FOIA Number: 2018-0764-F

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Correspondence - SLT - Incoming - 2/99 [3]

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	6	3

Todd A. Summers
02/08/99 06:42:34 PM

Record Type: Record

To: Daniel N. Mendelson/OMB/EOP, Gina C. Mooers/OMB/EOP

cc: Sandra Thurman/OPD/EOP, Richard J. Turman/OMB/EOP, Barbara A. Menard/OMB/EOP, Melany Nakagiri/OMB/EOP

Subject: Proposed Meeting & Draft Agenda Items

As a follow-up to my suggestion that we meet to discuss needle exchange and other FY2000 items, let me throw out a list of issues we might also want to go through:

Needle Exchange

There is a "dear colleague" already circulating by Tiahrt et al recommending a permanent funding ban. We'd like to work with you to oppose that movement.

FY2000 Funding

We'd like to know how best to use our contacts on the hill in a coordinated way to maintain or increase AIDS funding.

International Funding

We have had poor luck engaging Bob Kyle in a discussion on international AIDS funding and would like your help. The President promised the AIDS council more money here, and we could not get Bob to come up with any. Elena has talked to Jack and Josh about it, but I have no update as of yet.

Prisons

We would like to have some meetings on HIV/AIDS and prisons within the next month or two. One meeting would include a few community folks and a variety of HHS/Justice people to talk about ways to improve our response in the Federal system and ways to encourage a better response at the state/county/local level (where HIV prevalence is much higher). The second would be government folks only to talk about the same issues, and our response to the Correctional Officer Health and Safety Act (which we signed last session) - it requires, among other things, mandatory HIV testing and counseling/care. FCO

We are also unhappy about a BoP policy that limits care to prisoners in half-way house programs - any prisoner receiving on-going medical care who becomes eligible for pre-release is told that they can either stay in jail to receive care or go out and find it on their own - they're given 30 days supply of drugs - that's it. Not much of a model for supporting continuity of care.

Haven't talked to Michael Deich's folks yet.

Accountability

We need to follow up on our conversations about HRSA and CDC. Joe O'Neill is leaving HRSA (it's a strong rumor, anyway) and we're not sure that HRSA is prepared for the pending reauthorization process. HHS has also done little to bring folks together to make sure we're all on the same program.

We also continue to have problems with CDC's use of HIV prevention dollars. For example, they claim over 1,050 FTEs for HIV/AIDS, but there are only 550 or so in the two biggest divisions (Prevention and Surveillance). Even ASMB privately claims frustration (one might argue that it's their

job to get this information, but hey).

HCFA

There are a raft of issues relating to Medicaid, Medicare, and Jeffords-Kennedy we should discuss - probably could stand a whole meeting in and of itself. I'm most interested in J-K and how we can help - I also need to get more info on how it's going to play out for the states (how do they apply? how will the demo money be allocated?). Pelosi's folks have been asking for details and we haven't got any to share.

FY2001

We'd like to start conversations about the FY2001 budget earlier than later. There were some good ideas that didn't get well-covered because of the usual rush - can we start soon to talk about things?

So this is the list - we can cover as many as you want - I just thought it might be easier to at least go through the list to prioritize.

Todd

Todd A. Summers
02/23/99 11:01:36 AM

Record Type: Record

To: Daniel N. Mendelson/OMB/EOP
cc: Richard J. Turman/OMB/EOP, Melany Nakagiri/OMB/EOP
bcc: Records Management
Subject: Re: FYI - Additional Information on CDC's HIV Prevention Program

Thanks - I'll look these over and offer comments.

I think the biggest concerns with CDC are:

1. CDC lacks a coherent and comprehensive strategy to reduce HIV infections.
2. We have inadequate information on how HIV prevention dollars (and staff coded to HIV) are utilized - particularly in conjunction with a strategy.
3. The CDC structure does not allow for coordination and responsibility - HIV prevention funding is spread throughout CDC, and while the NCHSTP Director (Dr. Gayle) has some responsibility for coordination, she has no authority outside her Center.

Thanks.

Todd

Daniel N. Mendelson

Daniel N. Mendelson

02/23/99 09:54:10 AM

Record Type: Record

To: Todd A. Summers/OPD/EOP
cc: Melany Nakagiri/OMB/EOP
Subject: FYI - Additional Information on CDC's HIV Prevention Program

FYI, and I would be interested in your views before I visit CDC next month.
---------- Forwarded by Daniel N. Mendelson/OMB/EOP on 02/23/99 09:53 AM ----------

Melany Nakagiri 02/22/99 07:20:28 PM

Record Type: Record

To: Daniel N. Mendelson/OMB/EOP@EOP

cc: Jennifer M. Forshey/OMB/EOP@EOP, Barbara A. Menard/OMB/EOP@EOP, Richard J. Turman/OMB/EOP@EOP

Subject: FYI - Additional Information on CDC's HIV Prevention Program

Based on your interest in the HIV Prevention program at CDC , we have requested that CDC brief you on their current efforts when you go down to CDC on March 31st.

We also thought it might be helpful to include some of the key points we learned from the CDC's HIV Prevention presentation to us in January, for your information. We have also faxed over a few of the most relevant slides from this presentation.

I. Overview: The two branches working on HIV within the National Center for HIV, STD, and TB Prevention are: 1) the HIV Surveillance and Epidemiology program, which tracks the disease and carries out research, and 2) the Division of Intervention Research and Support (DHAP), which is responsible for the community planning grants. The Surveillance Branch is funded at about $100 million with 250 FTEs and the DHAP Branch is funded at $300 million with about 220 FTEs.

II. Surveillance: One of the new major accomplishments in this area is a new diagnostic test that, used in combination with the old assay test, will allow CDC to recognize recent infections (within the last 108 days) which should improve efforts to make sure that recently infected people get into care right away. The old assay tests only indicated whether a person was HIV-positive, not how long ago the person was infected.

CDC has also released draft guidelines recommending that all states track cases of HIV, not AIDS (as is currently done on a national level). Only 31 states currently track HIV cases.

III. Prevention: This branch provides about $250 million per year to State/City Health Departments and currently, there are 56 grantees (50 states and 6 cities funded). This branch also provides $18 million per year directly to 94 community-based organizations (CBOs) and also provides $9 million to 21 national and regional minority organizations. We asked whether CDC would consider consolidating the grants so that CDC could provide the grants to states and states could then fund the CBOs. CDC said they would consider this, although their original intent was to fund organizations that were overlooked by the state grant process.

Two Key Points:

1) Tracking Funding to the Epidemiology of the Disease. For years we have been asking how CDC's HIV prevention funding to states affects the epidemiology of the disease in a given area. CDC now seems to have the capacity to track some of this information and has begun using it to actively manage their program, which is overdue, but great. We have faxed you a draft CDC report that illustrates both the percentage of total state funding (represented as the amount spent on Health Education and Risk Reduction (HERR) activities) that is spent on African Americans and the percentage of total AIDS cases that African-Americans represent. CDC is focusing its efforts on those states where the difference between these two percentages is quite large, indicating that the funds are not being spent consistent with the epidemiology of the disease in a given state.

2) Effectiveness of CDC's Counseling and Testing (C/T) Programs. Our concern here (which we have shared with ONAP and some of the advocates) is the practicality of funding CDC counseling and testing programs when the return rate for people who receive testing is relatively low (people are not returning to find out their test results and if needed, getting into care) compared to those who receive testing services in Ryan White C/T sites (where the return rate is 90-95%). We might think about ways to better manage the C/T funds at CDC to focus on those sites with a higher return rate or to think about moving all of the

C/T programs into Ryan White. As more sites begin to utilize newer, rapid HIV tests, this may become less of an issue -- though it may also raise the question of whether we should try to rethink our overall strategy for the best way to provide HIV counseling and testing services.

---------- Forwarded by Melany Nakagiri/OMB/EOP on 02/22/99 03:30 PM ----------

Daniel N. Mendelson

02/18/99 09:47:54 AM

Record Type: Record

To: Jennifer M. Forshey/OMB/EOP@EOP

cc: Melany Nakagiri/OMB/EOP@EOP, Richard J. Turman/OMB/EOP@EOP, Gina C. Mooers/OMB/EOP@EOP

Subject: CDC visit

When we go to CDC, please make sure that the HIV / AIDS programs are on the agenda. What are we doing, how is money being spent, where would advocates change these priorities, what would marginal dollars go for ...

