

File: AIDS

THE WHITE HOUSE
WASHINGTON

MEMORANDUM TO ALL STAFF OF THE AIDS POLICY COORDINATOR'S OFFICE

FROM: Carol H. Rasco

SUBJ: Interim Director

DATE: August 2, 1994

I am pleased to share with you that Patsy Fleming has been named this afternoon as the interim National AIDS Policy Coordinator.

Patsy will be in the office tomorrow to set up interim measures as to office procedures, etc. before leaving for the conference in Japan.

Thank you in advance for the courtesy and cooperation I know you will provide Patsy.

cc: Patsy Fleming

THE WHITE HOUSE
WASHINGTON

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

August 2, 1994

Statement by the Press Secretary

President Clinton today appointed Patricia S. Fleming to serve as interim National AIDS Policy Coordinator.

Fleming, currently special assistant to Health and Human Services Secretary Donna E. Shalala, will serve until a permanent coordinator takes office.

"This Administration has made significant strides in the fight against this terrible epidemic. We've increased our budgets for AIDS research, treatment and prevention, and have fought hard to provide health insurance for all Americans, regardless of pre-existing conditions. Patsy Fleming will make sure we don't lose our momentum," said the President.

Fleming, who served as administrative assistant to the late Representative Ted Weiss (D-NY), specializing in AIDS and public health issues, said she will return to HHS once a permanent AIDS policy coordinator takes office. Fleming said she expects the interim appointment will last less than two months and that she is not a candidate for the permanent appointment.

Next week Fleming will represent the Administration at the Tenth International Conference on AIDS in Yokohama, Japan.

"Though we've made considerable progress in coming to grips with this epidemic, much more remains to be done," Fleming said. "I'm pleased to accept this appointment to help smooth the transition to a permanent AIDS policy coordinator."

Added Secretary Shalala, "Patsy Fleming has been an invaluable member of our HHS team. I know that she will be a tremendous asset to the AIDS office during this interim period."

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: _____

Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: Fleming

Send copy to (original to CHR): _____

Schedule ? : Accept Pending Regret

Designee to attend: _____

Remarks: _____

August 2, 1994

AUG - 5 REC'D

Ms. Carol Rasco
Assistant to the President for Domestic Policy
The White House
Washington, D.C.

Dear Carol:

It is with pleasure that I agree to serve as the Interim National AIDS Policy Coordinator.

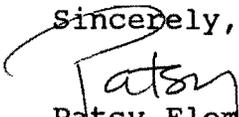
I understand that I am being asked to take this position in order to provide continuity to the Administrator's AIDS policy. I will serve in this capacity between the resignation of Kristine Gebbie and the appointment of the new AIDS Policy Coordinator. I will be detailed to the White House from the Department of Health and Human Services.

There are several conditions for my taking this temporary assignment that you have agreed to. They are:

1. I will occupy this position until September 15 at the latest, at which time I will return to HHS.
2. The Presidential HIV/AIDS Advisory Council will not be appointed while I am serving as the Interim AIDS Coordinator.
3. I will be able to spend approximately two days per week at HHS.
4. I will not be available to the media for interviews except for one press availability on the day of the announcement.
5. I am not a candidate for the permanent position of National AIDS Policy Coordinator.

Thank you for your confidence in my ability to fill this position. I will enjoy working with you.

Sincerely,


Patsy Fleming
Special Assistant to the Secretary

file: AIDS

THE WHITE HOUSE
WASHINGTON

August 4, 1994

MEMORANDUM FOR THE WHITE HOUSE MILITARY OFFICE
BOBBY CHUNN (FAX 395-4076)

FROM: ANDREA S. RUTLEDGE *ARR*
OFFICE OF MANAGEMENT AND ADMINISTRATION

SUBJECT: Interim AIDS Policy Coordinator

Ms. Patsy Fleming has been named the Interim AIDS Policy Coordinator. She should be placed on the priority transportation list and receive full membership in the White House Staff Mess. Ms. Fleming can be reached at P6/(b)(6).

Please delete Kristine Gebbie from the priority transportation list and the rolls of the White House Staff Mess. Ms. Gebbie has left the White House Office.

Thank you for your assistance and support.

cc: Carol Rasco

THE WHITE HOUSE

WASHINGTON

August 4, 1994

MEMORANDUM FOR PATSY THOMASSON, SPECIAL ASSISTANT TO THE
PRESIDENT FOR MANAGEMENT AND BUDGET AND DIRECTOR

FROM: Carol H. Rasco, Assistant to the President for
Domestic Policy 

SUBJECT: Transportation Authorization for Patsy Fleming

I am attaching a copy of the President's announcement naming Patsy Fleming as interim National AIDS Policy Coordinator and asking that she be listed on the priority transportation list. As noted on the press release, Ms. Fleming will serve in this interim position until a new Coordinator is named.

Please feel free to call me or my assistant, Rosalyn Miller, if further information is needed.

Thank you.

THE WHITE HOUSE
WASHINGTON

January 20, 1994

MEMORANDUM TO SENIOR STAFF

FROM: MACK McLARTY
SUBJECT: HIV/AIDS Education Briefing

The President mandated that all senior White House staff attend HIV/AIDS education briefings. Many of you failed to attend the sessions put on by Kristine M. Gebbie in November. The President wants all federal employees to undergo such training; it is essential that we here in the White House lead by example in this critically important area.

Kristine has now scheduled make-up briefings for senior staff on Jan. 26 and Feb. 8. If you did not receive HIV/AIDS training in November, make every effort to attend one of these two sessions, both of which will begin at 9 a.m. in Room 180 of the OEOB. If you have any questions, please contact Kristine at [P6/(b)(6)], or Lance Alworth at [P6/(b)(6)].

*I did it previously.
CHasso*



DEPARTMENT OF HEALTH & HUMAN SERVICES

Chief of Staff

Washington, D.C. 20201

JUN 24 1994

JUN 24 REC'D

MEMORANDUM TO CAROL RASCO
CHRISTINE VARNEY

FROM:

KEVIN THURN *Jim Haugis for*

SUBJECT:

NEW AIDS TREATMENT DRUG *file*

Attached for your information is a press release announcing the approval of a new AIDS treatment drug. This will be released on Monday morning.

If you have any questions please call.

DRAFT

#168

P94-???

Arthur Whitmore (301) 443-3285

DRAFT DRAFT DRAFT DRAFT

~~Arthur Whitmore~~

The Food and Drug Administration today announced the approval of stavudine, or D4T -- the fourth drug approved for the treatment of AIDS and HIV infection.

Stavudine is an antiviral agent of the nucleoside analog class, which includes zidovudine (AZT), didanosine (ddI) and zalcitabine (ddC). Nucleoside analogs are thought to slow the progression of AIDS by inhibiting HIV replication. Data indicate that this class of drugs may delay the onset of AIDS symptoms in HIV-infected individuals, and may extend survival in some.

Stavudine is specifically approved for the treatment of adults with advanced HIV infection who no longer respond to other drugs.

"Unfortunately, there is no cure for this disease," said FDA Commissioner David A. Kessler, M.D., "but stavudine is an important drug because it gives people with AIDS -- and their doctors -- another treatment option, when currently available drugs become less effective."

Data supporting the approval were obtained in an ongoing trial of stavudine versus continued AZT in HIV-infected adults with CD4 cell counts between 50 and 500 and at least 24 weeks of prior AZT treatment. CD4 cell counts reflect the strength of the immune system, and counts in healthy individuals are normally 1,000 or higher. Twelve weeks into the trial with 359 patients, the mean CD4 cell count in patients receiving stavudine increased by 22 cells per milliliter of blood, while the mean count in patients continuing on AZT declined by 22.

(More)

DRAFT #168**-2-**

Stavudine's major side effect is peripheral neuropathy -- characterized by pain and tingling or numbness in the hands and feet. Between 15 and 21 percent of patients in stavudine trials reported the condition, which appears to be dose-related and can usually be reversed through withdrawal from treatment.

Stavudine was the first drug granted parallel track status by FDA. The parallel track policy allows the agency to make available promising new drugs to patients before approval. Since October

~~the drug was granted parallel track status, about 11,000~~
patients have been enrolled for treatment with stavudine.

The application for stavudine was submitted under FDA's accelerated approval mechanism. Under this mechanism, drug effectiveness is assessed by surrogate rather than clinical endpoints. The major surrogate endpoint in the stavudine trials is CD4 cell counts. In approving stavudine, the agency concluded that the increase in CD4 counts is a likely indicator of a meaningful clinical benefit.

In addition, the rules of accelerated approval require applicants to continue studies to evaluate the true clinical benefit of the drug. If the data fail to verify a clinical benefit, the accelerated approval may be withdrawn.

FDA's Antiviral Drugs Advisory Committee reviewed the stavudine application on May 20, 1994. Based on the data presented, the committee felt that the drug is likely to provide clinical benefits to adult AIDS patients with advanced HIV infection who are intolerant of other approved therapies.

Stavudine is manufactured by Bristol-Myers Squibb Co. of New

(More)

- 3 -

DRAFT #168

York, N.Y., under the trade name Zerit.

FDA is one of eight Public Health Service agencies in HHS.

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THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

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Remarks: _____



JUN 8 REC'D

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

JUN 3 1994

MEMORANDUM FOR KRISTINE GEBBIE

FROM: Nancy-Ann Min

ls: Nancy-Ann Min

SUBJECT: National HIV Action Agenda

AIDS FILE

We have reviewed the draft National HIV Action Agenda prepared by your staff, and we are generally supportive of most of what is presented in it (see attached comments). However, we have several concerns about the final set of action items contained in the draft Agenda related to the establishment of a national HIV/AIDS information dissemination system.

It is not clear what the overall resource and cost implications would be for such a system. From the description in the draft Agenda, it is unclear why this system would be needed, what purposes it would serve, and what would be its scope and outputs. Because the purposes of the system are not defined clearly, it is also not apparent what types of data would be needed, what the requirements would be for configuring the data, and what type of system would be required to process and disseminate the information. These factors would ultimately influence the overall cost of implementing and operating the system.

In addition, although the draft Agenda states that the system would be developed with existing technologies and expertise, it is not clear whether the system would be financed solely by the Federal government, states, the private sector, or some combination of all three. Further, if the system is Federally financed either in full or in part, it is not apparent whether there are funds in the President's FY95 Budget to support such a system.

We also note that the Vice President has launched a National Information Infrastructure (NII) initiative, which defines the Federal government's role in establishing information networks as one of setting goals and promoting private sector competition in the development and operation of these networks. Based upon the descriptions in the draft Agenda, it is not clear whether the information dissemination action items would be consistent with the goals of the NII. I expect that the Vice President will be very interested in this because of his interest in information systems and health care reform. You may want to contact Greg Simon of the Vice President's staff to seek his assistance.

Therefore we recommend that the final section of the draft Agenda be deleted or revised significantly to address these concerns. We would be willing to help you and your staff revise the final section of the draft Agenda.

Attachment

cc: Carol Rasco
Gregory C. Simon

4/4/94 DRAFT----DRAFT THE WHITE HOUSE
WASHINGTON

DRAFT

Please send written comments by April 29, 1994 to:
Andrew Barrer, Ph.D.
Office of the National AIDS Policy Coordinator
FAX: (202) 632-1096
Questions: (202) 632-1090

National HIV Action Agenda
April 1994

INTRODUCTION

From the National AIDS Policy Coordinator

The National HIV Action Agenda is a leadership statement.

It has been developed by the Office National AIDS Policy to give direction to our overall national effort to end the HIV/AIDS epidemic; the epidemic some have called the health crisis of our times. The action steps described within provide guidance and markers for the nation. The action steps are activities the nation can begin within a six-month horizon. Many are long-term or continuous, while others are short-term or immediate.

In the next iteration of the National HIV Action Agenda many of the action items will have been accomplished. New goals will be substituted for goals attained or goals no longer appropriate as the epidemic and our ability to respond to it continually change.

