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White House Memoranda [2]

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THE WHITE HOUSE

WASHINGTON

November 29, 1995

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w/ Carol only. A
second memo will
replace this to the
President*

MEMORANDUM FOR THE PRESIDENT

THROUGH

Carol Rasco

FROM

Patsy Fleming *Paton*

SUBJECT

The Global AIDS Epidemic

I recently returned from a meeting of the governing board for UNAIDS, a new program cosponsored by several UN agencies including UNICEF, UNESCO, UNDP and the World Bank. Carol Rasco suggested that I inform you about the terrible effect of the AIDS epidemic worldwide and efforts being made by the new UN program to alleviate it.

Scope of the International HIV/AIDS Pandemic

While HIV/AIDS continues to be a serious problem in the US, in many developing countries the epidemic is much more advanced. One million people in the US have been infected with HIV; another 18 million people around the world suffer the same fate. Over three quarters of HIV infection around the world occurs through heterosexual transmission. At the global level, women and men are affected by HIV in almost equal numbers, usually in the prime of their economically productive years. By the year 2000, experts estimate that as many as 40 million people around the world will be HIV positive. Ninety percent will live in developing countries. Close to 5 million children will have been orphaned in this decade alone with estimates that the numbers will increase to 15 million worldwide by the year 2000.

Implications for Development

The pandemic's social and economic toll in the developing world is becoming increasingly apparent. As in the US, the health care costs for people with HIV/AIDS over the course of their illness is very high. Some countries currently spend one-quarter to one-half of their health budget on AIDS-related care, with studies indicating that this could rise to as much as eighty percent in parts of Africa and Asia by the year 2010. Families with sick relatives will bear the burden of years of lost productivity and income. In some Asian countries, these indirect costs are projected to be almost fourteen times as high as the epidemic's direct health care costs.

In addition to fragile and ill-equipped health care systems overwhelmed with AIDS patients, in the hardest-hit countries, the epidemic is having serious effects on other areas of society. Industries such as mining and trucking in Southern Africa are already experiencing major labor shortages due to high HIV prevalence among workers. There is evidence of human rights abuses. For example, Thai police have been involved in the forced trafficking of Burmese girls into Thailand,

an activity involving around 30,000 girls, fifty to seventy percent of whom become HIV-positive. In Rwanda, evidence is emerging that HIV has been used as a weapon of war with women being deliberately captured and taken to HIV positive soldiers to be raped. In some African countries, high infection rates among police and military personnel threaten internal and national security. UN-led peacekeeping operations will become increasingly affected as some countries find it difficult to supply healthy troops.

The Role of the United States

The US has been a major source of bilateral and multilateral funds for international HIV/AIDS activities. The US Agency for International Development, the Centers for Disease Control and Prevention and their non-governmental partners, and the National Institutes of Health have provided unparalleled technical assistance to AIDS programs in developing countries since 1986. If US development assistance is reduced by the levels proposed by Congress, I am convinced that it will have a direct and immediate impact on the ability of the world to overcome the challenge of HIV, due not only to the diminished US contribution, but also the political leverage that we bring to bear as a world leader. I am also convinced that important US foreign policy goals including democratization, economic development and peacekeeping may be compromised as the number of AIDS cases worldwide escalates.

UNAIDS

Currently, a major effort towards greater coordination and rationalization of resources allocated for HIV/AIDS within the UN system is underway. The governing bodies of WHO, UNICEF, UNDP, UNFPA, UNESCO and the World Bank have formed a new, joint and co-sponsored program which will become operational on January 1, 1996. UNAIDS will strengthen national capacity through policy development and research, technical support, advocacy and coordination at country, intercountry and global levels. As one of the donor countries providing strong leadership on this new program, the US has an obligation to commit the resources it has promised and see the initiative through. A global appeal will solicit additional support from nontraditional donor countries as well as encourage developing countries to increase contributions from their own national budgets. We have high hopes that this program will make a difference.

Lessons and Challenges

Though a vaccine is still far off, we have learned many valuable lessons in our struggle against HIV/AIDS. We have learned that HIV/AIDS is not "an outbreak", according to Dr. Peter Piot, Executive Director of UNAIDS. We have learned that condoms will never be enough; risk behaviors and the circumstances that lead people into them are complicated and dynamic. We have learned that we need to lower the social, cultural, religious and moral constraints on our ability to talk openly about human sexual behavior and raise the low status of women that impedes their capacity to negotiate safe sex with their partners. We also have learned that we need to end the marginalization and stigmatization of gay men, commercial sex workers, poor people, injecting drug users, women and youth that limit their access to information, condoms, health care and social support for behavior change.

AGENCY FOR INTERNATIONAL DEVELOPMENT
WASHINGTON, D.C. 20513**PANAFAX**

TO: Ms. Pasty Fleming
ORGANIZATION: NAPO
FAX # : (202) 632-1096
TELEPHONE: (202) 632-1090

FROM: Ms. Sally Shelton
OFFICE: AAA/G/PHN
FAX # (703) 875-4693 or (703) 875-4411
TELEPHONE: (703) 875-4708
DATE: November 29, 1995

NUMBER OF PAGES (INCLUDING COVER SHEET) 3

<u> </u> As Requested	<u> </u> For Your Information
<u> </u> For Clearance	<u> </u> For Comment
<u> </u> Per Conversation	<u> </u> Per Memorandum

Message:

AGENCY FOR INTERNATIONAL DEVELOPMENT
WASHINGTON, D.C. 20823ASSISTANT
ADMINISTRATOR

NOV 29 1995

MEMORANDUM

FROM: AA/G, Sally Shelton 
TO: NAPO, Patsy Fleming
SUBJECT: AIDS in the World

Thank-you for the opportunity to comment on this memorandum for the President and congratulations on capturing some of the essential elements important to his understanding of the international situation. I do have a few suggestions which might help to make the case stronger for continued U.S. support to this critical area.

First, by way of detail, I would spell out the United Nations Programme on HIV/AIDS (UNAIDS) the first time it appears; and after the word "cosponsored" simply list UNICEF, UNDP, UNESCO, UNFPA and the World Bank without reference to "several UN agencies", which leaves the impression that there are other UN participants not listed.

In a more substantive vein, the last two sentences of paragraph three which begins with , "The pandemic..." would be stronger if the discussion included economic and infrastructure impact on countries and/or communities; for example: World Bank economists project that over the next 15 years, the size of the Tanzanian economy could be 14 to 24 percent smaller than it would have been in the absence of AIDS; Other studies indicate that HIV/AIDS could reduce Kenya's gross domestic product by 14 percent within ten years, with per capita income declining by as much as 9 percent. The discussion of indirect costs may be a bit too unclear for your purposes in this memorandum. I would also expand the discussion beyond impact on healthcare infrastructure and healthcare costs to underline the point that the effects of the pandemic go well beyond the traditional health sector.

I think the discussion on human rights violations is important but I would be concerned with the identification of specific countries (eg. Thai police and Rwandan soldiers). Perhaps a more general statement such as, "Human rights issues are intertwined with the pandemic. Organized prostitution rings coerce young girls into having unprotected sex resulting in thousands of new infections, and ensuring the continued spread of the virus.

- 2 -

Civil strife and war also result in abuse of women and children including rape, which fosters the spread of HIV and isolates individuals from their communities and families. The discussion of the UN Peace Keeping forces might be better cast as a discussion of the threat of HIV/AIDS to social and political stability, particularly when some countries are facing levels of HIV infection within military and police factions as high as 50 and 60 percent.

One additional point in your paragraph about UNAIDS; it would be illustrative of our "strong leadership" to note that we are not only contributing approximately 25 percent of the working budget to the program, but also USAID has exercised significant leadership in the shaping of UNAIDS. In addition, the Chair of the PCB happens to be a USAID official.

In the final section, the reference to "outbreak" seems too cryptic and could be developed to discuss the idea that unlike many epidemics of the past, HIV/AIDS is now part of the human condition that will be with us for the foreseeable future. We must learn to deal with it for this and future generations. You may want to incorporate into your conclusion some of the ideas about tolerance and the lowering of constraints and the empowerment of women and marginalized populations into the context of HIV/AIDS as part of the "new" human condition.

I do think a brief para needs to be added laying out what we are doing (the first part of the memo articulately describes the magnitude of the problem). I suggest the following, perhaps after the last paragraph:

"In addition, we must continue the successful programs aimed at prevention and education being carried out around the world by USAID. These have contributed to a decline in infection rates in some countries, such as Thailand. Also, we are learning that treatment of Sexually Transmitted Diseases can reduce HIV transmissions dramatically. In sum, results are beginning to be achieved though the road ahead is a long one."

I hope you find these comments useful; and please do not hesitate to contact me or my staff if you have further questions.

FILE COPY

THE WHITE HOUSE

WASHINGTON

December 14, 1995 DEC 15 P12:16

MEMORANDUM FOR THE PRESIDENT

FROM: Carol H. Rasco, Assistant to the President for Domestic Policy
Patricia S. Fleming, Director, Office of National AIDS Policy

SUBJECT: Coverage of medical care for people with HIV/AIDS.

We understand that during the taping of the radio address last week, you asked a question regarding how working people with AIDS get health care coverage. While there are no data that distinguish between those working and not working, it is estimated that 15 percent of people with AIDS have private health insurance and roughly 30 percent have no insurance at all. Those with private insurance may have restrictions on their coverage (e.g., no prescription drug coverage) that limit their access to adequate care.

Government programs are the primary source of health care coverage for people living with HIV/AIDS overall. As you know, nearly 50 percent of people living with AIDS receive Medicaid benefits. Another five percent are eligible for Medicare.

Many of those who are not on Medicaid or Medicare and are uninsured or underinsured rely on clinics and programs funded by the Ryan White CARE Act to receive outpatient care. In addition to supporting outpatient clinics, Ryan White funds AIDS drug purchase assistance programs in all the states, which pay for prescription drugs not covered by a third party payer. The demand on these programs is so great that several states have exhausted their funds for the program months before the end of the current grant period. Some states also use CARE Act funds to help those with private coverage meet their COBRA premiums, thus reducing the demand on Medicaid.

In addition, many people with AIDS, because they lack third party coverage, depend on public hospitals for inpatient care. A report by the National Public Health and Hospital Institute found that hospitals — both private and public — lose an average of \$92,000 a year on care of AIDS patients, with public hospitals incurring much higher costs.

THE WHITE HOUSE
WASHINGTON

November 29, 1995

MEMORANDUM FOR THE PRESIDENT

THROUGH: Carol Rasco

FROM: Patsy Fleming 

SUBJECT: New Therapies for HIV Infection

Carol told me of your interest in the new anti-HIV drugs which have received considerable press lately. This is a summary of anti-HIV drug approval status and relevant clinical information. (Drugs for HIV-related opportunistic infections are not included.) Because the news stories have been confusing, I'll begin with the FDA process.

■ *FDA Approval Process*

Data on new drugs are reviewed concurrently by FDA staff and an outside panel of experts (for anti-HIV drugs this is the FDA Antiviral Drug Advisory Committee). The Advisory Committee then forwards their recommendation for approval to the FDA which is not obligated to accept the committee's recommendations, but usually does so. (The FDA may also grant approvals and expanded labelling without committee comment.)

Accelerated Approval

Accelerated approval is a program that lets companies seek approval of drugs for serious or life-threatening illnesses based on surrogate or laboratory markers (in AIDS these are often a measure of CD4+ which is a type of white blood cell also called a T-cell, and/or a measure of how much virus is in the bloodstream) rather than more traditional clinical measures (in AIDS these tend to be death or the occurrence of opportunistic infections like pneumonia). For drugs approved under this program, the company is required to do follow-up studies that determine whether there is truly a clinical benefit. If the subsequent studies do not prove a clinical benefit, the FDA may withdraw the approval. However, approval has never been withdrawn and there is much concern that drug companies will not conduct these clinical studies after the drug becomes available through accelerated approval.

The advantage to this program is that drugs get out to people more quickly, and, because it is an FDA-approved therapy, insurance companies and Medicaid are more likely to cover the cost. ddI, ddC, D4T, and 3TC have all received accelerated approval. Approval for 3TC took only 140 days. (See attached chart for newly approved drugs and those in development.)

■ *Anti-Retroviral Therapies*

The life cycle of the virus provides a number of potential attack points for therapies. So far two classes of drugs have been developed -- nucleoside analogs and protease inhibitors.

Nucleoside Analogs

Nucleoside analogs work by inhibiting an enzyme, called reverse transcriptase, which is needed by the virus to replicate. Until recently, all drugs for HIV infection have been in this class. The currently approved nucleoside analogs are:

AZT (zidovudine or Retrovir)

ddI (didanosine or Videx)

ddC (zalcitabine or Hivid)

d4t (stavudine or Zerit)

3TC (lamivudine or Epivir) - Accelerated approval recently recommended for use in combination with AZT. Confirmatory clinical trials pending.

AZT is the oldest of the approved drugs. AZT is approved for single use and to prevent vertical transmission (where infection passes from mother to baby) while ddI, ddC, and D4T are approved for single use after AZT has failed or the patient has become intolerant to AZT. 3TC has been recently recommended for use only in combination with AZT; FDA action is pending.

Because the virus is adept at mutating, treatments like nucleoside analogs work only for a limited period of time. The good news is that studies have shown that combination therapy (the use of more than one anti-retroviral drug at a time) may improve the effectiveness of treatments. It appears that 3TC, when taken with AZT, forces the virus to mutate in a way that makes it more vulnerable to AZT, thereby increasing the effectiveness. However, much is yet to be learned about when to start therapy (since development of resistance is common), which combinations to use and at what dose, and in what order in order to provide the best clinical outcome for the patient.

Protease Inhibitors

The second class of drugs, which attack at a later stage in the viral life cycle than nucleoside analogs, are protease inhibitors. This type of drug works by blocking HIV proteinase, which is needed by the virus at the assembly stage to replicate.

The excitement about protease inhibitors is due to the fact that they are the first new class of anti-HIV drugs to reach clinical testing. Moreover, the efficacy of nucleoside drugs is limited and most have toxicities. The only protease inhibitor that has a New Drug Application filed with FDA so far is saquinavir. It was recommended for accelerated approval by the FDA Antiviral Drug Advisory Committee. The FDA is currently reviewing the data and is expected to make a decision soon. (See attached chart for status of protease inhibitor development.)

Because the mechanism of action of these two classes of drugs is different, it is possible that they may be more effective when used in combination. However, this is not proven yet and clinical trials will be needed to confirm what is now theoretical.

■ **Summary of New Anti-HIV Drugs**

Anti-Retroviral Class	Trade and Other Names	Company	FDA Antiviral Drugs Advisory Committee Status	FDA Approval Status
<i>Nucleoside Analogs</i>				
3TC	Epivir lamivudine	Glaxo Wellcome	Recommended for accelerated approval in combination with AZT	Received accelerated approval in combination with AZT
<i>Protease Inhibitors</i>				
saquinavir	Invirase	Hoffmann-La Roche	Recommended for accelerated approval	Pending
indinavir	Crixivan	Merck	NA -- No application submitted, early human studies underway	NA
ABT 536	Ritonavir	Abbott	NA -- No application submitted, early human studies underway	NA
VX 478		Glaxo Wellcome/Vertex	NA -- No application submitted, early human studies underway	NA
AG1343	Viracept	Argouron Pharmaceuticals, Inc.	NA -- No application submitted, early human studies underway	NA

THE WHITE HOUSE
WASHINGTON

October 20, 1995

MEMORANDUM FOR ALL STAFF

FROM: JODIE R. TORKELSON
ASSISTANT TO THE PRESIDENT FOR
MANAGEMENT AND ADMINISTRATION

SUBJECT: After hours and weekend access to the OEOb

Due to the outstanding need for passholders to have access to the OEOb after normal working hours and on weekends, we have negotiated the following guidelines with the Secret Service.

The South Court gate may be used as an entrance for passholders, during its hours of operation (see below), only when the 17th & G entrance is closed. The 17th & G entrance to the OEOb is open from 7:00am to 9:00pm, Monday through Friday, and 7:00am to 8:00pm on Saturday. Therefore, passholders may access the South Court gate from 9:00pm to 10:30pm, Monday through Friday, 8:00pm to 10:30pm on Saturday, and 7:00am to 10:30pm on Sunday.

Visitors should continue to use the Southwest Gate to enter the complex after 9:00pm, Monday through Saturday, and all day on Sunday. The South Court is not equipped with the necessary equipment to receive visitors.

Please review the following gate times for the complex:

Pennsylvania Avenue	7:00am - 8:00pm
17th & G	7:00am - 9:00pm, Monday through Friday; 7:00am - 8:00pm Saturday; closed on Sunday
North Court	5:30am - 5:30pm (Exit only, Exception: Passholders may enter this gate from 5:30am until 17th & G opens)
South Court	7:00am - 10:30pm
Southwest	24 hours/7 days
Northwest	24 hours/7 days
East Appointment	24 hours/7 days
NEOB	24 hours/7 days

Please call Management and Administration with any questions at x62861. Thank you for your cooperation.

THE WHITE HOUSE

WASHINGTON

JUL 17 1995

Dear Friend:

Thank you for requesting a message from the President.
I am happy to send you the enclosed.

Please be aware that the White House has long-standing guidelines governing the use of Presidential messages. The enclosed message may be used only at the time for which it was requested and for the specific purpose for which it was sought. Under no circumstance is the message to be altered, used for recruiting, reproduced for fundraising solicitations or annual reports, represented as an endorsement, used for advertising, or used for any other purpose without the written consent of the White House.

Thank you for your cooperation in adhering to these guidelines.

Sincerely,

A handwritten signature in dark ink, appearing to read "J. Dorskind", written in a cursive style.

James A. Dorskind
Special Assistant to the President
Director of Correspondence and
Presidential Messages

Enclosure

THE WHITE HOUSE

WASHINGTON

July 13, 1995

As we mark the eighth observance of World AIDS Day, I encourage communities across this nation and around the world to join in reaching out to people living with HIV and AIDS and in remembering those we have lost to this tragic epidemic.

Although the search for a vaccine and efforts to prevent further infection are moving forward, the rights of those who are affected by the disease remain among our primary concerns. This year's theme, "Shared Rights, Shared Responsibilities," highlights the importance of cooperation in ending discrimination and in fostering greater compassion and hope.

By raising awareness of the realities of AIDS, we serve to safeguard the human rights of people everywhere. We all have a role to play -- as individuals and as citizens, in our families and our communities, through governmental and nongovernmental organizations. We must support one another, offering the care, the dignity, and the peace of mind that everyone deserves. No one person can win this fight alone. It is only by working together that we will ensure continued progress toward a cure.

Bill Clinton

FILE COPY

THE WHITE HOUSE
WASHINGTON

October 3, 1995

MEMORANDUM FOR ALICE RIVLIN

FROM: Patsy Fleming 
SUBJECT: AIDS Funding in FY 1997

As the Office of Management and Budget begins its FY 1997 budget review, I want to share with you my hope for continued Administration leadership in fighting for increased spending for HIV/AIDS programs. As you know, two areas of AIDS programs are already considered investment priorities: the Ryan White CARE Act programs and research at NIH. Both need a continued commitment to increased funding. The newly appointed Presidential Advisory Council has identified prevention programs and housing for people with AIDS as two additional areas that require the commitment and protection accorded formal investment priorities during our budget deliberations. I fully agree with them about the centrality of these issues to a comprehensive response to the epidemic.

Prevention: Without a vaccine, prevention programs are critical to stemming the tide of HIV. After years of frankly discouraging performance, the CDC has reorganized its programs and reformed its approach to funding prevention programs through state and local health departments. We must make a continued effort to increase funding to assure the success of these new initiatives. With an ever increasing number of new cases affecting substance abusers, both CDC and SAMHSA must have resources to address these populations without losing ground gained among others -- for whom reinforcement of prevention efforts (and reaching new generations) must continue.

Housing: A number of years ago, the National Commission on AIDS found that nearly one-third of people with AIDS were homeless or at risk of homelessness. Without the housing and related services supported by programs like Housing Opportunities for People with AIDS, the success of our prevention and services programs can be rendered ineffective. The Administration took a strong stand in opposing the proposals to eliminate this program during the rescission fight; I hope we will continue to support increased funding as the need grows -- especially as the epidemic strikes more populations at greater risk of homelessness.

I also want to reemphasize the importance of continuing our investment in care and research programs.

Ryan White CARE Act: Especially as Congress moves to cut Medicaid spending, the need for safety net programs such as the Ryan White CARE Act will only increase. With new advances

in treatment, such as the protocol that can reduce transmission of HIV from pregnant women to newborns, the importance of CARE Act programs becomes even greater. I hope that our budget proposals will continue to keep us ahead of the curve by taking into account increasing caseloads, not just inflation.

National Institutes of Health: We are beginning to see the fruits of this investment -- including our tremendously increased knowledge of how HIV works in the immune system, the NIH-funded research that showed how to reduce the risk of transmission of HIV to newborns from infected mothers, the promise of a new class of anti-HIV therapies (protease inhibitors), and our significantly improved ability to manage and prevent the opportunistic infections associated with HIV. We cannot lose ground. We must continue to see increases (beyond inflation) in AIDS research funding to take advantage of these life-saving and life-extending scientific opportunities.

While growth in spending is an increasing challenge, with more than 76,000 new cases of AIDS diagnosed in the last year, along with an estimated 40,000 new HIV infections, the need for spending to keep pace with the growth in the epidemic is clear. Again, it is my hope that you will be able to support treating prevention and housing programs -- along with Ryan White and NIH -- as investment priorities during the FY 1997 budget cycle.

I am happy to work with you to assure that the justification for supporting increases in these programs is clear and consistent with what I know are the President's priorities.

n:rivlin.f97

THE WHITE HOUSE

WASHINGTON

July 5, 1995

Dear Mr. Leader:

I am writing to urge you to lead the Congress in passing the reauthorization of the Ryan White CARE Act before the summer recess. We cannot allow this crucial program to lapse.