SAN FRANCISCO AIDS FOUNDATION 995 MARKET STREET, SUITE 200, SAN FRANCISCO, CALIFORNIA 94103
VISITORS' ENTRANCE: ONE 6TH STREET AT MARKET

March 3, 1999

Sandra Thurman
Director, Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

SENT VIA FAX

Dear Sandy,

Thank you for meeting with Jane Silver, Terje Anderson, Julio Abreu, John Olinger and me on behalf of the NORA Needle Exchange Working Group on February 25th. We appreciate your continued and vocal support of this life-saving intervention.

Since our meeting, members of the working group have met with Danny Mendelson of the Office of Management and Budget (along with Todd Summers). We are also sending Vice-President Gore a letter this week requesting his assistance. In particular, we are asking that the Vice President work with you and others in the Administration to ensure: (1) that, through action and words, all members of the Clinton/Gore Administration – including General McCaffrey -- support the President's declaration of support for local efforts to fund needle exchange services by not undermining the Administration's own determination of the scientific efficacy of such programs; (2) that the Administration do everything in its power to strike the "direct and indirect" language from the proposed ban on needle exchange; (3) that the Administration strongly oppose Congressional efforts to adopt a permanent ban; and (4) that the Administration articulate clearly and disseminate broadly the scientific evidence in support of needle exchange. We appreciate your offer to reinforce these messages through your own communication with the Office of the Vice President, and will follow up with you in this regard.

We also want to thank you for agreeing to speak with Kevin Thurm in the near future to discuss the status of the Department's efforts to disseminate the science in a format that is easily understandable to local service providers, public health and elected officials. Your suggestion that, in addition to state health and elected officials, HHS distribute such materials to all CARE Act, CDC and SAMHSA grantees is one we hope the Administration will implement. In your conversation with Kevin Thurm, we would also ask that you emphasize the importance of having HHS Legislative Affairs engage in Congressional activities on this issue.

Once again, Sandy, we want to thank you for your ongoing support of local community's efforts to prevent HIV transmission through needle exchange, as well as your active efforts to promote the science. If you have any questions, please feel free to contact me at 415/487-3099.

For the NORA Needle Exchange Working Group,

Regina

Regina Aragón
San Francisco AIDS Foundation

cc: Todd Summers, Deputy Director, ONAP

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Letters
March 99
Cons-Africa

THE INDEPENDENT BUDGET

A Budget for Veterans by Veterans

February 18, 1999

Dear *Independent Budget* Recipient:

This is the 13th annual edition of the *Independent Budget*, a comprehensive analysis of the budget and policy needs of the Department of Veterans Affairs that serves as a counterpoint to the Administration's budget proposal. The *Independent Budget* is authored by four major veterans service organizations—AMVETS, Disabled American Veterans, Paralyzed Veterans of America and Veterans of Foreign Wars and endorsed by more than 60 veteran and civilian organizations that share the goal of improving services for our nation's 25 million veterans and their dependents.

The Administration's FY 2000 budget proposal once again ignores the critical health care, benefits, and compensation needs of veterans. The proposal flatlines the VA health care budget for the fourth consecutive year and falls more than $3 billion short of meeting the actual health care needs of veterans. The plan fails to account for the increasing costs of caring for aging veterans and grossly overestimates VA's ability to collect payments from third party payers. Although it calls for important new health care initiatives, including the expansion of screening and treatment for Hepatitis C and improved access to emergency care for certain veterans, it provides no increase in appropriated funding to achieve these goals.

Under the President's budget, almost 8,000 full-time VA health care employee positions will be eliminated. This massive staff reduction will further jeopardize the quality of VA services and may result in the reduction or elimination of vital health programs for veterans.

At the February 11, 1999 House Veterans Affairs Committee hearing on the FY 2000 budget, several members of the Committee lauded the *Independent Budget* and stated that the *Independent Budget* funding recommendations are a sound starting point for the development of a budget that meets the needs of veterans.

The *Independent Budget* coauthors call on the Administration and Congress to fulfill the commitment to the men and women who defended our nation by providing VA adequate funding to ensure the provision of high quality health care and benefits. Requests for additional information should be addressed to the Health Policy Department of the Paralyzed Veterans of America at (202) 416-7610.

Sincerely,

Kenneth Steadman
Chairman, *FY 2000 Independent Budget*

A Joint Project of:

AMVETS
4647 Forbes Boulevard
Lanham, Maryland 20706
301/459-9600

DISABLED AMERICAN VETERANS
807 Maine Avenue, S.W.
Washington, D.C. 20024-2410
202/554-3506

PARALYZED VETERANS OF AMERICA
801 Eighteenth Street, N.W.
Washington, D.C. 20006-3517
202/872-1300

VETERANS OF FOREIGN WARS
OF THE UNITED STATES
200 Maryland Avenue, N.E.
Washington, D.C. 20002
202/543-2239

SF AIDS FOUNDATION

SAN FRANCISCO AIDS FOUNDATION 995 MARKET STREET, SUITE 200, SAN FRANCISCO, CALIFORNIA 94103
VISITORS' ENTRANCE: ONE 6TH STREET AT MARKET

February 16, 1999

Dear Colleague:

The San Francisco AIDS Foundation is pleased to provide you with the enclosed copy of our new report, *Toward 2000: An HIV/AIDS Policy Agenda for California.* It describes the AIDS Foundation's major state policy and budget priorities for the coming year and we hope it will serve as a useful reference tool for you.

Continued state support for HIV/AIDS programs is critical to improving the quality of life for the approximately 100,000 individuals living with HIV in California. In recent years, deaths from AIDS have declined, but HIV infection rates continue unabated and more Californians are therefore living with HIV/AIDS than ever before. Because these individuals face numerous challenges (such as the need for adequate housing, appropriate health and mental health care, substance abuse treatment and other services), state policy makers face increasingly complex challenges in addressing this epidemic as the new century approaches.

Toward 2000 provides a brief overview of the HIV epidemic in California, as well as recommendations on a range of important issues affecting people living with HIV/AIDS and those at risk for infection, including: ensuring adequate state funding for HIV/AIDS programs, enactment of a non-names based HIV reporting system in California, reforming Medi-Cal and other programs providing access to adequate health care, and guaranteeing legal protection for local needle exchange programs.

We look forward to working with you in the coming year. If we can be of further assistance, please feel free to contact the San Francisco AIDS Foundation's Public Policy Department at 415/487-3080 or Fred Dillon directly at 415/487-3081.

Sincerely,

Regina Aragón
Public Policy Director

Fred Dillon
State Policy Director

The gay-owned newspaper
lgny
ESTABLISHED 1994
Lesbian & Gay New York

Need request for Speakers United Support Can't Listen

February 3, 1999

The White House Office of National AIDS Policy
Sandra Thurman, Director
Sarah Holewinski, Assistant
736 Jackson Place NW
Washington, D.C. 20503

Dr. Fauci

Dear Ms Thurman and Ms Holewinski,

I am writing to enlist your support in gaining White House involvement for a media event we'd like to conduct at The White House to honor the players and participants involved in the hunt for an HIV vaccine.

The purpose of the media event is to emphasize to the world the importance of volunteer involvement in the various clinical trials now underway in the scientific search for an effective vaccine that would prevent HIV transmission.

Despite an enormous amount of media attention in The New York Times, CNN, Good Morning America, Nightline, etc., captured by my participation and public inoculation in the current (currently the only) HIV vaccine phase III clinical trial, efforts to attract participants are so far disappointing. Given that these efforts are privately funded the incentive to fund future projects of this nature will depend largely on the success of the first phase III trials ability to attract adequate numbers of volunteers. My fear is that a failure to attract appropriate numbers of qualified participants to VAXGEN's efforts will chill future private efforts in America. To that end, I want to build a culture in which gay men desire greatly to involve themselves in HIV vaccine trials.

I want to gather leading scientists, researchers, advocates, representatives from both houses of congress, appropriate government agency heads, cabinet members and others for assembly at the White House for a ceremony honoring volunteers who have rolled their sleeves up and participated in various phases of vaccine efforts.