The commitment to provide the continuing national leadership necessary to end the epidemic is something this Administration takes very seriously. When President Clinton appointed me, he said "AIDS is terrifying. It inflicts tragedy on too many families. But ultimately, it is a disease; one we can defeat...with commitment and courage and constancy, and with vocal and responsible leadership from our nation's government."

The National HIV Action Agenda is organized into three areas for action: research, service, and prevention. In the day-to-day work of addressing the epidemic, however, the distinction between these areas is often blurred. It is only by coordinating efforts in all the areas and by focusing on common goals that we optimize our chances of ending this epidemic. It is incumbent upon everyone to understand that this epidemic is a national problem and it will take a national and unified effort to end it.

In 1993, 104,468 new cases of AIDS were reported nationally. In the United States, the virus has flourished in disenfranchised, disadvantaged, and marginalized populations. It is associated with some behaviors that are illegal and others which are

considered to be inappropriate by many. By doing so, the virus itself has managed to dilute the nation's ability to coalesce in common purpose. This document attempts to bring the nation's attention to the real issues: What should we do? What can we do? Where do we go from here?

Also, as a member of the world community, the United States has a responsibility to join other countries in the international effort. Therefore, in the Action Agenda, international HIV/AIDS issues are an important part of the three primary areas of research, service, and prevention.

The arrangement of three primary areas is not meant to give special emphasis to one over another. Research findings are the foundation for action. The National HIV Action Agenda attempts to drive the nation to resolve questions of cure and prevention, of drugs and behavior, by suggesting steps to enhance the organization of the effort and to improve communications among researchers engaged in the effort, between researchers and care givers, and between researchers and the prevention effort.

Service action steps aspire to better ensure that people and families affected by HIV can receive the care and support they need, that effective therapies are available, and that the length of life after infection is as long and healthy as possible.

In the prevention area the Action Agenda seeks to better focus efforts to interrupt transmission of the virus by improving the educational effort, improving the focus and enhancing efforts to reduce the risky behaviors associated with transmission, and by increasing the application of the science base in planning and program implementation.

The President and I are committed to the requirement that everyone affected be given "a seat at the table." Throughout the document, specific action steps to facilitate cooperation and leadership are stated.

With everyone's help, we can stop AIDS.

DRAFT

Kristine M. Gebbie, RN, MN, FAAN
National AIDS Policy Coordinator

Goal A: National HIV/AIDS research strengthened through coordination, planning, and evaluation.

Commentary: Billions of dollars are invested annually in the United States and abroad in an effort to further development of safe, effective therapeutics, prophylactic vaccines, and improved methodologies to reduce risky behaviors. Nevertheless, the challenges still to be faced by research into the Human Immunodeficiency Virus (HIV) disease and the Acquired Immune Deficiency Syndrome (AIDS) are profound. While progress has been made in many areas, there has been a recent lack of significant clinical advances in the treatment and prevention of the underlying disease. Given the scope of the scientific questions still unanswered, and the dimensions of the growing pandemic, there is a great need to search for creative ways to maximize public and private resources.

Action (A.1): Implement, as necessary, new formal planning linkages between federal agencies and departments engaged in HIV/AIDS biomedical or behavioral research, based on agencies' complementary research agenda and portfolios.

Commentary: Federal AIDS research programs have undergone continual evaluation and evolution since the beginning of the epidemic. The pace of evaluation and reform has accelerated significantly in the last year. Very likely, the next year will bring even closer scrutiny and intense public debate of the complex scientific, administrative, regulatory, legal, and ethical challenges and opportunities facing HIV/AIDS research today. Within the federal government, many agencies plan and budget HIV/AIDS research programs independently of one another, and current communications systems between researchers in the public and private sectors may not allow for sufficient timely coordination. Mechanisms for communications and planning must be fully evaluated and improved to maximize efficiency.

Action (A.2): Seek expeditious and full implementation of the National Institutes of Health (NIH) AIDS research program reforms provided in the NIH Revitalization Act of 1993.

Commentary: The Office of AIDS Research (OAR) of the NIH has been strengthened with centralized evaluation, planning, and budgeting authorities across all institutes of the NIH. ~~While the intent of the legislation is clear, it is important that the interpretation of the provisions of the Act be carefully monitored.~~

Action (A.3): Develop strong linkages between federally chartered advisory committees to coordinate development of complementary national HIV/AIDS research policies.

Commentary: The Office of AIDS Research (OAR) Advisory Council, the National Task Force on AIDS Drug Development, the Presidential HIV/AIDS Advisory Council and other advisory bodies will be critical for providing recommendations and input into the evolving national AIDS agenda; their independent policy deliberations must be coordinated.

Action (A.4): Ensure strong support for the role of behavioral and social science research related to biomedical research, treatment regimens (e.g., substance abuse treatment), and as the scientific basis for sound prevention programs.

Commentary: Findings from behavioral and social science research are critical to the control of the epidemic through the successful administration of prevention, research and treatment programs. This research, which has often been overlooked, must receive strong support, and findings from this research must be fully integrated into programs.

Action (A.5): Work with HIV/AIDS-affected communities and federal agencies to assure that the unique social and physiological characteristics of all HIV-affected populations are taken into consideration in the design of clinical trials and other research programs.

Commentary: Women, children, adolescents, ethnic and racial minority groups, injecting drug users, gay and bisexual men, lesbians and bisexual women and others have unique needs that should be accommodated both through appropriate inclusion in clinical trials and the conduct of trials specifically designed to address their needs.

Goal B: Government, industry, academia, and community attention focused on promising, innovative proposals that could expedite the discovery of new therapeutics for HIV/AIDS and build consensus toward potential solutions.

Commentary: The National Task Force on AIDS Drug Development, recently chartered by the Secretary of Health and Human Services has been formed to identify obstacles and opportunities in HIV/AIDS drug discovery and development. The work of this task

force must be strongly supported, with prompt response to its requests for information and recommendations for action. Additionally, other federal and private agencies should continue to evaluate programs and policies affecting HIV/AIDS drug development.

Action (B.1): Identify regulatory and legal obstacles to research collaboration among federal agencies and non-governmental entities.

DRAFT

Commentary: Technology transfer, the Cooperative Research and Development Agreements (CRADA), liability, patent issues, and drug pricing have been identified as potential obstacles or disincentives to AIDS research collaboration and investment. Working with the National Task Force on AIDS Drug Development, appropriate governmental and private sector groups must develop reforms to address these and related issues.

Goal C: Obstacles to the development of an HIV/AIDS prophylactic vaccine identified and removed.

Action (C.1): Utilizing existing reports and ongoing discussions, develop consensus and, when appropriate, design and implement legislative or administrative solutions to address the obstacles to vaccine development.

Commentary: A number of governmental and non-governmental committees have published recommendations concerning scientific, legal, ethical, cultural, and administrative issues facing vaccine development. This is a continuing process with ongoing fora within NIH and the Department of Defense among others. Consensus among the recommendations must be formed and the recommendations must expeditiously become policy to pave the way for widespread development, clinical testing, and use of prophylactic vaccines in the United States and other countries.

Goal D: Domestic research planning and priority-setting integrated with international efforts.

Action (D.1): Explore mechanisms for increased international collaboration.

Commentary: Research activities cannot be viewed from a strictly national perspective. Working with U.S. and internationally-convened fora, public and private HIV/AIDS research programs should be evaluated to improve mechanisms for communication and collaboration to increase efficiency and productivity.

Goal E: Continued and expanded access to quality mental and physical health services for people living with HIV/AIDS.

Action (E.1): Develop and implement an affordable universal health insurance plan which will provide coverage for HIV/AIDS related physical and mental health services, including substance abuse treatment.

Commentary: Populations who may traditionally have had little or no access to health care have been disproportionately impacted by the epidemic. This lack of access may be due to reasons of finance or to actual and perceived discrimination. ~~By providing a universal health care plan,~~ the nation will be better able to address the needs of people living with HIV/AIDS.

Through the Health Security Act.

Action (E.2): Encourage individuals to ascertain their HIV status and ensure appropriate linkages to treatment and services are available for those who test positive.

Commentary: Many individuals living with HIV are not aware of their serostatus. Counseling and testing programs must include outreach to individuals who may engage in high risk behavior to encourage them to ascertain their HIV status. Counseling and testing activities must encourage individuals to obtain their test results, reinforce safer behavioral practices, and provide adequate referral mechanisms including treatment providers.

Action (E.3): Work with Congress, agencies of the Public Health Service, constituent groups, and members of affected communities to ensure continuation of the Ryan White Comprehensive AIDS Resources Emergency Act and other federal programs which provide HIV/AIDS services to ensure that they continue to meet the care needs of the HIV/AIDS community.

Action (E.4): Expand the availability of quality mental and physical health services for people living with HIV/AIDS.

Commentary: People living with HIV/AIDS are often unable to obtain services in many communities, particularly in some rural areas where they may be required to travel many miles. Much of the care needed by people living with HIV/AIDS infection is basic care which could be provided by family physicians, home health

care aides, family members, or other community-based service providers. However, treatment guidelines, adequate information, and training must be provided to those practitioners if they are to provide those services.

Action (E.5): Identify barriers to the availability of mental and physical health services, coordinate with appropriate agencies, community service organizations, constituent groups, people living with HIV/AIDS, and providers to remove those barriers.

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Commentary: Because of limited access to care, many individuals only obtain acute care services in emergency situations. It is critical that HIV/AIDS-related services provide outreach to individuals and populations that may be difficult to reach, such as the homeless, through the traditional public health model. It is critical that in the creation of service delivery models, people living with HIV participate in program design and implementation.

Action (E.6): Stimulate development and implementation of effective evaluation methodologies for service delivery programs and for comprehensive networks of service delivery.

Commentary: In developing service delivery models, the planners must include evaluation methodologies that are capable of determining whether the programs are providing adequate access and care. Federal agencies coordinating service delivery nationally must encourage system-wide evaluation of service delivery networks and individual programs.

Action (E.7): Develop appropriate information dissemination mechanisms which facilitate rapid transfer of research findings, new clinical information, and appropriate educational material to public and private providers of care services.

Action (E.8): Ensure that care guidelines and other such materials are kept current and incorporate, at the earliest possible time, changes in the state of the art.

Action (E.9): Encourage all appropriate agencies, organizations, and institutions to provide HIV/AIDS training to providers both public and private.

Commentary: Because people living with HIV/AIDS and their families experience the disease and its effects in an almost infinite variety of ways, service needs are multiple and diverse. In many communities, dramatic and innovative ideas have emerged which, if disseminated and supported, could make an enormous difference.

Goal F: Early intervention information is provided to all those living with HIV.

Action (F.1): Encourage coordination and collaboration among federal agencies, state and local governments, non-governmental organizations, and service providers to provide people living with HIV accurate and timely information about early intervention and preventing opportunistic infections.

DRAFT

Commentary: Requires increasing linkages from the counseling and testing facilities to service providers as well as greater coordination between prevention and other services at the local level.

Action (F.2): Develop and implement programs to inform HIV service providers on ways to prevent opportunistic infections and coordinate efforts with tuberculosis elimination programs at all levels.

Commentary: Primary among the opportunistic infection concerns is the prevention of tuberculosis, which is posing greater threats to the HIV-affected community.

More than a third of the current cases of AIDS are a product of the ongoing, companion epidemic of drug dependency and abuse. There is a shortage of effective treatment services and many barriers keep substance abusers from accessing the services which do exist. Of great concern are injecting drug users. While there is universal agreement an ideal solution lies in finding ways to interrupt injection--and that remains the long term commitment. However, minimizing transmission is the immediate problem.

Goal G: People living with HIV/AIDS as well as people and families affected by HIV have access to a wide array of community and supportive (or enabling) services.

Action (G.1): At national, state, and local levels, promote coordination of community groups, acute care facilities, state and local governments, private funders, and others that are provid-

ing HIV/AIDS-related services to ensure that a comprehensive continuum of care and services are available and accessible.