There is strong bipartisan support for the Ryan White CARE Act. The initial legislation was approved by overwhelming margins in both houses (95-4 in the Senate and 408-14 in the House) and signed into law by President Bush. Funding for this program has been endorsed from both sides of the aisle throughout the five years of the program and the reauthorization bill in the Senate has 60 co-sponsors. It is a program vital to the lives of Americans living with HIV and AIDS. Its existence has had a dramatic impact on the quality and length of their lives while helping to reduce the cost of their care.

The CARE Act provides direct services to people living with HIV and AIDS through grants to states, cities, community organizations, and local clinics. It emphasizes outpatient care in clinics and other facilities and is designed to relieve the burden on public hospitals and other more expensive inpatient facilities.

It has been a tremendous success in meeting this mandate. By lessening the demand on public hospitals and other facilities, valuable inpatient resources have been freed to care for patients with other diseases, and people with HIV and AIDS have been able to lead more productive lives in their communities. The CARE Act approach serves as a model for delivering more cost-effective health care for people with all diseases.

In 1994, the CARE Act provided care to more than 200,000 uninsured and underinsured people living with HIV or AIDS and early intervention services to another 85,000 people. The Act also funded HIV counseling and testing to nearly 100,000 Americans, provided pharmaceutical assistance to 75,000 individuals, and supported more than 15,000 women and children participating in AIDS-related clinical trials.

Let me share with you the story of one person who has been helped by this program -- one person whose experience with the CARE Act is typical of literally hundreds of thousands of other

The Honorable Bob Dole
Page Two

Americans who have benefitted from this law. "Debbie" is a 27 year old woman living with AIDS in a rural part of South Carolina. Until recently, few doctors in Debbie's hometown were willing to treat AIDS patients in part because so many were uninsured. With funding from the Ryan White CARE Act, the County Health Department opened a clinic in the town of Orangeburg that operated six days a month with a rotating staff of five physicians and three nurses. The clinic's staff has taught Debbie's mother to care for her daughter at home. When Debbie is too sick to come to the clinic, the staff comes to her. Not only has this prevented more costly hospitalizations, but it provides Debbie and her mother peace of mind. Debbie's Mom calls the clinic's staff her "guardian angels."

The Ryan White CARE Act is a model of compassionate caring for people in need. At a time when AIDS is the leading cause of death of young adults, we cannot let reauthorization of the CARE Act be held up by divisive arguments about how people contracted HIV. Nor should we be deterred by the false argument that people with HIV and AIDS are getting more help than those with other diseases. In fact, total federal spending in FY 1995 for research, treatment, prevention, Medicaid, Medicare, and income supplements for AIDS is less than one-third that for cancer and less than one-sixth that for heart disease. (AIDS spending is \$6 billion, cancer is \$17.5 billion, and heart disease is \$38 billion.)

In the United States, an average of 220 Americans are being diagnosed with AIDS every day and an average of 109 Americans are dying of this disease each day. Now is not the time to retreat in our national response to this terrible disease. We must move forward to meet the very real needs of Americans living with HIV and AIDS. We can certainly do more, we cannot do any less.

I hope you will join me in urging the Congress to move forward promptly with a five-year reauthorization of this vital program without complicated amendments so that we can once again show the American people that their government can provide the assistance they deserve.

Sincerely,

Bill Clinton

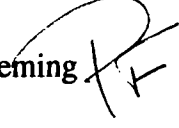
The Honorable Bob Dole
Majority Leader
United States Senate
Washington, D.C. 20510

THE WHITE HOUSE

WASHINGTON

AUG - 8 1995

MEMORANDUM FOR BOB NASH

FROM: Patsy Fleming 

SUBJECT: President's Advisory Council on HIV/AIDS

I am forwarding to you two letters on behalf of nominees to the President's Advisory Council on HIV/AIDS. I am told your office has a standard response to such nominees.

At this time, I am not proposing adding any additional people to the Council -- beyond those already announced and those still in the review process.

Thanks.

n:\nash

June 16, 1995

MEMORANDUM FOR THE PRESIDENT

FROM: Patricia S. Fleming

SUBJECT: AIDS-related Issues for U.S. Conference of Mayors Meeting

I. SUMMARY

In preparation for your meeting with the U.S. Conference of Mayors, I wanted to brief you on several AIDS-related issues that may arise. Mayors are particularly interested in the short-term and long-term future of the Ryan White CARE Act at HHS; the Housing Opportunities for People with AIDS program at HUD; the Administration's proposal for a Performance Partnership Grant that includes AIDS prevention programs at CDC; and existing prohibitions against use of Federal funds for clean needle exchange programs.

II. DISCUSSION: RYAN WHITE CARE ACT

The Mayors have been among the strongest supporters of the Ryan White CARE Act since its enactment in 1990. They have approved a resolution endorsing reauthorization of the program and approving of the Administration's fiscal year 1996 budget request for this program.

Title I of the program provides direct assistance to 42 cities that are hard hit by the epidemic (defined as a cumulative caseload of 2,000 or more). Title II of the program directly funds states but some of that money also makes its way to Title I cities. During your Administration, funding for the Ryan White CARE Act through FY1995 has increased 108 percent, bringing the program to full funding. In the FY1996 budget alone, you have proposed a 14 percent increase in Ryan White funding. That includes a \$50.5 million increase in Title I. And the number of Title I cities has increased from 25 to 42.

Legislation is pending in both houses of Congress to reauthorize this program for five years. The Senate bill -- coauthored by Senators Kassebaum, Kennedy, and Hatch -- was approved by the Labor & Human Resources Committee by a unanimous vote but has been held off the floor by a "hold" by Senator Helms. Senator Kassebaum plans to meet with Senator Helms to try to persuade him to allow the bill to come to the floor. There are currently 59 co-sponsors and the Majority Leader has indicated that he wants 60 sponsors before he goes to the floor. The House bill has only recently been introduced and is pending in the Commerce Committee.

Mayors may be concerned about some of the formula changes being considered. The Administration has remained neutral on formula issues and has been sharply criticized by state and local officials for that stance. Both the House and Senate bills would create a "single appropriation" for Titles I and II. This would eliminate much of the fighting between proponents of the two titles over appropriations but has some city officials worried. Other provisions would reduce the amount of "double-counting" in the Ryan White formulas so that states with Title I cities would receive smaller Title II grants. This has Mayors and Governors from those states nervous.

III. DISCUSSION: HOPWA

Many Mayors will be concerned about the future of the Housing Opportunities for People with AIDS (HOPWA) program at the U.S. Department of Housing and Urban Development. Created in 1990, this program provides funding to 43 cities and 23 states and to a number of non-profit community-based organizations to provide housing for low-income individuals and families affected by AIDS.

The FY1996 request for HOPWA is \$186 million, which is the same amount appropriated for FY1995.

HOPWA is one of the programs involved in the FY1995 rescissions fight. The House originally voted to rescind all \$186 million; the Senate voted to retain full funding. Conferees compromised on a \$30 million cut. That reduction was one of 13 items cited by you in your message to the Congress warning of a veto.

HOPWA is also one of several HUD programs scheduled for reauthorization this year. HUD has proposed to keep the program intact for two more years and then fold it into a larger community housing program. Efforts to eliminate this program are expected in both houses of Congress.

IV. DISCUSSION: PERFORMANCE PARTNERSHIP GRANTS

Mayors have been a central player in our effort to prevent the spread of HIV and AIDS. Seven cities (New York, San Francisco, Los Angeles, Philadelphia, Chicago, Houston, and Atlanta) receive direct funding from CDC for AIDS prevention activities. The Mayors have been very supportive of the Administration's creation of the Community Planning Process, which has empowered state and local health departments, working with community representatives, to help design prevention strategies that are appropriate for each community.

The Administration's proposal to create a Performance Partnership Grant that combines HIV/AIDS with tuberculosis control and STD prevention programs has some Mayors concerned. They are particularly concerned about the proposal to eliminate direct funding of cities and send all money to the states after three years.

V. DISCUSSION: NEEDLE EXCHANGE PROGRAMS

Congress has placed restrictions on the use of Federal funds for programs that exchange clean hypodermic needles for used needles. Such programs have been funded by several cities and one or two states as well as numerous non-profit organizations. Federal statutes require HHS to prove that such programs will reduce transmission of HIV, reduce use of injectable drugs, and not result in new injection drug users. Dr. Philip Lee, the Assistant Secretary for Health, has determined that we cannot yet meet those tests.

The Conference of Mayors is considering a resolution calling for a lifting of the ban on use of Federal funds for needle exchange programs.

file copy

THE WHITE HOUSE
WASHINGTON

August 8, 1995

MEMORANDUM FOR THE PRESIDENT

THROUGH: Carol Rasco

FROM: Patricia S. Fleming, *Patricia S. Fleming* Director, Office of National AIDS Policy

SUBJECT: Recommendations of the Presidential HIV/AIDS Advisory Council

I want to report to you on the recommendations of the Presidential HIV/AIDS Advisory Council and our plans to respond to them. Members of the Council were pleased with their first meeting and delighted with the opportunity to discuss their recommendations with you.

A copy of the Council's recommendations including preamble and goals is attached. The Council made eight recommendations, most of which are already the policy of the Administration and some of which are actively under discussion.

(1) The President himself must engage the American public through a National Summit that encompasses the scientific, medical, social, and political aspects of the AIDS epidemic.

The objective of this recommendation is to communicate the need for Presidential leadership in refocusing the attention of the American people on the epidemic. A summit would be one approach. This would be an important opportunity to communicate to both the American people and the AIDS community the Administration's commitment to fighting this epidemic and the importance of a commitment from all Americans to join in the fight. My office will discuss this with other White House staff to come up with possible options for conducting a summit and the various forms this could take in response to this recommendation.

(2) The President should then proceed with an address declaring the battle against HIV a national health priority and laying out his vision for the end of this epidemic.

Council members were nearly unanimous in their view that the Administration has done a good job in putting the right policies and priorities in place but they feel strongly that we have failed to communicate those successes. A major address by you would serve both to highlight what has been accomplished and to set a path for future efforts. Like Franklin Roosevelt's campaign against polio and Richard Nixon's war on cancer, you could chart your vision for a world free of HIV and AIDS that would tie together what we are doing and what we will do in the future.

Other opportunities for visibility include the signing of the Ryan White CARE Act in September and the release of the report on the state of the epidemic among adolescents, which should be ready this fall.

(3) The President should make HIV prevention an investment priority in his FY 1997 budget.

While AIDS prevention programs have not been an investment priority -- unlike AIDS research and the Ryan White CARE Act -- funding for prevention programs has been increased 18.4% (25% including the FY 1996 budget request). In FY 1994, however, the Administration did not request an increase in prevention funding based, in part, on the need to address structural problems with the prevention effort. With those problems addressed by a CDC reorganization and introduction of community planning, the time is ripe for a greater investment and focus on prevention. More needs to be done regarding emerging problem populations -- substance abusing men of color, women of color, adolescents, and young gay men. In addition, the Public Health Service is in the process of developing a demonstration program that would merge funding streams from CDC, SAMHSA, and HRSA into a comprehensive approach to prevention among substance abusers.

(4) The President should continue his support of the Ryan White CARE Act and should endeavor to prevent the Congress from attaching unnecessary funding restrictions.

You have done this. While Congress may not match your budget requests for the CARE Act, we are working with HHS and OMB to assure that the Administration's budget reflects the need for additional resources as the epidemic grows. In addition, as resources become tighter, my office is working with PHS to assure that the CARE Act focuses on essential primary care and supportive services for those most in need.

(5) The President must maintain a strong commitment to the entitlement status of the Medicaid program, including a willingness to veto any legislation that inadequately funds or transforms Medicaid into a block grant.

I think the Council was quite encouraged by the Administration's position on Medicaid. The stakes for people with AIDS are very high in this debate -- since over half of people living with AIDS are dependent on Medicaid for their health care, including over 90 percent of children with AIDS.

(6) The President must continue to demonstrate his strong support for the Housing Opportunities for People with AIDS (HOPWA) and other Federal housing programs that serve people living with AIDS. The President should make housing for people with AIDS a FY 1997 budget priority.

The Council was pleased with the Administration's support for these programs. As a result of a floor amendment to the House VA-HUD appropriations bill, so far funds for FY 1996 may match the Administration's request for the HOPWA program. Unfortunately, that is not the case for other housing programs on which people with AIDS are dependent. My office is working with HUD and OMB to be sure that our FY 1997 request continues to reflect this priority. There is an additional concern with the Administration's proposal for a merging of a number of housing assistance programs into the Affordable Housing Fund, which would

ultimately include the AIDS housing programs in FY 1998. More work needs to be done to assure that the housing needs of people with AIDS will be met in this new structure.

(7) The President should continue to show strong support for a coordinated Federal approach to HIV/AIDS research, including continued support for the Office of AIDS Research (OAR).

The Council was pleased with the Administration's defense of the AIDS research budget at NIH during the House Appropriations Committee consideration of the Labor-HHS bill. Issues still remain regarding the Department of Defense's research program. Neither the House nor the Senate defense appropriations bills contain sufficient funds to continue DOD AIDS research at the current level. However, the House Appropriations Committee inserted into the Labor-HHS bill a requirement that the NIH fund the remainder of the DOD research effort. My office is working with NIH, DOD, and OMB to try to work out this issue.

(8) In talking publicly about HIV, the President should vigorously speak out against HIV-related discrimination and condemn prejudice based on race/ethnicity and sexual orientation, which damages our efforts to combat AIDS.

This is something the Council, during its deliberations, acknowledged is very much a part of your response to the epidemic. Your continued visibility in this area is important for countering the rhetoric of people like Jesse Helms and giving the AIDS community a sense of real support from the government. In addition, the Council heard a very impressive presentation from the Justice Department on the scope of legal efforts to enforce the Americans with Disabilities Act as it relates to people with HIV.

One issue raised during your meeting with the Council was the matter of discriminatory HIV testing policies by several Federal agencies. Earlier this year, I convened a working group of representatives from the Departments of State, Defense, Labor, and Justice to discuss their policies with representatives of the Public Health Service. Several of these policies seem arbitrary and absent necessary protections for the individuals involved. We are working to resolve these matters and will have a plan for you shortly.

Attached for your information is a letter from you to the Council members thanking them for their recommendations and pledging to work toward their implementation. This draft is working its way through channels in Presidential correspondence. I will follow up with a lengthier memo to the Council detailing the steps we are taking to move on the recommendations. We will also be developing for your approval a more detailed proposal in response to the summit proposal.

Attachments:

Council recommendations

Draft response to Council

Memorandum for the President/August 8, 1995/Page 4

Draft letter to council members

Dear ----

I am pleased to have received the recommendations on HIV/AIDS policy and initiatives developed during the July 27-28 meeting of the Presidential HIV/AIDS Advisory Council.

I am impressed with the breadth, clarity, and specificity of your suggestions. As we develop our response to them, I want to assure you of my commitment to work with you to achieve the many goals we have in common.

I have asked Patsy Fleming to develop an action plan in response to these recommendations. She will be communicating with you our plans in the very near future.

Thank you for your hard work and I look forward to meeting with you again when we can demonstrate our implementation of your recommendations.

Sincerely,

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

REPORT ONE

INITIAL STEPS FOR PRESIDENTIAL ACTION

JULY 28, 1995

OUR MISSION

Our mission is to provide information and recommendations to the President regarding programs and policies to promote effective prevention of HIV disease, advance research on HIV and AIDS, and promote quality services to persons living with HIV disease and AIDS.

PREAMBLE

With over 250,000 Americans having died of AIDS, an estimated 1 million more currently infected, and over 40,000 new infections each year, it is critical that the President of the United States commit to use his personal leadership to raise the level of public education, compassion and concern.

He must make the battle against AIDS one of the most visible and continuing priorities of his Presidency. The cost to our country, in life, in lost productivity, in financial terms, in anguish and in grief, is incalculably large.

The Council will work intensively with the President over the coming months to issue more recommendations. Because we do not have the luxury of time, we are issuing a few initial recommendations for the President that require immediate attention. We believe that visible and courageous leadership on the part of the President can and must provide the spark that ignites the American people and brings them together in unprecedented partnerships between people with HIV, health care providers, researchers, foundations, business, spiritual leaders, community activists, political leaders of both parties, and Americans of all races and sexual orientations.

The majority of our recommendations will be presented in the coming months. After these first two days of meetings we feel compelled to advocate the following goals and actions:

D. RESEARCH

- The President should continue to show strong support for a coordinated federal approach to HIV/AIDS research, including continued support for the Office of AIDS Research (OAR).

E. COMBATING DISCRIMINATION / SOCIAL PREJUDICE

- In talking publicly about HIV, the President should vigorously speak out against HIV-related discrimination and condemn prejudice based on race/ethnicity and sexual orientation which damage our efforts to combat AIDS. The President should strongly and visibly oppose any amendments to HIV-related legislation which are designed to divide the American people along lines of sexual orientation, substance use history, race/ethnicity, or other factors.

GOALS/RECOMMENDED ACTIONS (cont.)

B. Prevention

- **The President makes HIV Prevention an investment priority during budgetary decision making.**

The President's investment priorities -- including biomedical research and the Ryan White CARE Act -- have consistently received significant funding increases. HIV prevention programs, such as specific population based targeted programs, demand a similar level of commitment.

C. SERVICES

- **The President should continue his support of the Ryan White CARE act and should endeavor to prevent the Congress from attaching unnecessary funding restrictions. He should also continue to vigorously support funding levels for the Ryan White CARE Act that are responsive to the rising caseloads and costs of delivering comprehensive services to people with HIV/AIDS and make it a budget priority.**
- **The President must maintain a strong commitment to the entitlement status of the Medicaid program, including a willingness to veto any legislation which inadequately funds or transforms Medicaid into a block grant.**
- **The President must continue to demonstrate his strong support for the Housing Opportunities for People with AIDS (HOPWA) and other federal housing programs that serve people living with AIDS. The President should make housing for People with AIDS an FY 97 priority.**

GOALS/RECOMMENDED ACTIONS

A. LEADERSHIP

Much of America has lapsed into a complacency about AIDS even while the epidemic continues to expand its path of devastation. The President must commit to use his personal leadership to raise the level of public education, compassion, and concern by pledging to make the battle against AIDS one of the most visible and continuing priorities of his Presidency. He should courageously ask the American public to confront the difficult issues of sexuality, drug use, and social and racial prejudice that profoundly damage our ability to combat the disease. More important than a single media event, however, is an ongoing commitment and strategy from the President to seek out opportunities to **frequently** confront the AIDS crisis wherever appropriate. Therefore we recommend that:

- **The President himself must engage the American public through a National Summit which encompasses the scientific, medical, social and political aspects of the AIDS epidemic. This Summit, which should be held by the end of this year, should consider the impact of race, culture, poverty, disability, region, gender, sexual orientation, and age on our ability to develop an effective national AIDS strategy.**
- **The President should then proceed with an address declaring the battle against HIV a national health priority and laying out his vision for the end of this epidemic.**

THE WHITE HOUSE
WASHINGTON

July 10, 1995

MEMORANDUM FOR ALL AGENCY AND DEPARTMENT HEADS

FROM: Patricia S. Fleming 
Director, Office of National AIDS Policy

SUBJECT: AIDSWALK DC

AIDSWALK is a fundraising event benefitting the Whitman Walker clinic and other HIV/AIDS service organizations. It will be held on September 23, 1995. The Office of Personnel Management (OPM) has given approval for the organizers of AIDSWALK in Washington, DC to fund raise within the Federal workplace for their event during the months of July and August only.

AIDSWALK is an extremely important local event that supports HIV prevention, research, and service for our neighbors, colleagues, and families.

More information on AIDSWALK can be obtained from Mike Frederickson at (202) 797-3508. If you have any other questions on HIV, please feel free to contact the Office of National AIDS Policy at (202) 632-1090.

Please join in making this effort a success.

THE WHITE HOUSE
WASHINGTON

April 21, 1995

MEMORANDUM FOR HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

FROM: PATRICIA S. FLEMING



SUBJECT: FEDERAL WORKPLACE HIV/AIDS EDUCATION INITIATIVE

On September 30, 1993, President Clinton directed all Federal Departments and Agencies to provide their employees with comprehensive workplace education on AIDS and HIV. I am pleased to report that this effort has proceeded very well and is nearly complete. As of March 31, nearly 75 percent of Federal employees have participated in HIV/AIDS education programs. This is a tremendous achievement and one in which we should all take pride.

AIDS remains the number one national public health problem in our country. The Centers for Disease Control and Prevention reported recently that AIDS is now the leading cause of death among Americans between the ages of 25 and 44. Last year, more than 40,000 Americans lost their lives to this insidious disease and nearly 81,000 other Americans were diagnosed with AIDS. These shocking statistics remind each of us of the importance of education of working-age Americans.

The response to the Federal Workplace HIV/AIDS Education Initiative has been very positive. My office has received numerous letters and telephone calls from Federal employees discussing their positive experiences and stressing the usefulness of this information for them, their families, and their communities. There also have been a small number of complaints from employees who, for whatever reason, do not wish to participate in these classes. Let me take this opportunity to commend each of you for the sensitive way in which these occurrences were handled.

Under the terms of the President's memorandum, AIDS training was to be completed by March 31. Since the initial training period is complete, we must now move into a second stage of integrating such training into the workplace consistent with training on such subjects as substance abuse, sexual harassment, and other topics.

Memo for Heads of Executive Departments and Agencies

April 21, 1995

Page 2

Individual agencies should determine the scope of and participation in this stage of training for all personnel within their agencies. The standard chosen by the agencies should be consistent with personnel policies for similar training programs. Each of us should continue to strongly encourage current and future employees to participate in HIV/AIDS education.

If you need further information or assistance in this area, please feel free to contact my office at (202) 632-1090.

Thank you, again, for your cooperation and assistance in this important endeavor.

THE WHITE HOUSE
WASHINGTON

April 21, 1995

MEMORANDUM FOR HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

FROM: PATRICIA S. FLEMING



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Memo for Heads of Executive Departments and Agencies

April 21, 1995

Page 2

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If you need further information or assistance in this area, please feel free to contact my office at (202) 632-1090.