Ideally, the President would speak, but the First Lady or VP Gore would also make an excellent impression. Volunteers could be greeted personally. A speech could be made about the importance of finding a vaccine to end transmission of HIV and lauding the efforts of the companies involved and the key scientists and researchers leading the efforts. Any speech should emphasize the importance of volunteerism.

It would be done in front of the world media.

What I want is:

- The event to occur on May 17

- A speech by The President, First Lady or V.P. Gore
- Standard organizational involvement by the White House: adequate facilities, scheduling, etc.
- A White House press release about the event
- A volunteer(s) seated in front of the speaker (President) receiving an inoculation.

Other matters, such as travel arrangements, food and accommodations can be organized by the committee that we are currently organizing around this effort.

Please let me know if you need more information in order to proceed.

Sincerely,

Troy Masters
Publisher, LGNY

PS: How's this for an invitation to the POTUS, FL, VP

The honor of your presence would be greatly appreciated at a press reception on May 17, 1999 to honor the volunteers (and family members), scientists, researchers and advocates who are involved in the efforts to find a vaccine to prevent transmission of HIV.

Your presence would greatly enhance the visibility of the efforts and help drive home the importance of volunteering and participating in the various phases of clinical trials that are now underway or about to begin: volunteerism has been a key call to arms of your administration and is essential in the fight to end transmission of HIV worldwide.

Your administrations goal of finding a vaccine to prevent HIV transmission within 10 years can not be achieved without volunteers who are brave enough to roll their sleeves up and test the effectiveness of any vaccine candidates. This will require a significant paradigm shift in the way we think of AIDS because it is not about treatment and it's all about people who are threatened but not yet infected. Such a shift in thinking can only be led by someone as powerful and influential as you.

I hope your office will contact me with an affirmative response in this regard. Troy Masters, 212-388-0064.

Sincerely,

Troy Masters
Volunteer, AIDSVAX phase III volunteer

Rolling Up Their Sleeves, Volunteers Take On a Killer

Continued From Page B1

there is a front of activism that needs to be developed, that's it. To that end, I'm giving my behavior over to science. This is like signing for permission to end the AIDS crisis."

Whether the vaccine to be injected into Mr. Masters has any promise is a matter of heated debate. Some scientists and advocates for people with AIDS are skeptical, and fear that the experiment will drain the pool of people willing to participate in future trials of AIDS vaccines. They also worry that volunteers will get a false sense of security about the vaccine, which could expose them to infection.

But the vaccine, produced by Vaxgen Inc. of South San Francisco, has drawn attention to an area of AIDS research that until recently has been overshadowed by the success of another treatment, drug cocktails that include protease inhibitors.

In the last few years, H.I.V. vaccines have emerged as a major priority of AIDS research efforts. The Federal Government spends $200 million annually in search of a vaccine, and devotes more money to vaccine research every year.

"It is now the favored direction of endeavor," said Dr. Anthony S. Fauci, director of the National Institute of Allergy and Infectious Diseases.

A handful of vaccine candidates, including a federally supported one involving a weakened canary pox virus, are at various stages of development. But none are as far along as the Vaxgen vaccine. In June, the Food and Drug Administration authorized full-scale testing, which is financed by Vaxgen.

"Up until this vaccine was moved forward, no vaccine was tested for efficacy anywhereelse in the world," said Dr. Seth Berkley, president of the International AIDS Vaccine Initiative, a nonprofit group based in Manhattan. "We're now moving into trials, which is what we have to do. It's the only way to learn."

The major question the new tests aim to answer is how effective the experimental vaccine will be among people who are exposed to H.I.V. because of high-risk sexual practices in the United States and intravenous-drug use in Thailand.

In New York City, Vaxgen hopes to recruit 600 healthy, uninfected volunteers. In addition to the clinic at Bellevue, the recruits are to be inoculated at clinics run by the Mount Sinai School of Medicine and the New York Blood Center. Nationwide, the 5,000 participants will include gay men as well as women who engage in risky heterosexual behavior. A randomly selected two-thirds will receive the vaccine and the rest will receive a placebo.

At the Bellevue clinic, the goal is to recruit at least 150 volunteers by June, enrolling between 20 and 30 people a month.

Three weeks ago, the clinic began placing advertisements in gay publications. Doctors were asked to tell patients about the study and to put fliers in their waiting rooms. Next month, the clinic may sponsor a couple of parties, with gift giveaways, in gay clubs where counselors can recruit volunteers in person. Counselors are also speaking with gay groups that cater to Latino and black men.

> Some scientists see a vaccine experiment as a shot in the dark.

The initial recruitment focuses on gay men, but the plan is to branch out and aggressively recruit women. Counselors have contacted half a dozen community groups concerned with women's health, and are setting up meetings with their directors.

However, the study's administrative coordinator at the Bellevue clinic, Robert Hagerty, acknowledges that recruitment is difficult. "We haven't had huge numbers of people calling," he said.

One of the main obstacles will be to convince people that the vaccine is safe. "Every person who comes in raises that fear," Mr. Hagerty said. "We answer their questions directly and honestly. You can't get H.I.V. from this vaccine." Previous studies of the vaccine, on animals and humans, have demonstrated its safety, researchers say.

So far, the Bellevue clinic has seen 11 men who were determined to be eligible for the study. Two have received vaccinations.

Arriving at the clinic for his first visit last week, Mr. Masters wore black jeans with a white T-shirt. His short dark hair was slicked back to hide the gray. He said he had put himself forward after losing nearly all of his friends in the last two decades.

For hours, Mr. Masters answered a blizzard of questions. Would his participation in the study cause him subconsciously to have unprotected sex? Mr. Masters shook his head. What situations might tempt him to do so? How many sexual partners has he had in the last six months? Did he know that he might not be able to take part in future H.I.V. vaccine trials? Did he know that he might not be able to serve in the military? "Oh, as if I could," he said.

Mr. Masters sees himself as a crusader. "People are terrified of vaccines," he said. "The word that keeps coming up is, 'You're going to let yourself be a guinea pig.'

"I know we can create a culture where going to vaccine trials is something that people want to do. It's O.K. for people to do and it's safe. It's the right thing we should be doing if we are H.I.V.-negative."

An experimental AIDS vaccine may be a particularly tough sell to some of the hardest-hit populations, including young gay men and blacks. Health officials have long contended with the belief, popular among some blacks, that H.I.V. is a man-made virus and that acquired immune deficiency syndrome is a genocidal plot.

In an exam room at Bellevue the other day, Mr. Masters stared at a needle as it was pressed slowly into a vein to draw blood for an H.I.V. test.

Also in the room was Michael Marmor, one of the principal investigators for the N.Y.U. trial. Mr. Marmor, an epidemiologist, recalled that he was squeamish about needles when he was 8 years old. He was a participant in the polio vaccine trials of 1954, which involved hundreds of thousands of children across the country.

Mr. Marmor said the Vaxgen trial is similar to Jonas Salk's polio vaccine trials. He pointed out that the Salk vaccine was not 100 percent effective, but it still saved many people before a better vaccine came along.

"It's exactly at the same stage of testing, the last stage, when they do efficacy and evaluate what percentage of infections are prevented," said Mr. Marmor, who also conducted some of the earliest epidemiological work on Kaposi's sarcoma, an AIDS-related cancer, in 1981.

The Vaxgen vaccine is an updated version of one that an advisory panel of experts rejected four years ago for Federally financed large-scale testing in the United States. The experts had expressed doubts about its effectiveness, questioning its benefit to a significant proportion of recipients.

The original vaccine was developed from only one strain of H.I.V., the one most commonly found in the United States. The new version will provide broader coverage to patients because it is derived from two strains of H.I.V. that are prevalent in the nation, according to Dr. Donald P. Francis, a virologist who is leading the international vaccine research effort and is president of Vaxgen.

But some scientists doubt the vaccine's efficacy, saying earlier tests show that it improved only one part of the immune system involving antibodies, and consequently is unlikely to protect large numbers of recipients. Antibodies are proteins formed to destroy invading germs in the blood.

Many scientists believe that an effective H.I.V. vaccine will need to boost another element of the immune system, killer T-cells that destroy virus-infected cells.