DRAFT

Action (G.2): Stimulate and encourage appropriate agencies to develop helpful materials describing available services so families and individuals affected by HIV/AIDS will be empowered to access them.

Action (G.3): Encourage enforcement of prohibitions against discrimination in health care settings and encourage the creation of new protections to ensure access to care for people living with HIV/AIDS.

Action (G.4): Encourage appropriate agencies and governments to coordinate and link health care and supportive services (e.g., primary care, substance abuse, clinical trials, and HIV-related care).

Goal H: That treatment protocols and supportive service needs unique to minorities, women, adolescents, and children receive appropriate consideration in the planning, development, and implementation of all service-related activities.

Action (H.1): Identify the components of programs to address the unique health care and supportive service needs of minorities, women, adolescents, and children living with or affected by HIV/AIDS, and work with appropriate agencies to incorporate these elements into relevant programs.

Commentary: Lack of access, common to all populations disproportionately impacted by HIV/AIDS, is more critical among populations that have either lacked resources or been subjected to discrimination. In developing and implementing service delivery programs, the needs of these populations must be addressed, and, where necessary, additional resources must be applied.

Goal I: Updated information on HIV/AIDS management is communicated internationally.

Commentary: In many countries, current treatments are unfamiliar to local providers. Using information dissemination techniques, information on diagnosis, treatment, and prevention can be communicated around the globe rapidly and in a cost effective manner.

Action (I.1): Working in coordination with the United Nations-sponsored HIV/AIDS program, identify a mechanism to provide ongoing updated training in HIV management.

DRAFT

Action (I.2): Establish an advisory group of U.S. entities involved in international HIV activities for the purpose of global HIV issues and policy development.

Commentary: Many U.S. organizations represent ongoing projects relating to all aspects of HIV/AIDS throughout the world. Their insights into the practical aspects of the epidemic can provide crucial information for policy development.

PREVENTION

Goal J: Educational programs, activities, and campaigns that provide accurate and timely information to all Americans on how to prevent HIV transmission.

Commentary: National prevention campaigns and local community programs must deliver a consistent prevention message overall if they are to be effective. The prevention program design model shall include active participation of the target populations in all components of the program design and implementation. Wherever possible, members of the target population must participate in accessing people at high risk, especially for hard-to-reach populations.

Enact the Health Security Act, through which health insurers could
Action (J.1): ~~Develop and implement an affordable health insurance plan that would provide coverage for HIV prevention and would support a health system which promotes public health infrastructure re-building.~~

Action (J.2): Develop a continuum of HIV prevention services that are culturally diverse and linguistically specific and contain input from the diverse populations effected by AIDS.

Commentary: Prevention programs must provide both individual and community-level interventions. Although more individuals are being tested today than were a few years ago, counseling and testing programs alone are not reaching those most at risk and are not bringing about the behavior changes necessary to stop transmission. To this end, programs and messages must be aimed at the individuals at high risk for infection. Counseling and testing activities can continue to be used as a diagnostic tool with continued counseling on prevention intervention and any necessary treatment.

Action (J.3): Develop consistent prevention education messages to be used in HIV prevention programs at the national, regional, state, and local levels.

DRAFT

Commentary: Where research findings are available regarding risky behavior, they should be used in the development of linguistically specific, developmentally appropriate, and culturally-based prevention messages that speak of abstinence or sexual activity within a long term mutually monogamous, committed relationship as the surest way of preventing transmission, but also encourage safer sexual and substance-use practices for individuals.

Action (J.4): Sustain the federal agencies ongoing prevention campaigns to sponsor targeted national media campaigns that will specifically address HIV prevention.

Commentary: National media campaigns demonstrate the leadership of the federal government in delivering targeted prevention messages to persons at risk for HIV infection.

Action (J.5): Encourage communities throughout the country to follow the federal government's lead and carry the message of prevention to local populations at risk.

Action (J.6): Increase technical assistance from federal agencies to assist state and local governments and non-governmental organizations to develop targeted campaigns through community interventions and the media.

Commentary: To increase effectiveness, prevention messages must be population-specific. Therefore, they should be delivered through appropriate media and use language and imagery that most effectively communicates the message. Federal agencies engaging in HIV prevention activities should encourage state and local

governments and private agencies to provide targeted media campaigns and implement well-chosen community interventions.

DRAFT

Action (J.7): Encourage businesses and media to participate in national and local efforts for HIV prevention by sponsoring campaigns and activities in local media and in places of business.

Goal K: Community consultation routinely sought in the development and implementation of educational programs and campaigns.

Action (K.1): Develop and deliver prevention messages in an effective and appropriate manner for the intended audience.

Action (K.2): Target efforts to the needs of populations that may be particularly susceptible to HIV transmission: gay and bisexual men (including gay men of color), substance users, sexual and needle-sharing partners of substance users, and youth in high-risk situations (especially out-of-school and gay youth).

Commentary: Primary in this effort is prevention education for youth, both in and out of school. Messages stress building self-esteem and self-sufficiency. To obtain the most effective community consultation, collaboration between governmental and non-governmental organizations will be encouraged at all levels. Federal funding agencies should increase technical assistance to encourage partnerships.

Action (K.3): Continue the implementation of the community planning process and encourage state and local governments to expand the use of this representative process to set priorities at the state and local levels.

Goal L: An array of HIV preventive services available and accessible to substance abusers in treatment on the streets.

Action (L.1): Coordinate activities and policies within the federal government such that the elements of the Public Health Service, the Office of National Drug Control Policy, and oth-

er involved entities work together toward a common goal of a drug-abuse-free and an AIDS-free society.

DRAFT

Action (L.2): Identify and develop methods to encourage the entry of all psychoactive drug dependent people, with particular attention to injecting drug users, into public or private treatment programs.

Action (L.3): Encourage utilization of new or sterile needles and syringes among injecting drug users who are unwilling or unable to utilize treatment or abstain from injecting practices.

Action (L.4): Initiate policy discussions and encourage study of the concept of "harm reduction" to broaden the policy alternatives available as the nation confronts the double and interrelated epidemics of drug dependency and HIV/AIDS.

Goal M: A safe blood supply worldwide.

Commentary: This issue cuts across international boundaries and is amenable to increased blood screening, the use of deferral criteria for blood donors, and other efforts.

Action (M.1): In cooperation with the World Health Organization, Global Program on AIDS promote the "Blood Safety Initiative."

Action (M.2): Include blood safety standards in all U.S. sponsored international service programs.

Goal N: Comprehensive, continuing HIV prevention programs for international use through existing host country infrastructure.

Action (N.1): Develop a comprehensive HIV/AIDS educational exchange among national AIDS coordinators world-wide using electronic media.

Action (N.2): Work with foreign governments to develop a training program to educate members of their military orga-

nizations so that they can teach civilian communities HIV prevention.

DRAFT

Commentary: After developing and successfully implementing HIV/AIDS training for U.S. military personnel, the concept can be translated to foreign militaries world-wide, some of which have extremely high infection rates.

CROSS-CUTTING

Suggest removal of activities to be carried out with U.S. funds

ATI initiative

INFORMATION DISSEMINATION

Goal 0: A national HIV/AIDS information dissemination system.

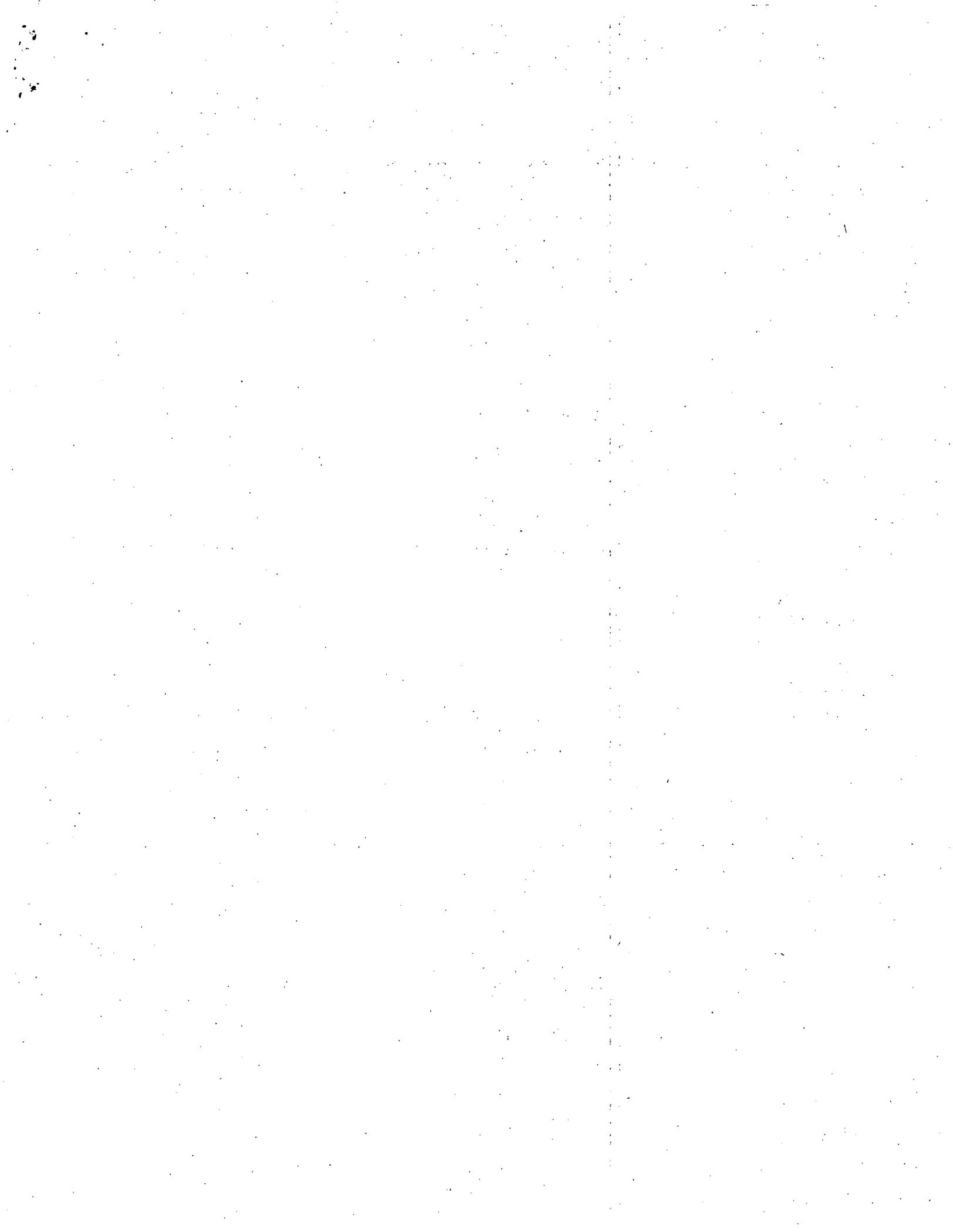
Commentary: All possible users of HIV/AIDS information should have access to the information they need and obtaining it should be easy. Implementation of an all-inclusive, easy access system can be developed with existing technologies and expertise. All AIDS information should be available to the public via a single telephone access number. Transfer among databases to the appropriate information system should be transparent to the user.

- Action (0.1):** Develop a technological, inter-departmental portal through which AIDS information can be disseminated.
- Action (0.2):** Establish a interdepartmental group to identify and discuss the issues and to establish a coordinated national HIV information dissemination policy.
- Action (0.3):** Develop an HIV information plan to be followed by all relevant agencies.
- Action (0.4):** Provide a forum for community-based HIV organizations and people affected by HIV/AIDS to express their informational needs and the problems they encounter in obtaining the needed information.
- Action (0.5):** Develop a training and technical assistance program for users of the national HIV information system.

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file: AIDS

THE WHITE HOUSE
WASHINGTON

July 13, 1994

MEMORANDUM TO CAROL RASCO

FROM: Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

SUBJECT: Prevention meeting summary - June 30, 1994

On June 30, 1994 the Office of National AIDS Policy (ONAP) hosted a meeting of "HIV Prevention, Looking Back, Looking Ahead," a project of the Harvard AIDS Institute and the University of California at San Francisco. This project is being made possible through a generous contribution of the Kaiser Family Foundation.