Thank you, again, for your cooperation and assistance in this important endeavor.

**OFFICE OF NATIONAL AFFAIRS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
Washington, DC 20503

Phone: 202-632-1090
Fax: 202-632-1096

FACSIMILE COVER SHEET

TO: The Secretary, Department of State

FAX NUMBER: 202/647-5939

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
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FACSIMILE COVER SHEET

TO: The Director, Central Intelligence Agency

FAX NUMBER: 703/749-9582

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Agriculture

FAX NUMBER: 202/720-2166

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Commerce

FAX NUMBER: 202/482-4576

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Defense

FAX NUMBER: 703/697-9080

FROM: Patricia S. Fleming

DATE: April 21, 1997

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL ACADEMIES
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FACSIMILE COVER SHEET

TO: The Secretary, Department of Education

FAX NUMBER: 202/401-0596

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Energy

FAX NUMBER: 202/586-4403

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Health and Human Services

FAX NUMBER: 202/690-7755

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt..

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Housing and Urban Development

FAX NUMBER: 202/708-2476

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt..

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EXECUTIVE OFFICE OF THE PRESIDENT**

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Interior

FAX NUMBER: 202/208-6956

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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EXECUTIVE OFFICE OF THE PRESIDENT**

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FACSIMILE COVER SHEET

TO: The Attorney General, Department of Justice

FAX NUMBER: 202/514-4371

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Labor

FAX NUMBER: 202/219-8822

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Secretary, Department of Transportation

FAX NUMBER: 202/366-7202

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Secretary, Department of the Treasury

FAX NUMBER: 202/622-0073

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: Director, USAID

FAX NUMBER: 202/647-1770

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: Director, Arms Control and Disarmament Agency

FAX NUMBER: 202/647-4920

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: The Administrator, Environmental Protection Agency

FAX NUMBER: 202/260-0279

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

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FACSIMILE COVER SHEET

TO: Chair, Equal Employment Opportunity Commission

FAX NUMBER: 202/663-4110

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

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FACSIMILE COVER SHEET

TO: Director, Federal Emergency Management Agency

FAX NUMBER: 202/646-3930

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
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750 17th Street, N.W.
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FACSIMILE COVER SHEET

TO: Director, General Services Administration

FAX NUMBER: 202/219-1243

FROM: Patricia S. Fleming

DATE: APRIL 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL ACADEMIES POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
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Phone: 202-632-1090
Fax: 202-632-1096

FACSIMILE COVER SHEET

TO: Director, Office of Personnel Management

FAX NUMBER: 202/606-2573

FROM: Patricia S. Fleming

DATE: April 21, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

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FACSIMILE COVER SHEET

TO: Director, General Services Administration

FAX NUMBER: 202/219-1243

FROM: Patricia S. Fleming

DATE: April 24, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt..

**OFFICE OF NATIONAL AFFAIRS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
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Phone: 202-632-1090
Fax: 202-632-1096

FACSIMILE COVER SHEET

TO: Director, Office of Personnel Management

FAX NUMBER: 202/606-2573

FROM: Patricia S. Fleming

DATE: April 24, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
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Phone: 202-632-1090
Fax: 202-632-1096

FACSIMILE COVER SHEET

TO: Administrator, NASA

FAX NUMBER: 202/358-2810

FROM: Patricia S. Fleming

DATE: APRil 24, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
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Phone: 202-632-1090
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FACSIMILE COVER SHEET

TO: Director, Federal Emergency Management Agency

FAX NUMBER: 202/646-3930

FROM: Patricia S. Fleming

DATE: April 24, 1995

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

Please call Carmena Parris to confirm receipt.

**OFFICE OF NATIONAL AIDS POLICY
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FACSIMILE COVER SHEET

TO: CHAIRMAN, FEDERAL COMMUNICATIONS COMMISSION

FAX NUMBER: 418-2801

FROM: PATRICIA FLEMING

DATE: 4-24-95

PAGES INCLUDING COVER SHEET: 3

COMMENTS:

THE WHITE HOUSE
WASHINGTON

June 21, 1995

MEMORANDUM FOR TONY LAKE AND ALICE RIVLIN

FROM: Carol H. Rasco *CHR*
Subject: Funding of USAID AIDS programs

As you know, the HIV epidemic is raging at almost unimaginable rates in Africa -- with some geographic areas seeing infection rates well over 50 percent. Beyond the human tragedy, this also has tremendous potential for political destabilization. USAID has supported a significant number of bilateral AIDS programs as well as given US support to UN-related multilateral efforts in an effort to stem this tide.

I understand that the international aid portions of the budget are very much in flux and that although the Administration is supporting full funding of international programs, this may, in the end, not be the result. Given the growing threat of HIV in Africa and also, increasingly, Asia, I hope that we will be able to protect USAID's AIDS-related funding as much as possible.

I would be deeply grateful for any personal attention you can give this matter.

cc: Patricia Fleming

*TO: Patsy
From: Carol Rasco*

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From: William A. Fletcher (to POTUS)

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Date of Response: 6-13-95

June 13, 1995

MEMORANDUM FOR THE PRESIDENT

FROM: Patricia S. Fleming

SUBJECT: NIH Response to Letter from Mr. William A. Fletcher regarding AIDS vaccine research.

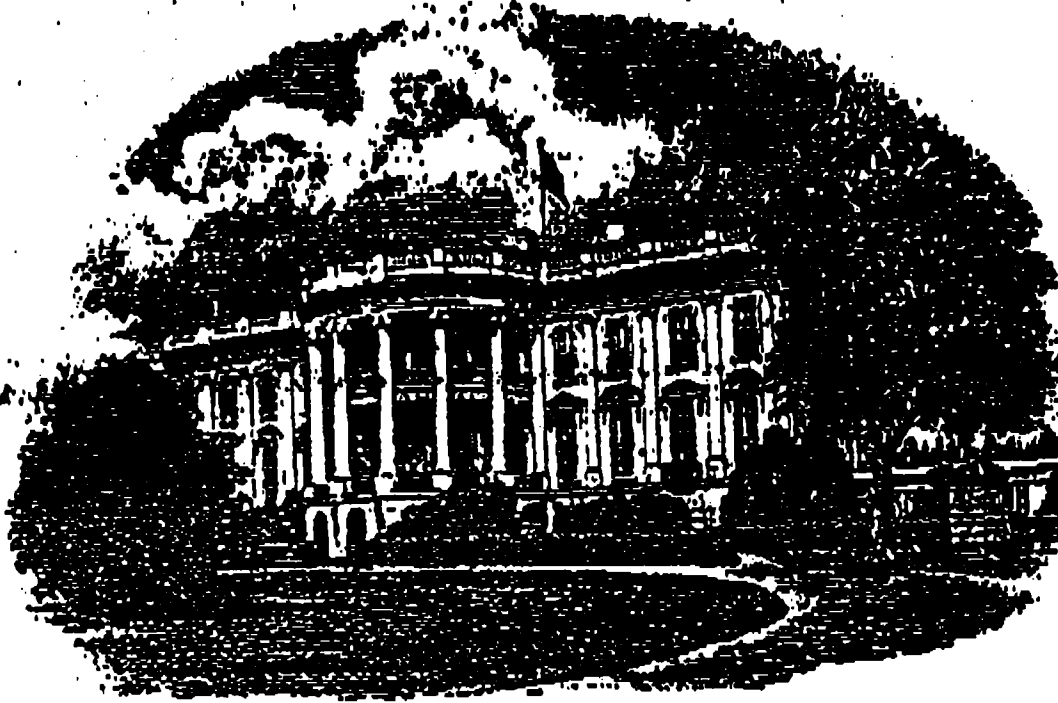
Following is the material provided by the Office of AIDS Research at the National Institutes of Health in response to the issues raised by Mr. William A. Fletcher in his recent letter.

Background

Developing a vaccine or vaccines that are safe and effective in preventing HIV infection in exposed individuals is a major public health priority in the national and international effort to combat this pandemic. NIH is exploring various strategies to stimulate a protective immune response against HIV infection through basic research, animal models, and clinical trials and to determine which strategies offer the most promise for further development. Vaccines also may serve as immunomodulators to improve immune function and diminish disease progression in HIV-infected individuals and may potentially prevent HIV transmission from mother to fetus. Approaches currently being pursued in the development of potential vaccines include the use of synthetic viral peptides, recombinant products, genetic recombinant products, and whole-killed virus.

The NIH research agenda for the development of AIDS vaccines has been carefully developed, based on advice and recommendations from eminent scientific experts in vaccine development. This consultative process has been ongoing and continues to build consensus on new scientific opportunities and breakthroughs in AIDS vaccines. Such notable experts as Jonas Salk, the late Albert Sabin, David Baltimore, Maurice Hilleman and John Robbins have participated in this process.

**THE EXECUTIVE OFFICE OF THE PRESIDENT
THE WHITE HOUSE
WASHINGTON**



Date 6-26-95
From Susan Beveridge
Number of pages including cover 3
Fax number 202/632-1096 Phone Number 632-1090
To: Commissioner J. Patsy Fleming
With National Aids Policy Office
Regarding William A. Fletcher
Comments As discussed - Please FAX NAPO's

response (if any) to my attention -
Thank you

Susan Beveridge

The attached correspondence received in the White House is faxed to your office for handling.
Please return the fax with a copy of your written response or telephone report to the following address:

Ms. Sue J. Smith
Director, Office of Agency Liaison
Room 6, OEOB
The White House
Washington, D.C. 20500

Telephone No.: 202/456-7486
Fax No.: 202/456-2992

Note: We do not have copy of the enclosures mentioned in
Susan Fletcher's letter. See -

JUN-26-95 MON 14:24

JUN-25-1995 16:13 FROM WHITE HOUSE AIDS POLICY TO

913014964843

P.02

UNIVERSITY OF CALIFORNIA

Pam -> Jim BC sig
Reply ASAP
Pam will see him at the end of June

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SANTA BARBARA • SANTA CRUZ

SCHOOL OF LAW (BOALT HALL)
 BERKELEY, CALIFORNIA 94720-7200
 FAX NO. (415) 642-4171
 TELEPHONE (415) 642-4030

June 1, 1995

President William J. Clinton
 The White House
 Washington, D.C. 20500-2000

Dear Bill:

Linda and I were delighted to see Hillary in San Francisco on Saturday. She got great coverage in the papers and on the local TV news for her commencement speech at San Francisco State. Good job! I mentioned briefly to Hillary the following important problem with AIDS vaccine.

I have learned from a friend who does vaccine research and development that American AIDS researchers have not seriously tried to develop old-fashioned whole, killed virus vaccine. (The Salk polio vaccine is of this type.) The explanation for this somewhat incredible state of affairs appears to be:

Government-funded development: NIH has not been willing to fund development of whole, killed-virus vaccine. The basic technology of developing whole, killed-virus vaccine is known, and NIH appears to be more interested in funding cutting-edge basic research. This does not make much sense to me, but the fact is that NIH has not provided funds. DOD has begun work to develop a traditional vaccine; that effort is under serious budget pressure from Congress and within DOD, and it may not survive.

Private development: No private company is working on development of whole, killed-virus vaccine. The financial incentives for private companies are just not there. Profits are low, and perceived threat of liability is very high. (California genetic engineering companies Genentech and Chiron are working on high-tech, genetically engineered "subunit" vaccines. These may or may not work; preliminary results are not very promising.)

I spoke on Friday with Donald Kennedy, the former President of Stanford and former head of the FDA. He confirmed this story. He is convinced there is a small but real chance that an old-fashioned whole, killed virus vaccine will work. There is no question in his mind that it is an avenue worth pursuing, given

the lack of success we are having with other approaches. I, too, have been convinced that a killed, whole virus vaccine is an approach we cannot afford to ignore.

A heretofore estimate of development costs of a whole virus vaccine, before costs of clinical trials, is somewhere between 5 and 30 million dollars. This is small potatoes. The federal government is now spending about 2 and a half billion dollars a year on AIDS, of which more than a billion is going to research.

Your staff may want to contact a few people before making more formal approaches. I suggest the following:

- (1) Dr. Donald Kennedy
Professor and Former President, Stanford University
(415) 725-3745
- (2) Dr. David Baltimore
Professor of Molecular Biology and Immunology, MIT
Former President, The Rockefeller University
(417) 853-2133

A knowledgeable non-scientist whose judgment I trust is:

Ira Michael Heyman
Secretary of the Smithsonian Institution
Former Chancellor, University of California, Berkeley
(202) 208-4177

If your staff calls the officials at NIH, they are likely to be told, as an initial response, that such a vaccine has been tried. When pressed by scientists who know what they are talking about, however, NIH will not stick with that argument. It is important to get behind this initial defensive reaction.

For background information, I attach materials prepared by my friend, Dr. Burt Dornan, President of Acrogen, Inc. Acrogen has unsuccessfully sought funding from NIH and other sources. Though I trust Dr. Dornan, I emphasize that I am not recommending funding specifically for his company. If the U.S. decides to fund such development, Acrogen would obviously have to compete with others for such funding.

I hope to see you when you are here for the UN celebration in June. Thank you again for the nomination to the Ninth Circuit. So far, so good in the Senate. Linda sends her love.

Sincerely,

Wally
William A. Fletcher

Questions and Answers

Question: What has NIH done to advance the concept of a whole-killed HIV vaccine toward clinical testing?

Answer: NIH has evaluated inactivated whole-killed HIV viral vaccine analogs in animal models and plans to build on these studies and compare whole-killed virus and pseudovirions. In the chimeric SHIV model, inactivated HIV was not protective when the product was formulated in alum but was protective when the product was formulated in a novel proprietary adjuvant is expanding this study to include more macaques and is negotiating a comparative study of this whole-killed preparation and pseudovirions formulated in the same adjuvant. This will provide a head-to-head comparison of these two particle-based designs.

NIH continues to advise grantees interested in studying whole-killed HIV vaccine through unsolicited applications for research grants. Neither solicited or unsolicited mechanisms yet resulted in funding the development of a whole-killed HIV vaccine, because the peer-review process did not judge them to be of sufficient scientific merit.

NIH, through NIAID's Preclinical Master Agreement mechanism, solicited production of novel vaccine designs for human testing in FY94. A whole-killed vaccine was not proposed by any offeror, perhaps because of the research questions that must be addressed prior to initiation of production for human trials. NIH will consider utilizing this mechanism to produce a whole-killed HIV vaccine in FY96 if unsolicited mechanisms are not successful in filling this gap and depending on the availability of resources.

NIH is working with Connaught Ltd. on evaluation of a particle-based HIV vaccine similar to whole-killed HIV. Connaught has developed a cell line containing a modified HIV genome that lacks the HIV regulatory elements and includes specific small deletions to inactivate several viral genes required for HIV replication. An AIDS Vaccine Evaluation Group trial is planned, provided that the company addresses several FDA safety concerns.

For a whole-killed HIV vaccine to be usable, complete inactivation of the virus must be attained. NIH held a meeting to determine if a critical safety issue in the production of whole-killed HIV could be addressed. The consensus of the meeting was that inactivation could be satisfactorily achieved.

Mr. Fletcher cites information from Drs. Burt Dorman and Donald Kennedy regarding a perceived lack of interest on the part of NIH in whole-killed virus research for the prevention of HIV. The NIH continues to support an active vaccine research and development program which does include this approach. While this approach has proved successful for several viral diseases, such as polio, rabies, and hepatitis A, and is worthy of pursuit for the protection against HIV infection, there remain significant scientific uncertainties, technical limitations, and safety concerns that must be addressed prior to the testing of this type of HIV vaccine in human clinical trials.

I Government Funded Development

The NIH is supporting studies to evaluate vaccine candidates, including whole-killed virus vaccines and live attenuated (weakened) vaccine candidates in extensive preclinical testing to address these scientific questions and technical constraints. These programs include projects to evaluate the safety and efficacy of a whole-killed simian immunodeficiency virus (SIV) vaccine in monkeys. Since SIV is similar to HIV and causes an AIDS-like disease in monkeys, the knowledge gained from this research will be helpful in assessing the potential safety and efficacy of whole-killed HIV vaccines. In addition, the NIH is supporting research on the safety of vaccine candidates that are similar to whole-killed virus vaccines but are synthetically produced and thus represent safer vaccine candidates.

II Private development

There are a number of biotechnology and pharmaceutical companies developing whole-killed HIV vaccines. For example, the Salk/Immune Response Corporation is currently testing a whole-killed vaccine candidate in HIV-infected individuals. NIH is collaborating with Connaught LTD (Canada) in the pre-clinical and clinical evaluation of a particle-based HIV vaccine that is similar to a whole-killed HIV vaccine. Immuno-Ag (Austria) is collaborating with the Walter Reed Army Institute of Research in developing a whole inactivated HIV vaccine. In addition, Retroscreen (England) is collaborating with ISI (Italy) in developing a whole-killed HIV vaccine.

The NIH will continue to support the development and evaluation of potential vaccines. In fact, NIH has a long history of collaboration with pharmaceutical manufacturers and biotechnology firms in developing these critical vaccines for prevention of disease. However, it must be noted that the legal issues associated with liability are real, remain unresolved, and discourage many companies from pursuing this research.

III Acrogen, Inc.

Acrogen, Inc. has not been successful in obtaining NIH funding through the competitive grant application process and scientific peer review. NIH staff have and will continue to provide technical and administrative assistance to Acrogen as well as other researchers in academia and industry who are interested in obtaining NIH funding.

Question: What is known about whole-killed viral vaccines?

Answer: There have been notable successes in the development of whole-killed vaccines for the prevention of viral diseases, including include polio, rabies, influenza, hepatitis A, and several veterinary vaccines. There have also been a few catastrophic failures. For example, an inactivated respiratory syncytial virus induced an immune response that enhanced rather than inhibited viral infection. This resulted in the death of several infants in a clinical trial. Other problems occurred with inactivated measles vaccine, including short-lived immunity and increased frequency of atypical measles, which is characterized by very high fever, abdominal pain, and exacerbated rash. The conclusion of past research suggests that while whole-killed vaccines are often successful, success is not guaranteed.

Question: What is the basis for thinking that a whole-killed virus might stimulate a protective immune response so that subsequent exposure to HIV would not lead to AIDS?

Answer: Exposing an individual to the antigens on the surface of a whole-killed virus preparation may permit the immune system to "see" the virus exactly as it would be "seen" during infection but in a non-pathogenic form. A whole-killed virus might therefore stimulate immune responses that prevent disease if the person is subsequently exposed to the virus. A successful whole-killed vaccine therefore requires that the outer surface of the live virion is faithfully preserved in the whole-killed virus preparation.

Question: Can one assure that the whole-killed vaccine is safe?

Answer: Although infectivity may be completely abrogated in the vaccine preparation, the presence of HIV RNA and viral proteins in whole-killed preparations present other safety concerns. In the presence of active integrase and reverse transcriptase inside the virion, viral DNA might be produced and integrated into the host genome, perhaps with detrimental effects. The only human cell lines in which HIV will readily grow are transformed T-cells. The FDA is extremely reluctant to consider such a source for a vaccine for human use.

Question: What progress has been made in determining if a whole-killed HIV vaccine might protect people from HIV?

Answer: Whole-killed HIV vaccines have not protected chimpanzees from HIV infection. Salk/Immune Response Corp. has developed a whole-killed HIV vaccine which is being tested in individuals who have already been infected with HIV. This product failed to protect a chimpanzee from HIV infection. Behringwerke has also reported that a whole-killed HIV vaccine failed to protect chimpanzees from HIV infection. Rhesus monkeys given whole-killed simian immunodeficiency virus (SIV) vaccine were protected from infection with SIV in numerous experiments. However, this protection appeared to be due to an immune response not directed against viral antigens, but rather against components incorporated into the virus as they were grown in cell culture.

Question: What scientific questions need to be addressed prior to human trials of candidate HIV vaccines?

Answer: Because of its chemical structure, HIV is not likely to be as good a candidate for development of a whole-killed vaccine as was other viruses. Polio and hepatitis A are robust viruses and retain all their structural proteins during large scale production and purification. Rabies glycoprotein is a single transmembrane protein that is an integral part of the virion and remains in the membrane during production and purification of the virus. These whole-killed vaccines induce high-titers of neutralizing antibody that are maintained for one to two years. In contrast, HIV surface glycoprotein is readily shed from the surface of the HIV particle; the whole-killed Salk vaccine did not elicit detectable neutralizing antibody to HIV.

Question: What other federal agencies or private companies are involved in the development of a whole-killed HIV vaccine?

Answer: Walter Reed Army Institute of Research is collaborating with Immuno-Ag to produce a whole inactivated HIV vaccine. The company has made a prototype envelope subunit vaccine and tested it in humans, and has made a licensed whole-inactivated virus vaccine for tick-borne encephalitis. Retroscreen, a company in England, is collaborating with an Italian company, ISI, on such a vaccine.

PF + file

June 16, 1995

MEMORANDUM FOR THE PRESIDENT

FROM: Patricia S. Fleming

SUBJECT: AIDS-related Issues for U.S. Conference of Mayors Meeting

I. SUMMARY

In preparation for your meeting with the U.S. Conference of Mayors, I wanted to brief you on several AIDS-related issues that may arise. Mayors are particularly interested in the short-term and long-term future of the Ryan White CARE Act at HHS; the Housing Opportunities for People with AIDS program at HUD; the Administration's proposal for a Performance Partnership Grant that includes AIDS prevention programs at CDC; and existing prohibitions against use of Federal funds for clean needle exchange programs.

II. DISCUSSION: RYAN WHITE CARE ACT

The Mayors have been among the strongest supporters of the Ryan White CARE Act since its enactment in 1990. They have approved a resolution endorsing reauthorization of the program and approving of the Administration's fiscal year 1996 budget request for this program.

Title I of the program provides direct assistance to 42 cities that are hard hit by the epidemic (defined as a cumulative caseload of 2,000 or more). Title II of the program directly funds states but some of that money also makes its way to Title I cities. During your Administration, funding for the Ryan White CARE Act through FY1995 has increased 108 percent, bringing the program to full funding. In the FY1996 budget alone, you have proposed a 14 percent increase in Ryan White funding. That includes a \$50.5 million increase in Title I. And the number of Title I cities has increased from 25 to 42.