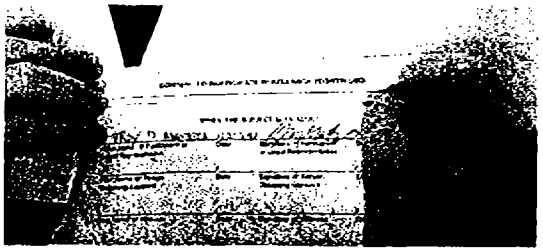
"I don't think we will learn anything that we don't already know," said John Moore, a staff investigator at the Aaron Diamond AIDS Research Center in Manhattan. "I think it's a great shame they are testing in New York. It's a travesty they are doing it anywhere."

More than half of the clinics that will participate have been selected. But not every clinic that has been approached is rushing to take part. In Houston, one community research organization turned Vaxgen down a few months ago. An ethics board at the Houston Clinical Research Network decided that participating in the study would prevent its patients from enrolling in more promising vaccine studies.

Mr. Masters shrugs off the naysayers. Sitting in the exam room the other day, he said the Vaxgen experiment is a beginning and a big deal. He also senses a circle closing for him. He is memorializing the pain that the epidemic has caused him, the dozens of friends who have died of AIDS.

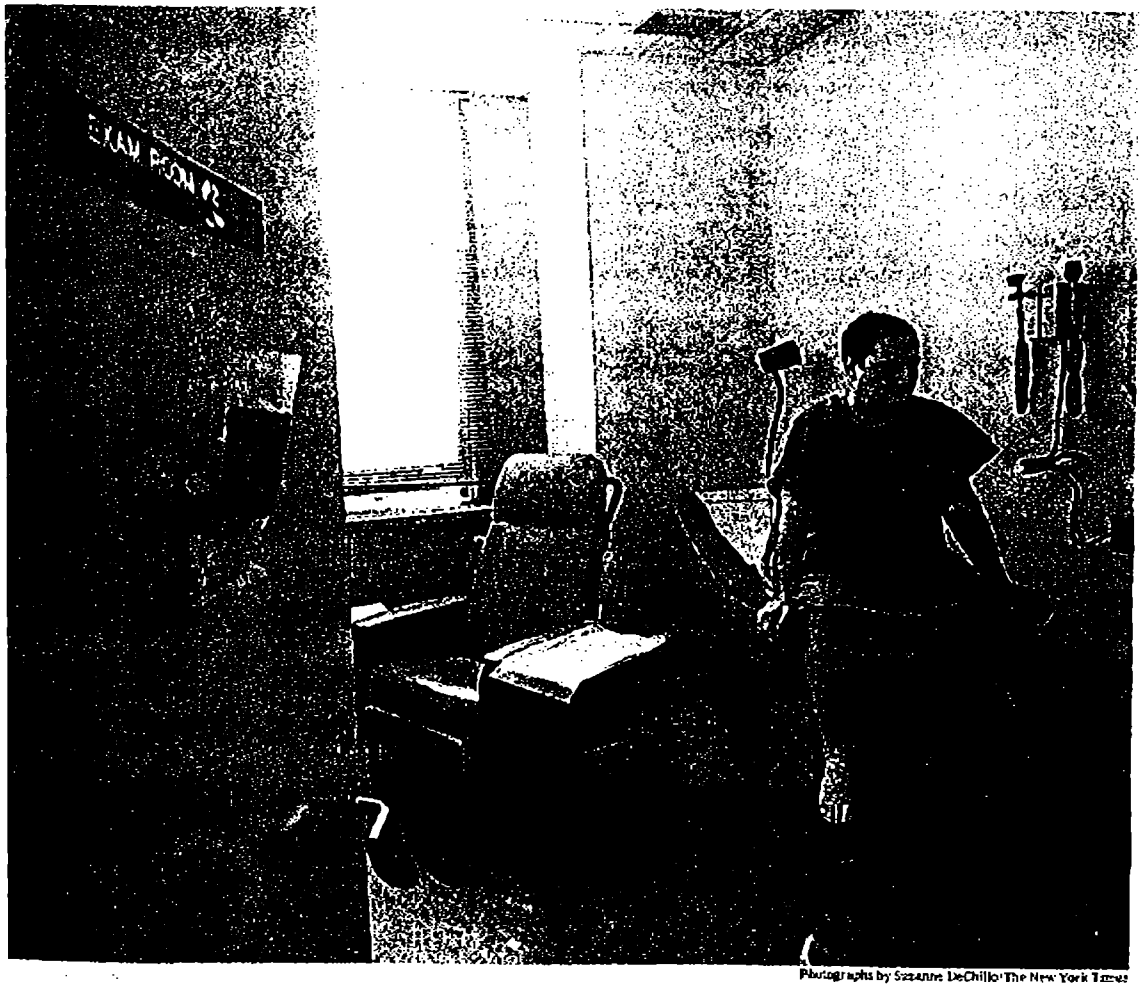
"It is a way of trying to shut the door on this whole thing," he said. "It is empowering."

FEB-03-99 WED 06:52 PM LGNY PREMIER INTERACTIVE FAX NO. 2126916185 P.04/05



Rolling Up Their Sleeves To Take On a Killer

Volunteers Begin Test of AIDS Vaccine



Photographs by Suzanne DeChillo/The New York Times

By LYNDA RICHARDSON

As Troy Masters sat in a hospital exam room the other day — poked, pricked and interrogated by doctors on the most intimate details of his life — his eyes reddened and his voice broke as researchers asked if he was sure of what he was doing.

Mr. Masters is an affable 37-year-old with a sly sense of humor and a soft Tennessee drawl. He is also gay, H.I.V.-negative and sexually active, a profile that makes him a fitting candidate for the world's first full-scale test of a vaccine to prevent AIDS.

Last week, Mr. Masters became one of the first volunteers in New York City to qualify for the experiment, which is to be conducted by a California company in as many as 50 clinics across the nation, including three in Manhattan. The vaccine trial will involve 5,000 volunteers in the United States and 2,500 in Thailand. Mr. Masters's first shot is scheduled for 10 tomorrow morning.

"It's anxiety-producing and exciting at the same time, but I'm going to have to live with this crisis one way or the other," he told doctors from the New York University School of Medicine, which runs one clinic at Bellevue Hospital Center. "I don't feel scared away from the study, if that's what you mean. I want to do this."

Mr. Masters has agreed to be inoculated seven times over the next three years with a genetically engineered vaccine, known as Aidsvax, to find out whether it works. Researchers say he cannot contract H.I.V. from the vaccine because it contains a fragment that is not capable of reproducing. But he may appear to be H.I.V.-positive on a standard blood test because of the presence of vaccine-induced antibodies.

In return, Mr. Masters gets only a $3 Metrocard and $10 for each visit to the AIDS Clinical Trials Unit at Bellevue. He may also get a sore arm, headaches, a rash, a fever and other side effects that are not yet known. And if he is discriminated against because of a false-positive test result, and wants to seek legal redress, he will have to pay for a lawyer himself.

Mr. Masters, publisher of a biweekly newspaper called Lesbian & Gay New York, took all this in on a recent morning. Then, with a flourish, he signed the consent forms to be screened for the study and to be tested again for the human immunodeficiency virus, the final hurdle.

"The virus needs a vaccine," he said. "If

Continued on Page B5

oy Masters, above, unteered to test an erimental AIDS cine at Bellevue spital Center last ek. At top, he ied a consent n. Below, a re-rcher labeled a vial is blood.

"The virus needs a vaccine. If there is a front of activism that needs to be developed, that's it. To that end, I'm giving my behavior over to science. This is like signing for permission to end the AIDS crisis."

TROY MASTERS
publisher of Lesbian & Gay New York and a volunteer in a nationwide AIDS vaccine trial

FEB-03-99 WED 06:54 PM LGNY PREMIER INTERACTIVE FAX NO. 2126916185 P.05/05
Page B-1, The New York Times, December 21, 1998

The gay-owned newspaper
lgny
ESTABLISHED 1994
Lesbian & Gay New York

Fax

To: Sandra Thurman and Sarah Holewinski, The White House Office of National AIDS Policy

From: Troy Masters, Publisher, Lesbian and Gay New York

Page One of Five

Sarah,

Please confirm with me that you have received this.