The project is aimed at increasing the nature of primary HIV/AIDS prevention activities conducted by physicians and other health care professionals engaging in primary care. Recent surveys indicate that health care professionals have not been discussing the issues of HIV/AIDS prevention with their patients who may be at risk. This is perceived to be caused by the fact that primary care professionals have the same inhibitions about discussing behavior, especially sexual behavior.

At the meeting on June 30, which was coordinated with the assistance of ONAP staff, 32 representatives of associations of health care professionals and Federal government agencies came together to discuss what types of activities could be used to prompt health care professionals to include HIV/AIDS prevention in their interviews with patients. Among the associations represented were: American Medical Association, National Medical Association, American Nurses Association, American Association of Physicians for Human Rights, Association of Nurses in AIDS Care and several others.

During the luncheon, Steve Morin, Ph.D., Legislative Aide for Congresswoman Nancy Pelosi, discussed health care reform, Congressional action on health care reform and HIV/AIDS prevention provisions within the Health Security Act. The participants were able to have a frank discussion on the implications of health care reform for their organizations and practices.

The meeting concluded with discussion of what would be the next steps to be followed, including increased training, exploration of reimbursement mechanisms, centralized mechanisms for dissemination of information to clinicians and several others.

A list of participants is attached.

HIV Prevention: Looking Back, Looking Ahead

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file: AIDS

JUN 10 REC'D

THE WHITE HOUSE
WASHINGTON

RECEIVED

Carol Rosco
fyp

JUN - 7 1994

May 25, 1994

MEMORANDUM TO KRISTINE GEBBIE

FROM: Carlos Vélez, J.D. *CN 8/62*

Subject: Strategy for Governmental/Non-Governmental Collaboration on Needle Exchange

On April 29, 1994, Andrew Barrer and I met with Camille Barry and Sarah Vogelsberg of the Office of the Secretary, HHS, and Lorraine Fishback, OASH/OHPE, to discuss what strategy we could follow to gather consensus within the administration and the HIV/AIDS and substance abuse communities on the issues related to needle exchange programs. Although Fran Page is the lead person on substance abuse issues, she was not able to participate in this meeting. The primary focus of the meeting was the need to arrive at a common theme that could be the administration's position on the need to address needle exchange from a public health perspective.

We narrowed down the basic requirements for framing the discussion. Although we are aware of the congressional restriction which must be fulfilled (i.e., reduction in HIV transmission without an increase in injecting drug use in the community), we also recognized that demonstrating these two issues by themselves may not be sufficient to gain popular support for needle exchange programs. This process must include the assessing of the public health impact of needle exchange and the implementation of programs were the prohibition to be lifted (i.e., what shape should needle exchange programs take and what restrictions will be imposed on their implementation).

We all agreed that following a more global strategy would be beneficial. To that end, we agreed that a high-level meeting within HHS will be necessary to arrive at consensus on what will be the department's position, especially in relation to the health impact and programmatic implementation, prior to approaching other governmental and non-governmental entities. Andrew and I agreed to work with OS and OHPE to arrive at this HHS position. Once the HHS position is arrived at, an interdepartmental agency including Justice and ONDCP would be necessary to arrive at a common administration position.

In order to attain this more global perspective on needle exchange as part of substance abuse issues, and following subsequent conversations, it will be expeditious to conduct at least one focus session with community representatives, researchers and members of interested groups in the areas of HIV/AIDS prevention, services and research and the substance abuse

prevention and treatment advocacy community. These meetings will assist in the development of principles in the area of HIV/AIDS and substance abuse policy coordination, and will not be limited to discussions in the area of needle exchange. Once the various alternatives and issues are discussed, the administration will be better prepared to make a determination on substance abuse issues globally and needle exchange specifically to satisfy the congressional and public health requirements. It was apparent from the discussion on April 29 and other discussions, that the process will take several months to be completed.

The participants in the April 29 meeting agreed to go back to their office to seek input from other staff on how the process will be framed and what type of public health issues must be addressed as part of the discussion. A follow-up meeting will be arranged with the same participants from OS and OHPE within 3 weeks to discuss the logistics for the HHS/PHS senior staff meeting.

cc: Fran Page
Andrew Barrer
Tim Fox
Camille Barry
Sarah Vogelsberg
Lorraine Fishback

file: AIDS

THE WHITE HOUSE
WASHINGTON

February 23, 1994

MEMORANDUM FOR ALEXIS HERMAN

KEITH BOYKIN
BEN JOHNSON
FLO McAFEE

FROM W. STEVE LEE
EXECUTIVE ASSISTANT
OFFICE OF THE NATIONAL AIDS POLICY COORDINATOR

THROUGH: KRISTINE M. GEBBIE
NATIONAL AIDS POLICY COORDINATOR

SUBJECT African-American Religious Leaders White House Summit on
HIV/AIDS on 02/28/94 and the Black Church National Day of Prayer
for the Healing of AIDS

On Monday, February 28, the Office of National AIDS Policy (ONAP) in conjunction with Black religious leaders across the nation will host a summit in the White House complex. We are anticipating around 50 guests. A rough agenda is attached.

The purpose of the summit is educate the African- American religious community and encourage them to make a commitment to work closely with the federal government in response to the HIV/AIDS epidemic. The summit will encourage the religious leaders to take a pro-active role in preventive education programs for their denominations/ congregations/communities; and to provide support for those already infected with HIV.

This summit is also a "kick-off" for the Black Church National Day of Prayer for the Healing of AIDS. The National Day of Prayer will be on March 6, 1994 and will be a nation-wide unified day of prayer across hundreds of African-American churches.

In addition to the support lent to this process by hosting the summit, we are recommending that the President join in the day of prayer by attending services at one of the churches participating in the National Day of Prayer. A specific schedule proposal is attached.

DAY OF PRAYER CHURCH ATTENDANCE
FEBRUARY 23, 1994
PAGE TWO

PARTICIPANTS: TBD

OUTLINE OF EVENTS: Church attendance

REMARKS REQUIRED: NONE

MEDIA COVERAGE: TBD

FIRST LADY'S ATTENDANCE: Yes, if she was already scheduled to be with the President that day.

RECOMMENDED BY: Carol Rasco, Assistant to the President for Domestic Policy

CONTACT: Steve Lee and John Paul Gurrola, Office of National AIDS Policy, 202/632-1090.

THE WHITE HOUSE
WASHINGTON

SCHEDULE PROPOSAL

February 23, 1994

TO: Ricki Seidman, Assistant to the President for
Appointments and Scheduling

FROM: Kristine M. Gebbie
National AIDS Policy Coordinator

REQUEST: For the President to attend services at a church participating in
the Black Church Nat'l Day of Prayer for the Healing of AIDS

PURPOSE: To demonstrate support for community and religious
partnerships with the government in education and prevention
efforts regarding HIV and AIDS.

BACKGROUND: The African-American faith community has expanded what was
a New York event into a National Day of Prayer. This effort
has been lead by Pernessa Seele of Balm in Gilead, one of the
clergy who joined the President for breakfast in November to
discuss HIV issues.

The African-American community has been disproportionately
affected by the AIDS epidemic; their communities and churches
must have greater involvement in HIV and AIDS service and
prevention. Support for this day would be a very effective
statement from the President.

**PREVIOUS
PARTICIPATION:** NONE

DATE AND TIME: Sunday, March 6, 1994 Time: **TBD**

DURATION: one and one half hour

LOCATION: **TBD [Depending on where the President is that day, a
church participating in almost any major city could be
selected.]**

THE BALM IN GILEAD, INC.

*"An Organization Dedicated to Healing the African American Community
Through Prayer, Health Education and Advocacy"*

**African American Religious Leaders Summit on HIV/AIDS
and
Press Conference for
The Black Church National Day of Prayer for the Healing of AIDS**

**Preliminary Schedule
Monday, February 28, 1994**

**8:00 a.m. Assemble
Lobby of The Old Executive Office of the White House Complex
17 Pennsylvania Avenue NW**

**8:15 a.m. Continenal Breakfast
4th Floor**

Greetings:

Blessing of the Food:

9:00 a.m. White House Complex Tour & Photo Opportunity

9:30 a.m. White House Conference Center

**Introduction & Welcome
Kristine Grebbie
Pernessa Seele**

**Introduction of Moderator
The Rev. Canon Frederick Williams
The National Chairperson, The Black Church National Day of Prayer for the Healing of
AIDS & Rector, The Church of the Intercession
New York, NY**

**Opening Prayer:
The Rev. Cecily Broderick
St. John Episcopal Church
Hempstead, LI**

Solo: Claude Jay Jones, II
There Is A Balm In Gilead

10:00 a.m. AIDS In The African American Community
????? Dr. Satcher?

10:30 a.m. The Politics of AIDS In the African American Community
????? Congressman Charles Rangel ?

10:45 a.m. The Faces of HIV/AIDS

Phil Wilson, AIDS Project Los Angeles, Los Angeles, CA

Denise Stokes

Sharon Flavors, Community Family Planning Council, New York City

11:15 a.m. Theological Perspectives & Responses

Rev. Dr. James A. Forbes, Jr., Senior Pastor, The Riverside Church, New York City
"Hard Talk: Breaking the Silence"

Rev. Dr. Jeremiah Wright, Pastor, Trinity United Church of Christ, Chicago, Ill
"The truth about Health Care & HIV from the African American Perspective"

Rev. Patricia Reeberg, Executive Director, Council of Churches of the City of NY
"Ideals & Practical Solutions: Healing Resources in the Black Church Tradition"

Rev. Dr. John Hurst Adams, Founder & Chairman Emeritus, The Congress of National Black Churches; Presiding Bishop, African Methodist Episcopal Church
"The Black Church Participation In the Political Process of the HIV/AIDS Crisis"

12:30 p.m. LUNCH (Roundtable Discussion)

1:30 p.m. PRESS CONFERENCE

The Black Church National Day of Prayer for the Healing of AIDS
(signing of an ecumenical statement during the press conference)



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF ADMINISTRATION
Washington, D.C. 20503

MEMORANDUM FOR KATHLEEN A. MCGINTY, DEPUTY ASSISTANT TO THE
PRESIDENT FOR ENVIRONMENTAL POLICY

✓ CAROL RASCO, ASSISTANT TO THE PRESIDENT FOR
DOMESTIC POLICY

ROBERT RUBIN, ASSISTANT TO THE PRESIDENT FOR
ECONOMIC POLICY

FROM: PATSY L. THOMASSON *Patsy Thomasson*
SPECIAL ASSISTANT TO THE PRESIDENT
AND DIRECTOR OF THE OFFICE OF ADMINISTRATION

SUBJECT: AIDS Education Program

In support of President Clinton's memorandum on HIV/AIDS education, the Office of Administration (OA) has been working closely with the Office of the National AIDS Policy Coordinator to develop and implement an education program mandated for all staff of the Executive Office of the President (EOP). Specifically, we are providing technical assistance in the area of program planning, proposal development, overall coordination, contract negotiation, scheduling and training delivery.

The purpose of this memorandum is to inform you of the American Red Cross training program proposal approved by Kristine Gebbie, National AIDS Policy Coordinator, and to request your support and assistance for the success of this education program.

We are negotiating with the American Red Cross, Office of HIV/AIDS Education, to provide instruction to the entire EOP workforce. There will be separate education sessions for managers and supervisors, as well as for non-supervisory employees. Instruction for managers and supervisors will focus on certain workplace issues which require management action.

