# NLWJC - Kagan

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# AIDS - General [1]

AIDS - general

THE WHITE HOUSE

WASHINGTON

December 17, 1998

**MEETING WITH THE PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS**

| | |
|---|---|
| **DATE:** | December 18, 1998 |
| **LOCATION:** | Cabinet Room |
| **BRIEFING TIME:** | 5:15 pm to 5:45 pm |
| **EVENT:** | 5:45 pm to 6:15 pm |
| **FROM:** | Bruce Reed/Chris Jennings/Sandy Thurman |

## I. PURPOSE

You will be meeting with members of the President's Advisory Council on HIV/AIDS to discuss the Administration's progress in addressing the AIDS epidemic.

## II. BACKGROUND

The Council requested a meeting with you to address its recommendations on ways to improve the Administration's response to the HIV/AIDS epidemic. The Council recognizes your commitment to improving HIV/AIDS care, research, and prevention. They support recent efforts to highlight international efforts to fight HIV/AIDS, the new initiative on HIV/AIDS in the minority communities, and on increases in research investments. However, the Council has been publicly critical of the Administration in some areas, particularly its commitment to HIV prevention. This meeting provides an opportunity for you to personally reaffirm your commitment to the Council and the seriousness with which you take the issue.

Questions from the Council will focus on four areas:

-- **Access to Treatment**: The Council will seek your leadership on expanding access to treatment for indigent persons with HIV who under current law must wait until they reach a level of disability to qualify for Medicaid, which covers the treatments that would likely have forestalled their progression to AIDS. Initial reviews, prompted by a request by the Vice President, determined that such an expansion is not cost neutral and therefore cannot be done administratively through a Medicaid 1115 waiver. However, the Administration has worked extremely hard to expand access to promising HIV/AIDS therapies by supporting substantial increases in the AIDS Drug Assistance Program and advocating for the Jeffords-Kennedy legislation (which includes a demonstration program that would allow states to define disability, substantially increasing access to Medicaid by persons who would become disabled but

for care). Support of this legislation by the Council and the AIDS community would be very beneficial. [Council presenter: Thomas Henderson]

-- **Promoting HIV Testing**: Approximately 30% of persons infected with HIV do not know they are infected, complicating prevention efforts and delaying helpful treatments. The Council will ask for your support of a national "get tested" campaign focusing on higher-risk populations (youth, persons of color, women). This is a reasonable proposal, and one which is already under consideration through the budget process. [Council presenter: Alexander Robinson]

-- **Vaccine Research**: Last spring, you announced your desire to find a vaccine for HIV within ten years. Two weeks ago, on World AIDS Day, you announced a 33% increase in vaccine research funding at the NIH (up $47 million to $200 million). The Council is highly supportive of your ongoing leadership on this issue, but has some concern about the 18 months it is taking to find a director for NIH's new vaccine research center and about the need for increased inter-agency coordination. NIH has assured us that its progress on vaccine research has not been hampered by this vacancy and that filling the position is a top priority for NIH Director Dr. Varmus. [Council presenter: Helen Miramontes]

-- **Increased AIDS Funding**: Funding for HIV/AIDS programs has more than doubled during your Administration, with Ryan White funding up 266% and AIDS research up 67%. The Council is concerned that prevention and international funding have not benefited from similar increases. CDC's prevention budget is over $640 million and has increased 34% since you took office; the Administration is focusing on insuring that prevention funds are used effectively and are targeted to those at highest risk. As for international funding, USAID's AIDS budget has increased 64% during your Administration. You also just announced on World AIDS Day a new $10 million effort to help developing countries respond to the needs of children orphaned by AIDS. Finally, may announce $479 million in Ryan White Title I grants to 50 metropolitan areas most heavily impacted by HIV/AIDS; these grants include extra funds for minorities that are part of your recently announced initiative on HIV/AIDS in racial and ethnic minorities. [Council presenter: Regina Aragón]

In your closing remarks (see attached talking points), you may highlight recent Administration activities on HIV/AIDS, including:

-- World AIDS Day event at which you announced an AIDS orphan initiative at USAID, increased vaccine research funding from the NIH, and a delegation to Africa led by Sandy Thurman.

-- Minority initiative announcement on October 28th at which you declared HIV/AIDS to be an ongoing and severe crisis in racial and ethnic minorities and announced $156

million in additional funding to address the crisis.

- -- Historic HIV/AIDS funding achievements in the FY99 budget negotiations with Congress.

- -- Strongly advocated for other policies that help people with HIV/AIDS, including an enforceable patient bill of rights; the Jeffords-Kennedy legislation that allows people with disabilities -- including people with AIDS -- to stay in or return to work; and substantial increases in research funding at the NIH.

## III. PARTICIPANTS

Briefing Participants:
Bruce Reed
Virginia Appuzo
Karen Tramontano
Chris Jennings
Sandy Thurman
Richard Socarides

Program Participants:
**YOU**
Sandy Thurman
Bruce Reed
Virginia Appuzo
Karen Tramontano
Chris Jennings
Sandy Thurman
Richard Socarides
Dr. Scott Hitt, Council Chairperson
Members of the Council

## IV. PRESS PLAN

Pool still photographers at the top of meeting; single print reporter thereafter. Verbatim transcript to be provided to press following meeting.

## V. SEQUENCE OF EVENTS

- -- Sandy Thurman will introduce **YOU** to members of the Council.
- -- Dr. Scott Hitt will make a brief opening statement.
- -- Council member Rabbi Joseph Edelheit will provide an overview of the message of the Council to you.

-- Four members of the Council will provide brief background statements and identify specific issues on which they seek Administration action. (You will have the option to seek clarification or respond--see attached Q & A.)
-- **YOU** will make brief closing remarks, thanking the Council for its hard work and reaffirming your commitment to continuing the fight against AIDS--see attached talking points.

## VI. REMARKS

Talking points provided by the Office of National AIDS Policy.

## VII. ATTACHMENTS

-- Talking points for closing remarks.
-- Q & A for discussion purposes.
-- List of Council members and brief biographies.

**President's Advisory Council on HIV/AIDS**

**Member List**

**CHAIR**

**R. Scott Hitt, M.D.**

Dr. Hitt, is a physician at the Pacific Oaks Medical Group in Beverly Hills, California. He is the Chair of PACHA.

**PRESENTERS**

**Regina Aragón**

Ms. Aragon serves as the Public Policy Director for the San Francisco AIDS Foundation. She was an attendee of the 1995 White House Conference on AIDS.

**Rabbi Joseph Edelheit**

Rabbi Edelheit serves at the Temple Israel in Minneapolis, Minnesota.

**B. Thomas Henderson**

Mr. Henderson, a person living with HIV, serves at the Texas General Land Office in Austin, Texas. He has been active in AIDS and human rights issues for numerous years.

**Helen Miramontes, M.S.N., R.N., FAAN**

Ms. Miramontes is an Associate Clinical Professor and Deputy Director of the International Center for HIV/AIDS Research and Clinical Training in Nursing, at the School of Nursing at the University of California at San Francisco. She has a son living with AIDS.

**H. Alexander Robinson, M.B.A., C.P.A.**

Mr. Robinson, a person living with HIV, is a private consultant. He formerly served as the ACLU's chief lobbyist for AIDS, gay/lesbian civil rights, disability issues. He serves as the Co-Chair for the Prevention Subcommittee of the PACHA.

**ATTENDEES**

**Stephen Neal Abel, D.D.S.**

Dr. Abel is the former Director of Dentistry at the Spellman Center of St. Clare's Hospital in New York City. Dr. Abel now serves as the Oral Health Policy Liaison in the Office of the Medical Director at the New York State Department of Health/AIDS Institute.

**Terje Anderson**

Mr. Anderson is the Chair of the Health Resources Services Administration Advisory Committee and is currently the Deputy Executive Director of the National Association of People with AIDS (NAPWA). He was an attendee of the 1995 White House Conference on AIDS.

**Barbara Aranda Naranjo, Ph.D., R.N.**

Dr. Aranda Naranjo serves at the University of the Incarnate Word, School of Nursing in San Antonio, Texas. She was an attendee of the 1995 White House Conference on AIDS.

**Judith Billings, J.D.**

Ms. Billings, a woman living with HIV, is the former superintendent of schools for a Washington State school system. She now serves at Targeted Alliances, Education Consulting Services.

**Ambassador Charles W. Blackwell**

Charles W. Blackwell is the founder of Native Affairs and Development Group and serves as its President and Director. He is also the Chickasaw National Ambassador to the United States of America by appointment of the Chickasaw Governor with confirmation by the Chickasaw Legislature.

**Nicholas Bollman** [NOT ATTENDING]

Mr. Bollman is presently a Senior Program Director for the James Irvine Foundation. He was an attendee of the 1995 White House Conference on AIDS.

**Jerry Cade, M.D.**

Dr. Cade, a person living with HIV, is the Co-Founder and Medical Director of University Medical Center's HIV Inpatient Unit and Outpatient Clinic in Las Vegas, Nevada. He was an attendee of the 1995 White House Conference on AIDS.

**Lynne M. Cooper, D.MIN.**

Dr. Cooper has served as the President of Doorways, an interfaith AIDS residence program, for the past nine years. She is also the director of the National AIDS Housing Coalition Board.

**Robert Fogel**

Mr. Fogel is an attorney at Hilfman and Fogel in Chicago, Illinois. He is the Chair of the International Subcommittee of the PACHA.

**Debra Fraser-Howze**

Ms. Fraser-Howze is the founder/director of the National Black Leadership Commission on AIDS in New York City. She is also the Co-Chair of the Racial Ethnic Populations Subcommittee of the PACHA.

**Kathleen Gerus**

Ms. Gerus, a person living with HIV, currently serves at the Midwest AIDS Prevention Project in Sterling Heights, Michigan. She has served as co-chair of the Women's Advisory Committee of the National Hemophilia Foundation.

**Phyllis Greenberger**
Ms. Greenberger is currently serving at the Society for the Advancement of Women's Health Research in Washington, D.C. She is the former Associate Director for Government Relations at the American Psychiatric Association.

**Nilsa Gutierrez, M.D., M.P.H.**
Dr. Gutierrez is the former director of the New York State AIDS Institute, and is currently the medical director of the Health Care Financing Administration's New York Regional Office.

**Bob Hattoy**
Mr. Hattoy, a person living with AIDS, currently serves as the White House Liaison at the U.S. Department of Interior.

**Michael T. Isbell, J.D.**
Mr. Isbell is the former deputy executive director of the Gay Men's Health Crisis in New York City, and currently practices law at a private law firm in New York City. He is the Co-Chair for the Prevention Subcommittee of the PACHA.

**Ronald Johnson**
Mr. Johnson, a person living with HIV, is currently managing director for public policy, communications, and community relations at the Gay Men's Health Crisis in New York City. He formerly served as the Citywide coordinator for AIDS policy in the Office of the Mayor, City of New York.

**Jeremy Landau**
Mr. Landau, a person living with HIV, resides in Santa Fe, New Mexico. He is currently the Chair of the Prisons Subcommittee of the PACHA. He is the former director of the National Rural AIDS Network.

**Alexandra Mary Levine, M.D.** [NOT ATTENDING]
Dr. Levine serves as a Professor of Medicine, Chief of Hematology, and Medical Director at the University of Southern California School of Medicine in Los Angeles, California. She is the Chair for the Research Subcommittee of the PACHA.

**Steve Lew**
Mr. Lew, a person living with HIV, is the Director of Research and Technical Assistance at the Asian and Pacific Islander Wellness Center in San Francisco. He is the co-chair of San Francisco's Ryan White HIV Services Planning Council.

**Miguel Milanes**
Mr. Milanes is the former HIV/AIDS Program Coordinator and current Executive Assistant to the District Administrator for Dade/Monroe Counties (Miami), in the Office of HIV/AIDS Services, Florida Department of Health.

**Reverend Altagracia Perez, STM**
Reverend Perez is currently serving at the Church of Saint Phillip the Evangelist in Los Angeles, California. She is also the Co-Chair for the Racial Ethnic Populations Subcommittee of the PACHA.

**Michael Rankin, M.D., M.P.H.**
Dr. Rankin is Chief, Psychiatry and Mental Health Services, VA Northern California Health Care System in San Francisco, California.