Troy

Dr. Fauci

150 Fifth Avenue • Suite 600 • New York, NY 10011 • 212-691-1100 • 212-691-6185 Fax • lgny@lgny.com

260 Timothy Rd.
Athens, GA 30606
February 21, 1999

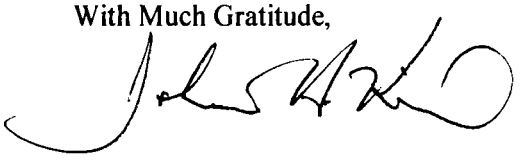
Sandy Thurman
National AIDS Policy Director
736 Jackson Place
Washington, D.C. 20503

Dear Ms. Thurman:

I am faxing a resume that briefly explains my involvement with the community and various University of Georgia organizations. I have realized that the title, "University of Georgia Dance Marathon," is not as self-explanatory as I once thought. I am also sending a return, express-mail envelope. It is required that I send letters of recommendation with my application packet for it to be considered complete.

I can not thank you enough for your willingness to help me. I am pushing close to the deadline and realize that you are an individual with vast responsibilities and limited time. My father and I hope you are doing well and I look forward to seeing you again.

With Much Gratitude,



Johanna Kiehl

February 24, 1999

MEMORANDUM

SUBJECT: White House AIDS Director to Speak at EPA Headquarters

FROM: Romulo L. Diaz, Jr., Assistant
Administrator for Administration and
Resources Management

TO: All EPA Headquarters Employees

I am pleased to announce that Ms. Sandy Thurman, Director of the White House Office of National AIDS Policy will be speaking to EPA employees on March 3rd at 11:00 a.m. in the EPA auditorium. Ms. Thurman's presentation is entitled, "The Disproportionate Impact of HIV/AIDS on America's Minority Communities."

Despite tremendous progress in the development of new drugs for treating HIV/AIDS, the disease remains a major public health concern. In particular, HIV/AIDS has become increasingly prevalent in communities of color across the nation. The Congressional Black Caucus, the NAACP, the National Council of La Raza, the Coalition of Spanish Speaking Mental Health Organizations, and others have called for major efforts to address the impact of HIV/AIDS in America's minority communities. In keeping with EPA's interest in public health, children's issues and improving the quality of life in our communities, Ms. Thurman will highlight the Administration's actions to address the impact of HIV/AIDS on our communities, and the measures we can all take to combat this deadly disease.

In addition to Ms. Thurman's presentation, EPA has arranged two testing and counseling sessions during the week of March 1st. Confidential testing and counseling will be available at the main health unit at Waterside Mall all week by appointment. Please call 260-4347 for an appointment. On Wednesday, March 3rd, the Whitman-Walker Clinic will offer anonymous testing using the Orasure oral test method. The Clinic will conduct the tests from their van, which will be located at the West Tower parking lot from noon to 3:00 p.m. on Wednesday.

The program is being cosponsored by EPA's Office of Administration and Resources Management (OARM), Blacks in Government (BIG), Gay, Lesbian and Bisexual Employees Organization (GLOBE), and the Office of Civil Rights.

I encourage all EPA employees to attend Ms. Thurman's presentation and learn more about an important public health issue in America today. If you have any questions about this program or related activities, please call Jeff Davidson at 260-1650.

JHPIEGO CORPORATION

International Education and Training in Reproductive Health

An affiliate of Johns Hopkins University

February 23, 1999

Sandra Thurmond
Director
White House office of AIDS Policy
736 Jackson Place
Washington, DC 20503

Dear Dr. Thurmond:

You may have seen the enclosed article on the front page of the *New York Times* this week about cervical cancer. In this country, women are being screened, treated and cured of cervical cancer. In developing countries, it is the leading cause of female cancer deaths.

JHPIEGO is launching a public health intervention for the eradication of cervical cancer in developing countries. It is based on the use of proven technologies for the identification and treatment of precancerous lesions of the cervix that are appropriate for use in low-resource settings and can be provided even in the most remote areas. (See up-coming *Lancet* lead story)

Given your global presence and influence in world health and stable markets, I am delighted to enclose two press clippings on JHPIEGO's Cervical Cancer Prevention Program (CECAP), published in the latest edition of the ***World Ecology Report***. The "Promise of Prevention" article is a brief overview of the problem and possible solutions to the leading cause of cancer deaths among women in developing countries. A one column description of JHPIEGO's Cervical Cancer Prevention program is the content of the other clipping.

CECAP is a program that impacts on all levels—from formulating national policies regarding women's reproductive health to influencing opinion and behavior at the community level. The visibility and impact will reach all levels of the international health community—International health organizations, the United Nations, legislators, women's health and business associations, and more than 10,000 international NGO's operating throughout the world. It is our hope to enlist your interest and advocacy as we set the stage to implement this global cervical cancer prevention program (CECAP).

Please feel free to call or e-mail me at 410. 614.2460 or **mmcmanus@JHPIEGO.org** for further information.

Sincerely,

Maureen McManus
CECAP Development Advisor
cc: Noel McIntosh, President

Brown's Wharf • 1615 Thames Street, Suite 200 • Baltimore, MD 21231-3447 USA
Telephone: (410) 955-8558 • FAX: (410) 955-6199 • http://www.jhpiego.jhu.edu

HAPPY VALENTINE'S DAY

I hope you're sticking to your New Year's resolutions and are looking forward to a Valentine's Day full of romance and roses. My New Year's resolution included a commitment to a very special and powerful event in the battle against breast cancer. I'd like to tell you about it.

On October 1, 2 and 3, 1999 I'll walk 60 miles from Lake Lanier all the way to Atlanta with more than 2,000 other courageous people to raise money for awareness and early detection of breast cancer. (A co-worker of mine, Suzanne Beck, has also made this commitment and we will be training together). The net proceeds from the event will benefit Avon's Breast Cancer Awareness Crusade, a non-profit initiative of Avon Products, Inc. In partnership with the National Alliance of Breast Cancer Organizations (NABCO), grants are awarded to non-profit organizations that educate women about the facts of breast cancer and the benefits of early detection and treatment.

I have agreed to raise $1700 in pledges between now and the beginning of AVON's Breast Cancer 3-Day on October 1, 1999. I need your help. Would you make a fully tax deductible pledge (on the enclosed pledge form) to help me meet my goal? Please keep in mind how far I'm walking and how long I will have to train for AVON's Breast Cancer 3-Day between now and October.

Personally, I have not been effected by breast cancer but, as a woman, I know that breast cancer is almost of epidemic proportions. 1 of 9 women in the U.S. will develop breast cancer in her lifetime. Breast cancer is the second leading cause of cancer death for all women, and the leading cause of death in women between the ages of 40 and 55. Both its cause and the means for its cure remain undiscovered. Currently, one million American women have the disease, but don't know it. And they probably won't know about their potentially fatal illness for another five to eight years. That's why I'm walking. To do something big – something that would challenge me as much as breast cancer challenges 2 million survivors in the U.S. I hope that you will be a partner with me in this effort.

Valentine's Day is about love. That's the spirit in which I am doing AVON's Breast Cancer 3-Day. I hope you'll help. Thanks in advance for your generosity and support.

Sincerely,

Marty

Marty Crossman

HARVARD UNIVERSITY
JOHN F. KENNEDY SCHOOL OF GOVERNMENT
CAMBRIDGE, MASSACHUSETTS 02138

February 5, 1999

Ms. Sandra L. Thurman
Under Secretary
Executive Office of the President
Office of National AIDS Policy
808 19th St., N.W.
Washington, DC 20006

Dear Ms. Thurman:

With public opinion, political fortunes, and information technology in a constant state of flux, managing change is more difficult than ever. It's also never been more crucial to success in the public sector. I'd like to introduce you to an innovative program designed to help you manage change, as well as sharpen your managerial and analytical skills. It's the **Senior Managers in Government (SMG)** program at Harvard's Kennedy School of Government.

