations***

Presenter:_____

BOB HATTON

HELENE GAYLE

MARK DAWSON

STEVE

INTRO

AGENDA TOPICS/SPEAKERS/ORDER REVIEW THEN AGENDA

PRESS RELEASE ABSENCES [illegible]

PRESS RELEASE

INTRO

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CENTRUM [illegible] - CNN SINCE [illegible]

ASKED FOR ADVICE HELENE [illegible]

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AGENDA FOR PACHA MEETING WITH THE PRESIDENT
DECEMBER 18, 1998

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Presenter:_____

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

Presenter:_____

ISSUE 2: ***Need for a National HIV Counseling and Testing Awareness Campaign to be Administered out of the White House Office of National AIDS Policy***

Presenter:_____

ISSUE 3: ***AIDS Vaccine Development Progress***

Presenter:_____

ISSUE 4: ***The Critical Need for Expanded Investment In HIV/AIDS Programs in FY 2000***

Presenter:_____

ISSUE 5: ***Better Coordination and Improved Funding International Issues***

Presenter:_____

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Presenter:_____

ISSUE 7: ***"Severe and On-going Healthcare Crisis"*** and possible minority interventions in Racial and Ethnic Populations

Presenter:_____

PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

December 11, 1998

REVISED DRAFT - EMBARGOED UNTIL PACHA APPROVAL

MEMORANDUM FOR THE PRESIDENT

TO: Sandra L. Thurman
Through: Daniel C. Montoya, Executive Director
FROM: R. Scott Hitt, M.D.
RE: Presidential Briefing Memorandum

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

This Council places the issue of HIV/AIDS into the context of the President's legacy regarding HIV. We will ask that he does all he can to ensure that his legacy includes addressing HIV to the fullest extent and that carries even the most vulnerable of persons, especially in the developing worlds, into the 21st century.

HIV is increasingly a disease of people of color, both domestically and internationally. As such, the Council has focused its attention on several key issues that will directly affect the nation's response to HIV in communities of color. Our prioritization of the severe and ongoing health crisis in communities of color builds upon the President's own goal of ending racial disparities in health outcomes in the United States.

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

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.

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-- 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 use a broader range of programs (other entitlement and federal discretionary programs) and a longer budget time frame to determine budget neutrality for the purpose of the 1,115 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 2: ***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 the White House Office of National AIDS Policy to develop and oversee 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 3: ***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.

ISSUE 4: ***The 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 who, because they are unaware of their HIV-status, are at increased risk for passing the virus on to others and are missing out on early care and treatment opportunities. With 50% of new HIV infections currently related to injection drug use, the Council also urges the Administration to continue to expand substance abuse treatment services, and to support other, scientifically sound prevention programs for injection drug users and their partners.

2. CARE Act and ADAP

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

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.

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.

Presidential Advisory Council on HIV/AIDS
AGENDA
Meeting with the President
December 18, 1998

Introduction by Sandra L. Thurman

Reverend Altagracia Perez

Introduction - Welcome/Background

Presenter: R. Scott Hitt, M.D. & Rabbi Joseph Edelheit

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

Presenter: Regina Aragon

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

Presenter: Tom Henderson

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

Presenter: Alexander Robinson

ISSUE 4: ***Lack of Progress on Implementing Stated Goal of an HIV Vaccine Within 10 Years***

Presenter: Alexandra Levine or Helen Miramontes

ISSUE: ***Improved Agency Coordination and Improved Global Funding for HIV/AIDS***

Presenter:_____

ISSUE: ***Improved HIV prevention, treatment for the incarcerated, continuum of care for those being released, and protection of the public health.***

Presenter:_____

ISSUE: ***"Severe and On-going Healthcare Crisis" and focus on Racial and Ethnic Populations***

Presenter:_____

Closing: President William Jefferson Clinton

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 this week of Hannukah and one week before Christmas, we are all reminded that both religious holidays promise us "light" during the darkest time of the year. As your Advisory Council we want to help you fulfill your vision, to bring the light of hope, to those living with HIV/AIDS.