**Debbie Runions**
Ms. Runions is a person living with HIV, is a community advocate from Nashville, Tennessee. She serves on numerous boards and advisory commissions.

**Sean Sasser**
Mr. Sasser, a person living with HIV, tested positive for HIV at the age of 19. He was an attendee of the 1995 White House Conference on AIDS.

**Benjamin Schatz, J.D.**
Mr. Schatz is currently executive director of the Gay and Lesbian Medical Association in San Francisco, California. He was a founder/director of the AIDS Civil Rights Project at the National Gay Rights Advocates.

**Richard Stafford**
Mr. Stafford, a person living with HIV, is from Minneapolis, Minnesota.

**Denise Stokes**
Ms. Stokes, a person living with HIV, is a community activist dedicated to HIV education, awareness and prevention. Ms. Stokes joined **YOU** as keynote speaker at the October White House event announcing $156 million in funding targeted to African American and other minority populations.

**Bruce Weniger, M.D.**
Dr. Weniger is a physician at the National Immunization Program in the federal Centers for Disease Control and Prevention in Atlanta, Georgia.

**PRESIDENT WILLIAM J. CLINTON**
**MEETING WITH THE**
**PRESIDENT'S ADVISORY COUNCIL ON HIV/AIDS**
**DECEMBER 18, 1998**

**Talking Points**

- Thank you for all of the good work that you have been doing.

- Over the past six years, we have made a lot of progress, and I appreciate your recognition of that. Together, we have steered resources toward research, prevention and treatment efforts that have made an incredible difference in the lives of so many.

- We all know there is much more to do, in boosting prevention and international support, and in developing an HIV vaccine. I will make sure this vaccine remains a top priority for my administration.

- You've made a number of good suggestions, and I'm going to ask Sandy to help us move forward on them.

- You have a lot of friends and advocates here - the First Lady, the Vice President, Mrs. Gore, Secretaries Shalala and Cuomo, and certainly Sandy - who have done a tremendous amount to increase awareness of AIDS. I want you to know that we will always be committed to the fight.

- Together, we will beat this epidemic both here at home and around the world.

December 16, 1998

**MEETING WITH THE PRESIDENT'S ADVISORY COUNCIL ON HIV/AIDS**

**QUESTIONS AND ANSWERS**

Q: **Current HHS guidelines encourage early treatment of HIV to forestall the onset of AIDS, yet access to Medicaid coverage for that treatment is generally restricted to those who have progressed to AIDS. How are you going to help increase access to treatment?**

A: This is a difficult challenge and we are taking steps to address it. You know I tried to solve this problem with universal health care.

The Vice President has taken leadership in this area, asking HCFA to look at solutions. Unfortunately, what we thought might be fixed quickly has turned out to be more difficult than expected. While we are committed to continuing our work to look at long term responses, we've also been working on interim solutions:

- Sandy Thurman has set up an internal task force to develop solutions
- we've succeeded in getting significant increases in the AIDS Drug Assistance Program--$175 million (61%) increase in FY99--and the Ryan White CARE Act overall--$271 million (23%) increase in FY99 and 266% since FY93
- we strongly supported the Jeffords-Kennedy legislation, which includes a demonstration program that helps states provide Medicaid coverage to people with HIV before they get AIDS - I hope you'll continue to work with us to get legislation like this passed in the coming year
- HCFA has been working with States that are seeking to develop waivers to expand their coverage to people living with HIV. We have talked with HCFA, and they have assured us that they will continue to aggressively provide support and assistance to States that want to develop demonstration programs that work.

I recognize the need and promise you that I and the Vice President will stay on top of this issue and do everything in our power to see that people with HIV don't have to get sick before they get treatment.

Q: **We are concerned that our national effort to stop the spread of HIV is not working, and that the number of new HIV infections in this country has stayed at 40,000 per year. In addition, at least 30% of those that are HIV positive don't know it, which means they are likely to continue the activities that spread the infection. The Council would like to recommend a new national "get tested" campaign to encourage people at risk to seek HIV counseling and testing services. Will you**

**support that request?**

A: I think it sounds like a good idea. Let me ask Sandy to take a look at the proposal and give me her recommendations. I do believe we need to do a better job with our work on prevention, not only for HIV but for a variety of preventable illnesses. Secretary Shalala and Surgeon General Satcher have been focusing a great deal of energy on prevention, particularly in racial and ethnic minorities. Dr. Satcher has been helping to lead their Race and Health Disparities initiative, which includes HIV and AIDS as one of six targeted illnesses.

Young people are also in need of greater attention. I believe that some of the impact of the anti-drug campaign by our Office of National Drug Control Policy will help since the abuse of drugs and alcohol plays a key role in young people taking risks with HIV.

**Q: Last March, you announced your commitment to finding a vaccine for HIV within ten years. That was 18 months ago. The Council is concerned that the effort to develop a vaccine is not progressing fast enough. NIH has yet to hire a director for its new vaccine center and the different Federal agencies that are involved in vaccine research aren't coordinated. Will you encourage NIH Director Varmus to get the vaccine center director position filled? Will you support Sandy Thurman's office in facilitating cross-agency coordination?**

A: I certainly appreciate the need for an HIV vaccine. This past World AIDS Day we did an event here that focused on the international epidemic, and I am just staggered by the impact that AIDS is having on so many nations around the world. I have asked Sandy to go to Africa in January to look at the AIDS orphan issue and to report back to me with recommendations on further actions we might consider. I know that a vaccine is our best and maybe only hope of stopping this terrible disease.

As for the vaccine center director, we have talked with Dr. Varmus and he has assured us that he is being very aggressive in his efforts to find just the right person for the position. Part of the delay has been his commitment to finding the very best person. He also assures us that the vaccine research effort has not been slowed down by this vacancy, and that in fact they are very pleased with their progress. NIH is increasing its vaccine research funding this year, up $47 million (33%) to $200 million. I also know that Dr. Nathanson, the new director of the Office of AIDS Research at NIH, is very committed to vaccine research and is providing great leadership.

As for the interagency coordination, Sandy and Dr. Varmus have talked about that. I understand that they're initiating regular vaccine research meetings that will be open to all the different agencies, and the community groups working on this issue. I will talk with Sandy about this and see if there is more that we can do.

**Q: While we have had great success in AIDS funding with your leadership, the Council is concerned that there are still a great many unmet needs. We are particularly concerned that HIV prevention activities at the CDC and international assistance through USAID have not received needed increases. Will you commit to increasing AIDS funding in FY2000, particularly in prevention and international relief?**

**A:** We are working on developing the FY2000 budget now, so it is a work-in-progress. I do know that you have a great team of advocates at OMB. Jack Lew, Josh Gotbaum, Sylvia Matthews, and Dan Mendelson are all committed to doing the best that we can in addressing the need for additional AIDS funding.

With respect to prevention funding, I can say that we fully understand the need to increase and improve our HIV prevention activities, and to pay particular attention to communities of color, to women, and to young people who are at highest risk. We're taking a look not only at the need for increased funding, but making sure that what we are already investing is being used most effectively.

As for international funding, we've gotten good support from USAID although I know Brian Atwood would like more. This is going to be a very challenging budget year for us, and I don't want to be overly optimistic about our ability to repeat the kind of increases we were able to obtain in FY99. Nevertheless, we will do our very best to support appropriate funding levels for our international AIDS efforts, and the other AIDS programs as well.

| SELECTED HIV/AIDS INVESTMENTS | FY99 | Increase from FY98 | Increase from FY93 |
|---|---|---|---|
| **Ryan White CARE Act** | **$1.4 billion** | **23%** | **266%** |
| *AIDS Drug Assistance* | *$461 million* | *61%* | *787%** |
| **HIV Prevention (CDC)** | **$657 million** | **5%** | **34%** |
| **AIDS Research (NIH)** | **$1.8 billion** | **12%** | **67%** |
| *Vaccine Research* | *$200 million* | *33%* | *145%* |
| **Housing (HUD)** | **$225 million** | **10%** | **125%** |
| **International (USAID)** | **$131 million**** | **8%** | **64%** |

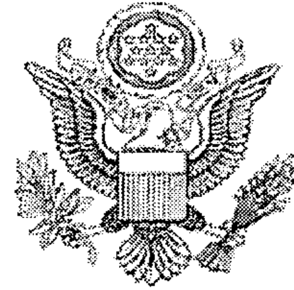
*since FY96, when separate program established
**includes $10 million emergency funding for AIDS orphan initiative

AIDS - general

*News from the*

# Office of National AIDS Policy

Executive Office of the President



***FOR IMMEDIATE RELEASE***

3:00 PM on February 1, 1999

Contact: (202) 456-2437

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## White House AIDS Czar Applauds FY2000 Budget Increases

*Washington, DC* - Sandra Thurman, Director of the White House Office of National AIDS Policy, applauded the Administration's leadership on HIV/AIDS as reflected in its Fiscal Year 2000 budget proposal to Congress. "Once again, President Clinton and Vice President Gore have demonstrated their commitment to ending this epidemic. There are substantial increases in AIDS-specific programs--over $162 million--as well as several special initiatives that will be critical to addressing the ongoing needs of those living with HIV/AIDS," said Thurman. "These include support for the Jeffords-Kennedy Work Incentives Improvement Act, Patients' Bill of Rights, increased Medicaid coverage for immigrants, and support for long-term care. As there are more and more Americans living with HIV and AIDS, it is vital that our response include those programs that benefit the broader disability community including people with HIV/AIDS."

"Most importantly, this Administration will continue its efforts to address HIV/AIDS in racial and ethnic minorities. Secretary Shalala's budget at HHS continues emergency funding for these efforts, announced by the President and the Secretary this past October," said Thurman.

Included in the budget proposal released today are the following:

- **$100 million increase in the Ryan White CARE Act**, which supports states and cities in caring for those living with HIV and AIDS;
- **$35 million increase in the AIDS Drug Assistance Program** to assist in providing life-saving treatments to people with HIV/AIDS who cannot otherwise afford them;
- **$36 million increase in early intervention** programs of Ryan White (Title III), with most of the new funding going to serve racial and ethnic minorities in furtherance of the Administration's efforts to address the racial disparity in HIV/AIDS;
- **$15 million increase in AIDS housing** at HUD, to increase housing support to states and urban areas most heavily impacted by AIDS through the Housing Opportunities for Persons With AIDS (HOPWA) program;

*[CONTINUED]*

- **$10 million increase in HIV prevention** and education at the CDC to initiative a "Know Your HIV Status" campaign targeting minority populations and youth; and
- **$35 million increase in AIDS research** at the National Institutes of Health to enhance efforts to find a vaccine, a cure, and better treatments.

The President's budget proposal also includes new initiatives that will provide substantial benefit to people living with HIV/AIDS, including:

- **Demonstration Program to Expand Disability Coverage**, allowing States to offer health coverage to individuals who meet an expanded definition of disability set by the States. This expanded definition--an important component of the Jeffords-Kennedy Work Incentives Improvement Act--will include persons who have a medical conditions, such as HIV or diabetes, that will become disabling but for the provision of Medicaid-covered services;
- **Flexibility to Cover People With Disabilities**: building on a provision of the 1997 Balanced Budget Act (BBA), this proposal will give States broad flexibility to set higher income and resource standards in Medicaid to encourage people with disabilities to return to work. In addition, Medicaid will allow States that adopt the more generous income and resource standards to cover individuals who no longer meet SSI and Social Security Disabled Insurance (SSDI) disability criteria because of medical improvement. States offering new options would receive grants to develop support systems that help people with disabilities--including those disabled by HIV/AIDS-- who return to work;
- **Tax Credit for Long-Term Care**: will help people with chronic illness or the families with whom they live. People with significant long-term care needs or their care givers would receive a $1,000 tax credit beginning in 2000. Approximately two million people would benefit, at a cost of $5.5 billion
- **Restored Medicaid Eligibility for Legal Immigrants** to three vulnerable groups of legal immigrants: children; pregnant women; and disabled immigrants whose eligibility for SSI would also be restored. As the President has pledged, and has achieved for other groups so affected, this would reverse an inequity enacted in welfare reform. Over 50% of adults and 90% of children living with HIV/AIDS depend on Medicaid, making this restoration critically important to addressing the needs of legal immigrants living with HIV/AIDS.
- **A Strong and Enforcable Patients' Bill of Rights** remains a top Administration priority, though it is not specifically included in the FY2000 budget proposal. For those persons living with HIV/AIDS who must interact regularly with the health care system, the key provisions of the Bill of Rights--access to specialists, coverage of emergency room services, continuity of care, internal and independent external appeals, and patient protections--are absolutely critical.