Designed for SES-level executives in the federal government and their international and private sector counterparts, **SMG** is an intensive three-week course that addresses complex problems such as managing coherent strategies, mobilizing support, and developing credibility with the media. Using case studies from public and private sector experience, the curriculum focuses on key public management issues including:

- Management of change
- Organizational strategy
- Political management
- Service delivery and operation
- Policy design and analysis
- Human resource management
- Negotiation
- Ethics and leadership

In addition, participants bring their own unique challenges with them, and these challenges are often incorporated into the program. Chaired by Professor Roger Porter, who served for more than a decade in the White House in senior economic policy positions, the faculty is comprised of distinguished professors and skilled practitioners who offer a wealth of specialized knowledge and practical experience. Recent **SMG** participants include the executive assistant to the vice-president, the legislative director and general counsel to a U.S. Senator, and the senior vice-president of a major international health care corporation, to name just a few.

The 1999 **SMG** program will take place in Cambridge on the Harvard University campus. The enclosed brochure describes the program in detail. If you have additional questions, please don't hesitate to call me at (617) 495-8856, ext. 7116.

Sincerely,

Marie-Christine Ryckaert
Program Director
Senior Managers in Government

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Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

SMG

Program for Senior Managers in Government

7116

John F. Kennedy School of Government
HARVARD UNIVERSITY

APPLICATION FOR ADMISSION

Program for Senior Managers in Government (SMG)
August 1–20, 1999 *Program fee: $8,900*
Application deadline: May 31

(Applications received after the deadline will be considered only if there are places available in the class.)

Name of Applicant _____
Last First Middle

Title or position _____

Organization _____

Application Instructions

1. Make sure you have indicated (above) to which program you are applying.
2. Please type in your application information.
3. Please provide all information requested on all four pages of the application and sign it at the bottom of page 4. Limit your responses to the space provided only.
4. Fill in your name at the top of the sponsorship endorsement and give it to your sponsor to complete and sign. The Admissions Committee will not consider your application until both portions have been received.

Return the application to:
Marie-Christine Ryckaert
Director, SMG Program
John F. Kennedy School of Government
Harvard University
79 John F. Kennedy Street
Cambridge, MA 02138
Phone: 617-495-8856
Fax: 617-495-3090

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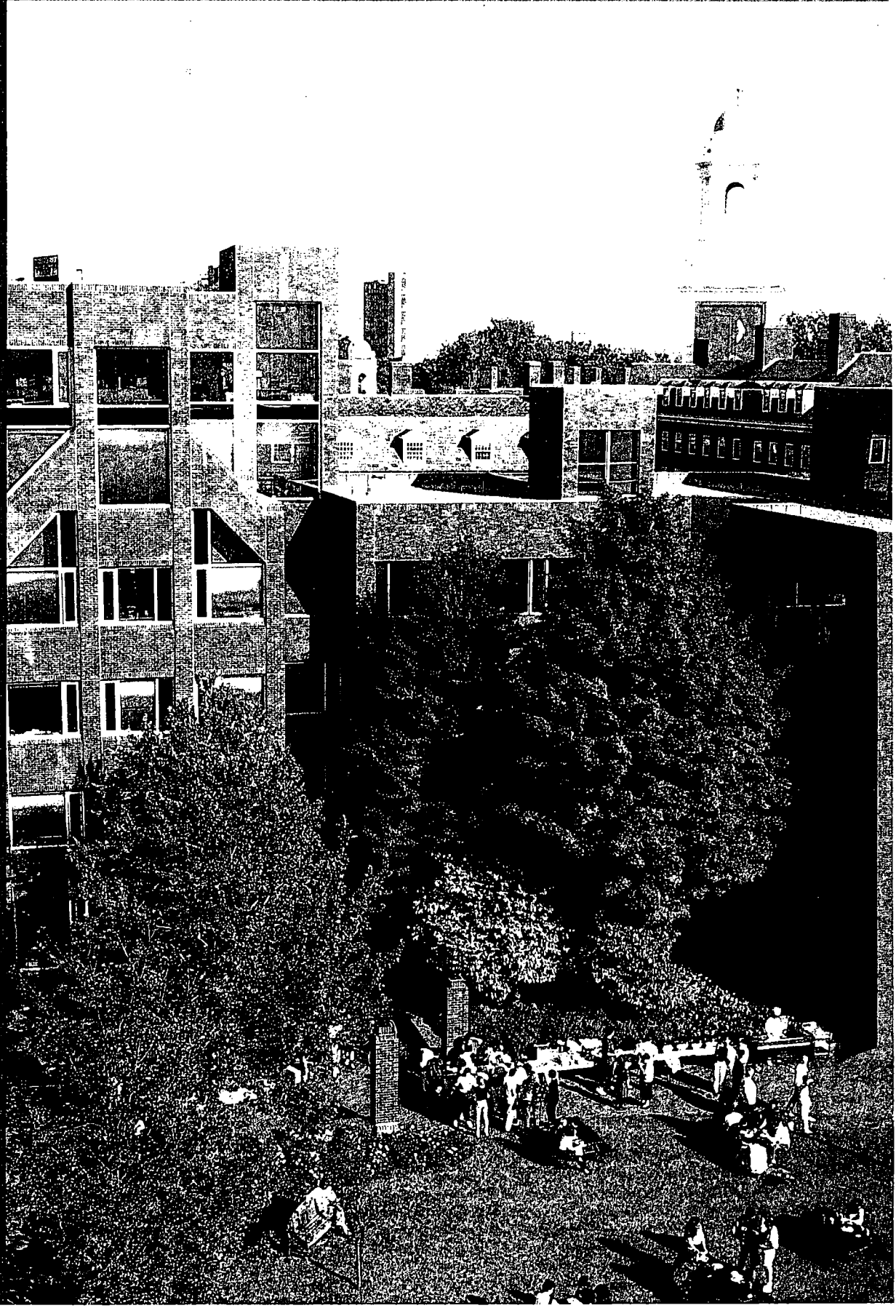
SMG

Program for Senior Managers in Government

August 1–20, 1999



John F. Kennedy
School of Government

Harvard University

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

February 24, 1999

MEMORANDUM FOR ALL EXECUTIVE OFFICE OF THE PRESIDENT EMPLOYEES

FROM: MARK LINDSAY
DIRECTOR
OFFICE OF ADMINISTRATION

SUBJECT: Transition of EOP Publications Office

The Office of Administration is pleased to announce that on April 1, 1999, the EOP Publications Office will transition from paper to electronic distribution of documents. The Fax-on-Demand system, which is not Y2K compliant and is no longer cost effective to upgrade, will also cease at that time. This decision was based on a thorough cost analysis study conducted by IS&T which determined that the average cost per copy for the electronic document distribution via the Presidential publication server is $0.02 while the average cost per copy for the Publications Office to distribute paper/fax documents is $6.34. Additionally, Library and Research Services statistics show that calls to the Fax-on-Demand system have declined from 39,457 in FY 1996 to 11,355 in FY 1998 and the decline continues in FY 1999. Telephone calls requesting paper copies of documents have declined from 37,745 in FY 1996 to 17,911 in FY 1998 and this decline also continues in FY 1999.

EOP agencies are encouraged to distribute documents through their home page on the Internet. If you do not already have an agency home page on the Web, the Information Services and Technology Division will assist you in creating one. Should agencies wish to continue paper distribution of documents, they are encouraged to use the Government Printing Office (GPO) or a commercial clearinghouse for this purpose. The General Services Division, Graphic Design and Printing Management Branch of OA, the OA liaison with the Government Printing Office, can assist you in using GPO and the staff of the EOP Publications Office will gladly work with you to find alternative distribution sources.

The staff currently assigned to the EOP Publications Office transfers to IS&T effective April 1, 1999 to assist in the electronic distribution of documents via the White House Home Page. Their institutional memory and expertise will still be available to assist in the transition. Additional information is attached at enclosure (1).

With this transition, the distribution of White House and EOP documents moves into the 21st century.

Enclosure

EOP AGENCIES AND THEIR METHODS OF PUBLICATION DISTRIBUTION

As a prelude to discontinuing the physical distribution of paper copy documents for the EOP Agencies, Library and Research Services Division undertook a study of how EOP agencies currently distribute publications and how they handle incoming telephone calls relating to their publications.

Susan Hawthorne and Karen Barbuschak reviewed the historical files for the Publications Office and found no documents requiring EOP agencies to use the services of the Publications Office. This is as expected since the nature of the documents range from classified to general unclassified distribution. Distribution procedures are at the discretion of each agency. Some agencies wish to control the distribution of even the unclassified while others have a long-standing relationship with GPO for distribution of very large-volume publications.