Since the President's memorandum mandated full participation by EOP staff, the most equitable method of funding the cost of training is for each EOP agency to cover the cost for its employees. We have negotiated a training agreement which includes the cost of instruction and materials. Each agency will be charged a percentage of the total training program cost. The cost will be calculated based on the percentage of the agency authorized Full Time Equivalent (FTE) level. For the Office of Policy Development the approximate cost is \$600.00.

file

The Personnel Management Division (PMD) has been assigned responsibility for managing this EOP initiative. Mary Beck, Division Director, and members of her staff are eager to share detailed information on this education program, as well as address any issues or concerns. You will receive scheduling information as soon as it is finalized. Current plans include presenting the program to managers and supervisors first, followed by the rest of the staff.

We are excited about leading the charge on HIV/AIDS education and look forward to your support and involvement.

Attachment

cc: Andrea Rutledge

~~Call Andrea & tell her~~ *email 2/8/94 nam*
this all sounds fine to me!

THE WHITE HOUSE
WASHINGTON
September 30, 1993

MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

SUBJECT: AIDS at Work

Halting the spread of HIV/AIDS and caring for those already touched by the disease is our common responsibility. Sadly, if you do not know someone with HIV/AIDS, you soon will. Every 17 minutes an American dies of AIDS; one of every five Americans knows someone who has died of AIDS; over one million Americans are already infected with HIV.

HIV/AIDS affects everyone in this Nation. Preventing the spread of HIV/AIDS and its associated human and economic costs is crucial to the success of health care reform. Likewise, enlightened, nondiscriminatory workplace policies are essential to both our efforts at reinventing government and at lowering health costs. This Administration and this Nation must do all within our power to prevent discrimination against those infected with HIV. I am committed to facing the difficult issues raised by HIV/AIDS.

This is an Administration of action and leadership by example. Today's Cabinet meeting discussion of HIV/AIDS is the beginning. All of you are asked to develop and fully implement comprehensive HIV/AIDS workplace policies and employee education and prevention programs by World AIDS Day, 1994, beginning with your Senior Staff.

To begin this process:

- * Each Cabinet Secretary shall designate a member of his/her Senior Staff to implement ongoing HIV/AIDS education and prevention programs and to develop nondiscriminatory workplace policies for employees with HIV/AIDS.
- * These designees, with the Office of the National AIDS Policy Coordinator (ONAPC), shall form a working group to implement this directive.

- * The Office of Personnel Management (OPM) shall review its current HIV/AIDS workplace guidelines and assist in the development of workplace policies in the departments and agencies, as directed by ONAPC. OPM should pay particular attention to ensuring that the administrative burden on the departments and agencies is minimized.
- * The National AIDS Policy Coordinator shall report to me quarterly on the progress of each department and agency, beginning January 1, 1994.
- * The White House Staff and the Staff of the Executive Office of the President (EOP) will participate in HIV/AIDS education and prevention training prior to World AIDS Day, December 1, 1993.

HIV/AIDS is the health crisis of this century; it cannot be allowed to extend into the next. Only through education and prevention can we stop its spread. Only through aggressive and coordinated efforts at medical research can we find a cure. Join me on World AIDS Day, 1993, to remember the hundreds of thousands of American dead and the millions of Americans infected or suffering because of this disease; help me to vividly demonstrate this Administration's commitment to end the HIV/AIDS epidemic.

William Clinton

THE WHITE HOUSE

WASHINGTON

June 22, 1994

NOTE TO: Phil Lader
George Stephanopolous
Alexis Herman

FROM: Jeremy Ben-Ami

CC: Carol Rasco ✓

Attached is the press statement from
AIDS Action Council which I mentioned
in my note yesterday. It was released
to the press last night.

NEWS

from For immediate release:
June 22, 1994

Contact: Lynora Williams
tel.: 202-986-1300, ext. 33



WHITE HOUSE AIDS POLICY OFFICE FALLS SHORT

One year after the appointment of the first White House AIDS policy coordinator, AIDS Action Council and AIDS advocates across the country view the coordinator's office as yet another bureaucratic roadblock standing in the way of a coordinated federal response to the AIDS epidemic.

"The AIDS epidemic is growing more complex and intransigent. We need a White House coordinator that keeps AIDS in the center of the president's radar screen, not a public relations spokesperson who spends time giving speeches and making public appearances," says Daniel T. Bross, AIDS Action executive director. "The Office of National AIDS Policy, headed by Kristine Gebbie, is not meeting the mission hoped for by thousands of AIDS advocates. Although we continue to share our concerns with members of the Clinton administration, no action has been taken to date. Unfortunately, AIDS is still an issue that the White House prefers to dance around instead of embracing as a top domestic priority."

Among other things, the office has failed to:

- effectively advocate within the administration and on Capitol Hill for increased federal funding for HIV/AIDS programs;
- collaborate with federal departments and agencies to develop a comprehensive federal AIDS plan; and
- work with the president to promote public leadership in fighting the AIDS epidemic.

more

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June 22, 1994

Page Two

"We would like to see the Office of the National AIDS Policy function simultaneously as a SWAT team and as a shuttle diplomacy group--responding swiftly to AIDS policy crises as well as building wider consensus within the federal bureaucracy on steps to be taken. Serious evaluation and reorganization of this office is badly needed."

Gebbie was formally appointed by President Bill Clinton on June 25, 1993, and began work in Washington on August 1, 1993. The appointment of a White House AIDS policy coordinator was seen by the AIDS communities as the fulfillment of a Clinton campaign promise and one of many steps needed to bring urgent attention to the AIDS crisis. Over 20 federal agencies and departments maintain AIDS programs, but there is little coordination among them. In assessing the contribution of the AIDS policy office, AIDS Action recalled the recommendations of two coalitions--National Organizations Responding to AIDS and Federal HIV/AIDS Agenda '93. Both coalitions made specific recommendations during the presidential transition about how the office might work (see enclosed).

AIDS Action welcomed the appointment of an experienced public health official with expertise in HIV/AIDS prevention. But the organization's disappointment and disaffection with the office are growing. Gebbie's office has been plagued by miscues and an ill-defined sense of mission. AIDS Action and many fellow advocates now feel that the office has actually become a stumbling block to the development and implementation of better policies.

AIDS Action Council, founded in 1984, is the only national organization devoted solely to lobbying the federal government on AIDS policy, legislation and funding. AIDS Action Council represents more than 1000 community-based AIDS service organizations throughout the United States.

###

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: _____

Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: AIDS _____

Send copy to (original to CHR): _____

Schedule ? : Accept Pending Regret

Designee to attend: _____

Remarks: _____

THE WEXLER GROUP

MAY 12 REC'D

1317 F Street, N.W.
Suite 600
Washington, D.C. 20004
202-638-2121
202-638-7045 Telecopy

Anne Wexler
Chairman

FAX COVER SHEET

NAME: CAROL RASCO

FAX: 456-2878

FROM: ANNE WEXLER

PAGES: 3

DATE: MAY 12, 1994

ANY PROBLEMS WITH THIS TRANSMISSION PLEASE CALL 202-662-3725

MESSAGE:

AS WE DISCUSSED YESTERDAY, THE FOLKS OF AIDS ACTION AND I TRIED TO STOP THIS. WE THOUGHT WE HAD BEEN SUCCESSFUL. CLEARLY, WE WERE WRONG. WE'LL CONTINUE TO TRY TO KEEP THIS FROM SNOWBALLING. ALL THE BEST.

CONFIDENTIALITY NOTE:

The information contained in this facsimile message is legally privileged and confidential information intended only for the use of the individual or entity named below. If the reader of this message is not the intended recipient, you are hereby notified that any dissemination, distribution or copy of this telecopy is strictly prohibited. If you have received this telecopy in error, please immediately notify us by telephone and return the original message to us at the address above via the United States Postal Service. Thank you.

MAY 12 REC'D

News Release

Contact: A. Cornelius Baker
Director, Public Policy & Education
202.898.0414

A CALL FOR THE RESIGNATION OF KRISTINE GEBBIE AS THE NATIONAL AIDS POLICY COORDINATOR

William J. Freeman
Executive Director

Washington, D.C.
May 11, 1994



NAPWA

**NATIONAL
ASSOCIATION
OF PEOPLE
WITH AIDS**

The National Association of People with AIDS (NAPWA) calls for the resignation of Kristine Gebbie as the National AIDS Policy Coordinator.

At the request of NAPWA, Ms. Gebbie met today with the NAPWA staff and the Policy Committee Chair of NAPWA's Board of Directors. The meeting was called to discuss the Office of National AIDS Policy and its role in the implementation of a national strategy to end the HIV epidemic.

Regretfully, we do not believe that Ms. Gebbie can provide the strong leadership that is necessary in this challenging position. Nearly one year after being appointed, Ms. Gebbie has proven incapable of creating a significant role for the Office of National AIDS Policy. A concrete strategy to address the multiple challenges of the HIV epidemic has not been forthcoming. More than one million Americans are currently living with HIV disease, and already hundreds of thousands of Americans have died of AIDS. In the face of this devastating epidemic, the lack of urgency that Ms. Gebbie brings to this office is unacceptable.

The challenge of HIV in the United States demands that we wage a war on this disease. While our nation has made progress in its attempts to address the HIV epidemic, piecemeal solutions exist where comprehensive and decisive action is required. An action plan must be implemented to address not only the medical and scientific aspects of HIV disease, but also the social and economic circumstances that contribute to the destructiveness of this epidemic. Without addressing poverty, racism, and homophobia – root causes of the epidemic – any "National HIV Action Agenda" is assured of failure.

President Clinton must take the lead in building both a national consensus and a political framework that will enable us to end the HIV epidemic. We

believe that the President must move quickly to invigorate the Office of National AIDS Policy and provide the following:

- o **Visionary Leadership.** We can end the HIV epidemic. We *must* clearly demonstrate a commitment to this goal through prevention and research that focuses on a cure. Action must follow words. **President Clinton must articulate a vision for ending the HIV epidemic and he must work with the Congress and all of our national leaders to implement an action plan for the nation with clearly identified goals, objectives, and responsibilities.**
- o **Coordination and Strategy.** Thirteen years into the epidemic, precious time continues to be squandered. All branches and departments of the federal government, key representatives of non-governmental organizations, the private sector, and individual Americans must be brought together to create a framework that will produce immediate results. **We call upon President Clinton to convene a dynamic and forceful working group within the White House to direct the implementation of a comprehensive action plan.**
- o **Resources.** In order to defeat the HIV epidemic, the Clinton Administration must establish clear priorities for the targeted allocation of scarce resources. **The Clinton Administration must set priorities that include targeted research on promising therapies, a national prevention campaign and increased funding for crucial medical and support services. In addition to setting these priorities, the Office of National AIDS Policy must take responsibility for securing the resources needed to address all aspects of the HIV epidemic.**

NAPWA continues to view the Office of the National AIDS Policy Coordinator as an essential leadership center for the nation's response to the devastation of the HIV epidemic. However, President Clinton must reexamine the structure and role of this office with the urgency that this epidemic demands.

###

NAPWA supports all Americans affected by the HIV epidemic with information and educational resources, national advocacy for people living with HIV disease and technical assistance programs for community-based organizations. In an effort to prevent the spread of HIV disease and facilitate a richer quality of life for HIV-infected individuals, NAPWA builds meaningful partnerships among people with HIV, service providers, business, government and philanthropy.

*orig: CHR w/ source doc
xc: Seanan Fuji
This pg. only*

THE WHITE HOUSE
WASHINGTON

Jew AIDS

May 19, 1994

MEMORANDUM TO CAROL RASCO

FROM: KRISTINE M. GEBBIE *J. Gebbie for*
NATIONAL AIDS POLICY COORDINATOR

SUBJECT: Publication of May 19 MMWR article on two new instances of household HIV transmission

The purpose of this memo is to alert the President's staff of the upcoming publication of two new cases of HIV transmission which may cause negative feedback from conservative circles.

On May 19, CDC will publish in the Morbidity and Mortality Weekly Report (MMWR) two new instances of HIV infection in situations when a family member has become infected while having interaction with another family member living with HIV. The transmission modes have not been clearly identified, which may be grounds for public concern and renewed calls for mandatory testing and isolation of individuals living with HIV/AIDS.