HIV/AIDS still darkens the path to that bridge into the 21st century, to which you have prophetically led us; how can we help you illuminate the darkness which hides the path. We must warn you that there are some who are in danger of being unable to follow when you lead us across that bridge into the 21st century. How can we be sure that the 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 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.

PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

December 11, 1998

REVISED DRAFT - EMBARGOED UNTIL PACHA APPROVAL

MEMORANDUM FOR THE PRESIDENT

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Through: Daniel C. Montoya, Executive Director
FROM: R. Scott Hitt, M.D.
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Action Items:

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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.

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ISSUE 2: ***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:

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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 the White House Office of National AIDS Policy to develop and oversee 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 3: ***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.

ISSUE 4: ***The 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 who, because they are unaware of their HIV-status, are at increased risk for passing the virus on to others and are missing out on early care and treatment opportunities. With 50% of new HIV infections currently related to injection drug use, the Council also urges the Administration to continue to expand substance abuse treatment services, and to support other, scientifically sound prevention programs for injection drug users and their partners.

2. CARE Act and ADAP

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

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.

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.

Presidential Advisory Council on HIV/AIDS
Meeting with the President

December 18, 1998

Talking Points
for
Scott Hitt, MD

- 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.

- 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.
~~Erskine Bowles, John Podesta, Karen Tramontano,~~

- (If not already done, have each advisory council member state their name and city.) ~~(Will they have name tags???)~~
[illegible]

- Acknowledge and thank him for the recent White House events focusing on AIDS, including the World AIDS Day announcement of new international funding, additional 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 place on very critical issues.

- 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. This effort, for what seems to be for the first time, focused the efforts of the African American community on this disease in a way that has not occurred before. It has made a tremendous impact on African American leadership, and now our challenge is to expand this focus to other communities of color. Erskine Bowles —

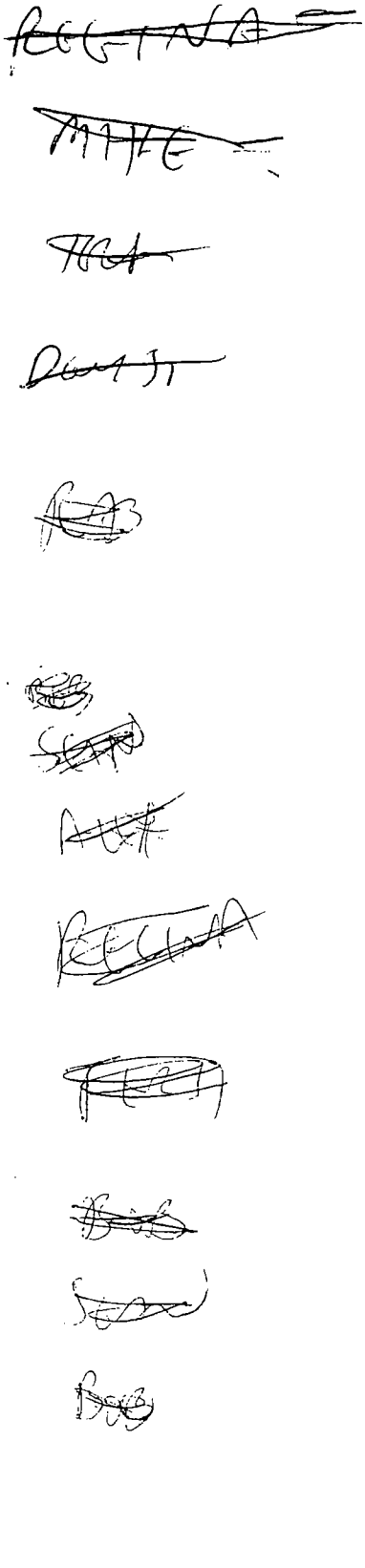
- Remind him that media reports continue to tell the American public that HIV is manageable, that deaths are down, and that the new treatment drugs are working. What they often fail to mention is that NEW infections continue at about 40,000 a year, that many people do not have access to the new drugs, 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.