White House Office

The main publications coming out of the White House Office are the press releases and briefings. Press Office distributes print copies to members of the press. Paper copies are distributed to the public by the EOP Publications Office. Electronic copies are available from the White House Web site, e-mail, and the fax-on-demand system.

Questions from the public regarding press releases are handled by Public Affairs and the EOP Publications Office.

Office of the Vice-President

The primary publication coming out of this office is also press releases. Almost no paper distribution is done. This office prefers electronic distribution using the White House Web site, e-mail, and in-house faxing. The OVP "rarely" uses the EOP Publications Office.

Any questions regarding releases are referred back to the OVP's Press Office or Domestic Policy.

Council of Economic Advisers

The primary publication of CEA is the annual Economic Report of the President. There is occasional demand for the testimony or speeches of the Chairman. Paper copies are distributed through the EOP Publications Office not GPO. The Chairman of CEA wants all citizens to have access to a free copy of the Economic Report regardless of whether they can access the Internet or not. CEA relies heavily on the Publications Office to meet this need as they have little staff in-house to do mail outs. CEA publications are also available electronically through GPO Access and links on the White House Web site. The Economic Report also appears on the CD-ROM of the Budget of the United States Government.

Questions regarding CEA Publications are directed to the Press Office if inquirer is a reporter. Otherwise, calls are directed to the Chief of Staff's office which also serves as the central information office for CEA.

Council on Environmental Quality

The main documents produced by CEQ are annual reports on various environmental topics and the NEPA guidelines. Paper distribution is primarily through GPO, although the office maintains some in-house mailing lists. Electronic copies can be obtained from their Web site.

Questions regarding CEQ publications come in on their main line and are then referred to the appropriate staff member.

National Security Council

The main document produced by NSC is the annual National Security Strategy. This and any other statements or press releases are released through the White House Press Office. Paper distribution is done through the EOP Publications Office. NSC rarely, if ever, uses GPO. Electronic copies are available on the White House Web site.

Any questions regarding NSC publications are referred to their Defense Policy office.

Office of Management and Budget

OMB produces several types of publications. The main one is, of course, the Budget of the United States Government and related volumes. OMB also produces Circulars and Bulletins which provide guidance to other agencies, and occasional reports mandated by Congress.

The Budget and related volumes are distributed in paper by GPO. They are also available electronically via a link on OMB's Web site to GPO Access. A CD-ROM is also produced annually by GPO containing the Budget and the Economic Report of the President. Circulars and Bulletins are available in print from the EOP Publications Office and most Circulars are also available on the fax-on-demand. All Circulars appear in the Federal Register and would therefore also be on GPO Access. OMB Forms are only available on the fax-on-demand not in print.

Questions regarding OMB publications are referred to their Public Affairs office. Press releases come out of their Communications office.

Office of National Drug Control Policy

ONDCP produces several types of publications: the annual Drug Strategy, a budget summary, Performance Measures of Effectiveness, bulletins, and occasional white papers. They do some in-house mail outs, but most distribution is through a contract with a document clearinghouse which handles both paper distribution through GPO and electronic distribution by loading documents onto the Web for ONDCP.

ONDCP has an 800 number on the Web for any questions regarding publications. Calls are then referred to the appropriate office as are any calls coming in on the main line.

Press releases are handled by their Public Affairs office.

Office of Policy Development

Most publications coming out of OPD are issued in conjunction with other federal agencies which arrange for their distribution. The occasional independent report issued by OPD is distributed by GPO. The NEC also has a Web site.

Office of Science and Technology Policy

OSTP issues a biennial report plus occasional one time reports on various topics. Most distribution is done in-house with each division maintaining its own mailing list. Copies are also sent to NTIS for sale. OSTP has a new Web site to which most publications are being added.

Any questions regarding publications come in on the main line and are then referred to the appropriate division.

President's Foreign Intelligence Advisory Board

The reports they prepare are for the President and are classified. They do not prepare any publications for distribution.

United States Trade Representative

Reports issued by USTR are mandated by Congress. The two main reports are both annual: Annual Report of the President on Trade Agreements, and, National Trade Estimate Report on Foreign Trade Barriers.

Printing is done by a private contractor in conjunction with GPO. GPO makes some copies available for sale, but USTR distributes most through in-house mail outs. Each member of the House and Senate receives a copy of the two main documents mentioned. Each division within USTR also maintains their own mailing list for distributions to embassies, etc. Copies may also be picked up from the USTR Public Affairs office in the Winder Building. USTR also maintains a Web site for electronic distribution of its publications.

Any questions regarding publications start with the Public Affairs office, then to the Policy Coordination office which has responsibility for most publications, and then to specific divisions if necessary.

HUMAN
RIGHTS
CAMPAIGN

February 1999

Dear Friend:

Enclosed please find a copy of the latest issue of *HRC Quarterly*, our newsmagazine which reaches more than 250,000 fair-minded Americans nationwide. The Spring 1999 issue includes updates on the 10th Anniversary of National Coming Out Day, the results of Midterm elections, the Family Research Council's targeting of the Ryan White CARE Act, and the status of the Hate Crimes Prevention Act.

In the course of your busy schedule, I hope you have a moment to review our *Quarterly* which highlights our most recent strides toward securing basic civil rights for lesbian and gay Americans.

Sincerely,

Winnie Stachelberg
Political Director

919 18th Street NW, Suite 800 Washington, D.C. 20006
phone (202) 628 4160 *fax* (202) 347 5323 *e-mail* hrc@hrc.org

until it's over

AIDS ACTION Fax

To: Sandra Thurman Office of National AIDS Policy

Fax: 4562439

Date: Tuesday, February 23, 1999

Pages: 3

From: AIDS Action

Note:

National Organizations Responding to AIDS (NORA):

Please sign-on to this important letter, letter follows.

_____ **Yes, sign-on our organization to this important letter!**

Organization: _____

Contact Name: _____

Phone #: _____

1875 Connecticut Avenue, NW Suite 700 Washington, DC 20009

Tel: 202-986-1300 Fax: 202-986-1345 Email: aidsaction@aidsaction.org

www.aidsaction.org

Please return (fax) this sheet to Jeannette Sebes at AIDS Action. Fax #: 202-986-1345

Deadline for sign-on is Tuesday, March 2 at 5PM. Sign-ons will not be added after Tuesday.

Feel free to call or e-mail with any questions or concerns.
Phone: **202-986-1300 x3030**
E-mail: **nora@aidsaction.org**

Thank You

February 23, 1999

Nancy-Ann Min DeParle, Administrator
Health Care Financing Administration
200 Independence Avenue, SW
Room 314-G
Washington, DC 20201

Co-Chairs

David Harvey
AIDS POLICY CENTER FOR CHILDREN, YOUTH AND FAMILIES

Miguelina Maldonado
NATIONAL MINORITY AIDS COUNCIL

Executive Committee

Terje Anderson
NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

Julia Cohen
PLANNED PARENTHOOD® FEDERATION OF AMERICA

Rose Gonzalez
AMERICAN NURSES ASSOCIATION

Jeff Jacobs
AIDS ACTION COUNCIL

Seth Kilbourn
HUMAN RIGHTS CAMPAIGN

Sara Cintron Milo
AMERICAN ASSOCIATION OF DENTAL SCHOOLS

Jane Silver
AMERICAN FOUNDATION FOR AIDS RESEARCH

Dear Ms. DeParle,

On behalf of the National Organizations Responding to AIDS (NORA), we are writing to urge that you approve Maine's request for a Medicaid 1115 waiver to grant life-extending therapies to low-income state residents infected with HIV. We also wish to reiterate our support for a nationwide Medicaid expansion for low-income persons with asymptomatic HIV. NORA is a coalition of over 175 health, labor, religious and professional advocacy groups that represent a broad consensus on HIV and AIDS-related issues policy, and funding levels.