Action

We are confident that the two cases of infection do not reflect new or unknown means of transmission, in fact, both patient history summaries cite a lack of transmission pre-cautions taken by the infected individuals. The public health authorities are taking the steps necessary to inform persons at risk of HIV infection on how to prevent transmission in similar situations. The information on how to prevent infection is widely available, and can be obtained by calling toll-free the National AIDS Hotline (800-342-AIDS).

To: Kristine Gebbie

From: EXPK/OCDHIV1/kwf1

5-19-94 12:54pm p. 4 of 7

EMBARGOED until 5:00 EDT**CDC**
CENTERS FOR DISEASE CONTROL
AND PREVENTION**MMWR****MORBIDITY AND MORTALITY WEEKLY REPORT**NOTE
↑*Epidemiologic Notes and Reports***Human Immunodeficiency Virus Transmission
in Household Settings — United States**

Transmission of human immunodeficiency virus (HIV) has been reported in homes in which health care has been provided and between children residing in the same household (1-6). CDC has received reports of two cases of HIV infection that apparently occurred following mucocutaneous exposures to blood or other body substances in persons who received care from or provided care to HIV-infected family members residing in the same household. This report summarizes the findings of the epidemiologic and laboratory investigations, which underscore the need to educate persons who care for or are in contact with HIV-infected persons in household settings where such exposures may occur.*

Patient 1

A 5-year-old child whose parents were both HIV-infected tested negative for HIV antibody in 1990 and July 1993 but tested positive in December 1993. In February 1994, all other close household contacts of the child tested HIV-antibody negative.

From January through December 1993, when the child was likely to have become infected, the child's parents were the only known HIV-infected persons with whom the child had any contact. During this period, the child lived with both parents until the father's death as the result of acquired immunodeficiency syndrome (AIDS) in May 1993. The child continued to live with the mother, who had AIDS, until 8 days before the child's last negative antibody test in July 1993. The child then lived in foster care.

To: Kristine Gebbie

From: EXPK/ODDHIV1/kwf1

5-19-94 12:54pm p. 5 of 7

EMBARGOED until 5:00 EDT

The child had several opportunities for contact with HIV-infected blood and exudative skin lesions. Based on the mother's medical records and history, from March through August 1993 the mother had recurrent, purulent, exudative skin lesions (diagnosed as prurigo nodularis) on her face, neck, torso, buttocks, and extremities. She frequently scratched the lesions until they bled, left the lesions uncovered, and discarded onto the furniture or the floor the gauze and tissues used to wipe the exudate. During periods when the mother's skin lesions were uncovered and draining, the child frequently hugged and slept with the mother. In addition, the child intermittently had scabs from impetigo and abrasions that the mother sometimes picked off and caused to bleed. When the mother had intermittent gingival bleeding, she periodically shared a toothbrush with the child. From January through May 1993, the child had no known contact with the father's blood or body fluids, although the child sometimes used his toothbrush.

No other situations were identified in which the child potentially may have been exposed to HIV-infected blood or had contact with an HIV-infected person. There were no known HIV-infected persons in either the foster home or the school, and the child had no known contact with blood in these settings. Based on interviews and medical record reviews, no household members at either the parents' home or foster home engaged in injecting-drug use. Based on history and physical examination, sexual abuse of the child was believed to be unlikely. During 1993, the child had no injections, blood transfusions, vaccinations, or invasive dental or medical procedures.

Proviral DNA from peripheral blood mononuclear cells obtained from the mother and the child was amplified by polymerase chain reaction. By direct sequencing, the two DNA fragments encompassing 343 nucleotides of the V3 and flanking regions of the gene encoding the HIV-1 envelope glycoprotein (gp120) were genetically similar, differing by only 2.6%. No specimen was available from the child's father.

Patient 2

In August 1991, a 75-year-old woman was evaluated because of fatigue and malaise and tested positive for HIV antibody; her adult son died in August 1990 as the result of AIDS. Her CD4+ T-lymphocyte count was 837 cells/uL. She had been married for approximately 50 years; her husband tested negative for HIV antibody. The patient reported no other sex partners and denied all risk factors for HIV infection, including injecting-drug use and receipt of blood or blood products since 1978; she had not been employed in a health-care setting. The woman had a cholecystectomy in December 1990; in February 1992, all members of the surgical team tested negative for HIV antibody.

Her son had lived in the household from September 1989 until his death. He initially was able to care for himself; however, in July 1990 (6 weeks before his death), his mother began to provide daily nursing care for him (e.g., bathing, feeding, changing diapers, and repositioning his urinary catheter). Although she had been informed of the need to wear gloves while providing such care, she reported inconsistent adherence to this recommendation. She could not recall any direct exposures to her son's blood. Her son did not require intravenous fluids or medication in the home nor did he have an intravascular device. No needles or other sharp instruments related to his care were in the home. Dermatologic conditions had not been noted.

The son had hemorrhoids and diarrhea, but neither visible blood nor melena had been noticed at home. The mother reported skin contact with her son's feces on at least one occasion. While hospitalized in February 1990, he had upper gastrointestinal bleeding; endoscopy revealed chronic gastritis and duodenitis. During hospitalization in June 1990, he had an episode of lower gastrointestinal bleeding. No such bleeding episodes occurred at home.

To: Kristine Gebbie

From: EXPK/000HIV1/kwf1

5-19-94 12:54pm p. 6 of 7

EMBARGOED until 5:00 EDT

The son had poor dentition and gingivitis around his upper molars, and his mother frequently handled the cotton-tipped swabs her son used for his oral hygiene care, although she attempted to avoid touching the cotton tips with bare hands. She reported having infrequent small cuts on her hands but had no history of dermatitis or other skin lesions. There were no blood specimens available from the son for HIV DNA sequencing.

Reported by: Div of HIV/AIDS and Hospital Infections Program, National Center for Infectious Diseases, CDC.

Editorial Note: The findings of the investigations described in this report indicate the transmission of HIV as the result of contact with blood or other body secretions or excretions from an HIV-infected person in the household. In both instances, exposures occurred after the source-patients had developed AIDS; consequently, relatively high HIV titers may have been present in their blood.

For patient 1, who had had direct exposure to purulent and bloody exudates from the mother's open skin lesions, transmission may have been facilitated by the child's broken skin and the mother's manipulation of the child's skin lesions. Patient 2 most likely became infected while providing nursing care for her son. Although the precise mode of transmission is unknown, she had direct contact with her son's urine and feces; because of his chronic gastritis and duodenitis, some blood could have been present in his feces, even though the blood was inapparent to his mother. In addition, she could have had other unrecognized or unrecalled exposures to her son's blood.

Even though previous reports have documented HIV transmission as the result of skin or mucous-membrane exposure to HIV-infected blood, HIV is not easily transmitted by this route. Based on assessment of health-care workers exposed to HIV-infected blood, the risk for HIV transmission has been estimated to be less than 0.1% for a single mucous-membrane exposure (95% confidence interval=0.006-0.50) (7). The risk is probably lower for skin exposures to HIV-infected blood and even lower, if present at all, for skin exposures to body secretions and excretions without visible blood (7,8). Although previous reports document that HIV has been isolated from urine (9) and that HIV nucleic acid—but not infectious HIV—has been detected in feces (10), transmission of HIV by urine or feces has not been reported.

Although contact with blood and other body substances can occur in households, transmission of HIV is rare in this setting. In addition to the two patients in this report, six previous reports have described household transmission of HIV not associated with sexual contact, injecting-drug use, or breast feeding (Table 1). Of these eight reports, five were associated with documented or probable blood contact ([1,3-5] and patient 1 in this report). In the sixth report, HIV infection was diagnosed in a boy after his younger brother had died as the result of AIDS; however, a specific mechanism of transmission was not determined (6). Two reports involved nursing care of terminally ill persons with AIDS in which a blood exposure might have occurred but was not documented ([2] and patient 2 in this report); in both reports, skin contact with body secretions and excretions occurred.

Persons who provide nursing care for HIV-infected patients in home settings should employ precautions to reduce exposures to blood and other body fluids (11). In particular, needles and sharp objects contaminated with blood should be handled with care. Needles should not be recapped by hand or removed from syringes. Needles and sharp objects should be disposed of in puncture-proof containers, and the containers should be kept out of reach of children and visitors. Bandages should be used to cover cuts, sores, or breaks on exposed skin of persons with HIV infection and of persons providing care. In addition, persons who provide such care should wear gloves when there is a

EMBARGOED until 5:00 EDT

possibility of direct contact with HIV-infected blood or other body fluids, secretions, or excretions. Because urine and feces may contain a variety of pathogens, including HIV, persons providing nursing care to HIV-infected persons should wear gloves during contact with these substances. In addition, even when gloves are worn, hands should be washed after contact with blood and other body fluids, secretions, or excretions.

Because of the social, economic, and medical benefits of home care, the number of persons with AIDS who receive health care outside of hospitals is increasing. Persons infected with HIV and persons providing home care for those who are HIV-infected should be fully educated and trained regarding appropriate infection-control techniques. In addition, health-care providers should be aware of the potential for HIV transmission in the home and should provide training and education in infection control for HIV-infected persons and those who live with or provide care to them in the home. Such training should be an integral and ongoing part of the health-care plan for every person with HIV infection.

Additional infection-control recommendations are contained in a recently updated brochure published by CDC, *Caring for Someone with AIDS: Information for Friends, Relatives, Household Members, and Others Who Care for a Person With AIDS at Home*. This brochure is available free in English or Spanish from the CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003; telephone (800) 458-5231 or (301) 217-0023.

References

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7. Ippolito G, Piro V, De Carli G, Italian Study Group on Occupational Risk of HIV Infection. The risk of occupational human immunodeficiency virus infection in health care workers: Italian Multicenter Study. *Arch Intern Med* 1993;153:1451-8.
8. Henderson DK, Fahey BJ, Willy M, et al. Risk for occupational transmission of human immunodeficiency virus type 1 (HIV-1) associated with clinical exposures: a prospective evaluation. *Ann Intern Med* 1990;113:740-6.
9. Levy JA. Pathogenesis of human immunodeficiency virus infection. *Microbiol Rev* 1993;57:183-289.
10. Yolken RH, Li S, Perman J, Viscidi R. Persistent diarrhea and fecal shedding of retroviral nucleic acids in children infected with human immunodeficiency virus. *J Infect Dis* 1991;164:61-6.
11. CDC. Recommendations for prevention of HIV transmission in health-care settings. *MMWR* 1987;36(no. 2S).

* Single copies of this report will be available free until May 20, 1995, from the CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, MD 20849-6003; telephone (800) 458-5231 or (301) 217-0023.

THE WHITE HOUSE

WASHINGTON

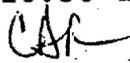
May 5, 1994

MEETING WITH MOTHERS' VOICES

DATE: May 5, 1994

LOCATION: Roosevelt Room

TIME: 10:15 a.m. to 10:30 a.m.

From: Carol H. Rasco 

I. PURPOSE

You will drop by a meeting Carol Rasco is having with MOTHERS' VOICES which is a nationwide grassroots AIDS advocacy network working to change public attitudes and policies locally and nationally.

The group asked for a thirty minute meeting with you and instead we offered them a meeting with Carol with a visit by you. They will be telling Carol their family stories and will probably tell one story while you are present.

II. BACKGROUND

This is the second year they have gathered signatures on Mothers' Day cards to public officials....last year you received hundreds of them. They will be delivering them on the Hill today. The cards say there will be no Mothers' Day until there is a cure for AIDS.

You have met several of these mothers and their children at different times:

Carol DiPaolo and her son, Joey
Linda Mowrer and her son, Michael Hartranft
Lili Rundback, a founder of the group

III. PARTICIPANTS

Approximately 36 members of Mothers' Voices and/or family members.

Carol Rasco

John Garrola of the AIDS Office

IV. PRESS PLAN

White House Photographer only.

V. SEQUENCE OF EVENTS

Carol will be listening to the family stories when you enter. She will transition you into the meeting. For closing remarks you should:

Thank them for their dedication.