*[CONTINUED]*

## BUDGET TABLE

| ANALYSIS OF FY2000 BUDGET SELECTED AIDS PROGRAMS | 1999 Enacted | 2000 Proposed | $ Change | % Change |
|---|---|---|---|---|
| **HRSA - Ryan White (HHS)** | | | | |
| Title I | 505,200 | 521,200 | + 16,000 | + 3% |
| Title II (excluding ADAP) | 277,000 | 287,000 | + 10,000 | + 4% |
| Title II (ADAP) | 461,000 | 496,000 | + 35,000 | + 8% |
| Title III (Early Intervention) | 94,300 | 130,300 | + 36,000 | + 38% |
| Title IV (Women, Children, Youth) | 46,000 | 48,000 | + 2,000 | + 4% |
| Dental Services | 7,800 | 8,000 | + 200 | + 3% |
| AIDS Education Training Centers | 20,000 | 20,000 | + 0 | + 0% |
| **Subtotal** | **1,411,300** | **1,510,500** | **+ 99,200** | **+ 7%** |
| **Office of the Secretary (HHS)** | | | | |
| Discretionary fund for minorities | 50,000 | 50,000 | + 0 | + 0% |
| **Subtotal** | **50,000** | **50,000** | **+ 0** | + 0% |
| **CDC (HHS)** | | | | |
| HIV Prevention and Education * | 657,000 | 667,000 | + 10,000 | + 2% |
| **Subtotal** | **657,000** | **667,000** | **+ 10,000** | + 2% |
| **SAMHSA (HHS)** | | | | |
| CSAT (HIV-specific) | 76,441 | 79,539 | + 3,098 | + 4% |
| CSAP (HIV-specific) | 16,402 | 15,992 | (- 410) | - 2% |
| **Subtotal** | **92,843** | **95,531** | **+ 2,688** | **+ 3%** |
| **NIH (HHS)** | | | | |
| AIDS Research | 1,798,424 | 1,833,826 | + 35,402 | + 2% |
| **HUD** | | | | |
| HOPWA | 225,000 | 240,000 | + 15,000 | + 7% |
| **TOTAL** | **$ 4,346,821** | **$ 4,396,857** | **$ 162,290** | **+ 4%** |

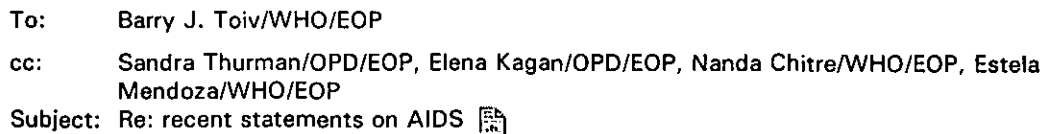
Copies of the Fiscal Year 2000 Budget and supporting documents can be found on the web at: http://www.access.gpo.gov/su_docs/budget/index.html

##30##

AIDS - general

**Todd A. Summers**
07/20/98 03:10:29 PM

Record Type: Record



To: Barry J. Toiv/WHO/EOP

cc: Sandra Thurman/OPD/EOP, Elena Kagan/OPD/EOP, Nanda Chitre/WHO/EOP, Estela Mendoza/WHO/EOP

Subject: Re: recent statements on AIDS

Relative to the inquiries made by Jeff Ballou:

He is responding to a press conference held this afternoon by AIDS Action Council at which criticisms were made of the Administration's AIDS policies. In particular, they cited:

1) Delay in naming a Director for the Vaccine Center at the NIH, which is part of the response to the President's speech over a year ago (at Morgan State University) that established the goal of developing an HIV vaccine within ten years.

2) No new money for HIV prevention in the President's FY99 budget proposal.

3) The needle exchange decision, heightened by this morning's takeover of our office by AIDS activists.

On background only, I informed him of the following:

1) Vaccine Center director: While this position was important, the delay in the search process has not hampered our progress. I told him that we had been assured by Drs. Varmus and Fauci that they were proceeding without delay, although they were clear to say that this is a long term, aggressive goal so we should expect slow progress in the pursuit of a HIV vaccine. I suggested that he contact Dr. Varmus' office or Neil Nathanson, the new Director of the Office of AIDS Research at the NIH (I have called them to give them a heads-up).

2) HIV Prevention Funding: I told him that there was in fact some additional money ($5 million) included in the budget for HIV prevention, but that it was part of the Race and Health Initiative line item and not the HIV prevention line item. I did say that we currently fund about $640 million to the CDC for HIV-related activities and that we were working with the CDC to insure that the money is being spent in the most effective manner possible. I also said that the Secretary of HHS and CDC were developing a response to the CBC's request for a "state of emergency" declaration by the Secretary, and that HIV prevention funds would be looked at as part of that review.

3) Needle exchange protest: I told him what had happened this morning, and that he should call back for a comment from Sandy.

As for Presidential statements, Steve asked when was the last time the President made a major announcement or speech on AIDS and I said that the last I recalled was the World AIDS Day proclamation but that I would have to check. I said that he had made brief comments in the interim

AIDS - general

**Q:** What is your response to activists' criticism of the Administration for not hiring a Director of the new vaccine center at NIH?

**A:** While this is an important position, we do not believe that any delays in hiring a new Vaccine Center director are slowing our work on HIV vaccine research. It is critically important to find just the right person for this position, and we fully support the efforts of NIH Director Varmus and his staff to do the kind of comprehensive search that is necessary. In the interim, we are very pleased about the recent appointment of Dr. Neil Nathanson to run the Office of AIDS Research at the NIH and are confident that his leadership will be critical to keeping this process on track. Since the President took office, funding for HIV vaccine research has gone up 86 percent.

**Q:** How can the Administration claim that it is committed to HIV prevention when it didn't ask for any new money in its FY99 budget proposal?

**A:** Actually, there was a request for $5 million in additional funds as part of the Race and Health Initiative. We are already spending almost $640 million at the CDC alone on HIV prevention and have been working with HHS and the CDC to insure that we're spending that in the most effective way possible. We also understand that in developing its response to the CBC call for a declaration of a "state of emergency" HHS and CDC will be looking at our HIV prevention funding to make sure that it's being appropriately targeted to those at greatest risk of infection.

AIDS - general

Sarah T. Holewinski

03/16/98 05:33:38 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: Needle Exchange Talking Points

**ABBREVIATED TALKING POINTS ON NEEDLE EXCHANGE**

**The Clinton Administration**
**A Record of Fighting the AIDS Epidemic**

It has been more than 15 years since the epidemic of HIV/AIDS struck our nation. In that time, more than 600,000 Americans have been diagnosed with AIDS and more than 300,000 men, women, and children have died of AIDS. President Clinton has worked hard to reinvigorate the response to HIV and AIDS, providing new national leadership, substantially greater resources, and a closer working relationship with affected communities.

**Overall Increases.** Since President Clinton took office in 1993, overall funding for AIDS related programs has increased by more than 55%.

**Supported the Ryan White CARE Act.** President Clinton in five years has tripled funding for the Ryan White CARE Act, the largest distributor of funds for medical and support services to people living with HIV and AIDS. In 1996, the Administration earmarked Ryan White funds for the AIDS Drug Assistance Program to help those without insurance obtain much needed prescription drugs; since then, ADAP funds have increased by 450%.

**Supported the National Institutes of Health.** The Administration has increased NIH AIDS research funds by 50% in five years. In 1993, President Clinton signed the NIH Revitalization Act creating a permanent Office of AIDS Research at NIH and investing it with new authority to plan and carry out the AIDS research agenda.

**Accelerated AIDS Drug Approval to Record Times.** Since 1993, the Food and Drug Administration has approved 9 new AIDS drugs, 20 new drugs for AIDS-related conditions, and three new diagnostic tests. Included in the approvals are a class of drugs known as protease inhibitors, which, in combination with previous drugs, have shown tremendous promise in the treatment of HIV progression.

**Pushed for an AIDS Vaccine.** On May 18, 1997, the President challenged the nation to develop an AIDS vaccine within the next ten years. He has supported that goal by dedicating an AIDS vaccine research center at the National Institutes of Health and encouraging domestic and international collaboration among governments, medical communities and service organizations.

**Increased Access to HIV Prevention Services for Youth.** In a directive issued on World AIDS Day 1997, President Clinton instructed each Federal agency to identify all programs under its control that offer opportunities to youth for preventing HIV infection and develop within 180 days a plan through which those programs can increase preventative education as well as support services for those already infected.

**Protected Medicaid.** The President fought to preserve Medicaid coverage for people living with AIDS. Nearly 50% of people with AIDS and 92% of children with AIDS rely on Medicaid for health coverage. He also revised eligibility rules for Social Security Disability Insurance to increase the number of HIV+ persons who qualify for benefits.

AIDS - general

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Message Sent To:

Bruce N. Reed/OPD/EOP
Christopher C. Jennings/OPD/EOP
Sylvia M. Mathews/WHO/EOP
Elena Kagan/OPD/EOP
Nanda Chitre/WHO/EOP

AIDS - general

THE WHITE HOUSE

WASHINGTON

***URGENT***

**MEMORANDUM FOR BRUCE REED**

From: Sandra L. Thurman
Director, Office of National AIDS Policy
(202) 632-1090

Date: February 4, 1998

Re: **Congressional Hearing on HIV Issues - Feb. 5, 1998**

---

At the request of Rep. Coburn, Rep. Bilirakis (Chair, House Subcommittee on Health and Environment) has scheduled a hearing tomorrow (February 5, 1998) on a range of HIV-related issues that could raise controversy. This memo provides you with a briefing on these issues and the existing Administration positions.

Though the specific intent of the hearing is not entirely clear, topics appear to include:

- HIV testing of pregnant women and babies
- Mandatory contact tracing
- Criminalization of intentional HIV transmission
- Mandatory HIV names reporting
- Mandatory testing of those accused of sexual assault

HIV testing of pregnant women and babies

Some conservative Members support mandatory testing of pregnant women as a way to identify those with HIV so as to provide treatments that reduce the likelihood of transmission of HIV to the baby. This is both unnecessary and ill-advised. The Ryan White CARE Act already includes a provision that requires states to implement testing of babies if they are unsuccessful in achieving specific reductions in perinatal transmission. In fact, pediatric AIDS cases have declined 43% since 1992, largely because of the efficacy of voluntary efforts and advances in therapy.

Mainstream health and public health organizations oppose mandatory HIV testing. They believe, as we do, that such an approach will drive the epidemic underground.

> ***Administration Position:*** *Maintain current policy of supporting states to implement voluntary counseling and testing of pregnant women. Oppose mandatory testing as an unproven strategy that is more likely to inhibit care than enhance it.*

Mandatory contact tracing
Proponents of mandatory contact tracing argue that traditional models of infectious disease control (e.g., TB) would be effective in identifying those who are HIV positive. Rather than have providers counsel HIV-positive persons to notify their partners and ask if they would like assistance, a mandatory approach would turn the tracing over to health departments. Mandatory and coercive strategies will drive people underground and inhibit access to testing and treatment. Currently, all states are required to have voluntary partner notification systems in place as a requirement of receiving CDC funding.

***Administration Position:*** *Oppose overly-prescriptive Federal requirement of contact tracing as an unnecessary infringement on state prerogatives to establish their own prevention strategies.*

Criminalization of intentional HIV transmission
Several Republican subcommittee members are believed to be proponents of creating federal criminal sanctions for intentional or reckless HIV transmission in response to the Chautauqua, New York case involving one man infecting many teenage girls. This is unnecessary given the fact that all 50 states have laws in place that criminalize the intentional transmission of HIV (either specifically or through reckless endangerment and assault provisions).

***Administration Position:*** *Oppose federal criminalization of HIV transmission; leave that decision to states, where it belongs.*

Mandatory HIV names reporting
Rep. Coburn will likely use the hearing to push to implement a Federal names-based HIV (not AIDS) surveillance system that includes a centralized, Federal registry of names. This particular approach is not supported either by the community or the CDC. The Administration's position on names-based HIV reporting systems at the state level is under current and active review. While we do believe that the time has come for tracking HIV infections in addition to AIDS cases, the use of surveillance systems based on names raises significant and real concerns about confidentiality, stigmatization, misuse of data, and utility of the data gathered that must still be addressed.