Legislation is pending in both houses of Congress to reauthorize this program for five years. The Senate bill -- coauthored by Senators Kassebaum, Kennedy, and Hatch -- was approved by the Labor & Human Resources Committee by a unanimous vote but has been held off the floor by a "hold" by Senator Helms. Senator Kassebaum plans to meet with Senator Helms to try to persuade him to allow the bill to come to the floor. There are currently 59 co-sponsors and the Majority Leader has indicated that he wants 60 sponsors before he goes to the floor. The House bill has only recently been introduced and is pending in the Commerce Committee.

Mayors may be concerned about some of the formula changes being considered. The Administration has remained neutral on formula issues and has been sharply criticized by state and local officials for that stance. Both the House and Senate bills would create a "single appropriation" for Titles I and II. This would eliminate much of the fighting between proponents of the two titles over appropriations but has some city officials worried. Other provisions would reduce the amount of "double-counting" in the Ryan White formulas so that states with Title I cities would receive smaller Title II grants. This has Mayors and Governors from those states nervous.

III. DISCUSSION: HOPWA

Many Mayors will be concerned about the future of the Housing Opportunities for People with AIDS (HOPWA) program at the U.S. Department of Housing and Urban Development. Created in 1990, this program provides funding to 43 cities and 23 states and to a number of non-profit community-based organizations to provide housing for low-income individuals and families affected by AIDS.

The FY1996 request for HOPWA is \$186 million, which is the same amount appropriated for FY1995.

HOPWA is one of the programs involved in the FY1995 rescissions fight. The House originally voted to rescind all \$186 million; the Senate voted to retain full funding. Conferees compromised on a \$30 million cut. That reduction was one of 13 items cited by you in your message to the Congress warning of a veto.

HOPWA is also one of several HUD programs scheduled for reauthorization this year. HUD has proposed to keep the program intact for two more years and then fold it into a larger community housing program. Efforts to eliminate this program are expected in both houses of Congress.

IV. DISCUSSION: PERFORMANCE PARTNERSHIP GRANTS

Mayors have been a central player in our effort to prevent the spread of HIV and AIDS. Seven cities (New York, San Francisco, Los Angeles, Philadelphia, Chicago, Houston, and Washington, DC) receive direct funding from CDC for AIDS prevention activities. The Mayors have been very supportive of the Administration's creation of the Community Planning Process, which has empowered state and local health departments, working with community representatives, to help design prevention strategies that are appropriate for each community.

The Administration's proposal to create a Performance Partnership Grant that combines HIV/AIDS with tuberculosis control and STD prevention programs has some Mayors concerned. They are particularly concerned about the proposal to eliminate direct funding of cities and send all money to the states after three years.

V. DISCUSSION: NEEDLE EXCHANGE PROGRAMS

Congress has placed restrictions on the use of Federal funds for programs that exchange clean hypodermic needles for used needles. Such programs have been funded by several cities and one or two states as well as numerous non-profit organizations. Federal statutes require HHS to prove that such programs will reduce transmission of HIV, reduce use of injectable drugs, and not result in new injection drug users. Dr. Philip Lee, the Assistant Secretary for Health, has determined that we cannot yet meet those tests.

The Conference of Mayors is considering a resolution calling for a lifting of the ban on use of Federal funds for needle exchange programs.

FILE COPY

**THE WHITE HOUSE
WASHINGTON**

June 7, 1995

MEMORANDUM FOR CAROL RASCO

FROM: Patsy Fleming *PF*

SUBJECT: DOD AIDS Research Funding

A request has been made by Leon Panetta's office for information about the cost of continuing the AIDS clinical trials now being conducted by DOD and the natural history study. Apparently this request follows on the heels of the Washington Post story about HIV infected military personnel who cannot continue to receive their medical care in clinical trials.

The request from Leon's office, however, did not include cost data for the rest of DOD's AIDS research program. Their work on vaccines is crucial, and the best being done in any part of the government. In addition, DOD is conducting behavioral prevention studies that are also very important to the U.S. both in the military and for the general population.

Is there some way to let those who have made the request for cost information from DOD expand this request to include the vaccine and behavioral prevention programs? I assume the request came about because there will be an attempt to find the funds.

MAY 31 1995

CC:
JENNIFER
KLEIN

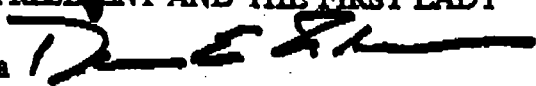
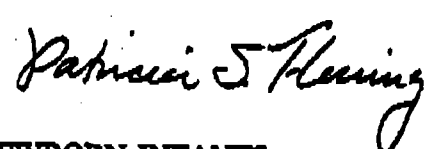
THE PRESIDENT HAS SEEN 5/30

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

CP

May 26, 1995

MEMORANDUM FOR THE PRESIDENT AND THE FIRST LADY

FROM: Donna E. Shalala Patricia S. Fleming, National AIDS Policy Director 

SUBJECT: HIV TESTING OF PREGNANT WOMEN AND NEWBORN INFANTS

Background

Recent scientific advances in the treatment of infants with HIV infection and in the prevention of perinatal transmission of HIV resulting from the AIDS Clinical Trials Group 076 (ACTG 076) have raised a series of public policy issues. Legislation by Rep. Gary Ackerman (D-NY) to "unblind" an HIV survey of childbearing women has also increased the political tension around these issues. The central policy questions raised by this science are:

- Should a blinded epidemiological survey of HIV in childbearing women be continued, discontinued, or "unblinded"?
- Should the Federal government impose mandatory testing on pregnant women or newborns?

In the last 15 months, the Department of Health and Human Services has responded aggressively to the scientific advances represented by ACTG 076 by issuing additional recommendations regarding HIV testing and treatment of pregnant women and newborn infants. It has also recently suspended the ongoing survey of childbearing women. With the survey suspended, HHS will shortly begin a consultative process with states, affected groups, medical professionals, and ethicists to deal with these issues.

I ACTG 076 Results

In February 1994, researchers funded by the National Institutes of Health (NIH) reported the results of ACTG 076, which found that the use of AZT by an asymptomatic HIV-positive woman during pregnancy, labor, and childbirth and by the newborn for six weeks following birth can reduce the risk of perinatal HIV transmission by as much as 67% (from an average of 25% to 8%). This is the first time we have been able to block transmission of HIV with a drug.

Page 2

II Testing and Treatment of Pregnant Women

✓ Pre-ACTG 076: As early as December 1985, guidelines issued by the Centers for Disease Control and Prevention (CDC) recommended that at-risk pregnant women and their partners should be counseled about HIV and offered a test. In 1987, CDC advised that at-risk women of child-bearing age should be counseled and voluntarily tested in order to discourage those who are HIV-infected from becoming pregnant.

Post-ACTG 076: Following the release of ACTG 076, CDC consulted with outside experts and developed a new set of guidelines for all pregnant women. The new guidelines recommend that doctors counsel pregnant women to accept voluntary HIV testing. Doctors should offer pregnant women who are HIV-positive treatment with AZT to lower the risk of transmission to their babies. The guidelines also recommend that women who have not received prenatal care or do not know their HIV-status at delivery, should be counseled and offered voluntary testing for themselves and their newborns before leaving the hospital. These draft guidelines, which drew strong support from medical, public health, and ethics groups, will be issued in final form in June.

III Testing and Treatment of Newborns

Since all babies carry their mothers' antibodies at birth, a test of a newborn simply reflects the mother's HIV-status -- not the newborn's own HIV-status. However, recent advances make it possible to effectively treat such babies to prevent certain AIDS-related conditions.

Until recently, CDC recommended that only those HIV-positive newborns with suppressed immune systems be treated with antibiotics to prevent *Pneumocystis carinii* pneumonia (PCP), a nearly always fatal opportunistic infection for babies with AIDS. In April 1995, CDC greatly expanded those guidelines to recommend treating all babies born to HIV-positive women with antibiotics beginning at 4-to-6 weeks for perinatally-exposed infants and continuing treatment through 12 months for HIV-infected infants.

It is critical to note that neither mandatory testing of newborns nor the unblinding of the CDC survey would prevent even one case of perinatal transmission of HIV, since to block transmission AZT must be administered during pregnancy and childbirth. Focusing on testing newborns would be too little, too late to save infants from HIV and AIDS.

IV CDC Survey of HIV in Childbearing Women

Beginning in 1988, during the Reagan Administration, CDC, in cooperation with state and territorial health departments in 45 states, DC, Puerto Rico, and the Virgin Islands, conducted an epidemiological survey of childbearing women in the U.S. to determine the prevalence of HIV infection in that population. The current cost of the survey is \$10.5 million a year.

Page 3

The survey uses leftover blood taken from approximately 45% of newborns during routine "heel stick" tests for genetic conditions. About 2.5 million babies are tested each year out of a total of 4.5 million babies born in the U.S. No additional blood is taken for this survey. To obtain the most accurate and unbiased scientific data and to conform with scientific and ethical review requirements and informed consent statutes, the results are "blinded," thus the women cannot be informed of the results. In fact, all identifiers are separated from the sample before an HIV test is run.

The CDC survey has been approved by numerous ethical review boards. Anonymous, unlinked testing has been accepted as a standard for monitoring the HIV epidemic by the World Health Organization. It would not be feasible to "unblind" this survey without first obtaining informed, written consent from the mothers. Such a change would fundamentally alter the survey, changing it from a surveillance tool to a testing program. Since some women would refuse testing because of their concern about a record of their infection, such an approach would skew the results and render the survey epidemiologically much less useful for monitoring the epidemic.

The survey has provided useful data on the prevalence of HIV among childbearing women and among women in general. CDC has found that an estimated 7,000 HIV-positive women give birth in the U.S. each year and that an estimated 2,000 of those babies remain HIV-positive themselves. The survey has been used to plan research, prevention, and care programs at the state, local, and federal levels.

However, the results of ACTG 076 and the resulting importance of testing women before or early in pregnancy, as well as the new guidelines for treatment of infants with PCP prophylaxis, dictated that this survey be reexamined. Thus, on May 11, with the concurrence of Secretary Shalala, Dr. Phil Lee, Assistant Secretary for Health, asked State Health Directors to suspend testing under the Survey of Childbearing Women and to join the PHS in a consultative process on the best way to proceed on monitoring the epidemic in women and infants, preventing perinatal transmission, and assuring care for HIV-positive pregnant women and newborns.

CDC and PHS officials currently are finalizing plans for a consultative process that will include Federal, state, and local health officials, medical and public health experts, medical ethicists, and members of affected populations. The process will focus on four issues: Counseling and testing of pregnant women; testing of newborns; treatment of HIV-infected women and infants; and monitoring of HIV in women and children. This process should be underway by July 1.

V The Ackerman Bill

The CDC survey has spurred a great deal of public debate, primarily around legislation by Rep. Gary Ackerman (D-NY) that would require states that conduct HIV testing of newborns to notify the mother or legal guardian of the test results.

Page 4

The Ackerman bill was first introduced in 1994, shortly after the release of the ACTG 076 findings, but saw no action that year. Congressman Ackerman has reintroduced the bill (H.R.1289), and now has 220 cosponsors (including 160 Democrats) ranging across the political spectrum. Mr. Ackerman has been very successful in gaining support for his bill, in part, due to the fact that he began his efforts before the CDC guidelines on counseling and testing were issued. Therefore, members of Congress who were not comfortable with his approach had nothing to be "for." Many members were approached on the floor before they had a chance to study the bill or consult their staff.

Mr. Ackerman has some misunderstandings about his legislation. While he says it would "save babies," the reality is the testing of newborns comes too late to prevent HIV transmission. It would, however, allow for PCP prophylaxis and warn HIV-infected women not to breast feed.

In reality, the Ackerman bill is a *de facto* proposal for mandatory testing of childbearing women. If it were to become law, the CDC surveillance study would be out of compliance with state statutes regarding informed consent. And it still would not prevent a single case of perinatal transmission of HIV.

Mr. Ackerman has modeled his bill on one by New York State Assemblywoman Nettie Mayersohn. Following a heated debate in 1994, New York agreed to establish guidelines for routine counseling and voluntary testing of pregnant women, much like those recently issued by CDC. Early results show a promising rise in the number of women being tested.

VI Mandatory v Voluntary HIV Testing

Throughout the AIDS epidemic, public health officials have pursued a policy of routine counseling and voluntary testing for HIV. The Federal government and the states have made a small number of exceptions to that policy (military recruits and active duty personnel, some Federal prisoners, Job Corps applicants, immigrants, and blood donors). In all other cases, our goal is to pull people toward testing, not to drive them away from it.

A voluntary approach is critical for HIV-positive pregnant women. The treatment required to prevent HIV transmission requires the woman to take AZT during pregnancy and childbirth, and to administer the drug orally to her child three times a day for six weeks after birth. To ensure success, we need maximum cooperation from the mother.

Evidence suggests that mandatory testing would severely damage the likelihood of cooperation by the mother. Indeed, there is strong evidence that routine counseling and voluntary HIV testing of pregnant women can be highly successful. For example, Atlanta's Grady Memorial Hospital has a 96 percent success rate in getting pregnant women to volunteer for an HIV test. Similar results have been reported at public hospitals in Miami, Los Angeles, and New York. Among the women who have tested HIV-positive, a very high percentage agree to AZT treatment.

Page 5

Conversely, there are several examples where the use of mandatory testing has had negative effects. They include:

- Efforts to impose mandatory drug testing are reported to have resulted in a sharp decline in the number of people seeking care. For women, the reason most frequently cited was a fear that they would lose custody of their children.
- In 1989, Illinois imposed mandatory HIV testing for marriage license applicants and saw a sharp increase in the number of couples crossing state lines to be married. The state repealed the law in 1991.

The use of routine counseling and voluntary testing has been supported by all of the major professional organizations in the country, including the American Academy of Pediatrics, American College of Obstetrics and Gynecology, the American Nurses Association, the Association of State and Territorial Health Officers, the American Public Health Association, and the Pediatric AIDS Foundation.

VII Additional Actions

In addition to the steps described above, HHS has taken other actions to respond to the results of ACTG 076. They include the following.

- The Food and Drug Administration has changed its labeling instructions for AZT to allow its use in pregnant women and newborns.
- The Health Care Financing Administration has instructed states to include perinatal use of AZT in their Medicaid drug formularies.
- NIH is funding research to follow the women and infants involved in ACTG 076 to determine the long-term effects of AZT treatment during pregnancy and childbirth.
- The Agency for Health Care Policy and Research is developing materials for consumers explaining perinatal transmission and AZT's role in reducing transmission.

VIII Conclusion

HHS's approach of counseling and voluntary testing for all pregnant women is a sound public health approach to preventing perinatal transmission of HIV. It has been demonstrated to be effective in getting women tested and to ensure that they cooperate with the full course of treatment for themselves and their newborns. We believe some thoughtful questions have been raised about continuing the CDC Survey of Childbearing Women. The upcoming consultation should produce several viable alternatives to the suspended survey that will allow us to continue vital surveillance of the epidemic and direct Federal resources where they will do the most good.

MAY 31 1995

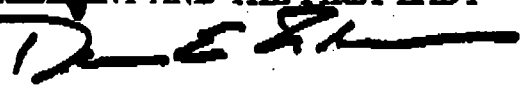
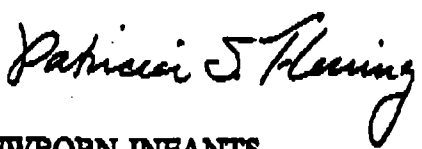
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JENNIFER
KLEIN

THE PRESIDENT HAS SEEN 5/30

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

May 26, 1995

MEMORANDUM FOR THE PRESIDENT AND THE FIRST LADY

FROM: Donna E. Shalala Patricia S. Fleming, National AIDS Policy Director 

SUBJECT: HIV TESTING OF PREGNANT WOMEN AND NEWBORN INFANTS

Background

Recent scientific advances in the treatment of infants with HIV infection and in the prevention of perinatal transmission of HIV resulting from the AIDS Clinical Trials Group 076 (ACTG 076) have raised a series of public policy issues. Legislation by Rep. Gary Ackerman (D-NY) to "unblind" an HIV survey of childbearing women has also increased the political tension around these issues. The central policy questions raised by this science are:

- Should a blinded epidemiological survey of HIV in childbearing women be continued, discontinued, or "unblinded"?
- Should the Federal government impose mandatory testing on pregnant women or newborns?

In the last 15 months, the Department of Health and Human Services has responded aggressively to the scientific advances represented by ACTG 076 by issuing additional recommendations regarding HIV testing and treatment of pregnant women and newborn infants. It has also recently suspended the ongoing survey of childbearing women. With the survey suspended, HHS will shortly begin a consultative process with states, affected groups, medical professionals, and ethicists to deal with these issues.

I ACTG 076 Results

In February 1994, researchers funded by the National Institutes of Health (NIH) reported the results of ACTG 076, which found that the use of AZT by an asymptomatic HIV-positive woman during pregnancy, labor, and childbirth and by the newborn for six weeks following birth can reduce the risk of perinatal HIV transmission by as much as 67% (from an average of 25% to 8%). This is the first time we have been able to block transmission of HIV with a drug.

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II Testing and Treatment of Pregnant Women

✓ Pre-ACTG 076: As early as December 1985, guidelines issued by the Centers for Disease Control and Prevention (CDC) recommended that at-risk pregnant women and their partners should be counseled about HIV and offered a test. In 1987, CDC advised that at-risk women of child-bearing age should be counseled and voluntarily tested in order to discourage those who are HIV-infected from becoming pregnant.

Post-ACTG 076: Following the release of ACTG 076, CDC consulted with outside experts and developed a new set of guidelines for all pregnant women. The new guidelines recommend that doctors counsel pregnant women to accept voluntary HIV testing. Doctors should offer pregnant women who are HIV-positive treatment with AZT to lower the risk of transmission to their babies. The guidelines also recommend that women who have not received prenatal care or do not know their HIV-status at delivery, should be counseled and offered voluntary testing for themselves and their newborns before leaving the hospital. These draft guidelines, which drew strong support from medical, public health, and ethics groups, will be issued in final form in June.

III Testing and Treatment of Newborns

Since all babies carry their mothers' antibodies at birth, a test of a newborn simply reflects the mother's HIV-status -- not the newborn's own HIV-status. However, recent advances make it possible to effectively treat such babies to prevent certain AIDS-related conditions.

Until recently, CDC recommended that only those HIV-positive newborns with suppressed immune systems be treated with antibiotics to prevent *Pneumocystis carinii* pneumonia (PCP), a nearly always fatal opportunistic infection for babies with AIDS. In April 1995, CDC greatly expanded those guidelines to recommend treating all babies born to HIV-positive women with antibiotics beginning at 4-to-6 weeks for perinatally-exposed infants and continuing treatment through 12 months for HIV-infected infants.

It is critical to note that neither mandatory testing of newborns nor the unblinding of the CDC survey would prevent even one case of perinatal transmission of HIV, since to block transmission AZT must be administered during pregnancy and childbirth. Focusing on testing newborns would be too little, too late to save infants from HIV and AIDS.

IV CDC Survey of HIV in Childbearing Women

Beginning in 1988, during the Reagan Administration, CDC, in cooperation with state and territorial health departments in 45 states, DC, Puerto Rico, and the Virgin Islands, conducted an epidemiological survey of childbearing women in the U.S. to determine the prevalence of HIV infection in that population. The current cost of the survey is \$10.5 million a year.

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The survey uses leftover blood taken from approximately 45% of newborns during routine "heel stick" tests for genetic conditions. About 2.5 million babies are tested each year out of a total of 4.5 million babies born in the U.S. No additional blood is taken for this survey. To obtain the most accurate and unbiased scientific data and to conform with scientific and ethical review requirements and informed consent statutes, the results are "blinded," thus the women cannot be informed of the results. In fact, all identifiers are separated from the sample before an HIV test is run.

The CDC survey has been approved by numerous ethical review boards. Anonymous, unlinked testing has been accepted as a standard for monitoring the HIV epidemic by the World Health Organization. It would not be feasible to "unblind" this survey without first obtaining informed, written consent from the mothers. Such a change would fundamentally alter the survey, changing it from a surveillance tool to a testing program. Since some women would refuse testing because of their concern about a record of their infection, such an approach would skew the results and render the survey epidemiologically much less useful for monitoring the epidemic.

The survey has provided useful data on the prevalence of HIV among childbearing women and among women in general. CDC has found that an estimated 7,000 HIV-positive women give birth in the U.S. each year and that an estimated 2,000 of those babies remain HIV-positive themselves. The survey has been used to plan research, prevention, and care programs at the state, local, and federal levels.

However, the results of ACTG 076 and the resulting importance of testing women before or early in pregnancy, as well as the new guidelines for treatment of infants with PCP prophylaxis, dictated that this survey be reexamined. Thus, on May 11, with the concurrence of Secretary Shalala, Dr. Phil Lee, Assistant Secretary for Health, asked State Health Directors to suspend testing under the Survey of Childbearing Women and to join the PHS in a consultative process on the best way to proceed on monitoring the epidemic in women and infants, preventing perinatal transmission, and assuring care for HIV-positive pregnant women and newborns.

CDC and PHS officials currently are finalizing plans for a consultative process that will include Federal, state, and local health officials, medical and public health experts, medical ethicists, and members of affected populations. The process will focus on four issues: Counseling and testing of pregnant women; testing of newborns; treatment of HIV-infected women and infants; and monitoring of HIV in women and children. This process should be underway by July 1.

V The Ackerman Bill

The CDC survey has spurred a great deal of public debate, primarily around legislation by Rep. Gary Ackerman (D-NY) that would require states that conduct HIV testing of newborns to notify the mother or legal guardian of the test results.