Thank them for being willing to share their stories.

State your commitment to research and health care.

Solicit their support for health care reform and ask them to talk it up as they visit the Hill.

VI. REMARKS

No prepared remarks necessary.

THE WHITE HOUSE

WASHINGTON

May 5, 1994

MEETING WITH MOTHERS' VOICES

DATE: May 5, 1994

LOCATION: Roosevelt Room

TIME: 10:15 a.m. to 10:30 a.m.

From: Carol H. Rasco *CSR*

file

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John Garrola of the AIDS Office

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VI. REMARKS

No prepared remarks necessary.

THE WHITE HOUSE
WASHINGTON

February 22, 1994

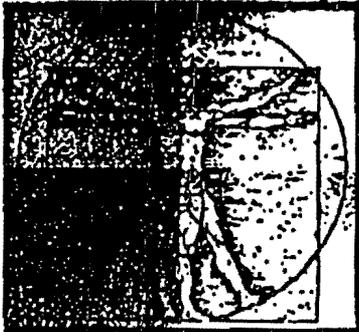
TO: Kristine Gebbie
FROM: Carol H. Rasco *CHR*
SUBJECT: Sanctuary Task Force *my nam*

I have been asked by White House staff if the administration has a position on this issue. I have enclosed a copy of materials forwarded to me on the issue. Do you have any guidance?

Thank you.

Sanctuary Task Force

1-800-Sanctuary



'There is no greater good than to relieve the suffering of another man'

The FDA's mission is to protect the public against harmful drug toxicities. Since the thalidomide scare of the '60's, the FDA has developed stringent guidelines and regulations for drug approval. It currently costs in excess of \$190 million and takes four to ten years to bring a single drug to the marketplace. As a result of the high costs and the lengthy approval process, many potentially beneficial drugs are being tested overseas or are never seeing the light of day. In fact, some of the drugs being tested in Europe were developed at the National Institutes of Health at U.S. taxpayers' expense.

We are 13 years into the AIDS epidemic and have only three FDA-approved HIV therapies, all of which have limited benefit. Patients with late-stage, life-threatening diseases are often excluded from U.S. drug trials, and are desperate for treatment now. Physicians and their patients have been frustrated in their attempts to gain access to promising therapies, and should have access to experimental drugs. Protecting the general public against harmful side effects is necessary, but we need to adopt a different standard for life-threatening diseases. There is no side effect worse than death.

The Sanctuary Drug Act offers a solution. By establishing a Sanctuary Board as a separate arm of the FDA, composed of prominent researchers and HIV-treating physicians, potentially beneficial, non-FDA approved drugs warranting scientific investigation will be identified and evaluated. Those agents deemed to be within the range of acceptable risk will be selected for study inclusion. Study participants will be limited to patients with less than one year to live. Sanctuary will supply and closely monitor the safety and efficacy of therapeutic agents in a structured, uniform study, wherein data will be collected, interpreted and disseminated to physicians via electronic data transmission. This structure will expedite our ability to recognize treatments with the potential for cure, allow alternative therapies to be scientifically evaluated, reduce exploitation by charlatans who prey upon the desperately ill with quack cures, and greatly reduce drug development costs. The expanded national access to drugs and information will also eliminate duplication of research on ineffective agents.

In dealing with the AIDS crisis, and with all incurable diseases, we must take bold and determined steps. In response to this, a group of HIV-treating physicians, AIDS activists, and HIV-infected and affected persons have recently formed the Sanctuary task force. Sanctuary will offer *hope* to the terminally ill -- an opportunity to improve their chances for survival and quality of life, and the opportunity to participate in the search for a cure.

OUTLINE FOR PROPOSED SANCTUARY DRUG ACT

- I. **PATIENT QUALIFICATIONS**
 - A. Life-threatening, incurable disease
 - B. Expected to have less than six months to live
 - C. Informed consent waivers, liability waivers
 - D. Mentally competent
 - E. Physician's verification of A through D

- II. **PHYSICIAN REQUIREMENTS**
 - A. Agrees to report to Sanctuary board on regular basis on patient status
 - B. Pays nominal fee for Sanctuary drugs
 - C. Limited to 100 patients/Sanctuary drug/year
 - D. Provide Sanctuary drugs to patients at cost

- III. **SANCTUARY DRUG/AGENT REQUIREMENTS**
 - A. Meets Sanctuary toxicity standards based on animal studies
 - B. Are not deemed dangerous or ineffective by the Sanctuary board
 - C. Are supplied to the Sanctuary at no cost by manufacturers
 - D. Removal from Sanctuary
 1. No marked improvement in patients, as compared with the natural progression of the disease, has been reported by physicians
 2. Shown to be dangerous
 3. More than 50,000 requests have been received by Sanctuary

- IV. **SANCTUARY BOARD**
 - A. Researchers, physicians, community activists
 - B. Maintain an acceptable standard of toxicity
 - C. Add to and remove from the Sanctuary medications/devices
 - D. Maintenance and dissemination of anecdotal results from participating physicians
 - E. Allowing/disallowing physician participation in program based on physicians' compliance with reporting requirements
 - F. Transmit toxicological summary data to physicians
 - G. Use funds collected from participating physicians to pursue the study of the toxicology of agents chosen by the committee for inclusion in Sanctuary that do not have drug company sponsorship or prior toxicological data (i.e., natural compounds or compounds showing promise in cell culture studies, but unattractive to drug companies for patent or profit reasons)

- V. **DRUG MANUFACTURERS**
 - A. May submit agents to Sanctuary without liability or loss of rights to compounds
 - B. May simultaneously pursue phase one, two, or three protocols as recognized by the FDA

- VI. **BENEFITS**
 - A. Speed in recognizing agents with great potential for cure
 - B. Agents without great profit potential would be evaluated/utilized
 - C. Alternative therapies scientifically evaluated
 - D. Drug development costs could be greatly reduced
 - E. Purity and dosage of agents would be standardized, assuring:
 1. Patient safety
 2. A level playing field for comparison of agents
 - F. Charlatanism reduced
 - G. Tens of thousands of productive lives might be salvaged

EXPANDED SANCTUARY DRUG ACT OUTLINE

I. PATIENT QUALIFICATIONS

- A. Life-threatening, incurable illness
- B. Expected to have less than 6 months to live
 - 1. As determined by actuarial tables
 - 2. Certified by treating/requesting physician
- C. Mentally competent - see Section I/B/2
- D. Informed consent , liability waivers
 - 1. Discussion between patient and treating physician detailing all risks and unknowns, Sanctuary function, rules for both patient and physician
 - 2. Patient agrees to hold harmless all parties involved in the production, administration, distribution, and involvement in the Sanctuary
 - 3. Discussion and patient's agreement are video taped, and consent and liability forms are signed by patient

II. SANCTUARY BOARD MEMBER QUALIFICATIONS

- A. Has been a primary care physician for 500+ HIV patients or practice has been devoted to HIV primary care for two or more years
- B. Agrees to report to Sanctuary board on a regular basis on patient status in a format designed by Sanctuary board
 - 1. Monthly meetings of participating physicians via teleconference or ISDN video phone. Equipment will be provided by the Sanctuary and remain the property of the Sanctuary.
 - 2. All meetings will be recorded and made available to the public.
- C. Physicians will not receive any compensation for serving on the Sanctuary, but will be indemnified against tort actions by the State.
- D. Physicians will be limited as to the number of patients allowed into the Sanctuary annually.
- E. Will provide Sanctuary agents to Sanctuary patients at cost.
- F. Physicians' charges to Sanctuary patients for other services will be at the physician's discretion.
- G. Term of membership to be two years
 - 1. Year One of Sanctuary - 10 member physicians
 - 2. Year Two of Sanctuary - 20 member physicians
- H. Appointment to Sanctuary membership by Sanctuary board/governor/president.

III. SANCTUARY BOARD AND STAFF

- A. Board appointed by governor/president
- B. Staff (minimal) hired by Board to manage data

- C. Responsibilities of Board
1. Monitor Sanctuary physician compliance
 2. Selection of agents for addition to Sanctuary
 3. Review Sanctuary physician reports of toxicology/efficacy of Sanctuary agents
 4. Contract with a cell culture lab (NIH, university) for initial toxicological studies on untested agents
 5. Act as liaison with pharmaceutical companies to insure cooperation with Sanctuary agenda
 6. Manage funds generated by Sanctuary agent fees and government funding or donations
 7. Prepare and make available to the public results of Sanctuary agents, good or bad.
 8. Establish the parameters of Sanctuary dissolution
 9. Choose physicians, patients, and agents for participation in Sanctuary
- D. Will receive no compensation for serving on the board, but will be indemnified against tort actions by the State

IV. PHARMACEUTICAL COMPANIES

- A. May submit agents to Sanctuary without liability or loss of rights to compounds
- B. May simultaneously pursue phase one, two or three protocols as recognized by the FDA.

V. SANCTUARY AGENTS

- A. Agent becomes known to Sanctuary board through
 1. Reading
 2. Anecdotal experience
- B. Agent under consideration is subjected to the following qualifying questions:
 1. Is the agent currently available to physicians via the compassionate use program? If so, exclude the agent from further consideration.
 2. Is the agent available in another country? (The patient can obtain the agent through a prescription.) If so, exclude the agent from further consideration.
 3. Is there evidence of effect against HIV in non-tumor human cell culture systems (e.g., PBMC's)? If there is no evidence of effect, the agent is excluded until data showing effect become available. Developing such data may be a function of the Sanctuary.
 4. Is the therapeutic to toxic ratio in human non-tumor cell culture less than 2^1 ? If so, the agent is excluded from further consideration. (Note: All agents are toxic if given in large enough amounts. Digoxin, with a therapeutic to toxic ratio of approximately 2^1 , is the currently accepted treatment for congestive heart failure, which has an average survival of around six months to one year. A therapeutic to toxic ratio of 2^1 means that twice the treatment dose can kill you.)

- C. The agent is subjected to the following questions in order to accelerate placement in the Sanctuary:
1. Has the agent ever been or is it currently being used in humans for another purpose? In either case, toxicity is known and the agent may go directly to Sanctuary unless it has been excluded in Section V/B.
 2. Testing
 - a. Assuming no animal toxicity is found, and the agent has never been used in humans for any purpose, the agent being considered for Sanctuary status must have at minimum the LD50 status (the dosage necessary to kill 50% of the test animals) in mice prior to being placed in Sanctuary. If no LD50 exists (some medications are so harmless, you can't really kill a test animal with any reasonable amount of the agent), then the agent must be shown to be tolerated at a dose at least 30 times greater than that expected to be used in humans as estimated on a mg/kg dosing schedule, and as derived from cell culture calculations using a volume of distribution of total body water (for example, let us say that 1 microgram/ml of compound Y is shown to kill all HIV infected cells in cell culture, has no cell culture toxicity on healthy cells up to 2 times this dose, and further, no LD50 could be found in mice at doses 30 times greater than that estimated to be used in humans on a mg per Kg basis. Then the mice should tolerate $.6 \times \text{the body mass in Kg} = \text{total body water in liters} \times [\text{total body water in ml}] \times [1 \text{ microgram/ml}] \times 30 = \text{the dose needed to be tolerated by the mouse.}$).
 - b. Animals will be maintained for one month post-exposure to assess more long-term pathological effects, and will be studied via necropsy to look for organ damage prior to placement of the agent into Sanctuary. If organ damage is found, the compound is excluded.
 3. Once the agent of interest has cleared the prior hurdles, it will be placed in Sanctuary
 - a. Initially, the drug will be released to ten physicians for use by ten patients, for one month.
 - b. The drug will be placed on provisional status for an additional month while data on original patients is being reviewed.
 - c. At this point, the Board will either approve continued use, or remove the agent from Sanctuary if an obvious pattern of toxicity is apparent.
 - d. If the Board approves continued use, the agent will be open to the next 100 requests.
 - e. When another 100 patients have received the drug for one month (or at any time prior if the Board so decides), the drug will again be placed on provisional status for a month while the data a

- f. If no pattern of toxicity has emerged, the agent will be made available to the next 1000 candidates (total patients exposed - 1110).
- g. At this point, the agent is closed to further use by anyone through the Sanctuary unless the Board votes to extend or enlarge the pool of patients receiving the agent.
- h. In any case, with each order of magnitude increase in patients taking or having taken the drug, a one month time-out will be observed to allow for collection and analysis of data, provided by the treating physician.