PRESENT CLIENT

UNMET NEED

OPPORTUNITY

NEW INITIATIVE



Mr. President, since you took office, the HIV/AIDS epidemic has changed dramatically. The development and rapid approval of new therapies to treat HIV has made a huge difference and has offered hope for many. Part of the ***good*** news is that AIDS-related deaths are down. AIDS diagnoses are down. More people are now ***living*** with HIV as a chronic disease, and that number is growing.

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

The new HHS-recognized standard of HIV care includes treatment with combination drug therapies prior to development of symptoms and before substantial deterioration of the immune system, resulting in disability.

However, in most cases, accessing Medicaid and Medicare, the principal HIV care coverage programs for almost 60% of HIV+ individuals, still requires those persons to be ***already disabled.*** Therefore, unlike those of us fortunate enough to be employed and adequately insured, those relying on Medicaid and Medicare for their health care are unable to access the new therapies. Instead of being able to enjoy the benefits of living longer and better lives, they are forced to wait until they become sick and unable to work before they can even begin treatment.

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

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

Mr. President, if the gridlock preventing progress on this issue is to be broken, your personal intervention to overcome the bureaucratic inertia is necessary.

Specifically, there are three areas which need your personal attention.

First, current Administration policy requires finding offsetting cost savings for budget neutrality purposes in Medicaid ***only.*** Even if reforming Medicaid rules to cover asymptomatic HIV+ results in savings in other federal entitlement or discretionary programs, those savings cannot be counted toward achieving budget neutrality.

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

Your direction to the Secretary of HHS and to the Director of OMB to include a broader range of programs and a longer budget window in the determination of budget neutrality for the purpose of the State 1115 waiver applications would go a long way toward facilitating their approval.

Second, 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 costs. While drug pricing should not be the only mechanism for achieving cost neutrality, the resulting significantly increased volume of federal, state and local governmental drug purchases makes accompanying drug cost reductions clearly both reasonable and essential.