***Administration Position:*** *Oppose the imposition of a Federal names-based HIV surveillance system. Instead, work with states, the community, and the CDC to develop standards for state surveillance systems.*

Mandatory testing of those accused of sexual assault
There has been for many years a call to require HIV testing of those indicted, accused and/or convicted of sexual crimes. Already existing legislation (The Crime Bill of 1994, the Ryan White CARE Act) speaks to this issue, providing that those accused of certain sexual offenses can, with a court order, be tested at the request of a victim; convicted sex offenders can be compelled to be tested. If anything additional is needed in this area, it is more support and counseling of the victim, with rapid HIV testing and follow-up care if necessary.

***Administration Position:*** *Oppose mandatory testing, and instead promote counseling, testing, and support of victims. This is an issue best resolved at the state level.*

AIDS - general

**Richard Socarides** 01/13/98 07:51:37 AM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:
Subject: AIDS Deaths Drop 60% In California

-------------------- Forwarded by Richard Socarides/WHO/EOP on 01/13/98 07:50 AM --------------------

**Doug.Case @ sdsu.edu**
01/10/98 01:31:00 AM

Record Type: Record

To: Stuart D. Rosenstein, Richard Socarides

cc:
Subject: AIDS Deaths Drop 60% In California

SAN FRANCISCO CHRONICLE
January 9, 1998
http://www.sfgate.com

AIDS Deaths Drop 60% In California
Wide distribution of new drugs credited

Sabin Russell, Chronicle Staff Writer

AIDS deaths in California dropped an astonishing 60 percent in the first six months of 1997 -- the strongest evidence to date that available new drugs may be saving thousands of lives.

The nearly two-thirds decline in AIDS deaths surprised and delighted researchers, who said yesterday that California's aggressive attempts to distribute anti-viral drugs to infected patients appears to be paying off.

``These numbers are huge. I've not seen anything like this,'' said Thomas Coates, executive director of the University of California at San Francisco's AIDS Research Institute.

Developed by the California Department of Health Services, at the request of The Chronicle, the figures show that the dramatic improvements in survival first noticed by Bay Area AIDS patients are substantial and statewide.

During the first six months of 1997, according to state records, 1,112 California residents died of AIDS. That is 60 percent below the 2,788 who perished in the same period one year earlier.

That compares with a 23 percent drop in death rates noted by the federal Centers for Disease Control, which measured AIDS deaths nationwide between 1995 and 1996. The difference between the new state figures and the older federal data strongly suggests that the trend toward fewer deaths is

accelerating.

Dr. Richard Selick, a CDC epidemiologist, said the California statistics are impressive. ``It's a sudden, dramatic drop that does suggest it would be the influence of a recent change in treatment,'' he said.

DRUGS TAKEN IN COMBINATION

The drop-off in death rates coincides with the widespread use of the newest anti-viral drugs, called protease inhibitors, which are taken in combination with older AIDS drugs.

Epidemiologists expected a decline in AIDS deaths in the latter part of the 1990s because infection rates fell dramatically in the mid- 1980s after it became clear that AIDS was caused by a sexually transmitted virus, and gay men in great numbers switched to safer sex practices.

But Selick said the steep pitch of the decline noted in California points to the effect of drugs, rather than a decade-old behavior change, which would have produced a steady but slower decline.

``This is a great payoff for all the research that has been going on for a decade and one half,'' said George Lemp, who coordinates AIDS research programs for the UC system.

``The drop in deaths would appear to exceed what you would expect from prevention,'' Lemp said. ``It's probably attributable to new therapy.''

MAKING TREATMENT AVAILABLE

Jim Creeger, research manager for the state Office of AIDS, described the drop-off in AIDS deaths as ``an awesome decrease,'' and he attributed it to California's effort ``to get these (protease inhibitor) drugs out on the street.''

He noted that the figures are preliminary because it takes time for county death records to be completed and sent to the state. However, he said such death records are ``more than 90 percent complete'' after six months, and the latest figures are based on numbers reported more than six months ago.

Creeger said he believes the figures will not change significantly as the remaining death records trickle in.

Dr. Steve Morin, director of public policy research at UCSF's AIDS Research Institute, said the availability of the new AIDS drugs varies dramatically from state to state.

``California and New York probably have the best programs in the country,'' said Morin. ``The worst states are those with the poorest Medicaid programs,'' like North Carolina, Mississippi and Florida.

Ever since it became apparent that the protease drugs were helping AIDS patients, federal funds have been pouring into the AIDS Drug Assistance Program -- but at rates far below what clinicians say is needed. The federal outlay for assistance program rose from $50 million in 1995 to $285 million in the current fiscal year. California has augmented the federal assistance program money with state funds -- more than $24 million is allocated for 1998. Governor Pete Wilson has proposed increasing that figure by $36 million in his new budget.

`TREATMENT ON DEMAND'

In San Francisco, coverage for protease drugs is so encompassing that Moran calls it virtually ``treatment on demand.'' The bill for AIDS drugs has risen to $13.5 million from $3.5 million in 1996.

Amid all the optimism, however, researchers caution that the lifesaving effects of the protease drugs may not last. There is also a fear that the good news will diminish the discipline required to maintain the safe sex practices that helped curtail the spread of the epidemic 15 years ago.

UCSF researcher Coates noted that the drop in death rates coincides with a

time dubbed ``the honeymoon period'' for protease drugs -- a time before scientists began to note that the virus seemed to be returning in some patients taking the drugs.

In fact, a San Francisco General Hospital study found that 53 percent of those taking the combination were showing signs that the AIDS virus was reviving in their bloodstreams. However, that study is recognized as not representing a typical sample of San Francisco AIDS patients.

``We can't emphasize how much we are not clear that this is going to last,'' said Ben Collins, spokesman for San Francisco based Project Inform.

``These drugs are difficult to take, and the regime is difficult to adhere to for a long period of time.''

More than 37,500 Californians now have AIDS, and 150,000 more have been found to be HIV-positive, the Department of Health Services reports.

The state's AIDS Drug Assistance Program, established in 1987, pays for drug treatments that can cost as much as $12,000 a year for low- or moderate-income HIV-positive people.

In the budget that Wilson plans to reveal today, he will ask the Legislature to add $36 million to the program. That would push total spending -- state and federal -- to $130 million. The AIDS Drug Assistance Program provides the drugs free, or at limited cost, to those with adjusted gross incomes of less than $50,000 a year. This year, nearly 20,000 people were enrolled.

Assemblywoman Carole Migden, D-San Francisco, said, ``It's a spectacular comfort to people in dire need of lifesaving medication.'' She called Wilson's proposal ``extraordinary.''

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AIDS - general

Sandra Thurman 12/07/97 06:02:53 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: Presidential Advisory Council on HIV/AIDS Report

The Council concluded its meeting on Sunday and released its final progress report.

While it still contains some criticism of the pace of the Administration's response, we were able to soften most of the rhetoric. The primary concerns expressed in the report relate to the expansion of Medicaid coverage to people with HIV not currently covered and to needle exchange. Our response is reflected in the statement text below. Copies of the report will be sent through the mail system (but call if you want one earlier).

We are continuing to work with the Vice President's office and HHS to respond accordingly.

## THURMAN STATEMENT

### Statement of Sandra Thurman
### Director, White House Office of National AIDS Policy
### on Presidential Advisory Council Report

For more than a decade we have relied on those on the front lines to sound the alarms -- and remind all of us of the urgency of this epidemic. This longstanding tradition has served people living with HIV and AIDS and all Americans well. And it is for this reason that the President appointed an advisory committee made up of those actively engaged at the community level in our nation's battle against AIDS. The overarching message of this report is loud and clear -- this epidemic is not over and we all have much more work to do.

Last week, on World AIDS Day, everyone stopped to acknowledge the tragedy of AIDS. But for those on the front lines of this epidemic -- every day is world AIDS day. And it is out of this sense of urgency and frustration that the Council puts forward its recommendations. I certainly understand their anxiety, and I share their desire to continue the progress that this Administration has made.

However, reports that this Administration has abandoned its desire to expand Medicaid access to life-saving therapies could not be further from the truth. This Administration certainly understands the urgency of ensuring that all people with HIV benefit from the promise of new and effective treatments. The fact that our initial attempt to expand Medicaid has turned out to be more difficult than anticipated in no way lessens the Administration's resolve to seek a

workable means of extending life-prolonging therapies to all those in need.

The Clinton Administration has a strong track record of addressing the needs of people living with HIV and AIDS:

- The President worked vigorously to save the Medicaid program, which is the largest single payor for AIDS services and treatment in the country -- in 1997, federal Medicaid expenditures for people living with HIV/AIDS totaled $1.8 billion, including nearly $500 million for AIDS drugs.

- The President established the HIV Vaccine Initiative, with the goal of finding a vaccine against HIV within 10 years.

- The President has pushed for increases in the Ryan White CARE Act, including a 450% increase in the State AIDS Drug Assistance Program since 1996.

- This Administration has supported the research that resulted in the new treatments that are saving so many lives, with funding for AIDS research at NIH increasing 50% since the start of this Administration.

There is no absence of will to meet this challenge; there is, however, a different sense of what can be accomplished in an often polarized political environment in which ideology can overwhelm science. The struggle to get the best quality of care and the best medications to all HIV-positive Americans is a very difficult fight and one I know that the President is committed to winning.

###30###

**WASHINGTON POST STORY**

December 07, 1997, Sunday, Final Edition
SECTION: A SECTION; Pg. A20

LENGTH: 378 words

HEADLINE: Advisers Chide Administration On AIDS Fight

BYLINE: Laura Meckler, Associated Press

BODY:
President Clinton's AIDS advisers are set to issue a harsh report card today accusing the administration of letting down its guard in the fight against AIDS.

AIDS-general

Todd A. Summers
12/04/97 09:49:33 AM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:
Subject: TALKING POINTS and Q&A FOR PRESIDENT'S ADVISORY COUNCIL MEETING

**TALKING POINTS ON REPORT FROM**
**PRESIDENT'S ADVISORY COUNCIL ON HIV/AIDS**

**The Clinton Administration continues its aggressive campaign against the AIDS epidemic**

- Obtained substantial increases in AIDS funding (discretionary programs at HHS up 60% since start of term)
- Established the HIV Vaccine Initiative, with goal of finding vaccine against HIV within 10 years
- Supported reauthorization and funding of Ryan White CARE Act - funding nearly tripled since start of Administration
- Supported research that resulted in the new treatments that are saving so many lives - funding for AIDS research at NIH increased 50% since start of Administration
- Increased specific Federal funding for the State AIDS Drug Assistance Program nearly 450% since 1996
- Created and Supported the Office of National AIDS Policy
- Protected Medicaid, which serves 50% of people with AIDS and 90% of children with AIDS

**Role of the President's Advisory Council is to provide advice from the community**

- We understand frustration of Council members - this is a terrible epidemic that gives rise to strong emotions
- If some members choose to resign, we respect but regret their decision - however, it would be our hope that they will stay at the table and work with the President to continue to make a difference
- President and the Secretary will continue to work with the Council to review their reports and to respond quickly and decisively

**The appropriateness of needle exchange programs should be determined by public health experts and scientists, not politicians**

- Administration worked aggressively to preserve the Secretary's authority to make determination on removing Congressionally imposed restriction on allowing local communities to decide on the use of federal funding for needle exchange programs
- Authority should remain with the Secretary because she is the chief public health officer of this country and with community public health experts -- this is an issue for public health experts to resolve
- Congress agreed, sustaining the Secretary's authority
- Secretary is evaluating available scientific reviews of needle exchange programs to determine appropriate course of action

**Q & A**
**Meeting of and Report from the**
**President's Advisory Council on HIV/AIDS**
**December, 1997**

**The PACHA accuses the Administration of having stalled on the AIDS crisis. Is this true?**
No. President Clinton and his Administration remain fully engaged in the effort to end this epidemic. We have supported substantial increases in AIDS funding for care, prevention, and research, even at a time when overall discretionary funding has been tight.