D. Problems

- 1. Paying for all this
 - a. Administration
 - b. Animal toxicology
 - c. Cell culture
 - d. Data base
 - e. Public access
- 2. Sources
 - a. Public funds
 - b. Donations
 - c. Agents will be provided to any licensed physician in the U.S. for a monthly user fee of \$100 per patient
- 3. The one patient for whom the agent was a Godsend
 - a. Any patient/physician user of the Sanctuary who decides to continue to take the agent of study after having been on the agent for more than four months (this being the usual termination point if no effect or toxicity is seen) will be allowed to continue to receive the agent at their discretion, provided they continue to report to the Sanctuary on the patient's condition monthly, and continue to pay the user fee.
 - b. This grace period will continue for up to six months after the agent has been removed from the Sanctuary for reasons of non-efficacy, but not for reasons of toxicity.
 - c. If no drug company has decided to pursue the agent for commercial use, and if the Sanctuary has not continued to expand access, or the Sanctuary has dropped the agent from further consideration, the agent will no longer be provided through the Sanctuary.
 - d. If toxicity was the reason for removal from the Sanctuary, then that agent will not be made available to anyone from that point onward.

MAY 13 REC'D

THE WHITE HOUSE
WASHINGTON

file: AIDS

May 12, 1994

MEMORANDUM TO CAROL RASCO, ASSISTANT TO THE PRESIDENT

FROM: Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

SUBJECT: Attached NAPWA press release

You may or may not have seen the attached press release, put out last evening by Bill Freeman, Executive Director of the National Association of People with AIDS. {For your information, despite its name, NAPWA is not a "membership organization" of individuals living with this disease. It is a lobbying and public policy organization with funding from a variety of corporate and foundation sources.}

I spent more than an hour with the key NAPWA staff members, and a member of the NAPWA Board, late yesterday afternoon. The meeting was scheduled at their request, to discuss policy issues, and the role of this office. During the course of the meeting, they identified their dissatisfaction with the structure of this office, stating that they felt it should be entirely free of any HHS involvement; and their preference for the appointee to my position to be much more "politically" visible. There were also questions about my "authority" to carry out policy. In addition to that, we discussed their perception that the Administration needed more passion in responding to the epidemic, that there should be an aggressive Congressional agenda for "action" to deal with homophobia and other social issues (with several references to the history of Congressional action on civil rights). We also reviewed the plans for the National HIV/AIDS Advisory Council, including the role the Council will be expected to play in turning the draft Action Agenda into real plans for both the federal government and the nation as a whole.

The meeting ended with a cordial round of handshakes, and commitments to continuing dialogue, including a couple of specifics regarding involvement with staff on specific issues. While it was clear that NAPWA and I did not see eye to eye on every issue, there was no rancor in the meeting, and no indication that they were unwilling to continue working to find the common ground between their views and those of others, including me.

MEMORANDUM TO CAROL RASCO**-2-****May 12, 1994**

I have talked today with Valerie Sutlow, the NAPWA Board member who was present. (Valerie works at the Institute of Medicine, and was a staff member of the old AIDS Program Office at HHS prior to my appointment.) I repeated to her my openness to work with NAPWA as with all groups interested in the epidemic, and my sense that we had identified some things needing response and would continue working together. I did express my frustration that the Association had not let me know that they had clearly decided differently after the meeting ended, a communication gap which makes ongoing work difficult.

If you have any questions, or would like to discuss this further, please give me a call. Thank you.

News Release

Contact: A. Cornelius Baker
Director, Public Policy & Education
202.690.0414

A CALL FOR THE RESIGNATION OF KRISTINE GEBBIE AS THE NATIONAL AIDS POLICY COORDINATOR

William J. Freeman
Executive Director

Washington, D.C.
May 11, 1994



NAPWA

**NATIONAL
ASSOCIATION
OF PEOPLE
WITH AIDS**

The National Association of People with AIDS (NAPWA) calls for the resignation of Kristine Gebbie as the National AIDS Policy Coordinator.

At the request of NAPWA, Ms. Gebbie met today with the NAPWA staff and the Policy Committee Chair of NAPWA's Board of Directors. The meeting was called to discuss the Office of National AIDS Policy and its role in the implementation of a national strategy to end the HIV epidemic.

Regretfully, we do not believe that Ms. Gebbie can provide the strong leadership that is necessary in this challenging position. Nearly one year after being appointed, Ms. Gebbie has proven incapable of creating a significant role for the Office of National AIDS Policy. A concrete strategy to address the multiple challenges of the HIV epidemic has not been forthcoming. More than one million Americans are currently living with HIV disease, and already hundreds of thousands of Americans have died of AIDS. In the face of this devastating epidemic, the lack of urgency that Ms. Gebbie brings to this office is unacceptable.

The challenge of HIV in the United States demands that we wage a war on this disease. While our nation has made progress in its attempts to address the HIV epidemic, piecemeal solutions exist where comprehensive and decisive action is required. An action plan must be implemented to address not only the medical and scientific aspects of HIV disease, but also the social and economic circumstances that contribute to the destructiveness of this epidemic. Without addressing poverty, racism, and homophobia -- root causes of the epidemic -- any "National HIV Action Agenda" is assured of failure.

President Clinton must take the lead in building both a national consensus and a political framework that will enable us to end the HIV epidemic. We

-- more --

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believe that the President must move quickly to invigorate the Office of National AIDS Policy and provide the following:

- o Visionary Leadership.** We can end the HIV epidemic. We must clearly demonstrate a commitment to this goal through prevention and research that focuses on a cure. Action must follow words. President Clinton must articulate a vision for ending the HIV epidemic and he must work with the Congress and all of our national leaders to implement an action plan for the nation with clearly identified goals, objectives, and responsibilities.
- o Coordination and Strategy.** Thirteen years into the epidemic, precious time continues to be squandered. All branches and departments of the federal government, key representatives of non-governmental organizations, the private sector, and individual Americans must be brought together to create a framework that will produce immediate results. We call upon President Clinton to convene a dynamic and forceful working group within the White House to direct the implementation of a comprehensive action plan.
- o Resources.** In order to defeat the HIV epidemic, the Clinton Administration must establish clear priorities for the targeted allocation of scarce resources. The Clinton Administration must set priorities that include targeted research on promising therapies, a national prevention campaign and increased funding for crucial medical and support services. In addition to setting these priorities, the Office of National AIDS Policy must take responsibility for securing the resources needed to address all aspects of the HIV epidemic.

NAPWA continues to view the Office of the National AIDS Policy Coordinator as an essential leadership center for the nation's response to the devastation of the HIV epidemic. However, President Clinton must reexamine the structure and role of this office with the urgency that this epidemic demands.

NAPWA supports all Americans affected by the HIV epidemic with information and educational resources, national advocacy for people living with HIV disease and technical assistance programs for community-based organizations. In an effort to prevent the spread of HIV disease and facilitate a richer quality of life for HIV-infected individuals, NAPWA builds meaningful partnerships among people with HIV, service providers, business, government and philanthropy.

file: AIDS

THE WHITE HOUSE
WASHINGTON

June 30, 1994

JUL 5 REC'D

MEMORANDUM TO: Carol Rasco
Anthony Lake
FROM: Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
SUBJECT: French "AIDS Summit" Initiative

While there is an official State Department cable being prepared to cover the meeting of June 17-18, I am providing this additional comment on the meeting and the process surrounding it.

Background

This meeting is the second called by the French government, with the stated intention of gathering heads of government together in 1994, to increase world-wide political support for the fight against HIV/AIDS. The early work was flawed, from the US perspective, by the lack of inclusion of developing countries, by a lack of clarity on the relationship to the emerging UN joint and collaborative program on AIDS, and by a lack of clarity on the relationship to the upcoming scientific AIDS meeting in Yokohama.

The April 17 meeting included only developed countries, with discussion focusing on how to move toward a productive, higher level meeting. Agreement was reached on the involvement of developing countries, a commitment to the "highest appropriate level" of participation in a December 1 meeting, and a plan for work in the interim, with the World Health Organization assisting in the mechanics.

In preparation for the June 17-18 meeting, the French arranged for briefing the previously uninvolved countries during the World Health Assembly and made arrangements for the attendance of non-governmental organizations including people living with HIV. Very little was done on developing the expected documents, or on keeping what was done consistent with the agreed-upon framework.

June 17-18 Meeting

Forty-one countries were participants, many of them represented by the Minister of Health. With representation from State (Sharon Hemond-Hrynkow), USAID (Helene Gayle), HHS (Patsy Fleming) and the White House (Gebbie), the US had a delegation

broadly representative of this government's interest in HIV/AIDS globally. The World Health Organization was an active partner in the meeting. Mme. Simone Veil served as the chair of the meeting, and continued to express her strong personal interest in a more effective response to the HIV epidemic, and her strong feeling that it is the world's political leaders who must become more involved and committed to the effort.

There was general agreement that the UN joint and co-sponsored program, and the Global Program on AIDS (GPA), provided the framework for action, and a structure for the technical work which needs to be done, additional political energy behind these efforts would be useful. While little was said directly, the question of whether "additional political energy" translates to "additional dollars" was clearly in the air.

The meeting ended with 5 areas of concern identified: safety of the blood supply, research including vaccine, care of those already infected, prevention, and protection of vulnerable population groups. A copy of the final communique from the meeting is attached. In each area some beginning work on the most significant issues was completed. A sixth issue, how to better coordinate activities within the framework of the GPA and the plans of host countries, was presented as a cross-cutting concern which should be addressed in any final action.

The GPA staff are to coordinate staff work between now and December, in order that the December meeting be a success. In discussions with Mme. Veil and Mike Merson of the GPA, the US emphasized that success at any high level meeting was dependent on good staff work done in time for appropriate review, comment and revision by participating governments.

Ongoing Work

In the time between now and December 1, a great deal of staff work must be done to prepare a statement or statements which could be agreed to by participating governments, which would make a difference in the global effort to stop the epidemic. The Yokohama International AIDS meeting in August, which is not a meeting of governments but a scientific gathering, will provide an opportunity for continued discussions or work on drafts, as many of the participants in the Paris meetings are planning in attending, including Fleming, Gayle and Gebbie.

For the US, some of the areas which will probably be included (such as harm reduction programs for injecting drug users, including syringe exchange) will push us to clarify domestic policy issues still under discussion. More importantly, if we are not in a position to announce any major new funding initiatives to back global HIV efforts, we will have to carefully

Page 3 - French "AIDS Summit" Initiative

consider what it is we will do to demonstrate real backing for whatever is identified as the eventual policy direction. The team of agencies which has participated so far will continue to work together to develop possible approaches.

A final area of decision-making for us will be the level of participation in the Paris meeting on December 1. Mme. Veil indicated that formal invitations from the Prime Minister of France would be in the mail to all involved governments within days. It is clearly the French expectation that Heads of Government will participate. The US has been clear that no advance decision has been made, and that our decision is dependent on the level and quality of the work done in preparation for the meeting. Secretary of HHS Shalala has indicated her interest in attending. Given the range of issues raised in the global HIV activity, it will be essential that USAID and State remain very active in this work. In collaboration with the State Department and HHS, I will convene an appropriate working group to respond to draft materials, and to develop a recommendation on composition of the US delegation to the December meeting.

Please let me know if you have any questions, or would like further information on the meeting, the work to date, or the plans for activity between now and December.

Attachment

cc: Timothy Wirth
Ed Malloy
Sharon Hemond-Hrynkow
Patsy Fleming