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The Ackerman bill was first introduced in 1994, shortly after the release of the ACTG 076 findings, but saw no action that year. Congressman Ackerman has reintroduced the bill (H.R.1289), and now has 220 cosponsors (including 160 Democrats) ranging across the political spectrum. Mr. Ackerman has been very successful in gaining support for his bill, in part, due to the fact that he began his efforts before the CDC guidelines on counseling and testing were issued. Therefore, members of Congress who were not comfortable with his approach had nothing to be "for." Many members were approached on the floor before they had a chance to study the bill or consult their staff.

Mr. Ackerman has some misunderstandings about his legislation. While he says it would "save babies," the reality is the testing of newborns comes too late to prevent HIV transmission. It would, however, allow for PCP prophylaxis and warn HIV-infected women not to breast feed.

In reality, the Ackerman bill is a *de facto* proposal for mandatory testing of childbearing women. If it were to become law, the CDC surveillance study would be out of compliance with state statutes regarding informed consent. And it still would not prevent a single case of perinatal transmission of HIV.

Mr. Ackerman has modeled his bill on one by New York State Assemblywoman Nettie Mayersohn. Following a heated debate in 1994, New York agreed to establish guidelines for routine counseling and voluntary testing of pregnant women, much like those recently issued by CDC. Early results show a promising rise in the number of women being tested.

VI Mandatory v Voluntary HIV Testing

Throughout the AIDS epidemic, public health officials have pursued a policy of routine counseling and voluntary testing for HIV. The Federal government and the states have made a small number of exceptions to that policy (military recruits and active duty personnel, some Federal prisoners, Job Corps applicants, immigrants, and blood donors). In all other cases, our goal is to pull people toward testing, not to drive them away from it.

A voluntary approach is critical for HIV-positive pregnant women. The treatment required to prevent HIV transmission requires the woman to take AZT during pregnancy and childbirth, and to administer the drug orally to her child three times a day for six weeks after birth. To ensure success, we need maximum cooperation from the mother.

Evidence suggests that mandatory testing would severely damage the likelihood of cooperation by the mother. Indeed, there is strong evidence that routine counseling and voluntary HIV testing of pregnant women can be highly successful. For example, Atlanta's Grady Memorial Hospital has a 96 percent success rate in getting pregnant women to volunteer for an HIV test. Similar results have been reported at public hospitals in Miami, Los Angeles, and New York. Among the women who have tested HIV-positive, a very high percentage agree to AZT treatment.

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Conversely, there are several examples where the use of mandatory testing has had negative effects. They include:

- Efforts to impose mandatory drug testing are reported to have resulted in a sharp decline in the number of people seeking care. For women, the reason most frequently cited was a fear that they would lose custody of their children.
- ✓ In 1989, Illinois imposed mandatory HIV testing for marriage license applicants and saw a sharp increase in the number of couples crossing state lines to be married. The state repealed the law in 1991.

The use of routine counseling and voluntary testing has been supported by all of the major professional organizations in the country, including the American Academy of Pediatrics, American College of Obstetrics and Gynecology, the American Nurses Association, the Association of State and Territorial Health Officers, the American Public Health Association, and the Pediatric AIDS Foundation.

VII Additional Actions

In addition to the steps described above, HHS has taken other actions to respond to the results of ACTG 076. They include the following.

- The Food and Drug Administration has changed its labeling instructions for AZT to allow its use in pregnant women and newborns.
- The Health Care Financing Administration has instructed states to include perinatal use of AZT in their Medicaid drug formularies.
- NIH is funding research to follow the women and infants involved in ACTG 076 to determine the long-term effects of AZT treatment during pregnancy and childbirth.
- The Agency for Health Care Policy and Research is developing materials for consumers explaining perinatal transmission and AZT's role in reducing transmission.

VIII Conclusion

HHS's approach of counseling and voluntary testing for all pregnant women is a sound public health approach to preventing perinatal transmission of HIV. It has been demonstrated to be effective in getting women tested and to ensure that they cooperate with the full course of treatment for themselves and their newborns. We believe some thoughtful questions have been raised about continuing the CDC Survey of Childbearing Women. The upcoming consultation should produce several viable alternatives to the suspended survey that will allow us to continue vital surveillance of the epidemic and direct Federal resources where they will do the most good.

THE WHITE HOUSE
WASHINGTON

April 28, 1995

MEMORANDUM FOR NANCY-ANN MIN

FROM: Patsy Fleming 

SUBJECT: PHS Performance Partnership Draft Legislation

I want to offer a number of comments related to the proposed performance partnerships for SAMHSA and CDC. I strongly support the general thrust of this legislation, as a far more credible alternative to block grants and an attempt to introduce greater flexibility with continued accountability. However, I have some general concerns as well as some specific issues with the proposals.

While these comments reflect my views, they have been informed, in part, by consultation with organizations working in HIV, STDs, and TB regarding the CDC partnership. Unfortunately, there has been little outreach from other sources to affected communities on either the CDC or SAMHSA proposals. The result has been often unfounded fears about what is actually in this legislation. I hope that, as we move forward with this process, the relevant agencies will spend more time talking with their constituencies about the Administration's plans and the implications of this proposal. I think we can win them to our side -- but only if we actively work with them. This applies to SAMHSA as well.

One way to reassure constituency groups is to assure them that non-governmental organizations will be part of the decision-making process throughout the development and implementation of the performance partnerships. The discussion of both national core objectives and individual state objectives should be a negotiation not just with state health departments, but also with affected communities. **I recommend that this consultation be required in the legislation itself.**

For the most part, this legislation is very general in defining these partnerships. We are leaving a good deal to the discretion of the agencies when it comes to implementation. For the most part, I think this is wise. However, I hope that we will be developing for the relevant committees a clearer sense of what our intention is when we talk about some of these concepts (such as performance indicators) so that Congress not impose on us approaches we never had in mind.

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SAMHSA Partnership:

Statewide planning and needs assessment requirement: I don't understand why this component of the current block grant is being repealed. It would seem to me as we grant more flexibility to the states, that the one qualifier ought to be that the expenditure of funds (and performance objectives) planned and based on a through assessment of need. It is puzzling to see that in the HIV/STD/TB partnership for CDC, we are extending the planning and needs assessment requirements, to include STD and TB for the first time, but we are pulling back for substance abuse and mental health. **I recommend that statewide planning based on a needs assessment be required.**

Priorities: As I have mentioned in earlier meetings on this subject, I am pleased to see the continuation of the HIV set aside and I support the increase in the threshold requirement. This will keep an important element of HIV-related services for substance abusers while not posing an unreasonable burden for lower incidence states. I am concerned, however, that injecting drug users and pregnant women are no longer identified as priority populations in the substance abuse grant. Both groups are particularly important in the context of the HIV epidemic. CDC reports that 75% of all new infections are related, directly or indirectly, to substance abuse. **I also recommend that the requirement for provision of TB services be restored.** The substance abuse population is at great risk for TB and every public health program reaching substance abusers must address this disease. **I also recommend that the set aside for pregnant women be restored.**

Planning councils: If part of the objective of the performance partnerships is to return as much decision-making to the local level, I hope that we can see fit to assure community input at all stages of decision making. It appears that only the mental health grant must be reviewed by a planning council. **I recommend that a planning council be established for the substance abuse part of the grant as well.**

For-profit entities: When appropriate, I have no objection to allowing for-profit entities to be funded under these grants, although **it would be preferable for this to occur only when a not-for-profit provider is not available.** However, to assure the best use of scarce resources, **for-profit entities should be required to accept the same reimbursement rate as not-for-profit or public entities.**

CDC Performance Partnership:

Merger of funding streams: I support the merging of HIV, STD, and TB funding streams. I believe that there is sound public health basis for this. I should point out, however, that there is considerable opposition to this from the various communities who are more comfortable

Memorandum on Performance Partnership Legislation

April 28, 1995

Page 3

with keeping the decisions about funding and programming separate. **I recommend a compromise in this area which would give CDC the authority to allow states to have separate planning processes for HIV, STDs, and TB where appropriate.**

Community planning: I am pleased to see the community planning process endorsed in legislation. I also think it is wise to extend a successful model to STD and TB programs. However, the value of the community planning process will be diminished if community planning groups are not part of the development of the performance partnership objectives. If community planning is to remain meaningful, then community groups must be involved in the development of national core objectives, as mentioned above, and community planning groups must be involved in developing the state-specific core objectives. **I recommend that, for example, there be a requirement for community planning group sign-off on a state health department's performance partnership objectives, just as there must be sign-off on a grant application.**

Performance partnership objectives: I strongly support the notion of introducing performance based measures into the grant programs. However, I am very concerned about our ability to find reasonable, affordable, and quantifiable performance partnership objectives for HIV prevention. I have had extensive discussions with community groups and others in an effort to identify potential examples of measures -- so far without success. Measuring the success of HIV prevention programs now requires measuring behavior changes -- which are either difficult or expensive or controversial (e.g., requiring sex surveys). If we look to quantifiable measures, then we might fall into the trap of process measures -- such as how many people were counseled and tested -- which will tell us nothing about whether those counseling and testing programs are good or whether the counseling and testing resulted in the desired outcome -- behavior change. **More qualitative objectives must be permitted while we work to find other more quantifiable measures.** Otherwise, we may well undercut the progress we have made in the last two years in moving HIV prevention programs away from relatively meaningless process measures.

Formula: **I recommend that we should not legislate the formula for this partnership.** HIV in particular, but also TB and STDs, are constantly shifting epidemics. The standards for the formula we would have used five years ago would have been very different from what we would choose today. The same is likely to be true five years from now. We need flexibility for this partnership grant more than any other.

If we do go ahead with legislating a formula, the one currently proposed is problematic in several ways. It does not take into account **the disproportionate impact of HIV among substance abusers** nor is it as sensitive to **the high rate of HIV among minorities** as it should be. In addition, it is also based on a survey of HIV infection among childbearing

Memorandum on Performance Partnership Legislation

April 28, 1995

Page 4

women that is under severe congressional attack, led by Rep. Gary Ackerman. **I recommend that we find less controversial elements for this formula that more closely identify the need.**

Directly funded cities: Although we understand that PHS intends to continue funding of cities now receiving HIV, STD, and/or TB funds directly because of the disproportionate impact HIV, STDs, and TB have had in those communities, the legislation is silent on this. **We should make explicit our intention to continue that direct funding.**

Direct funding of minority community based organizations: There was considerable opposition expressed by community groups to the inclusion of the CDC's current program of direct funding of minority community based organizations in the state performance partnership grants. I concur. The original intent of these direct grants was to overcome the historic neglect of minority concerns by certain health departments. While the community planning process is designed to overcome this problem -- and we are certainly hopeful that it will -- **I recommend that the legislation contain a mechanism to assure that CDC can intervene in a jurisdiction to directly fund minority CBOs that can address the prevention needs of communities that have been neglected by the community planning process and/or their health departments.** (The performance partnership grant incentives only reward success; they do not give CDC the authority to take corrective measures -- which can be problematic in instances such as this and strengthens the argument for retaining some direct funding capacity.)

Privacy. **I recommend the continuation of the privacy protections accorded STD program participants and their extension to the HIV and TB programs.** Without superseding state law, the Administration will be making an important statement to people participating in HIV and TB programs that their privacy is as important as those being treated for other STDs.

I hope these comments are helpful. I would be pleased to work with OMB and HHS to resolve these issues. Please contact me or Jeff Levi at 632-1090 to discuss these comments further.

cc: Robert Pellici
Richard Turman
Bill Corr
Eric Goosby

**OFFICE OF NATIONAL A DIS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
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Phone: 202-632-1090
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FACSIMILE COVER SHEET

TO: Richard Turman

FAX NUMBER: 395-3910

FROM: Patricia Fleming

DATE: 4-28-95

PAGES INCLUDING COVER SHEET: 5

COMMENTS:

COMPLETED

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TO: Robert Pellicci

FAX NUMBER: 395-6148

FROM: Patricia Fleming

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PAGES INCLUDING COVER SHEET: 5

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FACSIMILE COVER SHEET

TO: Bill Carr

FAX NUMBER: 690-6960

FROM: Patricia Fleming

DATE: 4-28-95

PAGES INCLUDING COVER SHEET: 5

COMMENTS:

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Gordon Agreess 395-7910 3910


Carmena —

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Thanks.

P.

n: partner.com

April 28, 1995

Recommendations
in BOLD. (I have
underlined them.)

MEMORANDUM FOR ROBERT PELLICI

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our ability to find reasonable, affordable, and quantifiable performance partnership objectives for HIV prevention. I have had extensive discussions with community groups and others in an effort to identify potential examples of measures -- so far without success. Measuring the success of HIV prevention programs ^{now} requires measuring behavior changes -- which are either difficult or expensive or controversial (e.g., requiring sex surveys) ~~to undertake~~. If we look to quantifiable measures, then we might fall into the trap of process measures -- such as how many people were counseled and tested -- which will tell us nothing about whether those counseling and testing programs are good or whether the counseling and testing resulted in the desired outcome -- behavior change. More qualitative objectives must be permitted while we work to find other more quantifiable measures. Otherwise, we may well undercut the progress we have made in the last two years in moving HIV prevention programs away from relatively meaning^{less} process measures. ← **Bold**

recommend that
Formula: ~~I believe that~~ we should not legislate the formula for this ^{partnership} grant. HIV in particular, (but also TB and STD) are constantly shifting epidemics. The standards for the formula we ^{used} would have set five years ago would have been very different from what we would choose today. The same is likely to be true five years from now. We need flexibility for this partnership grant more than any other.

If we do go ahead with legislating a formula, the one currently proposed is problematic in several ways. It does not take into account the disproportionate impact of HIV among substance abusers nor is it as sensitive to the high rate of HIV among minorities as it ~~might~~ ^{should}

be. In addition, it is also based on a survey of HIV infection among childbearing women that is under severe congressional attack, led by Rep. Gary Ackerman. *I recommend that* We need to find less controversial elements for this formula that more closely identify the need.

Although we understand that PHS intends to
Directly funded cities: ~~(The legislation is silent on)~~ continuing direct funding of cities now ~~also~~ receiving HIV, STD, and/or TB funds ^{directly} because of the disproportionate impact HIV, STDs, and TB have had in those communities. We should make explicit our intention to continue that direct funding. *the legislation is silent on this.* ← Bold

Direct funding of minority community based organizations: There was considerable opposition expressed by community groups to the inclusion of the CDC's current program of direct funding of minority community based organizations in the state performance partnership grants. I concur. The original intent of these direct grants was to overcome the historic neglect of minority concerns by certain health departments. While the community planning process is designed to overcome this problem -- and we are certainly hopeful that it will -- *I recommend that the legislation contain* ~~there must be~~ a mechanism to assure that CDC can intervene in a jurisdiction to ~~support minority CBOs that can~~ directly fund organizations addressing the prevention needs of communities that have been neglected ~~for some reason~~ by the community planning process and/or their health departments. (The performance partnership grant incentives only reward success; they do not give CDC the authority to take corrective measures -- which can be problematic in instances such as this and strengthens the argument for retaining some direct funding capacity.)

Memorandum on Performance Partnership Legislation/April 28, 1995/Page 7

^{recommen}
Privacy. I ~~support~~ the continuation of the privacy protections accorded STD program participants and their extension to the HIV and TB programs. Without superseding state law, the Administration will be making an important statement to people participating in HIV and TB programs that their privacy is as important as those being treated for other STDs.

I hope these comments are helpful. I would be pleased to work with OMB and HHS to resolve these issues. Please contact me or Jeff Levi at 632-1090 to discuss these comments further.

FILE COPY ✓

THE WHITE HOUSE
WASHINGTON

April 18, 1995

MEMORANDUM TO THE NATIONAL DISABILITY POLICY REVIEW TEAM

From: Diana Fortuna
Domestic Policy Council

Subject: SAVE THE DATE

The next meeting of the National Disability Policy Review Team will be held on Tuesday, May 9, 1995 from 3:30 - 5:00 p.m. in room 324, Old Executive Office Building. Please save the date.

If you are planning to attend and/or have questions, please contact Elisabeth Cohen (202-456-5571). Unfortunately, Elisabeth will be concluding her field placement with the Domestic Policy Council this week; for now, clearance will continue to be handled through her phone line. Elisabeth asked me to extend her appreciation for the opportunity to work with the members of the Review Team throughout this academic year. She has been an invaluable asset to the DPC staff, and we will miss her greatly.

We will be sending out the agenda in a few days. Thank you.

Distribution:

Roberta Achtenberg (Bonnie Milstein)
Gary Blumenthal
Carolyn Colvin & Susan Daniels
Speed Davis
Dennis Duffy
Eddie Espinosa
Judy Feder & Bob Williams
Patsy Fleming
W. Scott Gould (Ron Glaser)
Michael A. Grant
Judith Heumann
Joe Meade
Paul S. Miller (Andy Imparato)
Josephine Nieves (Stephanie Powers)
Fred Pang
Larry Parks (Carolyn Gunney)
Deval Patrick (Liz Savage)
Don Trilling

TOTAL NUMBER OF PAGES INCLUDING COVER: 1

CC: Ken Apfel, Lisa Fairhall, Debbie Fine, Richard Green, David Levine, Janey Looney, Bev Milkman, Lorraine Miller, Tracey Thornton

THE WHITE HOUSE

WASHINGTON

April 5, 1995

MEMORANDUM TO: WILLIAM J. CLINTON
PRESIDENT OF THE UNITED STATES

FROM: PATRICIA S. FLEMING 
NATIONAL AIDS POLICY DIRECTOR

THRU: CAROL RASCO
DOMESTIC POLICY ADVISOR TO THE PRESIDENT

SUBJECT: Michael Hartranft and the class action suit for people with hemophilia and AIDS

Ms. Linda Mowrer has a son, Michael Hartranft, who has hemophilia and AIDS. Michael is 19 years old and was admitted to the hospital over the weekend with his fifth case of PCP, an AIDS-related pneumonia. He has spoken with you twice in the last year. Ms. Mowrer is concerned about the dismissal of the class action suit for people with hemophilia and AIDS and asked that I ensure that you were aware of this issue.

History with Michael Hartranft

On St. Patrick's Day, 1994 you called Michael Hartranft at home after Christine Gebbie received a request from a friend from Michael's high school.

On May 5, 1994, the organization known as Mother's Voices was invited to a meeting in the Roosevelt Room. Michael and his mother were part of this gathering and spoke with you. Ms. Mowrer recalled her son's excitement that you signed his autograph book and hugged him after the meeting

Background on the Class Action Suit for People with Hemophilia and AIDS

In 1993 a class action suit was filed against four pharmaceutical companies and the National Hemophilia Foundation on behalf of people with bleeding disorders and AIDS. The suit was certified early in 1994 by the presiding judge, John Grady, in the United States Federal District Court in Chicago. The pharmaceutical companies appealed the certification and on March 17 the 7th Circuit Court of Appeals issued its ruling requiring Judge Grady to decertify the case as a class action suit.

Michael Hartranft
March 30, 1995
Page Two

The appellate court stated that the pharmaceutical companies would go bankrupt if the plaintiffs won. However, people such as Michael and his mother who are living with hemophilia and HIV are outraged at not being able to have their day in court to demonstrate their belief that these companies were negligent and allowed tainted blood supplies to be used. Ms. Mowrer believes the pharmaceutical companies knew that the blood factors used for transfusions could be contaminated with HIV a year and a half before Michael became infected. Although Michael and his family are pursuing their own legal action, many people living with a bleeding disorder and HIV are not able to finance a separate law suit and the statute of limitations will run out for them. Linda Mowrer believes that by dismissing the law suit, the judicial system is condoning the action of the health care system in a pursuit for profit at the expense of ensuring adequate health care.

Ms. Mowrer asked that you be informed of this situation. Should you wish to speak with them, their number is (717) 569-9268. The National Hemophilia Foundation, although a defendant in this case, can provide information on people living with a bleeding disorder and HIV. They can be reached at (212) 219-8180.

BK

Patsy

Linda Mowrer (~~000~~) called
for Lance.

Her son Michael has hemophilia
and AIDS.

The President called Michael
last St. Patrick's day.

She & Michael, as part of
Mother's Voices, met with the
President last May 5.

She spoke to Christine G.
several times.

Current concern:
The dismissal of the class
action suit for pw hemophilia

She would like your help & to
make sure the President knows.

(717) 569-9268

BK 3/20
10:30 am

Hemophilia Relief Act - being
considered to testify

TO <u>Lance / BK</u>	TELEPHONED	PLEASE CALL
DATE <u>3/20</u> TIME <u>10:20</u>	CALLED TO SEE YOU	RETURNED CALL
PHONE CALLS "WHILE OUT" RECORD	WILL CALL AGAIN	URGENT
	MESSAGE <u>Son, hemophilia Michael</u>	
M. <u>Linda Mowrer</u>	<u>St. Patrick's - President called</u>	
OF <u>Pennsylvania</u>	<u>May 5^{met} with (M) voices</u>	
PHONE <u>(717) 569-9268</u>	<u>spoke to Christine Gebbie</u>	
AREA CODE NUMBER EXTENSION	<u>re. dismissal of class action</u>	
	<u>suit for hemophiliacs</u>	
	TAKEN BY: <u>BK</u>	



THE NATIONAL HEMOPHILIA FOUNDATION

October 1, 1993

MEMORANDUM

TO: Chapter Presidents and Executive Directors

FROM: Glenn F. Pierce, MD, PhD
President

Val D. Bias
Chairman

Alan P. Brownstein
Executive Director

RE: NHF NAMED AS PARTY IN A CLASS ACTION LAWSUIT

As you may have already heard or have read in your paper, The National Hemophilia Foundation (NHF) was named in a class action suit that was filed in a Chicago federal court yesterday afternoon. The Foundation learned of this filing late yesterday evening.

At this time we have yet to be served with legal papers, but we are in the process of investigating the situation. We will provide you with additional information as we are able to do so, and most certainly in Indianapolis.

NHF will respond if served and will be fully vindicated in any court of law. NHF has worked on behalf of people with hemophilia for 45 years and will continue to do so.