Our accomplishments are remarkable. Investments in AIDS research have resulted in powerful new treatments that have helped reduce the numbers of AIDS deaths for the first time since the start of the epidemic. The Ryan White program, now funded at over a billion dollars, has allowed for a broad array of primary care and supportive services that is unparalleled. We have established a major initiative to find a vaccine against HIV within ten years.

The PACHA is expressing understandable frustration with a devastating epidemic. Presidential advisory councils are not intended to serve as "rubber stamps;" on the contrary, they are intended to provide independent, objective advice to the Administration. No doubt they are using this public document as a means to continue their advocacy with this Administration.

**What do you say to the PACHA members who are threatening to resign if the Administration does not approve needle exchange programs?**
We certainly understand the frustration of some of members of the President's Advisory Council on HIV/AIDS (PACHA). While their participation in the PACHA process is the most effective way for them to work with the Administration, they certainly have the right to choose to remove themselves. Unfortunately, that means that they will not have a voice at the table.

This Administration is very concerned about the continued spread of this epidemic, and is seriously reviewing the impact of needle exchange programs on curtailing HIV transmission among injection drug abusers. We worked diligently with the Congress to maintain the authority of the Secretary of Health and Human Services to remove the current restriction on the use of federal funds by local communities that choose to implement needle exchange programs. We did this because we believe that this is an issue best left to the public health experts and not to the politicians.

**Is the President going to allow funding for needle exchange programs?**
The decision to lift the Congressionally imposed restriction on the use of federal funds for needle exchange programs has been vested by Congress with the Secretary of Health and Human Services. She has not yet made that determination because she is studying the benefit of those programs in reducing HIV transmission and their impact on the use of illegal drugs. This is not the simple and obvious decision as has been characterized by AIDS activists. On the contrary, this nation has an epidemic of illegal drug use and we do not want to support something to address AIDS that will undermine our efforts on the drug epidemic. The President will continue to support the Secretary's process, and respects her ability to make a decision on needle exchange that is grounded in science and public health.

**The PACHA is debating HIV names reporting? What is that and what is the Administration's position?**
Many AIDS advocates, epidemiologists, and government officials now believe that our efforts to fight the AIDS epidemic would be improved with better information on the incidence of HIV infection. We currently rely primarily on the numbers of AIDS diagnoses or deaths as a measure of where this epidemic is currently and where it seems to be moving. However, because more and more people are living longer and longer with HIV and not progressing to AIDS, this data is increasingly out of pace with the front edge of the epidemic. This reduces our ability to initiate the kind of proactive prevention efforts necessary to stem the tide of new infections.

However, we are also very mindful of the very real concerns around confidentiality. The fear of disclosure of a positive HIV test result may inhibit many from getting tested, which is the first step in accessing medical care and avoiding further transmission. The Administration will continue to work with government and community experts to determine the best way to balance the need for more timely information on new infections with the imperative to promote HIV testing and access to care for those infected.

Message Sent To:

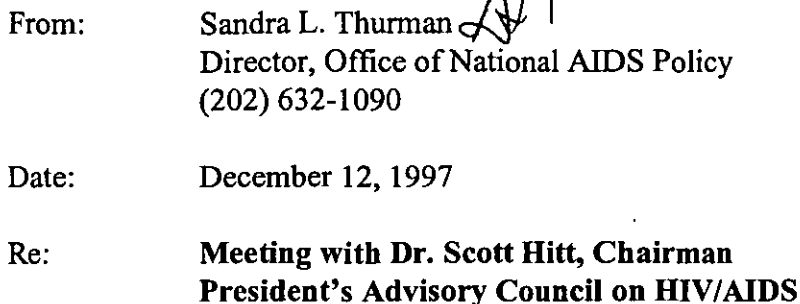
Michael D. McCurry/WHO/EOP
Joseph P. Lockhart/WHO/EOP
Joshua Gotbaum/OMB/EOP
Richard J. Turman/OMB/EOP
Barry J. Toiv/WHO/EOP
Maria Echaveste/WHO/EOP
Christopher C. Jennings/OPD/EOP
Sarah A. Bianchi/OMB/EOP
Craig T. Smith/WHO/EOP
Ann F. Lewis/WHO/EOP
Bruce N. Reed/OPD/EOP
Elena Kagan/OPD/EOP
Sylvia M. Mathews/WHO/EOP

AIDS - general

THE WHITE HOUSE

WASHINGTON

**MEMORANDUM FOR ERSKINE BOWLES**



From: Sandra L. Thurman
Director, Office of National AIDS Policy
(202) 632-1090

Date: December 12, 1997

Re: **Meeting with Dr. Scott Hitt, Chairman President's Advisory Council on HIV/AIDS**

---

Next Wednesday, you will be meeting with me and Dr. Scott Hitt, Chairman of the President's Advisory Council on HIV/AIDS. Dr. Hitt is a prominent, openly gay physician from Los Angeles with significant experience in the clinical management of HIV and AIDS, as well as local, state and national politics. He was an early supporter of the President in 1992.

This past Sunday, the Council released its Progress Report on the Administration's response to the epidemic (copy attached). While significant accomplishments with respect to funding and policy issues are recognized, the report is quite critical of the President and the Secretary of HHS. The Council's principal concerns are:

- a perceived de-prioritization of AIDS
- inaction on allowing Federal funding for local needle exchange programs
- mixed signals on Medicaid expansion.

Some background on these issues and our current policy positions:

**Prioritization of AIDS**

This concern relates primarily to the funding of discretionary AIDS programs. It became a particularly hot issue when the balanced budget agreement was completed and no AIDS programs were listed under the "protected" classification. Advocates interpreted this as a de-prioritization of AIDS, which had in previous years enjoyed classification as a budget priority.

This perception was exacerbated by requests in the President's FY98 budget (see attached table) that the community considered inadequate, particularly for the AIDS Drug Assistance Program for which the Administration sought no increase. Substantial increases were ultimately obtained, but Republican appropriators championed these increases.

As has been the case in previous years, HHS has asked for only minimal increases in its AIDS programs for FY99. In its first passback, OMB sought only level funding. While this is a time-honored exercise, several community members have gotten wind of the passback numbers and are quite upset that the Administration isn't pushing for adequate increases.

I have been working with OMB on a Presidential Initiative that would offer additional funding for the AIDS Drug Assistance Program, other parts of the Ryan White CARE Act, and the CDC's HIV prevention programs (representing a 6% increase overall).

**Needle Exchange**
This issue has become central to the AIDS community and, rightly or wrongly, it has become symbolic of the Administration's leadership on AIDS. AIDS advocates have long sought to give local communities the option to use Federal funds for needle exchange programs. Given that as many as 50% of new HIV infections are directly or indirectly related to injection drug use, those on the front lines are increasingly interested in having the flexibility to employ all strategies they deem appropriate.

During the FY98 Appropriations process, conservative Republicans made a vigorous attempt to rescind the current authority of the Secretary of HHS to remove the restriction on the use of Federal funding for needle exchange programs.[1] Congress, however, with strong support from the Administration, maintained the authority but imposed a six month moratorium on the use of Federal funds for needle exchange programs as a compromise. Many in the community believe that this leaves the door open for the Secretary to make a determination that Federal funds may be used prior to the expiration of the moratorium, and to allow the actual expenditure by states and local communities, at their discretion, as soon as the moratorium expires (3/31/97). The President's Advisory Council is <u>strongly</u> recommending in a letter to the President (copy attached) that he instruct the Secretary to act prior to the return of Congress on January 27, 1998.

**Medicaid Expansion**
This past April, the Vice President announced a request that HCFA study the possibility of a demonstration program that would expand Medicaid coverage to people with HIV. This was in response to recently released guidelines from the NIH that recommend treatment earlier in the course of illness. Unfortunately, we are in a "catch 22." Currently, many impoverished people have no access to treatment until they progress to full-blown AIDS, at which point they qualify for Medicaid--which pays for the treatment that may have forestalled the onset of AIDS.

The AIDS Drug AIDS Drug Assistance Program (part of the Ryan White CARE Act) helps, but because this is a limited discretionary program, there are many states that have cut off new applications, limited their covered formularies, or simply capped available benefits far below the annual cost of these treatments (+/- $15K/yr).

HCFA has completed its preliminary analysis, and has determined that expanding Medicaid would not be budget neutral. Last week, a spokesman for HHS told the press that the Medicaid expansion initiative was not feasible without making clear that we were still committed to working on a

---

[1]To act, the Secretary must determine that needle exchange programs (a) decrease HIV infection among participants and (b) do not increase the use of illegal drugs. Her report to Congress this past spring was determinative on the first test and less clear on the second.

solution. This press leak was very untimely, appearing in the *Washington Post* and the *New York Times* while the President's Advisory Council on HIV/AIDS was meeting here in Washington. Subsequent press coverage was quite intense, and was then fueled by the release of the Council's report. While I believe that we were able to sustain a tenable position with the public, it does place considerable pressure on us to maintain discussions on a long-term solution to the health care needs of people with HIV/AIDS and on a short-term response in the FY99 budget.

This is a very important issue to the AIDS advocacy community. They are perhaps appropriately concerned that continued reliance on discretionary programs like Ryan White for primary health care and treatments is a short term solution that leaves them vulnerable, and they are seeking more long term, systematic entitlement reform. While we will need to respond in FY99 with additional funds for care and treatment, that will not address their long term goal of modernizing Medicaid/Medicare coverage.

The Council's report expressed concern over "mixed signals" from the Administration. They had drafted language that was far more harsh but we are able to allay their concerns temporarily by arranging for a call from the HCFA Administrator, who clarified that the press article was not accurate and that HCFA would continue to work with the community to find a solution.

**Likely Requests from Dr. Hitt**

I believe that Dr. Hitt will ask for several things from you:

- a commitment to get the President to the next Council meeting in March;
- a commitment to pass the Council's report to the President; and
- a commitment to respond to their recommendations, particularly those relating to needle exchange and Medicaid expansion.

My recommendation is that you respond as follows:

| | |
|---|---|
| POTUS attendance at next Council meeting: | *you will support the request, but it will be dependent on scheduling* |
| Transmittal of Council Report to President: | *this Administration takes the Council's recommendations very seriously and will respond appropriately* |
| Needle exchange and Medicaid expansion: | *I have already instructed senior members of the Administration, led by Sandy Thurman and Bruce Reed, to address these issues and provide recommendations for action. The Vice President's office will also be working with us, particularly on ways to cover the cost of the new treatments.* |

Please let me know if you need any additional information.

## Discretionary AIDS Programs at HHS

| PROGRAM | FY97 Enacted | FY98 POTUS Budget | FY98 Enacted |
|---|---|---|---|
| **HRSA** | | | |
| Ryan White CARE Act | | | |
| *Emergency Relief* | 449,943 | 454,943 | 464,800 |
| *Block Grants* | 249,954 | 264,954 | 257,500 |
| *AIDS Drug Assistance Program* | 167,000 | 167,000 | 285,500 |
| *Early Intervention* | 69,568 | 84,568 | 76,300 |
| *Women, Children, Youth* | 36,000 | 40,000 | 41,000 |
| *Special Projects* | | | |
| *AIDS Educ. & Training Centers* | 16,287 | 17,287 | 17,300 |
| *Dental Reimbursement* | 7,500 | 7,500 | 7,800 |
| **Subtotal** | **$996,252** | **$1,036,252** | **$1,150,200** |
| **CDC** - HIV Prevention | 616,790 | 634,266 | 634,300 |
| **SAMHSA** - Substance Abuse Earmark | 55,122 | 52,920 | 55,122 |
| **NIH** - AIDS Research | 1,501,000 | 1,541,000 | 1,607,000 |
| **Subtotal** | **$2,172,912** | **$2,228,186** | **$2,296,422** |
| **TOTAL** | **$3,169,164** | **$3,264,438** | **$3,446,622** |
| | | + 3% | + 9% |

PRESIDENTIAL

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COUNCIL ON

HIV/AIDS

# Second Progress Report

## December 7, 1997

### PREAMBLE

In the 5 years since he assumed office, President Clinton has dramatically improved the national response to AIDS. Since 1993, funding for the Ryan White CARE Act has increased by 200 percent, spending on AIDS research has grown by 50 percent, HIV prevention funding has increased by 27 percent, and federal support for the Housing Opportunities for People With AIDS (HOPWA) program has grown by 104 percent. Approval of new drug therapies has been expedited. Due in large measure to the Office of AIDS Research (OAR), which was proposed by the Clinton Administration, AIDS research funds are spent more efficiently and strategically. As a result of improvements in the medical management of HIV disease, the nation has witnessed the first ever decline in the annual number of AIDS deaths. In addition, the President's AIDS vaccine initiative has placed a long-overdue spotlight on the world's reliance on the U.S. for the development of a safe, effective vaccine. As history will undoubtedly record, President Clinton is the first American chief executive to take serious action to address the AIDS crisis. However, most of these important strides occurred during the President's first term.