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

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

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

Ryan White CARE Act
FY 1999 Title I Awards

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Cleveland, Ohio	$2,933,058	($31,148)
Dallas, Texas	$10,164,078	($82,552)
Denver, Colo.	$4,150,341	($19,265)
Detroit, Mich.	$6,585,744	($73,909)
Dutchess County, N.Y.	$1,220,662	($12,153)
Ft. Lauderdale, Fla.	$10,810,324	($118,291)
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Ponce, Puerto Rico	$2,487,768	($33,849)
Portland, Ore.	$3,115,251	$0
Riverside-San Bernardino, Calif.	$6,463,388	($36,460)
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Vineland-Millville-Bridgeton, N.J.	$688,648	($8,732)
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Dallas, Texas	$10,164,078	($82,552)
Denver, Colo.	$4,150,341	($19,265)
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Dutchess County, N.Y.	$1,220,662	($12,153)
Ft. Lauderdale, Fla.	$10,810,324	($118,291)
Ft. Worth, Texas	$2,935,543	($21,606)
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Norfolk, Va.*	$1,948,137	($49,963)
Oakland, Calif.	$6,218,532	($55,004)
Orange County, Calif.	$4,300,690	($23,586)
Orlando, Fla.	$4,907,180	($54,824)
Philadelphia, Pa.	$16,011,451	($205,884)
Phoenix, Ariz.	$3,865,319	($19,445)
Ponce, Puerto Rico	$2,487,768	($33,849)
Portland, Ore.	$3,115,251	$0
Riverside-San Bernardino, Calif.	$6,463,388	($36,460)
Sacramento, Calif.	$2,578,873	($12,423)
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Las Vegas, Nev.*	$1,800,211	($25,747)
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New Haven, Conn.	$6,100,471	($62,746)
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New York, N.Y.	$96,961,856	($1,260,780)
Newark, N.J.	$14,390,269	($192,110)
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Oakland, Calif.	$6,218,532	($55,004)
Orange County, Calif.	$4,300,690	($23,586)
Orlando, Fla.	$4,907,180	($54,824)
Philadelphia, Pa.	$16,011,451	($205,884)
Phoenix, Ariz.	$3,865,319	($19,445)
Ponce, Puerto Rico	$2,487,768	($33,849)
Portland, Ore.	$3,115,251	$0
Riverside-San Bernardino, Calif.	$6,463,388	($36,460)
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Miami, Fla.	$21,248,387	($279,163)
Middlesex-Somerset-Hunterdon, N.J.	$2,555,029	($26,467)
Minneapolis-St. Paul, Minn.	$2,548,603	($12,783)
Nassau-Suffolk, N.Y.	$5,632,012	($49,963)
New Haven, Conn.	$6,100,471	($62,746)
New Orleans, La.	$5,695,360	($68,148)
New York, N.Y.	$96,961,856	($1,260,780)
Newark, N.J.	$14,390,269	($192,110)
Norfolk, Va.*	$1,948,137	($49,963)
Oakland, Calif.	$6,218,532	($55,004)
Orange County, Calif.	$4,300,690	($23,586)
Orlando, Fla.	$4,907,180	($54,824)
Philadelphia, Pa.	$16,011,451	($205,884)
Phoenix, Ariz.	$3,865,319	($19,445)
Ponce, Puerto Rico	$2,487,768	($33,849)
Portland, Ore.	$3,115,251	$0
Riverside-San Bernardino, Calif.	$6,463,388	($36,460)
Sacramento, Calif.	$2,578,873	($12,423)
St. Louis, Mo.	$3,664,771	($33,669)

- More -

San Diego, Calif.	$8,872,685	($52,934)
San Francisco, Calif.	$36,218,513	($67,788)
San Jose, Calif.	$2,486,136	($15,214)
San Juan, Puerto Rico	$11,912,865	($217,047)
Santa Rosa, Calif.	$1,127,018	$0
Seattle, Wash.	$5,303,343	$0
Tampa-St. Petersburg, Fla.	$7,236,728	($48,163)
Vineland-Millville-Bridgeton, N.J.	$688,648	($8,732)
Washington, D.C.	$18,322,558	($259,988)
West Palm Beach, Fla.	$6,711,944	($87,953)
TOTAL	**$479,482,810**	**$4,955,258**

* Includes formula funding and CBC award only.

Ryan White CARE Act
FY 1999 Title I Awards

Eligible Metropolitan Area	Title I Award	CBC Award
Atlanta, Ga.	$13,147,268	($157,991)
Austin, Texas	$3,175,509	($27,997)
Baltimore, Md.	$13,478,549	($202,463)
Bergen-Passaic, N.J.	$4,320,176	($48,163)
Boston, Mass.	$10,647,381	($68,508)
Caguas, Puerto Rico	$1,610,314	($29,348)
Chicago, Ill.	$18,227,884	($191,570)
Cleveland, Ohio	$2,933,058	($31,148)
Dallas, Texas	$10,164,078	($82,552)
Denver, Colo.	$4,150,341	($19,265)
Detroit, Mich.	$6,585,744	($73,909)
Dutchess County, N.Y.	$1,220,662	($12,153)
Ft. Lauderdale, Fla.	$10,810,324	($118,291)
Ft. Worth, Texas	$2,935,543	($21,606)
Hartford, Conn.	$4,019,409	($48,703)
Houston, Texas	$15,489,996	($177,707)
Jacksonville, Fla.	$3,683,146	($41,591)
Jersey City, N.J.	$5,015,785	($63,737)
Kansas City, Mo.	$2,952,910	($16,204)
Las Vegas, Nev.*	$1,800,211	($25,747)
Los Angeles, Calif.	$33,540,737	($261,519)
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