For further information, we have attached media reports from today's newspapers. Should you receive any media inquiries, please forward them to Anne King at NHF extension 3006. And, if you have any questions regarding this news, please feel free to call any one of us.



THE NATIONAL HEMOPHILIA FOUNDATION

Contact: Anne M. King
212/219-8180
Ext. 3006

NATIONAL HEMOPHILIA FOUNDATION STATEMENT REGARDING CLASS ACTION SUIT, SPECIAL ASSISTANCE

OCTOBER 28, 1993

Recently, NHF learned that it has been named as a defendant in a lawsuit filed in a Chicago federal court. Other defendants named in this suit include five pharmaceutical companies.

Allegations against the Foundation contained in this suit are entirely without merit, and the Foundation is prepared to vigorously defend its record of serving the hemophilia community, particularly during the AIDS epidemic.

As part of its work on behalf of people with hemophilia, the organization's overriding goal in recent months has been to secure assistance for the hemophilia community, and our greatest concern now is that this new situation not slow that process. We have been involved in discussions with members of the blood industry to encourage them to assume responsibility for meeting the tremendous needs of people with hemophilia who were infected with the AIDS virus (HIV) in the early 1980s, when the nation's blood supply and blood products were contaminated with HIV.

NHF recently rejected a proposal presented by three of five industry members involved in these discussions because it was viewed as being insufficient to

-2-

meet the needs of people with hemophilia and HIV. The three sponsors of this proposal are Alpha, Armour and Baxter. The Foundation continues its discussions with these and other industry members to determine how to meet the extensive needs of the hemophilia community, and it is pressing for resolution of these discussions in the near future.

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THE NATIONAL HEMOPHILIA FOUNDATION

August 9, 1994

MEMORANDUM

TO: Chapter Presidents and Executive Directors

FR: Glenn F. Pierce, MD, PhD
President

Jonathan Botelho
Chair, Board of Directors

Dennis Hirschfelder
Executive Director

RE: PROPOSED LAWSUIT SETTLEMENT

CC: Board of Directors
MASAC
NHF Committee Chairs
MANN Committee
Women's Advisory Committee

Since our preliminary communication to you last Tuesday, we have learned some additional information regarding the certification of the lawsuit as well as the proposed settlement between the plaintiffs in the lawsuit and Baxter and Armour. Baxter and Armour are two of the four pharmaceutical company defendants in the proposed class action.

On Friday, August 5, a hearing was held in Chicago with Judge John Grady, the judge presiding over the class action, and representatives of both the plaintiffs and defendants to discuss the proposed settlement, described below. At this hearing, the judge asked David Sbrager, the lead attorney for the plaintiffs, for his justification for "severing out these two defendants (Armour and Baxter) for what might be regarded as somewhat lenient treatment."

Further, Judge Grady indicated that he had made his decision on class certification and had almost completed writing his opinion. While his opinion is not finalized -- his written decision

-2-

is expected to be available August 15 -- he advised that he will grant certification of the class action only on the issue of the defendants' negligence. There were six areas considered for potential certification; the court indicated that it would grant certification on the negligence issue only. This could result in a consolidated trial on that limited issue.

We understand that the plaintiffs are currently discussing their options related to the settlement agreement and the class action.

Until we receive Judge Grady's written ruling, we will not have sufficient information to provide a complete analysis of the impact of this decision on the Foundation, on the lawsuit, and on the proposed settlement. We will provide further information on this issue as it becomes available to us.

Background on Proposed Settlement

- * A proposed settlement was announced August 2 between the steering committee of plaintiffs' attorneys -- including those for the twelve individuals who filed suit against four pharmaceutical companies and NHF on September 30, 1993 -- and two of the defendants, Armour and Baxter.
- * In the proposed agreement, Baxter and Armour would provide \$140 to \$160 million for the creation of a fund. Based on Baxter's and Armour's estimates of the number of claimants (approximately 5,000), the maximum a claimant could be expected to receive is \$30,000.

According to the terms of the proposed settlement document, before the pool of money would be split among the claimants, several expenses would "come off the top" including: \$2 million for costs associated with administering the settlement, \$1 million for a community support commission, composed of settlement class members, for "psycho/social, crisis hotline and similar support services." Legal fees would also be deducted from the pool of money before any distribution.

- * In the proposed agreement, claimants have been defined as individuals with hemophilia and HIV, their HIV-infected partners, their HIV-infected children, as well as non-infected family members and the estates of deceased individuals with hemophilia and HIV.
- * The Foundation was not aware of, nor involved in, the settlement discussions.

If this proposal is accepted by the court, the court would approve a settlement class against Armour and Baxter only. Participating individuals would give up their right to litigate against Armour and Baxter at any time, and in accordance with the terms of the settlement, Armour and Baxter would be dropped from any pending lawsuits.

-3-

Settlement Contingencies

The proposed settlement contains several contingencies that must be satisfied, or Armour and Baxter have the right to dissolve the settlement agreement.

According to one of the settlement's provisions, if more than 150 claimants "opt-out" of the settlement, it is considered void. To opt-out, an individual must formally request exclusion from the settlement.

In making a decision about participation in this proposed settlement, an individual should speak with an attorney to discuss his or her options.

We remain committed to defending the Foundation in the current class action lawsuit, and working in every way we can to provide assistance to the bleeding disorder community. We support any effort which enhances the well-being of people who have hemophilia with HIV. To that end, NHF's recent efforts have been focused on the legislative campaign. Its three components include: 1) healthcare coverage for all individuals with bleeding disorders, 2) changing the Social Security rules to make the application process for Social Security Cash Assistance Benefits easier for individuals with hemophilia and HIV, and/or chronic/symptomatic hepatitis, and 3) a Disaster Relief Fund making cash payments to individuals with hemophilia who are HIV positive, and to the estates of those who have died of AIDS.

We will continue to provide information on the settlement class and the proposed class action as we receive it. If you have questions, please feel free to call Anne King at NHF extension 3006.



THE NATIONAL HEMOPHILIA FOUNDATION

Contact: Anne M. King
212/219-8180
extension 3006

STATEMENT REGARDING CLASS ACTION LITIGATION

August 23, 1994

NHF is an independent, non-profit advocacy organization that serves the hemophilia community. During the 1980s, the Foundation, with its Medical and Scientific Advisory Council, collaborated with researchers, scientists and government experts regarding the emerging AIDS epidemic to formulate recommendations regarding the advisability of continued blood product use. NHF's recommendations were shared with all relevant groups, including government agencies, pharmaceutical manufacturers and blood banks.

During the early 1980s, the Foundation was run by a volunteer Board of Directors comprised largely of people directly affected by hemophilia. The Foundation's Board of Directors continues to have this same composition. A number of Board members from the early 1980s have since died as a result of AIDS.

We are unable to comment further due to the restrictions imposed by a class action lawsuit filed in a Chicago District Court last fall that names NHF as a defendant. This situation is common in litigation, and in this particular case, reflects both the recommendations of NHF's legal counsel and the directions of Judge Grady of the U.S. Federal District Court in Chicago.

As the legal case proceeds, we look forward to the opportunity to present accurate information on these issues during the proceedings of the trial, and are confident that the Foundation's actions during the period in question will be fully exonerated.

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THE NATIONAL HEMOPHILIA FOUNDATION

Contact: Anne M. King
212/219-8180
Ext. 3006

SECOND NATIONAL HEMOPHILIA FOUNDATION STATEMENT REGARDING CLASS ACTION SUIT

OCTOBER 1, 1993
3:30 p.m.

The National Hemophilia Foundation has been involved in discussions with members of the blood industry to encourage them to assume responsibility for meeting the tremendous needs of people with hemophilia who were infected with the AIDS virus (HIV) in the early 1980s, when the nation's blood supply and blood products were contaminated with HIV.

At a meeting earlier this week (9/29), three of five industry members involved in these discussions presented their joint proposal for NHF's review. The three sponsors for this proposal are: Alpha, Armour and Baxter. NHF is currently reviewing this proposal, and will be sharing and reviewing it further with members of the hemophilia community, and NHF's Board of Directors, at the Foundation's annual meeting next week in Indianapolis, Indiana.

NHF learned late last evening (9/30), through media reports, that it had been named in a class action suit filed in a Chicago federal court yesterday afternoon (9/30). The Foundation has yet to be served with legal papers concerning this action, and is in the process of investigating this situation. Therefore, we cannot comment on this matter until we have more

-2-

information, except to say that the overriding goal of NHF has been to secure assistance for the hemophilia community, and our greatest concern now is that this new situation not slow this process.

Several media reports about this situation have contained inaccurate information regarding NHF.

The accurate information is:

- More than 90 percent of NHF's funding is derived from government sources and contracts, NHF chapters and public donations; only five percent is derived from contributions made by pharmaceutical companies. NHF's funding has always been a matter of public record.
- NHF provided the hemophilia community with information about HIV and AIDS, in consultation with the Centers for Disease Control, as soon as the risk associated with the HIV contamination of the nation's blood supply and blood products was identified.

###

Contact: Anne M. King
212/219-8180
extension 3006

10/27 - 10/29
NHF Annual Meeting
Dallas, Texas
214/761-2943

STATEMENT REGARDING CLASS ACTION LITIGATION

November 3, 1994

NHF is an independent, non-profit advocacy organization that serves the bleeding disorder community. Beginning with the first diagnoses in July 1982 of a rare immune disorder (later named AIDS) in the hemophilia community, the Foundation with its Medical and Scientific Advisory Council, worked with researchers, scientists and government experts to respond to the emerging AIDS epidemic and to formulate recommendations regarding the advisability of continued blood product use. NHF's recommendations were shared with all relevant groups, including government agencies such as FDA and CDC, pharmaceutical manufacturers and blood banks.

During the early 1980s, the Foundation was run by a volunteer Board of Directors comprised largely of people directly affected by hemophilia and the AIDS crisis. A number of Board members from the early 1980s have since died as a result of AIDS. Today, the Foundation's Board of Directors continues to have the same composition. It is made up of people with hemophilia and hemophilia with HIV/AIDS.

Restrictions imposed by a class action lawsuit filed in a U.S. District Court in Chicago last fall, naming NHF as a defendant, prevent us from commenting in detail about matters pertaining to this case.

However, we are happy to comply with the order of the court to contact potential class members. We look forward to the opportunity to present accurate information about these issues as the legal case proceeds, and we are confident that the Foundation's efforts during this period will be fully exonerated.

We are also in full support of the Institute of Medicine's inquiry into events that surround the HIV contamination of blood products used by the hemophilia community in the early 1980s.

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THE NATIONAL HEMOPHILIA FOUNDATION

November 9, 1994

MEMORANDUM

TO: Chapter Presidents and Executive Directors

FR: Jonathan A. Botelho
President

Dennis C. Hirschfelder
Executive Director

RE: LEGAL UPDATE

cc: Board of Directors
MASAC
MANN Committee
Women's Advisory Committee

Last week, on November 3, Judge Grady of the U.S. District Court in Chicago, the court with jurisdiction over the class action filed against NHF and four pharmaceutical companies, issued an order regarding the lawsuit. The order provides *all* class members the opportunity to opt *out* of the class action as it relates to NHF, while remaining *in* the class action against the fractionators. In addition, Judge Grady also formally certified the class.

Judge Grady's order stated:

...there may be valid reasons why certain class members would elect not to assert claims against the NHF while still desiring to assert claims against the fractionator defendants. This raises the possibility of class members opting out solely to avoid asserting claims against the NHF. This consideration is sufficient to justify the creation of an opt-out procedure for class members as to the NHF only, while allowing for their continued class membership in the litigation against the fractionator defendants.

Thus, for those individuals who are interested in taking part in the class action, but who do not want to sue NHF, a means for doing so now exists.

-2-

We are very pleased that the court has recognized the unique circumstances of the hemophilia community in this lawsuit -- a lawsuit in which many people are being asked to make a trade-off between their desire for legal action and their feelings towards NHF. We appreciate the court's understanding in allowing individuals to separate these two issues.

Originally, the court had been expected to approve the formal notice and the plan for its distribution at the November 3 meeting. (The notice is the document that will be sent to all identifiable class members informing them of their legal rights.) These items have been deferred and are expected to be dealt with on the next court date, December 6. The plan for distribution will describe how the names will be identified.

If you have any questions about this new development, please feel free to call either of us or Jill Friedman at NHF extension 3036.



THE NATIONAL HEMOPHILIA FOUNDATION

**TO: CHAPTER PRESIDENTS AND EXECUTIVE DIRECTORS
HEMOPHILIA TREATMENT CENTERS**

**FR: INGRID MONTECINO
ACTING EXECUTIVE DIRECTOR**

DATE: JANUARY 18, 1995

RE: DELAY IN CLASS NOTICE DISTRIBUTION

Because of a new development in the ongoing legal process, the court has ordered a delay in the distribution of the notice.

The notice -- the document that will be sent to all members of the class informing them of their rights -- has been delayed because this past December, the fractionators filed a motion with the Seventh Circuit Court of Appeals challenging Judge Grady's order to certify the class. This process is called a petition for "writ of mandamus" in legal terms. To date, the appellate court has not yet decided on the writ, and has issued an order that the notice should not be distributed until it reaches a decision. Both the plaintiffs and fractionators will present their positions on this issue to the court on January 30th, and the appellate court issue their ruling sometime following the hearing. NHF is not part of this effort challenging Judge Grady's ruling.

We cannot predict the outcome of the hearing, and will let you know more information when it becomes available.

Prior to this delay, it had been expected that during the month of January the class notice would begin to be distributed. The court has indicated that it plans to ship postage-paid copies of the notice, in bulk, to chapters and other distribution points, for these organizations to send to their mailing lists.

If you have any questions, please feel free to call Jill Friedman at NHF extension 3036.

cc: Board of Directors



THE NATIONAL HEMOPHILIA FOUNDATION

STATEMENT REGARDING COURT RULING ON CERTIFICATION OF THE HEMOPHILIA CLASS ACTION SUIT

March 20, 1995

On Thursday, March 16, the 7th Circuit Court of Appeals issued its ruling which requires Judge Grady to decertify the case as a class action suit filed by members of the bleeding disorders community infected with the AIDS virus after using HIV contaminated blood products. This ruling was in response to the "writ of mandamus" which the pharmaceutical defendants filed with the Court in December, 1994.

NHF, also a defendant in this case, had no part in filing the petition for a writ of mandamus.

According to NHF president, Jonathan Botelho: "The National Hemophilia Foundation is in full support of the hemophilia community's efforts to gain compensation for the devastating impact of HIV and AIDS on people with bleeding disorders and their families."

The decision to decertify the class is subject to further appellate appeal, which may be pursued by the plaintiffs in this case. If the decision to grant this writ of mandamus is upheld, the case of the 12 plaintiffs in *Wadleigh vs. Rhone-Poulenc-Rorer et al.* would still be heard by Judge Grady. However, any extension of the statute of limitations period that might have resulted from the class being certified will end when the order decertifying the class is entered.

Restrictions posed by the lawsuit filed in the fall of 1993, prevent NHF from commenting further about the case at this time.

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THE WHITE HOUSE
WASHINGTON

March 28, 1995

[Handwritten signature]
PF ✓
No action

MEMORANDUM FOR ALL WHITE HOUSE STAFF

FROM:

ABNER J. MIKVA
COUNSEL TO THE PRESIDENT *[Handwritten signature]*

SUBJECT:

CONGRESSIONAL REQUEST FOR DOCUMENTS

As you may be aware, the House of Representatives recently adopted a resolution "Requesting Information from the President Concerning Actions Taken to Strengthen the Mexican Peso and Stabilize the Economy of Mexico" (the "Resolution").

The Administration has committed to provide documents responsive to the Resolution as promptly as possible. While the Resolution requests a broad range of documents, it expressly provides that the Administration need not produce particular documents or categories of documents when it is "inconsistent with the public interest" to do so.

Each member of the White House staff should promptly review his or her files and identify any documents on the subjects set forth in the Attachment to this memorandum. **All such documents should be provided to Stephen Neuwirth, Associate Counsel to the President, in Room 130 OEOB, by no later than 5:00 p.m. on Friday, March 31. To facilitate this process, members of the NSC staff should provide documents to the NSC Legal Adviser's Office, Room 348 OEOB.**

Please provide all documents in the subject areas set forth in the Attachment. The White House Counsel's Office, in consultation with the Department of Justice and the NSC Legal Adviser, will work with appropriate White House staff to make necessary determinations regarding the public interest, any applicable privileges, and conditions for disclosure of information to the House or designated Members.

Please contact Steve Neuwirth (ext. 6-7903) if you have any questions concerning this document request.

[Handwritten signature]
FLEMING, PATRICIA S.

WHITE HOUSE OFFICE

DOMESTIC POLICY COUNCIL

750 17TH ST NW

YOUR EMPLOYEE ASSISTANCE PROGRAM

For caring, confidential, professional
counseling help, call—

1-800-545-1221

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

March 28, 1995

PF
circ

MEMORANDUM FOR ALL EXECUTIVE OFFICE OF THE PRESIDENT EMPLOYEES

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

SUBJECT: Employee Assistance Program

Beginning in April 1995, the Executive Office of the President (EOP) is contracting with a new Employee Assistance Program (EAP) provider, The Sand Creek Group, Ltd., a national behavioral health care corporation to provide a comprehensive EAP.

The Employee Assistance Program (EAP) helps employees and their dependents deal with a variety of personal problems, including ones which negatively affect job performance. From time to time we all need help managing life and work stress. The EAP offers help with a wide variety of life concerns, at no cost to the employee.

Convenient, Easy Access to Service: The new EAP counselor is James Myricks. He will be available to see you and/or your family members on-site, by appointment or on a walk-in basis, in the New Executive Office Building (NEOB), Health Unit, Room 6101, from 1:00 - 5:00 PM each Wednesday. To schedule an appointment, call 1-800-545-1221.

24 Hour Telephone Crisis Intervention: Assistance is available at any time by calling 1-800-545-1221.

Confidential: The highest professional standards will be used to guard your confidentiality.

Professional: All of The Sand Creek Group counselors are highly trained, experienced, and licensed employee assistance counselors holding at least a masters degree in psychology, social work or a related behavioral health field.

Family Coverage: Dependents of EOP employees are eligible to use the program.

A handy wallet card, with the EAP telephone number, is attached.

If you have any questions about the EAP, please call Ann Calhoun on 5-1146 or send her an E-mail at Calhoun_A.

THE WHITE HOUSE
WASHINGTON

FILE COPY

March 20, 1995

MEMORANDUM TO: Jim Dorskind
Special Assistant to the President
Director of Correspondence and Presidential Messages

FROM: Patricia S. Fleming 
National AIDS Policy Office

SUBJECT: Appreciation to Presidential Messages' Staff

The staff in the Office of Presidential Messages, and Lori Abrams in particular, were very helpful in getting a section of the AIDS Memorial Quilt signed by the President for an AIDS awareness program held in Arizona on February 17. They were given short notice but were able to accommodate the unprecedented request in enough time to allow the letter and quilt to be part of a scheduled display.

I wanted to express my appreciation for their assistance. The event was a huge success and the President's letter and signed quilt panel were viewed by hundreds of participants.

THE WHITE HOUSE
WASHINGTON

February 15, 1995

FILE COPY

MEMORANDUM FOR SKILA HARRIS

FROM: Patricia S. Fleming 

SUBJECT: Friends for Life Award

The Whitman-Walker Clinic has selected Mrs. Gore as the recipient of their "Friends for Life" Award. I am pleased that the Whitman-Walker Clinic is honoring her for her support and her dedication to fighting AIDS. Please offer my congratulations to Mrs. Gore on being the recipient of this important award.

I encourage Mrs. Gore to accept the invitation to attend the "Friends for Life" activities. Events include an awards dinner to benefit the Elizabeth Taylor Medical Center and a brunch with His Excellency Jaques Andreani, the French Ambassador to the United States. Her presence will further demonstrate this Administration's commitment to AIDS issues and give renewed courage to those involved in the fight against AIDS.

Once again, my thanks and congratulations to Mrs. Gore.

Whitman-Walker Clinic

1407 S Street, N.W.
Washington, DC 20009

202/ 797-3500
FAX: 202/ 797-3504

TO:



FROM:

DON HENSE 797-3520

Number of Pages (Including Cover):

Date:

2-1-95

Message:

Thank you for your assistance
Hope to see you soon

This facsimile is intended only for use of the addressee named above and may contain legally privileged and/or confidential information. If you are not the intended recipient of this facsimile, you are hereby notified that any dissemination, distribution or copying of this facsimile is strictly prohibited. If you have received this facsimile in error, please immediately notify us by telephone and destroy.

Questions or Problems,
Please Call me at 202/ 797-35____
Thank you.

MEDICAL CENTER

WHITMAN-WALKER CLINIC

January 12, 1995

Mrs. Tipper Gore
Wife of the Vice President
Old Executive Office Building
Washington, DC 20501

Dear Mrs. Gore:

On behalf of the Board of Directors and the thousands of people we serve, it is my pleasure to inform you that you have been selected as the recipient for this year's *"Friend for Life"* award. On Saturday, April 22, 1995, Whitman-Walker Clinic will hold its annual spring gala, *Friends for Life* to benefit the Elizabeth Taylor Medical Center, the nation's first stand-alone facility devoted to treating people living with HIV and AIDS. We warmly remember that you served as the Honorary Chair of the dedication of this facility on November 19, 1993. *Friends for Life* provides an opportunity for workers and supporters of our work to pause and honor an individual who has contributed significantly in the battle against AIDS. Mrs. Gore, we believe you are that individual.

The evening will begin at 7:00 p.m. at the Warner Theatre, with the presentation of the *"Friend for Life"* Award. Following the presentation, the featured artist for the Gala will be one of our country's artistic treasures, the internationally acclaimed Alvin Ailey American Dance Theatre. We have invited Metropolitan Opera star, Jessye Norman, to join in this special performance. The evening will conclude with a beautifully staged dinner dance at the Old Post Office Pavilion with the theme "April in Paris".