Despite substantial and diligent efforts on the part of Office of National AIDS Policy (ONAP) Director Sandra Thurman, the ONAP staff, and the Executive Director of the Presidential Advisory Council on HIV/AIDS (PACHA), progress in the federal response to AIDS has stalled in recent months, contributing to a sense of diminished priority for AIDS issues during the President's second term. We are concerned that ONAP has not been provided with adequate staff or appropriate status within the White House structure needed to make it most effective. When the future of funding for the AIDS Drug Assistance Program (ADAP) was at risk earlier this year, AIDS advocates were forced to look to Congress, not the White House, for leadership. In May, the Vice President announced a 30-day expedited Administration review of the feasibility of expanding Medicaid to cover all indigent HIV-infected individuals; however, many months have passed, no pilot project has been put in place, and the Administration continues to send mixed and conflicting signals regarding its pursuit of the

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objective of expanding Medicaid coverage. The combination of these actions raises serious questions about the current priority of AIDS issues for the Administration.

In one crucial area of the federal response to AIDS—the national effort to prevent HIV transmission—the Administration, like its predecessors, has failed to lay out a coherent strategic plan of action. Funding for HIV prevention remains inadequate, particularly when compared with the monumental bill for medical expenses and lost productivity stemming from HIV disease. With respect to the sparse funding that does flow each year to State and local health departments to support HIV prevention activities, the Centers for Disease Control and Prevention (CDC) has incorporated community planning as a primary implementation strategy but has not fulfilled its oversight responsibility to ensure that States and localities effectively target the limited dollars available. Despite the scientifically verifiable evidence that has long existed regarding the efficacy of needle exchange programs, Secretary of Health and Human Services (HHS) Donna Shalala has yet to make the public health determination legally necessary to allow local communities to use federal funds to support this life-saving intervention. On this issue and others listed below, the Administration has sometimes failed to exhibit the courage and political will needed to pursue public health strategies that are politically difficult but that have been shown to save lives.

Recent medical developments have injected a spirit of hope in the battle against the disease. Hope, however, is fragile, and apathy is its enemy. Far too many Americans lack access to effective medications, and far too many patients are failing on the new drugs. Due to gaps in access to basic health care and social services, which make it difficult for many people with HIV to comply with demanding treatment regimens, the nation also faces the alarming risk of widespread HIV drug resistance. Tens of thousands of Americans—as many as one-half of them teenagers or young adults—become infected with HIV each year. Globally, new evidence indicates that the number of people infected with the virus is far larger than originally believed, and growing rapidly, underscoring the overwhelming need to develop a vaccine capable of bringing the worldwide epidemic under control.

Unfortunately, large segments of some populations affected by the epidemic do not have access to recent therapeutic advances. HIV infection continues to increase among women and other people of color. Blacks and Latinos continue to be disproportionately affected by the virus. On average, people with HIV infection in the U.S. are poorer in 1997 than they were 10 years ago. And, as the new therapies extend life for many people with HIV, the HIV-infected population grows, placing even greater burdens on already strapped systems of care.

With major challenges still ahead, and countless lives in the balance, now is not the time for complacency. History will judge this society by the choices we make. As a nation, we may either demonstrate the conviction and endurance needed to bring the epidemic to an end, or allow apathy and weariness to sow the seeds of even greater future loss of life. The right choice requires bold and courageous leadership. In order to take advantage of the solid achievements of

this Administration during its first term and to tackle still daunting issues regarding HIV/AIDS that remain, a renewed dedication to action is essential.

## PREVENTION SUBCOMMITTEE

More than 16 years after the epidemic was first recognized, the United States still has not laid out a coherent, effective national strategy to prevent HIV transmission. Experts estimate that more than 40,000 Americans will have become infected with HIV this year alone. Despite a wealth of knowledge regarding the elements of an effective HIV prevention strategy, there is little evidence that the nation has made significant progress in reducing the number of new HIV infections in recent years.

During the early years of the epidemic, former Surgeon General C. Everett Koop and eminent organizations such as the Institutes of Medicine and previous Presidential Commissions recommended that the country adequately invest in programs to provide frank, explicit, culturally relevant HIV prevention information to those at risk for sexual transmission. Similarly, leading experts have long recommended that the nation's leaders ensure the availability of drug treatment on demand and address counterproductive drug paraphernalia laws. Yet, many years later, our national prevention effort ignores these sound recommendations.

Studies of the populations most heavily affected by the epidemic have repeatedly demonstrated that prevention initiatives lead to substantial changes in self-reported sexual behavior. This research indicates that prevention programs that address sexual behavior are most effective when they provide explicit information in clear, culturally sensitive language, are ongoing, assist individuals in developing sexual negotiation skills, and are administered by members of the target population.

Perhaps most disturbing is the continued prohibition on federal funding for needle exchange programs despite clear scientific evidence of the efficacy of such programs in preventing new HIV infections without increasing substance use. At least 50 percent of new HIV infections are traceable to injection drug use. The HHS Secretary has for some time had the legal authority to lift funding restrictions, yet she has failed to do so. The Council applauds the Administration's successful effort earlier this year to preserve the Secretary's authority to waive funding restrictions. However, the Administration has thus far expended little effort to educate Congress and the American public about the effectiveness of needle exchange programs or to build political support for such programs. The Administration should demonstrate leadership on this issue by immediately certifying the public health utility of this life-saving intervention as a component of a continuum of effective HIV prevention services for injection drug users.

Although powerful evidence of the effectiveness of HIV prevention demands a robust and energetic response, the Administration has failed to provide such bold leadership. The federal investment in HIV prevention is disproportionately small compared to the amount of the

epidemic's annual price tag in medical care and lost productivity, let alone in human suffering and loss of life.

Moreover, the Administration often fails to make optimum use of its limited investment in HIV prevention. It has maintained outdated restrictions on the ability of some federally funded HIV prevention programs, especially those targeting school-aged youth, to provide explicit and appropriate information to those at greatest risk. As a result, many HIV prevention educators must censor themselves with an eye to retaining their funding rather than providing the most effective prevention message possible.

At least 25 percent of all new infections occur among individuals under the age of 22. While the CDC is taking steps to improve and expand its efforts to target youth at high risk for HIV infection, including gay youth and young women of color, the agency's efforts to educate youth regarding HIV remain uncoordinated and unevaluated. On World AIDS Day, the President issued a directive to all federal agencies to identify all programs serving young people that offer significant opportunity for preventing HIV infection and to develop a specific plan to use those programs to increase access to HIV prevention and education information, as well as to supportive services and care for those already infected.. This process provides a significant opportunity to assess, coordinate, and expand federal efforts to prevent HIV transmission among America's young people.

We are encouraged by the leadership of Dr. Helene Gayle at the CDC and are impressed by the senior team she has assembled. In particular, we appreciate both Dr. Gayle's involvement of affected communities in the development of HIV prevention strategies and the CDC's continued support of HIV prevention community planning. Unfortunately, the CDC inadequately monitors the public health uses to which federal HIV prevention funds are put by State and local health departments. Consequently, we are concerned whether limited prevention dollars target those at greatest risk. We strongly encourage the CDC to continue its recently strengthened efforts to track the expenditures of its grantees' prevention programs and to ensure that these expenditures address the needs of persons at greatest risk. We look forward to a report at our March meeting on recent expenditures analysis.

In 1996, President Clinton challenged the nation to reduce the number of new HIV infections each year until there were none. Sadly, no coherent plan exists for achieving this noble objective. In the absence of bold leadership and aggressive action on the part of the Administration, the nation stands little chance of substantially reducing the number of new infections.

## RESEARCH SUBCOMMITTEE

The President is to be highly commended for his leadership efforts to expedite the work of developing an AIDS vaccine. The President's announcement in May, 1997 of the goal of developing an AIDS vaccine within a decade, and the focus of attention on an AIDS vaccine during the Denver Summit meeting are greatly appreciated and acknowledged worldwide. But much more must be accomplished. Remaining to be addressed are the Council's prior recommendations for: (1) a significant and sustained increase in additional and new funding for AIDS vaccine development; (2) coordinated and comprehensive involvement by all relevant federal agencies in the effort; (3) close federal collaboration with the private sector, international community, and independent vaccine initiative; and (4) the convening of a public-private AIDS consultative forum.

We would like to commend the Food and Drug Administration (FDA) for its efforts in addressing some of the issues we raised concerning women and children infected with or affected by HIV/AIDS. The FDA has published proposed guidelines on expectations regarding inclusion of patients of both genders in drug development, analyses of clinical data by gender, assessment of potential pharmacokinetic differences by gender, and conduct of specific additional studies in women, where indicated. The Council reaffirms our previous recommendations and supports the FDA's proposed guidelines. We appreciate the FDA's efforts in seeing that the labeling process of marketed prescription drugs includes the accumulation and dissemination of pediatric data; however, we are still awaiting our requested review of the number of children actually enrolled in NIH-sponsored clinical trials.

Although it has not been enacted by Congress, the President and Vice President have continued to support the recommendation for a coordinated federal approach for HIV/AIDS research through support for the OAR, including staunch advocacy for a consolidated budget for AIDS research at the NIH.

Some progress on microbicide research has been achieved, and Secretary Shalala announced in July, 1996 that $100 million would be spent on microbicide research over the next 4 years. However, no new Federal full-time equivalents (FTEs) have been designated to this effort, no new Requests for Applications (RFAs) have been issued that might stimulate the interest of new investigators in the field, and there has been no response to our recommendation that a public health consensus panel be convened to assess the efficacy of available spermicides and other licensed products. Further, the Council has not received a detailed accounting of the monies expended for microbicide research, and we are concerned that no new monies have been designated specifically for this purpose.

Our recommendation to create mechanisms for the rapid translation of breakthrough findings into clinical practice has been partially addressed by the NIH in the area of biomedical research. Several approaches now exist; however, in the area of behavioral and social science,

creative mechanisms that facilitate rapid translation of these research findings still need to be developed.

## SERVICES SUBCOMMITTEE

HIV/AIDS requires extensive medical care. Access to such care upon diagnosis is essential and can often result in greatly extending both length and quality of life for those infected. HIV/AIDS medical care also is expensive and, therefore, for those without adequate health insurance or significant personal resources, often unavailable. The Administration's proposal for universal health insurance would have ensured such care for most HIV-infected Americans. Unfortunately, Congress rejected that proposal. As a result, we are left with a piecemeal system of health care in which many do not have access to basic primary medical care or the promising new combination drug therapies, which offer them the best chance for long-term survival. Medicaid, upon which more than 50 percent of people with AIDS rely for health care, and the Ryan White CARE Act are the existing programs through which most HIV/AIDS care is currently provided.

Since July, 1996, the Council has urged the Administration to begin reviewing existing programs and developing new approaches for providing primary medical care and access to the new drug therapies. In December, 1996, PACHA formally recommended that HHS develop new policies and provide requisite funding to ensure availability of these therapies to all those who need and cannot otherwise afford them, in accordance with HHS recommended treatment guidelines. In particular, we focused on the following actions:

1) **Leadership On Funding for HIV Treatment, Care, and Housing Services**. The President's budget, which is released each year in early February, is a reflection of the Administration's values and priorities. In 1997, the Council was deeply concerned that the President's FY 98 budget request recommended no increase for ADAP, and only modest increases for primary medical care and other critical support services through the Ryan White CARE Act and HOPWA. Recent reports of a 23 percent decline in AIDS deaths between 1995 and 1996 obscures the corresponding 11 percent increase in the number of people living with AIDS during this same period, creating increased need for additional services, including the promising new therapies. The Council is looking to the President's FY 99 budget request for a clear indication that the Administration understands both the continuing gravity and urgency of the epidemic and is committed to providing adequate funding support.