To compliment this very special weekend, we have proposed to His Excellency Jacques Andreani, The Ambassador of France, to host a VIP brunch at the Ambassador's residence on Sunday, April 23, 1995 for you and Miss Elizabeth Taylor, whom we have asked to serve as Gala Chair, and select guests and supporters. This brunch will be a significant expression of appreciation for all those who struggle diligently in this battle against AIDS. We would be honored if you could include this event as part of the *"Friend for Life"* award.

I would also like to take this opportunity to thank you again for your tremendous support of **AIDSWALK '94**. Over 40,000 individuals from the greater Washington area came together to raise over \$1.6 million for AIDS research, treatment, and education. It was a pleasure to have you and your family leading this significant effort. Mrs. Gore, we have witnessed first-hand your compassion and your commitment on this issue and know that you have the attributes of one who is a friend for life. You are respected for your continued support of other AIDS service organizations throughout the country and for a health care system which provides humane treatment for those living with HIV and AIDS. You are a beacon of hope to those of us at Whitman-Walker Clinic.

Mrs. Albert Gore
Page Two
January 12, 1995

It is a true partnership of caring that built the Elizabeth Taylor Medical Center, and it is this spirit of commitment that will enable it to meet the growing needs in this community. Hundreds of thousands of people across the nation will benefit from the research that is conducted at the Medical Center, and no other organization is better prepared than Whitman-Walker Clinic to make strides in the prevention and treatment of HIV and AIDS. The Clinic is known around the world for its commitment to progressive and compassionate care. Its continued strength, though, depends on us.

Mrs. Gore, we would indeed be honored if you would become the recipient of the 1995 "Friend for Life" Award. I know you feel as I do, that this battle is among the most important we face. I look forward to your positive response. Should you agree, would you please respond by February 1, 1995, so that we may have adequate time to prepare the invitations and the award.

With every good wish,



Jim Graham
Executive Director

Just - please file
JHB
FW

February 3, 1995

MEMORANDUM TO LEON PANETTA

From: Carol H. Rasco *CR*
Subject: Weekly Report - January 27 thru February 3, 1995

UPDATE ON KEY INITIATIVES

Welfare Reform

- NGA -- The National Governors Association approved a policy statement that provides guidance for lobbying on welfare reform should Congress pursue either a block grant or an individual entitlement. We met with NGA staff following the meeting and expressed our interest in working with them on emerging legislation.
- Congress -- Hearings continue in the House. Mark-up in subcommittee is scheduled for the 13th. We are meeting regularly with House members and staff to brief them and provide information and advice.

Crime

- Cops -- Next week, Justice will announce the cities selected to participate in the COPS FAST program; some 7,200 of the nation's smaller police departments have applied. In total, COPS FAST will allow approximately 4,600 police departments to hire 5,000 new officers (\$350 million). A scheduling request has been submitted for the President to participate in the COPS FAST announcement and reinforce his commitment to put 100,000 cops on the street.
- Other Crime Bill -- The House Judiciary Committee continues to mark-up anti-crime legislation -- and to undo much of what was accomplished last year. They have splintered their crime bill into 6 pieces and expect to start considering these bills on the floor next week.
- Law Enforcement Meeting -- A productive meeting with the Attorney General, the heads of the 12 national law enforcement organizations and yourself (Leon Panetta). No group expressed a desire to revisit last year's bill -- particularly the 100,000 cops program -- and all the groups are interested in working with the Administration on additional crime issues.

Immigration

- o We spent the week preparing for the roll-out of immigration policy and budget on February 7th at a Presidential event. We have a coordinated roll-out planning including legislative, advocacy and press briefings.
- o A meeting was held of the interagency subgroup working on design and anti-discrimination elements of verification pilot.

Empowerment Zones/Enterprise Communities

- o The Vice President continues to travel to the EZ sites. Paul Weinstein and Sheryll Cashin (NEC) are working with Treasury and OMB on a legislative proposal to make Los Angeles and Cleveland full EZs (they received the grant money but not the tax incentives).

AIDS

- o The AIDS office will hold a press briefing on the afternoon of February 6, to be followed by a briefing on the budget for constituency groups.

Health Care

- o Drafting has begun on the health care sections (including health care reform, WIC, immunizations, women's health and HIV/AIDS) of a document describing the status of Clinton Administration initiatives.
- o In preparation for testimony by Bruce Vladeck next week, work is underway on various policy areas including Medicare managed care options and Medicaid cap proposals.

Political/Government Reform

- o Unfunded Mandates -- By a vote of 360 to 74, the House passed H.R.5 -- "The Unfunded Mandate Reform Act of 1995". On January 27, the Senate passed S.1, the companion legislation by a vote of 86 to 10. Sally Katzen (OMB) and Paul Weinstein have submitted a memorandum on the outstanding Conference issues and recommendations for Administration action.
- o Line-Item Veto -- The House is expected to take up the Line-Item Veto starting today under an open rule. Paul Weinstein is working closely with OMB and Martha Foley to advise them of our concerns about the bill. The House is marking up the stronger version of the legislation, while the Senate keeps debating between moving an enhanced rescission bill (McCain) or an expedited rescission bill (Domenici).

OTHER ISSUES FOR IMMEDIATE ATTENTION

Drug Strategy

- o The Drug Strategy is set to be released next week. Senator Hatch has scheduled Judiciary Committee hearings on the Strategy for February 10th.

Assault Weapons

- o Senator Feinstein has warned us that 60 Minutes is working on a negative news piece on the assault weapons ban. They will argue that the ban has not been effective.

Brady Bill

- o February 28th will be the one-year anniversary of the Brady Bill going into effect. We are hoping to work with the Treasury Enforcement staff to issue a report on the Brady Bill's impact.

AIDS

- o The release of the Public Health Service (PHS) draft guidelines on HIV testing for pregnant women is scheduled for February 15. Because this material could be considered controversial, a comprehensive press and congressional briefing strategy is currently being developed by the AIDS Office in conjunction with HHS.

Massachusetts AFDC Withdrawal

- o Massachusetts notified HHS by letter last Thursday that it may drop out of the AFDC program because it will run out of state funds for the program on February 15. Beneficiaries were also notified that the program might be terminated. As part of a battle last year between the Governor and the state legislature over welfare reform, the Governor line-item vetoed portions of the state AFDC appropriation in an effort to pressure the legislature to adopt his plan. A plan to provide emergency funds for an additional 30 days is now under consideration by Massachusetts.

Waivers

- o Ohio Welfare -- HHS expects to be able to announce approval of Ohio's welfare reform waiver, "A State of Opportunity," next week. The project would supplement wages, provide transitional assistance, and require children to attend school.

Native Americans

- o Secretary Babbitt will hold the first meeting of the DPC Working Group on Indian Affairs on Monday, February 6 at the Department of Interior. This group is chaired by Secretary Babbitt, who will meet regularly with representatives from the Cabinet Departments at the Assistant Secretary level or higher.

Community Development Banks

- o Paul Weinstein is meeting with the proposed nominee to head the CDFI Fund, Kirsten Moi, about her nomination at Treasury (2/3). Kirsten is a Senior Vice President at the Equitable in New York. Paul is also meeting with Chris Edley of OMB and others about protecting the CDFI program from Republican rescission efforts (2/2).

Other

- o The Technology Learning Challenge Grant Program is currently scheduled for announcement by the Vice President (and possibly the President) during the week of February 13.
- o Janet Abrams, from the Domestic Policy Council staff, will work with Bill Galston who is serving as DPC point person for the National Campaign Against Teen Pregnancy.

EXTERNAL ACTIVITIES

Press

- o Patsy Fleming participated in an interview with the Los Angeles based Michael Jackson Radio Show.

Speaking Engagements

- o I addressed the NGA Winter Meeting's Plenary Session: "Children" on January 29.
- o Patsy recently addressed the National Conference on Runaway Youth.
- o As requested by the Office of Public Liaison, Bill Galston addressed:
 - students brought in by the National Association of Evangelical Colleges on the Middle Class Bill of Rights, and
 - members of the California School Board.

Other Meetings

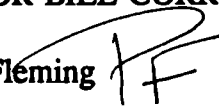
- o The DPC staff, in conjunction with HHS, organized the President's meeting with welfare recipients, former and current; and also in connection with Intergovernmental Affairs, the DPC hosted the President's Welfare Reform Working Session with elected officials at Blair House.
- o I met with representatives of the Massachusetts Hospital Association regarding health care reform.
- o Patsy met with Rich Tafel, head of the Log Cabin Republicans (a gay/lesbian organization).

THE WHITE HOUSE
WASHINGTON

December 20, 1994

FILE COPY

MEMORANDUM FOR BILL CORR

FROM: Patsy Fleming 
SUBJECT: SAMHSA Reauthorization

I want to flag for you a number of issues of concern to me in the context of the SAMHSA reauthorization that I hope your working group will keep in mind. I know I don't need to tell you how important is the link between HIV transmission and substance abuse and thus the importance of the block grant to AIDS prevention.

- **Coordination of the chronic substance abusers initiative with Ryan White.** This initiative, with its emphasis on providing community based, comprehensive, coordinated services should require strong coordination with any Ryan White CARE Act programs at the community level. Clearly, this is the population of substance abusers most likely to be infected or at risk for HIV infection. If they are infected, receiving HIV-related services might increase willingness to seek care for substance abuse as well. In any case, since some services proposed in the initiative are also included among Ryan White services, coordinating and avoiding duplication should be required. (We will also raise this issue in the context of Ryan White reauthorization.)
- **More involvement of affected communities in decisions regarding spending under the block grant.** In both the chronic substance abusers initiative and in general, such involvement would improve effectiveness. The community planning model developed at CDC — where the decision-making process includes both state and local health departments as well as the communities affected by HIV — is one that is equally applicable to the substance abuse block grant. The same principle applies: the closer decision making is to people who are to be served by the programs, the more likely they are to meet real needs at the local level. We will be happy to provide some of our experience in the AIDS community to help you develop such provisions for the block grant.
- **The HIV early intervention services set aside.** Some modification of this provision in the block grant is needed. A higher prevalence rate should be established for the set aside to kick in, since it was originally based on the old case definition. With the new case definition, some states are reaching this requirement even though they have relatively low incidence rates. There should also be a requirement of linking these efforts with Ryan White CARE Act programs. Finally, we know very little about how these funds are actually being spent; some effort at closer evaluation by SAMHSA would be helpful so we can better judge the impact of this provision.

- **The block grant set aside for prevention should be linked to the HIV prevention community planning occurring at the state and local level. This requirement is critical; it has been very hard for the CDC to get many of the state substance abuse agencies to come to the table. These programs need to be closely coordinated, since they are essentially targeting the same populations.**

- **The consolidation of demonstration programs into one demonstration authority per center raises concern about the future of the HIV-related mental health demonstration project. It has been our unfortunate experience that, without a specific set-aside, HIV-related programs tend to get lost as more "popular" issues get funded. This demonstration has had fairly good reviews, and we are concerned that it might be cut short before we know its true value.**

cc: Nelba Chavez

file

THE WHITE HOUSE
WASHINGTON

January 18, 1995

MEMORANDUM TO JEREMY BEN-AMI

FROM: Patsy Fleming 
SUBJECT: NGA's HIV Policy Statement

Policy Number: EC-10

Committee: Executive Committee

Title: HIV/AIDS

Summary: There is nothing unusual or alarming in this responsible policy statement. The state role as well as the federal role in prevention, research and services are spelled out quite accurately. Finally, the policy calls for strong action by all levels of government, and the reauthorization of the Ryan White CARE Act.

Red Flag Issue: This is a minor red flag issue, but one of interest to many governors, even though it is not specifically referred to in the policy statement. Title II of Ryan White authorizes funds that go directly to the state health departments to provide for care for AIDS patients and for drug reimbursement. There has been concern in the statehouses about the low level of funding for this program as compared with Title I which goes to the hardest hit cities. We can say that in the FY 96 budget Title II receives a larger increase than it has in previous years. Let me know if you want numbers, percentages, etc.

EXECUTIVE OFFICE OF THE PRESIDENT

Washington, D. C.

FAX TRANSMITTAL COVER SHEET

DATE: 17-Jan-95

TO: JEFF LEVI

SUBJECT: NGA POLICY STATEMENTS

FROM: JEREMY D. BENAMI 456-5584
DOMESTIC POLICY COUNCIL

If there are any problems receiving this transmission,
please call the sender, or (202) 395-7370.

A number of you received a request directly from Marcia Hale to put together information on NGA's proposed policy changes.

Two things:

(1) The assignments made some mistakes. I know a number of you have addressed this directly, but I want to be sure the following is the right list of assignments:

Transportation -- Mike and Paul, I assume you gave both issues to Michael Deitch if appropriate

Housing -- Paul, please work with Lynn

Immigration -- Steve, please get info from Mike

Workforce Excellence -- Mike, please get from Bill Galston

Natural Resources -- Brian: assigned correctly

Health Reform -- Chris and Jen Klein

Long Term Care/Medicaid -- Chris and Jen, could you please do these as well.

Indian Gaming -- Mike

→ HIV/AIDS -- Patsy, I will fax this to you

Equal Rights -- Steve, I will get this to you

Child care -- Gaynor, I will get this to you, we should talk

Talking Points

Gaynor -- They asked Bill to pull talking points on (1) Inter-governmental Progress/Federalism, (2) Education and (3) Re employment -- could you please work with Bill, Elaine and others as appropriate to pull the latest materials

Jen K -- Health and Medicaid

Brian -- Environment

Steve -- Immigration (not Mike obviously)

Jose -- Crime

(2) FORMAT

These should be very short, one pagers. Carol suggests the following format:

Policy Number:

Committee:

Title:

3 sentence summary: (what law do they want to change, what would

they change, etc.)
Of concern to the administration: what serious "red flags" does
the proposal raise. No need for a detailed policy
statement, just the red flags.

Please submit materials for this response through me so that we
can coordinate centrally - by c.o.b. Wednesday. If any problems,
please see me.

Thanks.

**NATIONAL
GOVERNORS
ASSOCIATION**



James G. Thompson
GOVERNOR OF W. VIRGINIA

National Transportation
 Board
 Executive Director
 Hall of the States
 444 North Capitol Street
 Washington, D.C. 20001-1512
 Telephone (202) 626-5500

EXECUTIVE COMMITTEE

Governor Howard Dean, M.D., Chair
Governor Tommy G. Thompson, Vice Chair
Raymond C. Schenpach, Executive Director

Proposed Changes in Policy

EC-7	Health Care Reform	Page 4
EC-10	HIV/AIDS	Page 19
EC-11	Long-Term Care	Page 26
EC-12	Medicaid	Page 32
EC-13	Conference of the States	Page 39

Reaffirm Existing Policy

EC-4	Indian Gaming	Page 40
EC-6	Political Self-Determination for Puerto Rico	Page 41
EC-14	Commonwealth Status for Guam	Page 42
EC-15	Public Pay and Pension Plans	Page 43
EC-16	Out-of-State Sales Tax Collections	Page 44
EC-17	Ethics in Government	Page 45
EC-18	Equal Rights	Page 46

New language is typed double-spaced and in ALL CAPS, with deleted material lined-throughout (—).

The Executive Committee recommends the consideration of three new policy positions, one of which is current interim policy, amendments in the form of substitutes to two existing policy positions, and the reaffirmation of seven existing policy positions (three with technical amendments). Pursuant to the recommendations of the Strategic Review Task Force, these proposals are time limited to two years. Background information and fiscal impact data follow.

1. Health Care Reform (Amendment in the form of a substitute to EC-7)

While federal efforts to develop a consensus on national health care reform have to date been unsuccessful, reform efforts in the states continue to move ahead. However, more needs to be done. This proposed policy describes policy areas where additional federal support is needed to facilitate and accelerate the development of state-based efforts. Included among the areas are the Employee Retirement Income Security Act (ERISA), the health insurance market, acute care services for low-income individuals and families, medical tort reform, and administrative simplifications.

2. HIV/AIDS (EC-10, amendment in the form of a substitute to C-17)

The human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) are critical public health problems. This proposed policy calls for strong action by all levels of government, including the reauthorization of the Ryan White Care Act, to address this disease.

3. Long-Term Care (New Policy Position, EC-11)

With an aging United States population, the demand for long-term care will continue to grow for the next half century. This proposed policy calls for a more integrated approach to long-term care that supports the availability of a continuum of services, including home- and community-based care, so that placement in nursing homes can be prevented or delayed for as long as possible. The proposed policy supports a comprehensive approach to long-term care and recognizes the importance of a viable market for long-term care insurance and managed care networks that address long-term care needs.

4. Medicaid (New Policy Position, EC-12)

The Medicaid program, now more than 18 percent of total state spending, continues to be the fastest-growing state expenditure. Over the last decade, the partnership between the states and the federal government has eroded to the point that states now have relatively little flexibility in administering this program. This proposed policy calls on the federal government to reestablish that partnership through a series of programmatic recommendations that restore important flexibility to states. Included among the recommendations are allowing more flexibility in establishing managed care networks, establishing institutional reimbursement rates, and designing and implementing home- and community-based care programs as an alternative to institutional long-term care. The proposed policy also opposes a unilateral cap on federal Medicaid spending and calls for the repeal of certain unfunded mandates.

5. Conference of the States (EC-13, Current Interim Policy Position adopted by the Executive Committee on December 19, 1994)

On December 19, 1994, the Executive Committee unanimously adopted this proposal as "interim" policy. The rules require the association to approve all interim policy at its next meeting.

It is proposed that state legislatures pass a "Resolution of Participation" in a conference of the states that would develop a "States' Petition" as a new form of communication between the states and Congress. Once adopted by a majority of the states, the petition would be presented to Congress for action.

6. Reaffirmation of Existing Policy Positions

Indian Gaming (EC-4)

Under the sponsorship of the Senate Committee on Indian Affairs, the Governors, attorneys general, and Indian tribal government leaders participated in a negotiation process aimed at resolving the conflicts arising out of the implementation of the Indian Gaming Regulatory Act (IGRA) of 1988. After numerous meetings and hearings, as well as hours of staff-level negotiation, no compromise was reached.

No action has been taken on this issue since Senator Inouye and Senator McCain, then chair and vice chair respectively of the committee, presented a substantially revised version of S. 2230 to amend IGRA in August 1994. The revised bill discarded the scope of gaming and process framework that was developed through months of negotiations between state and tribal government representatives and replaced it with scope of gaming language similar to the original IGRA and a fast-track compacting process for tribes. NGA forwarded a letter to Senator Inouye and Senator McCain expressing disappointment with the revised bill and predicting the Governors' vehement opposition to such legislation.

Senator McCain, the current chair of the committee, intends to revise the bill's language further and to introduce a third version around March 1, 1995. He has requested gubernatorial input. NGA's current policy on amending IGRA will be held over to allow Governors to review and revise their policy position based on new information gained through the negotiation process and recent court decisions. The objective would be to have policy developed in time for the 1995 NGA Annual Meeting.

Political Self-Determination for Puerto Rico (EC-6, with a technical amendment)

The National Governors' Association has continuously supported Puerto Rico's request for a plebiscite regarding its status either as a state of the Union, a commonwealth, or independent status. The Executive Committee once again endorses the right of the people of Puerto Rico to political self-determination made freely by majority vote.

Commonwealth Status for Guam (EC-14)

The Executive Committee recommends reaffirmation of NGA's support of legislation designating Guam as a commonwealth.

Public Pay and Pension Plans (EC-15)

The Executive Committee recommends reaffirmation of this policy, which states that these issues are the primary responsibility of state and local governments. It also calls upon the federal government to revise the Fair Labor Standards Act with regard to state and local government concerns.

Out-of-State Sales Tax Collections (EC-16)

The Executive Committee recommends reaffirmation of this policy. The Supreme Court, in its 1992 decision North Dakota v. Quill Corporation, said that interstate sales tax collection was not a due process question but a Commerce Clause issue to be determined by Congress. This policy calls upon Congress to exercise its powers to regulate interstate commerce and to grant states authority to collect the taxes owed on interstate mail transactions.

Ethics in Government (EC-17, with a technical amendment)

The Executive Committee recommends reaffirmation of this policy, which calls on every elected official to support actions to maintain citizen confidence in government.

Equal Rights (EC-18, with a technical amendment)

The Executive Committee recommends reaffirmation of the principles embodied in the Equal Rights Amendment.

EC-10. HIV/AIDS**10.1 PREAMBLE**

THE HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) ARE CRITICAL PUBLIC HEALTH PROBLEMS. NO STATE HAS BEEN UNTOUCHED BY THE DEVASTATING HUMAN AND ECONOMIC COSTS OF HIV AND AIDS. U.S. PUBLIC HEALTH SERVICE AND WORLDWIDE PROJECTIONS OF FUTURE INCIDENCE ARE STARTLING. IN SEPTEMBER 1994, MORE THAN 425,000 ACTIVE CASES OF AIDS WERE REPORTED IN THE UNITED STATES. IN 1991 AND 1992 ALONE, MORE THAN 220,000 PEOPLE DIED OF AIDS. STATE AND LOCAL GOVERNMENTS HAVE ALLOCATED SIGNIFICANT FINANCIAL RESOURCES TO THIS PROBLEM. IN FISCAL 1992, STATES SPENT \$401.9 MILLION ON HIV/AIDS PROGRAMS AND SERVICES BEYOND THOSE PROGRAMS FUNDED THROUGH THE MEDICAID PROGRAM. IN A NUMBER OF STATES, STATE AND LOCAL FUNDS FAR EXCEED FEDERAL SUPPORT. THE GOVERNORS STRONGLY BELIEVE, THEREFORE, THAT THE MAGNITUDE OF THE AIDS EPIDEMIC CALLS FOR STRONG ACTION BY ALL LEVELS OF GOVERNMENT, INCLUDING REAUTHORIZATION OF THE RYAN WHITE CARE ACT.

10.2 EDUCATION, PREVENTION, COUNSELING, AND TESTING

THE GOVERNORS RECOGNIZE THAT THE FEDERAL GOVERNMENT HAS MADE A SIGNIFICANT CONTRIBUTION TOWARD FUNDING AIDS RESEARCH AND PREVENTION ACTIVITIES. ALTHOUGH SCIENTIFIC PROGRESS HAS BEEN MADE, AN EFFECTIVE VACCINE OR A CURE FOR THE DISEASE REMAINS YEARS AWAY. IN THE ABSENCE OF A VACCINE OR A CURE, PREVENTION EFFORTS SUCH AS EDUCATION, PUBLIC INFORMATION, HIV COUNSELING AND TESTING, AND PERSONAL RESPONSIBILITY ARE THE MOST EFFECTIVE MEANS AVAILABLE TO PREVENT THE DISEASE FROM SPREADING FURTHER.

IN RECENT YEARS, STATE HEALTH DEPARTMENTS HAVE ASSUMED THE PRIMARY ROLE IN PLANNING AND COORDINATING HIV PREVENTION EFFORTS. ALL STATES ARE ENGAGED IN HIV PREVENTION COMMUNITY PLANNING WITH SUPPORT FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION. BEGINNING IN 1994, STATE AND TERRITORIAL HEALTH DEPARTMENTS HAVE BEEN REQUIRED TO IMPLEMENT A PLANNING PROCESS THROUGH WHICH THEY COLLABORATE WITH THEIR COMMUNITIES TO IDENTIFY UNMET NEEDS AND ESTABLISH PRIORITIES FOR HIV PREVENTION PROGRAMMING. IN GENERAL,

FEDERAL SUPPORT FOR PREVENTION EFFORTS HAS BEEN HELPFUL; HOWEVER, STATES MUST BE GIVEN SUFFICIENT TIME TO IMPLEMENT PREVENTION STRATEGIES THAT EVOLVE FROM THESE PLANNING ACTIVITIES. MOREOVER, STATES MUST HAVE THE FLEXIBILITY TO DESIGN AND IMPLEMENT PREVENTION PROGRAMS AT THE STATE AND LOCAL LEVEL THAT MEET NEEDS AND ARE CONSISTENT WITH COMMUNITY VALUES.

PREVENTIVE EFFORTS DIRECTED AT YOUNG PEOPLE—BEFORE THEY REACH THE AGE WHEN THEY MAY ENGAGE IN BEHAVIORS THAT PLACE THEM AT RISK OF INFECTION—ALSO ARE IMPORTANT. THE NATION'S YOUTH SHOULD BE AWARE OF THE RISK OF THE POSSIBLE SPREAD OF AIDS THROUGH INJECTION OF DRUGS. INFORMATION ABOUT AIDS SHOULD BE AN INTEGRAL PART OF SUBSTANCE ABUSE PREVENTION EFFORTS.

FINALLY, SPECIAL EDUCATION EFFORTS MUST BE MADE TO ENSURE THAT ALL MEMBERS OF THE MEDICAL AND HEALTH CARE COMMUNITY ARE KNOWLEDGEABLE AND HAVE CURRENT INFORMATION ABOUT AIDS PREVENTION. HEALTH PROVIDERS MUST BE MORE DILIGENT IN IDENTIFYING PEOPLE WHO ARE AT RISK OR WHO ARE INFECTED WITH HIV, PARTICULARLY IN POPULATIONS SUCH AS WOMEN AND ADOLESCENTS WHO ARE NOT AS FREQUENTLY RECOGNIZED AS AT RISK.

COUNSELING AND TESTING HAVE BEEN IMPORTANT COMPONENTS OF THE NATIONAL EDUCATION AND PREVENTION EFFORT. ACCESS TO COUNSELING SERVICES SHOULD BE AN INTEGRAL PART OF THE AIDS TESTING EFFORT, BOTH BEFORE AND AFTER TESTING AND REGARDLESS OF THE TEST RESULTS. COUNSELING AND TESTING REPRESENT MAJOR OPPORTUNITIES TO ENCOURAGE, ON A ONE-TO-ONE BASIS, THE BEHAVIOR CHANGES REQUIRED TO STOP FURTHER SPREAD OF THE HIV VIRUS. ALTHOUGH COUNSELING AND TESTING REMAIN IMPORTANT STRATEGIES TO ADDRESS THIS EPIDEMIC, THE NATION MUST CONTINUE TO SEEK ANY AND ALL STRATEGIES THAT WILL SUCCESSFULLY REDUCE THE TRANSMISSION OF HIV.

A KEY FACTOR IN CONTAINING THE SPREAD OF AIDS IS REDUCING THE USE OF INJECTION DRUGS. PROGRAMS SHOULD STRIVE TO ELIMINATE THE SIGNIFICANT WAITING TIME FREQUENTLY FACING BOTH THOSE WISHING TO RECEIVE TREATMENT FOR DRUG ABUSE AND THOSE DESIRING HIV TESTING AND COUNSELING. YET THE VAST MAJORITY OF DRUG USERS ARE NOT SEEKING TREATMENT. CONSEQUENTLY, OUTREACH SHOULD BE EXTENDED TO DRUG

USERS WHO ARE NOT CURRENTLY IN TREATMENT IN ORDER TO GET THEM INTO TREATMENT, ENCOURAGE THEM TO BE COUNSELED AND TESTED, AND EDUCATE THEM ABOUT THE DANGERS OF HIGH-RISK BEHAVIORS. ADDITIONALLY, APPROPRIATE MODELS TO ATTRACT DRUG USERS TO TREATMENT SHOULD BE DEVELOPED.

THE SOCIAL STIGMA ASSOCIATED WITH HIV/AIDS HAS CREATED A PARTICULAR PROBLEM FOR THE PREVENTION AND CONTROL OF THE DISEASE. OUT OF FEAR OF DISCRIMINATION, INDIVIDUALS WITH HIV AND AIDS WORRY ABOUT BEING IDENTIFIED. WITHIN THE CONTEXT OF SOUND PUBLIC HEALTH POLICY, STATES ARE ENCOURAGED TO REVIEW THEIR MEDICAL INFORMATION AND PRIVACY LAWS AND, WHERE NECESSARY OR APPROPRIATE, UPDATE THESE STATUTES TO SAFEGUARD THE RIGHTS OF TESTED INDIVIDUALS.

THE GOVERNORS ARE CONCERNED THAT INDIVIDUALS WHO TEST POSITIVE FOR HIV MAY FACE DISCRIMINATION, DESPITE THE FACT THAT ALL MEDICAL EVIDENCE TO DATE SHOWS THAT HIV CANNOT BE TRANSMITTED THROUGH CASUAL CONTACT. CLARIFICATION OF OR MODIFICATIONS IN LAWS SHOULD BE MADE WHERE NECESSARY TO PROTECT HIV-INFECTED INDIVIDUALS FROM INAPPROPRIATELY BEING DENIED OPPORTUNITIES IN AREAS SUCH AS EMPLOYMENT AND HOUSING.

10.3 RESEARCH

A COMPREHENSIVE NATIONAL EDUCATION AND PREVENTION PROGRAM, WITH SIGNIFICANT FEDERAL LEADERSHIP, MUST BE A CENTRAL COMPONENT OF THE NATION'S FIGHT AGAINST AIDS. AT THE SAME TIME, RESOURCES MUST BE DEVOTED TO RESEARCH—BOTH TO FIND A VACCINE FOR AIDS AS WELL AS TO DEVELOP A TREATMENT AND CURE FOR PRESENT AND FUTURE AIDS PATIENTS. THE FEDERAL GOVERNMENT HAS THE PRIMARY ROLE TO PLAY IN FUNDING AIDS-RELATED RESEARCH ACTIVITIES. THE GOVERNORS URGE THAT MONEY APPROPRIATED FOR AIDS RESEARCH BE USED EXPEDITIOUSLY AND THAT FUNDING PROVIDED FOR AIDS RESEARCH NOT BE MADE AT THE EXPENSE OF OTHER PUBLIC HEALTH PRIORITIES.

IN ADDITION TO THE SUBSTANTIAL COMMITMENT MADE BY THE FEDERAL GOVERNMENT, SOME STATES HAVE PROVIDED LEADERSHIP BY FUNDING AIDS RESEARCH WITH STATE DOLLARS. THE GOVERNORS URGE INCREASED COORDINATION BETWEEN FEDERAL AND STATE INITIATIVES IN THIS AREA TO

ENSURE THE MOST EFFICIENT USE OF RESEARCH DOLLARS. THE GOVERNORS ALSO URGE THE SPEEDY DISSEMINATION OF RESEARCH RESULTS TO THE SCIENTIFIC COMMUNITY, AS WELL AS PRACTITIONERS, TO ENSURE THAT RESEARCH FINDINGS CAN BE APPLIED AS EXPEDITIOUSLY AS POSSIBLE.

10.4 TREATMENT

OVER THE NEXT FEW YEARS, THE GROWING NUMBER OF AIDS AND AIDS-RELATED CASES WILL PLACE AN INCREASING STRAIN ON THE NATION'S HEALTH CARE DELIVERY SYSTEM. THE ESTIMATED COST OF TREATING A PERSON WITH HIV FROM THE TIME OF INFECTION TO DEATH IS \$119,000. FOR THOSE WHO RECEIVE NO TREATMENT UNTIL A DIAGNOSIS OF AIDS IS MADE, THE COST IS ESTIMATED AT \$69,000. NOW IS THE TIME TO BEGIN THE FISCAL AND CAPACITY PLANNING REQUIRED TO ADDRESS THESE FUTURE HEALTH CARE DELIVERY NEEDS. THIS SHOULD INCLUDE AN ASSESSMENT OF THE APPROPRIATE BURDEN OF AIDS HEALTH CARE COSTS THAT SHOULD BE BORNE BY THE PUBLIC AND PRIVATE SECTORS.

AT THE SAME TIME, WE NEED TO PROVIDE APPROPRIATE SERVICES TO THOSE INDIVIDUALS PRESENTLY SUFFERING FROM HIV INFECTIONS OR AIDS. ADEQUATELY ADDRESSING THE HEALTH CARE NEEDS OF AIDS PATIENTS REQUIRES ESTABLISHMENT OF A "CONTINUUM OF CARE," INCLUDING INPATIENT AND OUTPATIENT HOSPITAL SERVICES, CARE IN NURSING HOME AND ALTERNATIVE RESIDENTIAL SETTINGS, HOME CARE, HOSPICE CARE, PSYCHOSOCIAL SUPPORT SERVICES, AND CASE MANAGEMENT SERVICES. MANY STATE AND LOCAL GOVERNMENTS HAVE LED THE WAY IN PROVIDING HEALTH CARE SERVICES FOR PEOPLE WITH AIDS; HOWEVER, MORE RESEARCH IS REQUIRED TO DETERMINE THE MOST HUMANE AND COST-EFFECTIVE WAY OF PROVIDING AIDS-RELATED CARE. THE FEDERAL GOVERNMENT HAS FUNDED SEVERAL DEMONSTRATION PROJECTS TO DETERMINE MODELS FOR PROVIDING SERVICES TO AIDS PATIENTS. SUCH DEMONSTRATIONS SHOULD CONTINUE. FINALLY, AS THE NATION MOVES TOWARD NETWORKS OF HEALTH CARE, EFFORTS ARE NEEDED TO ENSURE THAT THE PREVENTION AND TREATMENT NEEDS OF PEOPLE AT RISK FOR OR INFECTED WITH HIV/AIDS ARE ADEQUATELY ADDRESSED IN MANAGED CARE SETTINGS. IN ADDITION, STRATEGIES MUST BE DEVELOPED THAT ENSURE THAT THOSE IN MANAGED CARE ARRANGEMENTS ALSO HAVE ACCESS TO OTHER SUPPORT SERVICES, SUCH AS SOCIAL SUPPORTS

AND HOME- AND COMMUNITY-BASED SERVICES, SO THAT THE CONTINUUM OF CARE IS MAINTAINED.

10.5 RYAN WHITE CARE ACT

THE GOVERNORS STRONGLY SUPPORT THE REAUTHORIZATION OF THE RYAN WHITE CARE ACT. FUNDS PROVIDED THROUGH THE ACT SUPPORT A NETWORK OF HEALTH CARE AND SUPPORT SERVICES IN CITIES AND STATES FOR PEOPLE LIVING WITH HIV INFECTION AND AIDS, ESPECIALLY THE UNINSURED WHO WOULD OTHERWISE BE WITHOUT CARE. THIS PROGRAM IS A CRITICAL ELEMENT IN AIDS PREVENTION, EDUCATION, AND TREATMENT EFFORTS BY STATES.

Time limited (effective Winter Meeting 1995-Winter Meeting 1997).

~~C-17~~ AIDS

~~-17.1~~ Preface

Acquired Immune Deficiency Syndrome (AIDS) is today the nation's number one public health problem. No state has been left untouched by the devastating human and economic costs of this fatal disease. U.S. Public Health Service and worldwide projections of the future incidence of the disease are startling. By the year 1991, it is expected that there will have been over 270,000 AIDS cases in this country alone—and 170,000 deaths. The Governors strongly believe that the magnitude of the present and future AIDS epidemic calls for concerted and immediate action by all levels of government in response to this public health crisis.

~~-17.2~~ Education and Prevention

The Governors recognize that the federal government has made a significant contribution toward funding AIDS research and prevention activities. Although scientific progress has been made, availability of an effective vaccine and cure for the disease are apparently years away. In the absence of a vaccine and a cure, prevention efforts such as education, public information, and counseling are the most effective means available to prevent the disease from spreading further. The federal government, in cooperation with state and local governments, the educational community, professional and services organizations, and the private sector, must take the lead on a national AIDS education campaign designed to prevent the further spread of the disease.

This education and prevention campaign will necessarily require an increased commitment of federal resources. Although this is an era of tight federal budgetary constraints, the seriousness of the problem calls for an increased federal investment. Further, funds appropriated by Congress in a given year should be expeditiously spent as part of an aggressive campaign to slow the spread of the disease. These resources should be devoted to a coordinated effort at the federal level to educate the general populace as well as segments of the population at particular risk.

Moreover, assistance should be provided to state and local governments, as well as community-based organizations, to assist them in this national education and prevention effort. If we are to be successful in changing attitudes and behaviors, this education campaign must use a variety of channels to reinforce the basic message of how to prevent the spread of AIDS. It will also be important to provide for evaluation of alternative approaches and their efficacy.

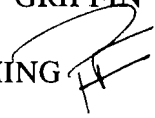
Similarly, AIDS educational efforts should not be limited to those areas presently experiencing a high incidence of AIDS. AIDS is a national public health problem which knows no geographical boundaries. Educational efforts in low incidence areas can play an important role in halting the spread of the disease.

THE WHITE HOUSE

WASHINGTON

December 14, 1994

MEMORANDUM FOR PAT GRIFFIN

FROM: PATSY FLEMING 

SUBJECT: COURTESY CALLS

The following are the names of key members of the House and Senate authorizing committees that deal with HIV/AIDS issues. I would like to schedule courtesy calls with these members as soon as possible. Please let me know whether or not there are any concerns.

Thank you.

HOUSE

Commerce Committee

Thomas Bliley (R-VA), Chairman

John Dingell (D-MI), Ranking Minority Member

Michael Bilirakis (R-FL)

Henry Waxman (D-CA)

Dan Frisa (R-NY)

Bill Paxon (R-NY)

Fred Upton (R-MI)

Gerry Studds (D-MA)

Edolphus Towns (D-NY)

SENATE

Labor and Human Resources Committee

Nancy Kassebaum (R-KS), Chairman

Edward Kennedy (D-MA), Ranking Minority Member

Orrin Hatch (R-UT)

James Jeffords (R-VT)

Dan Coats (R-IN)

Tom Harkin (D-IA)

Barbara Mikulski (D-MD)

THE WHITE HOUSE
WASHINGTON

December 12, 1994

FILE COPY

MEMORANDUM FOR CAROL H. RASCO

FROM: Patricia S. Fleming *RF*

SUBJECT: Invitation to the President to speak at National Youth Summit on HIV
Prevention

I have reviewed the attached invitation from the National Association of State Boards of Education for the President to participate in the National Youth Summit on HIV.

This would be an excellent opportunity to highlight the need for action on HIV prevention among adolescents and young adults. It would fit well with his emphasis on this subject on World AIDS Day and in the announcement of my appointment.

In addition, NASBE is a highly reputable organization so there is little concern about the nature of this meeting.

I would recommend an acceptance of the invitation.

My office would be pleased to provide any assistance necessary in preparing for such participation.

Thank you.

The White House
Washington

FAX COVER SHEET

OFFICE OF DOMESTIC POLICY

OLD EXECUTIVE OFFICE BUILDING

Washington, D.C. 20500

TO:

Richard S.

FAX NO:

632-1096

FROM:

Elisabeth Cohen 456 2846

FROM:

Jeremy Ben Ami PHONE: 456 5584

DATE:

12-12-94

TOTAL NUMBER OF PAGES: 5 COMMENT(S):

Richard, please give me a
call & let me know what
you think -

Thanks

Elisabeth

1012 Cameron Street
Alexandria, Virginia 22314

NASBE
NATIONAL ASSOCIATION OF
STATE BOARDS OF EDUCATION

12/11
THE PRESIDENT HAS SEEN

CRaso/Bleeker

Colleen

Scheduling Advice Memorandum

FROM:

BILLY WEBSTER

DATE:

12/5

TO:

JOAN BAGGETT
 ERSKINE BOWLES
 RAHM EMANUEL
 JOHN EMERSON
 MARK GEARAN
 JACK GIBBONS
 PAT GRIFFIN
 MARCIA HALE
 KAREN HANCOX
 ALEXIS HERMAN
 NANCY HERNREICH
 HAROLD ICKES
 WILL ITOH
 ANTHONY LAKE
 BRUCE LINDSEY
 AL MALDON
 KATIE MCGINTY

MACK MCLARTY
 ABNER MIKVA
 LEON PANETTA
 JOHN PODESTA
 JACK QUINN
 CAROL RASCO
 BOB RUBIN
 ELI SEGAL
 PATTI SOLIS
 GEORGE STEPHANOPOLOUS
 ANN STOCK
 CHRISTINE VARNEY (Education)
 MELANNE VERVEER
 DANNY WEXLER
 MAGGIE WILLIAMS
 TONY WILSON

RE: *National Association of State Boards of Education*
Natl Youth Summit on HIV

The Scheduling Office is considering the attached invitation.
 Please advise us:

- ☐ POTUS should/need not attend.
☐ POTUS should/need not attend but should send a representative

☒ If you think POTUS should attend please submit a scheduling proposal, WITH THE INVITATION ATTACHED, ASAP

Your Additional Comments:

PLEASE RETURN THIS MEMO TO ANNE MCGUIRE IN ROOM 185.5 BY asap

12-1
THE PRESIDENT HAS SEEN**NASBE**
NATIONAL ASSOCIATION OF
STATE BOARDS OF EDUCATION

November 30, 1994

William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue
Washington, D.C.

089181

Dear Mr. President:

This letter is to invite you to attend and support the National Youth Summit on HIV Prevention to be held in Washington, D.C. on May 6-9, 1995.

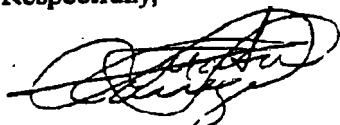
The Summit will be a forum in which over 150 youth from diverse backgrounds, including young people living with HIV, will be able to articulate their views about HIV prevention programs, and what more they feel the Nation should do to prevent HIV. The Summit will also be an opportunity for policymakers to hear directly from the Nation's youth. Finally, it will be a high-profile event designed to refocus attention on youth-centered HIV prevention programs.

Two critical elements will make this effort a success: youth involvement in the planning and implementation of the Summit; and a strong partnership between youth-serving organizations, private corporations, and the federal government. Indeed, the Summit's ongoing planning process addresses these two elements. The Summit's Executive Planning Committee includes youth, and representatives from national youth serving organizations and the federal government. Enclosed please find a list of executive committee members. Furthermore, the Summit is supported by the Centers for Disease Control and Prevention, INSURE, and over 50 national and local organizations concerned with young people.

While the work ahead is challenging, organizers are very committed to making the Summit a success. The Summit and its planning process will be greatly enriched by your caring leadership and support. Again, on behalf of the Summit's Executive Planning Committee, I invite you to be part of this very important process.

If you have any questions or need additional information, please do not hesitate to call me at 703-684-4000.

Respectfully,



Carlos A. Vega-Matos
Director, HIV Prevention /
Healthy Schools Project

Enclosure

1012 Cameron Street
Alexandria, Virginia 22314

703-684-4000
FAX 703-836-2313


Brenda Lilienthal Welburn
Executive Director

NATIONAL YOUTH SUMMIT ON HIV PREVENTION

Executive Committee

Yesenia Aguirre (Jessie)
1242 Market Street, 3rd Flr
San Francisco, CA 94102
Home address: 935B Fourteenth Street
San Francisco, CA 94114
phone 415-487-5777 (O) / 415-861-1060 (H)
415-560-7543 (P) / fax 415-487-5771

Carlton Duncan
Centers for Disease Control and Prevention
Mailstop K-42
4770 Buford Highway NE
Atlanta, GA 30341-3724
phone 404-488-5383 / fax 404-488-5962

Charlone Haynes
c/o Bart Haynes
3923 Wentworth Drive
Durham, NC 27707
phone 919-490-4965(H)
919-489-4300 (Family)
fax 919-684-5230

Jennifer Hincks-Reynolds
Advocates for Youth
1025 Vermont Ave. NW, Suite 210
Washington, DC 20005
phone 202-347-5700 / fax 202-347-2263

Stan Karson
Executive Director
INSURE
1001 Pennsylvania Avenue, NW
Washington, DC 20004-2599
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Lloyd Kolbe
Centers for Disease Control and Prevention
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The Academy for Educational Development
1255-23rd Street, NW
Washington, DC 20037
phone 202-884-8743 (O) / 202-543-6411 (H)
fax 202-884-8701 (O) / 202-543-6411 (H)

Stacey Mahoney
105 Trenton Place, SE
Washington, DC 20032
phone 202-737-7377 Children's Express
202-563-2246 (H) / 301-709-6974 (P)

John Moore
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(continued)

Brenda Lilienthal Weburn
Executive Director