2) **Expansion of Medicaid Coverage**. For thousands of people with HIV/AIDS, Medicaid provides their only avenue for primary medical care. Medicaid eligibility is now "triggered" by the onset of disability, but the new therapies are recommended as a means of *slowing disease progression* and thereby *avoiding* disability. Therefore, the current Medicaid eligibility criteria are in direct contradiction to the recommended standard of care for the treatment of HIV disease. Early access to the new therapies with supportive medical and social services is not only a

humane policy, but also, we believe, over the long term, a cost-effective strategy as well. Further, unlike ADAP within the Ryan White CARE Act, which covers only drug costs, Medicaid also covers associated primary medical care costs. In addition, since Medicaid is a needs-based entitlement rather than one that is subject to special annual appropriations (as is Ryan White), availability of the new drugs and associated medical services is driven by treatment needs, not by annual appropriations battles.

This past spring, Vice President Gore called for HHS to explore and report to him within 30 days on the feasibility of expanding Medicaid coverage to cover early-intervention HIV therapies. Accordingly, many dedicated public servants within HHS are working diligently to find a means of expanding Medicaid eligibility, and we commend their efforts. We are particularly encouraged that the Health Care Financing Administration (HCFA) has been working closely with the AIDS community and outside policy experts to attempt to develop a viable, cost-effective, ethically appropriate mechanism to provide such expansion. However, we have been deeply disappointed by the apparent absence of personal leadership on this issue from Secretary Shalala and by the mixed and conflicting messages from the Administration of its true intentions regarding this initiative. In a recent meeting attended by Council members, the Secretary suggested the alternative possibility of proposing increased support for ADAP. That option engenders skepticism since it was Congress, rather than the Administration, that proposed increased ADAP spending in the 1998 federal budget.

3) **Reduction of the Cost of New Therapies**. The Administration, in conjunction with State AIDS and other public health administrators—and with effective pressure from the advocacy community—has employed, with some success, a number of new ADAP purchasing mechanisms to reduce the cost of the new drug therapies. However, while we recognize the need of drug companies for cost recovery and a reasonable profit, the cost of drugs is still prohibitively high. Strong leadership from the Administration on this issue is urgently needed, particularly from the Vice President, who has worked with pharmaceutical companies in the past. There are successful examples of "jawboning" private industry on other price issues by other Administrations. Working together with Governors, community advocates, the insurance industry, and the pharmaceutical companies themselves, we believe the Administration can and must help reduce drug prices.

4) **Monitoring of Access to Therapies and Associated Medical Services in Private Managed Care Health Systems**. It has been feared (and in many cases, documented) that people with HIV/AIDS and other complex, disabling conditions would not be able to have access to needed drugs and specialists under managed care systems. The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry has just released its recommendations, which have been endorsed by the President. These recommendations are sensitive to the special needs and circumstances of people with HIV/AIDS, and are an important first step in assuring that people with HIV/AIDS continue to have access to the new therapies and associated medical services through their managed care providers and/or insurers. We commend

Secretaries Alexis Herman and Shalala and members of the Commission for this sensitivity and look forward to working with them to ensure implementation of these recommendations.

5) **A National Policy Dialogue on How to Provide Comprehensive HIV Care.** Last December, the Council recommended a national dialogue on how, over the long term, the federal government should structure and pay for medical and support services for people with HIV/AIDS. Currently, Medicaid, the Ryan White CARE Act, and other ancillary funding sources are providing critically needed support for sustaining a comprehensive continuum of HIV care. However, the impact of new drug therapies on the clinical course of and potential new manifestations of HIV disease must inevitably result in modification of the existing provision of services and will require additional funding. Despite significant efforts to promote a formal, structured, national policy dialogue, progress has stalled. At the same time, the changing nature of the epidemic has sparked a new sense of urgency for such dialogue, which, in many cases, has already begun at the local level. A comprehensive review of HIV service delivery and funding mechanisms at the federal, State, and community levels must be undertaken at the earliest possible date, with active participation by all affected parties.

6) **Indian Health Service.** We are greatly concerned that the Indian Health Service (IHS) still has not developed adequate HIV/AIDS prevention and treatment programs or ongoing communications with Native American organizations in the AIDS health care arena. Rural services, in particular, continue to have staffing and access problems. The IHS also has not provided updated case management guidelines that ensure cultural sensitivity and access to traditional treatments.

## DISCRIMINATION SUBCOMMITTEE

The Council has formally recommended that mandatory HIV testing by and/or discriminatory policies of the U.S. Foreign Service, the Peace Corps, the Job Corps, the State Department, and the military be rescinded unless justified by a compelling public health rationale. During its meeting with the President 2½ years ago, the Council raised this issue and the President responded in a supportive manner.

Since then, the Job Corps has revised its policy from requiring special mandatory testing to routine testing for HIV as part of its entry process. It retains more than 80 percent of those who test HIV-positive and provides requisite counseling and referral to medical care, regardless of whether HIV-positive applicants are subsequently accepted as students. This exemplary policy by the Job Corps should be commended.

The Department of Defense (DOD) maintains stringent standards for appointment, enlistment, or induction into military service. The DOD does not discharge individuals testing HIV-positive after appointment, enlistment, or induction solely on the basis of a positive test. Periodic medical evaluation of fitness for continued service of HIV-positive personnel is

conducted in the same manner as for personnel with other progressive illnesses. Evidence of HIV infection may not be used as a basis for any disciplinary action and HIV-positive personnel are assigned within the U.S. in order to ensure access to appropriate medical care. The DOD policies regarding HIV-infected individuals appear to be comparable to those for other medical disqualifications. Its policies regarding those subsequently infected are exemplary and should be commended.

The U.S. Foreign Service requires mandatory HIV testing, and those found to be HIV-positive are disqualified from entry (subject to a possible waiver, which is seldom granted) because of the resulting limitations on "worldwide availability" for placement. Foreign Service employees who become HIV-positive subsequent to entry are issued limited medical clearances and may serve in countries where adequate medical care is available. While treatment of subsequently HIV-infected individuals appears to be comparable to treatment of those with similarly serious medical conditions, more information is needed to clearly demonstrate equitable treatment. For those disqualified from entry, more data is needed to show the practical application of the worldwide availability for placement criteria and if HIV-infected applicants are, in fact, treated comparably to those with similarly serious medical conditions.

The Peace Corps requires HIV testing as part of a comprehensive pre-entry medical assessment. HIV is listed as a condition that, with rare exception, the Peace Corps is unwilling to reasonably accommodate. It further provides for deferred entry with certain conditions after a specific time period. Advances in HIV therapy and resulting improvements in general health and quality of life for HIV-infected individuals may require future recategorization.

After much debate and discussion, the CDC finally has scheduled a working group meeting of external experts for early 1998 to review CDC guidelines for preventing HIV transmission from infected health care workers. It is our sincere hope that this will lead to prompt revision of its current discredited and discriminatory guidelines.

## PRISONS SUBCOMMITTEE

Since 1990, HIV/AIDS has been the second leading cause of death in prisons. The incidence of AIDS in prisons is six times greater than the incidence in the general population. For many incarcerated persons, prison may be their first contact with medical and psychosocial interventions as well as their first opportunity for alcohol and drug treatment; therefore, prisons provide an ideal environment for prevention and education efforts. A prisoner's health status upon returning to society has a direct bearing on the health of the communities into which he/she returns.

Information from the Department of Justice concerning health care policy in prisons has been useful; however, the information we have received from the Federal Bureau of Prisons has been incomplete and lacking the substance necessary to assure us that the well-being of inmates

in our nation's prisons is not at risk. Information from the Department of Defense concerning military prisons and brigs was also requested, but has not yet been received by the Council. A number of concerns outlined in our 1996 report have not been addressed, and many appropriate recommendations from the National Commission on AIDS have not been implemented.

Since most incarcerated individuals do not remain incarcerated forever, discharge planning for inmates with HIV/AIDS is essential. Pre-release case management and discharge planning are important in ensuring that HIV-infected inmates who have been released or paroled have access to the broad range of services needed to make a healthy and successful transition back into their communities. We continue to believe that other alternatives for compassionate release, consistent with standards such as those adopted by the American Bar Association (ABA), should be examined as an alternative to the current Federal Bureau of Prisons guidelines.

During incarceration, inmates should have access to comprehensive and current medical therapy. It is our understanding that Medical Standards of Care include all FDA-approved treatment modalities. Appropriate use of these therapies needs to be closely evaluated. Federal prisoners should also have access to compassionate-use therapies that have proven efficacious but have not been FDA-approved.

The link between HIV and substance abuse has been clearly established, yet access to essential substance-use interventions continues to be variable among institutions. Federal officials report that "inmates who volunteer for treatment are admitted into residential substance-abuse programs in sequential order based on release date." While we applaud this effort, we encourage the Federal Bureau of Prisons to evaluate waiting periods and expand programs to accommodate all inmates seeking treatment. In addition, discussions should continue on inmate access to clean substance-use paraphernalia.

Although federal officials responded to our queries on protective barriers, they remain extremely resistant to changing their current policy which states, "condoms and/or dental dams are not medically necessary for use other than during sexual activity and therefore are not authorized." We feel that this approach is shortsighted. Also, the scientific literature does not support the Bureau of Prisons' concern that access to protective barriers would "create an environment in which control would be difficult." The documented transmission of sexually transmitted diseases (STDs) in prisons underscores the fact that sexual behavior is indeed occurring; therefore, this policy should be reconsidered and successful models using protective barriers should be examined.

Despite the policies and procedures developed by the Federal Bureau of Prisons, testimony from current and former inmates reveals that these policies are not administered evenly and uniformly. The Council remains committed to a stronger investment in HIV prevention and care for incarcerated individuals. We believe that such a commitment would be significant in reducing the spread of HIV disease within all of our communities.

## INTERNATIONAL SUBCOMMITTEE

Recent data has confirmed our fears that the global HIV/AIDS epidemic is, in fact, worse than had been predicted. Important as the new developments in therapy are in reducing the suffering and prolonging the lives of people living with HIV/AIDS in the few countries where treatment is possible and affordable, too little is being done to halt the relentless march of this disease in Africa, Asia, Latin America, and Eastern Europe. Thus, the President's leadership in setting as a goal the development of an AIDS vaccine in the next ten years merits sincere praise.

The inclusion of HIV/AIDS on the agendas of bilateral and multilateral meetings, such as occurred at the Denver Summit, also represents a significant achievement by the Administration. The Administration also deserves credit for ensuring the prompt filling of vacancies in the United States Agency for International Development (USAID) with individuals expert in the subject of HIV/AIDS. The dialogue between USAID and nongovernmental organizations is to be commended.

The global HIV/AIDS crisis, however, constitutes a direct threat to the economic and strategic interests of the United States. In light of the ever-worsening global epidemic, PACHA is disappointed that the Department of State has not conducted an evaluation of the successes and failures of its 1995 "International Strategy on HIV/AIDS." The Strategy was developed and issued in 1995 as a 2-year plan. It must be thoroughly assessed, and a current international strategy should be developed promptly with input from domestic and international organizations involved in the response to the global pandemic.

Until a vaccine is globally available, the United States must consistently and affirmatively reestablish its commitment to lead a worldwide effort to reduce the rate of new infections. Such leadership must include the direct involvement of Secretary of State Madeleine Albright, as well as increased funding of global AIDS programs in U.S. agencies and U.S.-supported international organizations. The lofty objectives contained in the International Section of the National AIDS Strategy must be pursued and achieved in a vigorous and coordinated U.S. government effort—before it is too late to make a difference in the social, economic, and political impacts of the pandemic.

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PRESIDENTIAL
ADVISORY
COUNCIL ON
HIV/AIDS

December 7, 1997

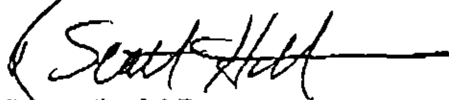
The Honorable William Jefferson Clinton
President of the United States
The White House
Washington, D.C. 20500

Dear Mr. President:

The Presidential Advisory Council on HIV/AIDS urgently recommends, based on an examination of extensive scientific research, that a determination that needle exchange programs effectively reduce HIV transmission *and* do not increase drug use be made by Secretary of Health and Human Services Donna Shalala immediately. The Council has made several recommendations of this nature during the past two years to no avail. The most recent Congressionally imposed moratorium prevents federal funding of any programs until April 1, 1998, and requires the Secretary to establish a framework for the implementation and funding of any such programs. The guidelines for needle exchange programs, as part of a continuum of HIV prevention and substance abuse treatment programs, should be developed during the remaining months of the moratorium in consultation with affected communities and exchange service providers. The debate at this time should no longer be *if*, but *how*, needle exchange programs should be established. The Presidential Advisory Council on HIV/AIDS strongly recommends that the determination by the Secretary on this issue occur before January 27, 1998.

Thank you for your attention to this important matter.

Sincerely yours,



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cc:
The Honorable Donna E. Shalala
Erskine Bowles
Sylvia Mathews
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Maria Echaveste
Don Gips
Elena Kagan
Chris Jennings
Josh Gotbaum

# Presidential Advisory Council on HIV/AIDS

## Passed Recommendations
December 7, 1997

### Prisons Subcommittee:

I. The Council recommends that the Director of the Office of National AIDS Policy convene a community and government meeting on AIDS in Prisons as soon as possible. Key constituencies should include advocates and experts, exoffenders, representatives of relevant government agencies, correctional health providers and departments, international experts, and other relevant persons or organizations.

### International Subcommittee:

I. The Presidential Advisory Council on HIV/AIDS recommends that the President direct the Department of State to promptly conduct an evaluation of the actions and outcomes resulting from its 1995 "International Strategy on HIV/AIDS" and to provide a copy of the assessment to PACHA as soon as possible.

**PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS**

**PASSED RECOMMENDATIONS**
**December 7, 1997**

**SERVICES SUBCOMMITTEE**

Assessment to Administration Response, Recommendation IV.B.1.
That the Administration take leadership in working with the States and the private sector to reduce the cost of pharmaceuticals to ADAP and Medicaid programs.

**Council Assessment**:

Through technical assistance and support from HRSA, more state ADAP programs have adopted multiple strategies in purchasing and distributing drugs at lower cost to people living with HIV. We commend the work of HRSA and State and community partners to achieve ODP Section 602 program cost savings and voluntary rebates on certain drugs.

- Despite these efforts, almost half of all ADAP programs will either run out of funding, or will impose restrictions on drugs or enrollments in order to prevent budget short-falls before the end of the ADAP fiscal year.

- Until a federal strategy for covering all who require PHS HIV standard of care therapies is realized, ADAP will continue to need substantial increases of new dollars, and HRSA should continue to support the States in adopting strategies to achieve lower cost.

**New Recommendations**:

V.B.1. We encourage HRSA to fully explore the strategy by which States can purchase health insurance coverage or continue health insurance payments using ADAP funding, when this is the optimal cost-saving strategy.

V.B.2. HRSA should strengthen technical assistance in the area of drug price negotiation to all State ADAP programs that have not achieved comparable prices from the ODP Section 602 program.

V.B.3. The price of drugs is directly related to the cost that taxpayers and other payors must incur, and is directly related to the access of people with HIV/AIDS to the new therapies. We urge that the Vice President continue his work with pharmaceutical companies, in collaboration with ONAP. We request that he vigorously assume a leadership role in reducing the price of HIV drugs.

**Access To Treatment**

**Assessment:**

New national treatment guidelines encourage early intervention with the new drug therapies as life-enhancing and possibly life-saving treatment for many HIV-infected people. Though these therapies have not yet proven to be a cure, they are the moral equivalent of a cure for those who can benefit from them. Therefore, as addressed in prior recommendations and in the Council's Progress Report, we believe that it is essential that the Administration and others explore every feasible avenue for ensuring access to the new drug therapies and associated medical services for those who have no health insurance coverage for this purpose.

We are both heartened and disappointed at the efforts of the Administration to achieve this end. The President and Vice President have committed themselves and the Administration in this direction, and many public servants within the Administration are working tirelessly in this effort. Others have dragged their feet or used "red herrings" to avoid this imperative, such as the "AIDS exceptionalism" argument, the logical conclusion of which is that we should lower our expectations for serving people with HIV/AIDS rather than raise our expectations for serving those with other chronic, disabling, or terminal diseases.

V.B.4 We urge continued and intensified leadership from the White House (the President, the Vice President, and the Office of National AIDS Policy) to explore all possible options for expanding access to the new therapies and associated medical services. These efforts should be directed from the White House itself, through a multiagency policy team; this will provide the strong evidence of a political will to continue this effort and the technical proficiency to leave no possible alternative unexamined. In particular, we urge continued efforts to develop a national Medicaid expansion pilot program, which could go beyond the current "budget neutrality" paradigm, testing the proposition that we should count all budget savings from any source, associated with the new interventions, and over the lifetime of care. We also urge the White House to engage Governors and their State officials in the development of Medicaid waiver applications (modeled after the fast-track process used early in the Administration to encourage welfare reform waiver applications). In addition, as reflected in the Council's recommendation regarding the FY 99 budget, we must have increases in ADAP and other Ryan White CARE Act titles to expand access now for those who can benefit from the new therapies.

# PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

## PASSED RECOMMENDATIONS
## DECEMBER 7, 1997

### PREVENTION SUBCOMMITTEE

Surveillance recommendations:

In order to better monitor progress toward the President's declared goal of decreasing the number of new infections (incidence) each year, and to better target prevention, services, care, and research efforts, the Council is strongly committed to improving the accuracy and usefulness of surveillance systems for the HIV/AIDS epidemic.

In an effort to be sure that whatever systems ultimately designed fulfill the desired needs, we are convinced that more considered research must be done.

The Council expresses its strong reservations regarding the use of a national HIV names reporting surveillance system. However, our concern is not simply Names Reporting versus Unique Identifiers, but rather what is(are) the best way(s) to collect meaningful, accurate data, in the least intrusive manner, that will enable us to bring this epidemic to an end.

I. We urge that the CDC issue a comprehensive public report on its analysis and scientific documentation of the impact of different surveillance systems on seeking/acceptance of HIV testing and care among and potential discriminatory impacts on, individuals and communities at risk for HIV infection. Such a report should also assess the accuracy, completeness and cost of data obtained under the various reporting systems. We recommend that any move to change reporting systems should not be made prior to the development and release of such a report and following an opportunity for community consultation.

II. We urge that, prior to recommending any changes in reporting systems for AIDS and HIV, the CDC be required to provide a comprehensive scientific justification that includes a detailed strategy and implementation plan about how it will obtain and present the data necessary to develop a comprehensive picture of the scope of the current and emerging HIV epidemic.

It is essential that adequate data about the prevalence and incidence of HIV infection be available to policy makers, service and prevention planners and providers, and various advisory and planning bodies at the national, State, and local levels. Only with such accurate data can we make appropriate resource and programmatic decisions necessary for effective prevention and care programs.

We recommend that such a plan address scientifically valid information about HIV

incidence and that prevalence will be obtained, with particular emphasis on understanding the spread of HIV stratified by race/ethnicity, age, gender, geography, sexual orientation, and risk factors. In addition, we believe that efforts also are warranted to utilize better laboratory methods for newly diagnosed persons with HIV infections to classify the clinical stage of the disease and resistance to antiviral agents. Ongoing efforts should be enhanced to monitor changing patterns of opportunistic infections and natural history of HIV disease in light of treatment advances.

In development of such a plan, we recommend that the CDC recognize the inherent limitations, weaknesses, and potential for abuse of any HIV case surveillance system (named, unique identifier, or anonymous) and instead use much more innovative methods to collect and interpret data from a wide variety of sources necessary to fully characterize the complex HIV epidemic. Specifically, we urge expanded use of such currently underutilized tools as blinded seroprevalence studies, mathematical modeling techniques, sentinel and random serosurveys, a greatly enhanced portfolio of behavioral research and behavioral surveillance activities, and other similar, innovative methods. Such activities will require a well coordinated strategy and a great deal of scientific creativity. Enhanced funding and technical assistance activities to allow States, localities, and various planning bodies to effectively utilize such data are essential and must be linked to these innovative efforts.

III. Whatever changes, if any, are made in HIV reporting policies at the national level, we strongly believe that several issues must be addressed. These include the following:

- Identification and implementation of steps to retain and expand anonymous testing options in all jurisdictions receiving CDC prevention and surveillance funding;
- Development and incorporation of confidentiality protection standards as part of any reporting system, including model laws and regulations, comprehensive record-keeping and database procedures, standards on use and matching of datasets, and penalties for improper use;
- Development of appropriate public information efforts to explain the system, especially to members of affected communities and health care providers;
- Adequate funding to States and local jurisdictions for the work of collecting, maintaining, and interpreting the collected data;
- Technical assistance to health departments, community planning groups, Ryan White planning bodies and consortia, and other appropriate groups on the meaning, limitations, and potential uses of this data; and
- Identification of steps to guarantee access to appropriate care and services for all individuals who test positive in any system.

SERVICES SUBCOMMITTEE

FY 1999

This new recommendation builds upon the Council's previous recommendation regarding Federal funding for HIV/AIDS Services (IV.A.1)

V.A.1 The Council urges the President to include in his FY 1999 budget request to Congress adequate increases in funding for federal HIV/AIDS programs, in order to appropriately address the increasingly complex health and service needs of people living with HIV/AIDS in America. In particular, the Council strongly recommends substantial increases in funding for the AIDS Drug Assistance Program (ADAP) and other medical and support services provided through the Ryan White CARE Act, the Housing Opportunities for People with AIDS (HOPWA) program and other housing programs serving the homeless and persons with disabilities. In keeping with the President's goal of reducing the number of new HIV infections until there are none, the Council also urges the President to propose a significant increase in federal funding for HIV prevention activities. The Council also strongly supports additional funding for substance abuse treatment services funded through the Substance Abuse and Mental Health Services Administration (SAMHSA). The President has already committed new dollars for vaccine development and microbicide research as well as for other relevant HIV/AIDS research interests. However, despite these increases, the monies committed remain inadequate, especially in the area of vaccine development. We urge the President to continue to increase funds for AIDS research in the FY 1999 budget. These budget increases would reflect this Administration's continued commitment to AIDS, as well as its stated commitment to expand access to early coverage for promising new therapies.

# Office of National AIDS Policy

**Executive Office of the President**

Release Date: December 7, 1997

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**Statement of Sandra Thurman**
**Director, White House Office of National AIDS Policy**
**on Presidential Advisory Council Report**

For more than a decade we have relied on those on the front lines to sound the alarms -- and remind all of us of the urgency of this epidemic. This longstanding tradition has served people living with HIV and AIDS and all Americans well. And it is for this reason that the President appointed an advisory committee made up of those actively engaged at the community level in our nation's battle against AIDS. The overarching message of this report is loud and clear -- this epidemic is not over and we all have much more work to do.

Last week, on World AIDS Day, everyone stopped to acknowledge the tragedy of AIDS. But for those on the front lines of this epidemic -- every day is world AIDS day. And it is out of this sense of urgency and frustration that the Council puts forward its recommendations. I certainly understand their anxiety, and I share their desire to continue the progress that this Administration has made.

However, reports that this Administration has abandoned its desire to expand Medicaid access to life-saving therapies could not be further from the truth. This Administration certainly understands the urgency of ensuring that all people with HIV benefit from the promise of new and effective treatments. The fact that our initial attempt to expand Medicaid has turned out to be more difficult than anticipated in no way lessens the Administration's resolve to seek a workable means of extending life-prolonging therapies to all those in need.

The Clinton Administration has a strong track record of addressing the needs of people living with HIV and AIDS:

- The President worked vigorously to save the Medicaid program, which is the largest single payor for AIDS services and treatment in the country -- in 1997, federal Medicaid expenditures for people living with HIV/AIDS totaled $1.8 billion, including nearly $500 million for AIDS drugs.
- The President established the HIV Vaccine Initiative, with the goal of finding a vaccine against HIV within 10 years.
- The President has pushed for increases in the Ryan White CARE Act, including a 450% increase in the State AIDS Drug Assistance Program since 1996.
- This Administration has supported the research that resulted in the new treatments that are saving so many lives, with funding for AIDS research at NIH increasing 50% since the start of this Administration.

There is no absence of will to meet this challenge; there is, however, a different sense of what can be accomplished in an often polarized political environment in which ideology can overwhelm science. The struggle to get the best quality of care and the best medications to all HIV-positive Americans is a very difficult fight and one I know that the President is committed to winning.

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