The Maine waiver would provide coverage for life saving medications, office visits, laboratory tests, case management services and hospitalizations. It would give low-income persons with HIV access to highly active retroviral therapy (HAART) which is proven to be both a medically appropriate and cost effective treatment. For example, a cost-benefit analysis from a New England hospital, presented at the 12th World AIDS Conference in Geneva, found that during the period of introduction and availability of HAART, "the total number of patients increased, [but] overall costs remained level and cost per patient per year decreased." Further, Maine's expansion proposes treatment that is consistent with the HIV treatment guidelines issued by the Department of Health and Human Services (HHS) recommending the use of antiretorival therapy early in the course of HIV infection, before the manifestation of symptoms. Since Medicaid eligibility requirements are incompatible with these clinical guidelines, the Maine waiver will take important steps to bring as many people as possible under the HHS guidelines.

We believe that both the health benefits and cost-effectiveness of early intervention, such as would be provided through the Maine waiver, are convincing arguments that support approval of the Maine waiver as being in the best interest of the government and its people. Therefore, we urge you to support this waiver to expand Medicaid to low-income people with HIV.

Cc:
The Honorable Donna Shalala
Chris Jennings
John Podesta Kevin Thurm
David Beier Sandra L. Thurman

until it's over

AIDS ACTION Fax

To: Sandra Thurman Office of National AIDS Policy

Fax: 4562439

Date: Thursday, February 25, 1999

Pages: 3

From: AIDS Action

Note:

National Organizations Responding to AIDS (NORA):

CORRECTION: The first letter faxed is the Medicare letter. This letter is the Work Incentives letter

Please sign-on to this important letter by Monday, March 1st, regarding the Work Incentives Improvement Act. Both of these letters are of a timely matter, so please respond ASAP!

____ Yes, please sign-on our organization to this important letter!

Organization:

_____

Contact Name:

_____

1875 Connecticut Avenue, NW Suite 700 Washington, DC 20009

Tel: 202-986-1300 Fax: 202-986-1345 Email: aidsaction@aidsaction.org

www.aidsaction.org

Phone #: _____

Please return this form to Jeannette Sebes at AIDS Action at 202-986-1345 by Monday, March 1st!

Please call or e-mail with any concerns or questions: 202-986-1300x3030 or nora@aidsaction.org

Thank you.

February 23, 1999

Dear Rep./Sen. XXXXX,

We, the undersigned members of the National Organizations Responding to AIDS (NORA) coalition strongly urge you to support the "Work Incentives Improvement Act of 1999" (S. 331), co-sponsored by Senators Jeffords, Kennedy, Roth, and Moynihan.

NORA is a coalition of over 175 health, labor, religious and professional advocacy groups that represent a broad consensus on HIV and AIDS-related issues policy, and funding levels.

The risk of losing health care coverage prevents many people with disabilities who receive public assistance from seeking employment. For people disabled by HIV, losing access to health care means losing access to life prolonging treatment. While not successful for all people with HIV, the new anti-retroviral therapies have, for now, restored the health and improved the quality of life for many people. Returning to work thus means risking the loss of the very treatments that make work a real possibility.

Under the "Work Incentives Improvement Act", individuals with disabilities who receive Social Security Income (SSI) or Social Security Disability Income (SSDI) would be able to access Medicaid health coverage if they returned to work. By providing working people with disabilities access to Medicaid, including prescription drugs and personal assistance services, the legislation would remove a major disincentive for people with HIV and AIDS to re-enter the job market.

We feel that the bill also authorizes time limited demonstration projects for states to increase Medicaid availability to people with disabling conditions who, without Medicaid services, would become functionally disabled and eventually come to rely on public assistance. We strongly support these demonstration projects which will allow people to remain healthy longer and supply essential data on the cost effectiveness of treating people before they become too disabled to work. We feel that the $300 million authorized for these projects is not sufficient. We urge you to support as high a funding authorization level as possible and a requirement that each project apply statewide. If just 1% of the 7.5 million Americans with disabilities become successfully employed, savings in cash assistance would total $3.5 billion over the work life of the individuals.

If you have not done so already, we ask that you to co-sponsor S. 331. If you already support the bill, please work to increase the funding and broaden the application of the Medicaid demonstration projects. This widely supported, bi-partisan legislation will improve the lives of millions of Americans, including many people with HIV and AIDS. It will provide better access to critical care services and, in the long run, save money.

Thank you for your attention to this matter.

Co-Chairs

David Harvey
AIDS POLICY CENTER FOR CHILDREN, YOUTH AND FAMILIES

Miguelina Maldonado
NATIONAL MINORITY AIDS COUNCIL

Executive Committee

Terje Anderson
NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

Julia Cohen
PLANNED PARENTHOOD® FEDERATION OF AMERICA

Rose Gonzalez
AMERICAN NURSES ASSOCIATION

Jeff Jacobs
AIDS ACTION COUNCIL

Seth Kilbourn
HUMAN RIGHTS CAMPAIGN

Sara Cintron Milo
AMERICAN ASSOCIATION OF DENTAL SCHOOLS

Jane Silver
AMERICAN FOUNDATION FOR AIDS RESEARCH

KCARC
KANSAS CITY AIDS RESEARCH CONSORTIUM

CLINICAL DIRECTOR: JAN MEIER
EXECUTIVE DIRECTOR: GARY R. JOHNSON
RESEARCH DIRECTOR: JAMES F. STANFORD, MD

4050 PENNSYLVANIA #230
KANSAS CITY, MO 64111
816.756-5116
FAX 816.756-5121

February 15, 1999

Sandra Thurman, Director
White House Office of AIDS Policy
736 Jackson Place NW
Washington, DC 20503

Dear Sandy:

Last spring you planned to speak at our annual HIV update conference on May 1. In conjunction with that engagement, we arranged a day of meetings with local HIV clients and service providers so you could hear their concerns. Circumstances forced you to cut your visit short and return to Washington before you could speak at our conference, however, as you departed, you asked me to invite you back at a later date, and said, "I owe you one!" I'm writing to collect on this pledge.

I'd like you to come to Kansas City in June to speak at a breakfast meeting of local community leaders, corporate representatives, HIV service providers and members of our HIV community when we commemorate the **10th anniversary of KCARC's founding**. I have also invited Dr. David Ho to speak at this gathering, which is tentatively scheduled for either June 9 or 10.

If you are able to confirm this meeting, I will begin working with the local HIV community to organize a day of meetings similar to those held April 30, 1998. Your presence meant a great deal to our clients and providers; repeating those meetings and the client-only luncheon will be very productive and inspiring.

Sincerely,

Gary

Gary R. Johnson
Executive Director

- Penal him in (Dark)!
- Confirm as soon as possible
- He will confirm if the date is going to be June 9 or 10.

Called and left VoiceMail

BOARD OF DIRECTORS:
David Bamberger, MD
Joseph Brewer, MD
Paul Feuer, PhD
Sheryl Feutz-Harter, RN, JD
Elliot Goldstein, MD
Annette Johnson
Julie Macaulay
David McKinsey, MD
Jacqueline Middelkamp
Judy Moore-Nichols
Kenneth Shaw
James F. Stanford, MD
Tom Trillin, DPM
Julie Wright, PharmD

KCARC SITES:
AIDS Project of the Ozarks/ Springfield
Baptist Medical Center
K.C. Free Health Clinic
KU Medical Center/VA
Plaza Infectious Disease/ St. Luke's Hospital
Research Medical Center
Statland Clinic/Menorah
Trinity Lutheran Hospital
Truman Medical Center

February 22, 1999

General Barry R. McCaffrey (Ret.)
Director
Office of National Drug Control Policy
Executive Office of the President
750 17th Street, NW
Washington, DC 20503

Dear General McCaffrey:

I thought that it might be a good idea to follow-up on my letter of February 2, 1999 regarding our need for refrigerated vans. You very thoughtfully offered to help in securing funds necessary for this purchase and we are eager to move forward. Separate from the vans, it is necessary for us to modify some of our in-kitchen equipment to accommodate a program of chilled food. We would like to coordinate the food preparation and delivery aspects of this transition.

I don't mean to overly press on this matter and I am sure that you have a great many projects on your hands. Nevertheless, we hope that you can help and I look forward to hearing from you.

Sincere regards,

Craig

Craig Shniderman
Executive Direcor

cc: Sandy Thurman
Mickie Ballotta, Director of Development & Public Relations
Fay Slattery, Director of Volunteer & Client Services

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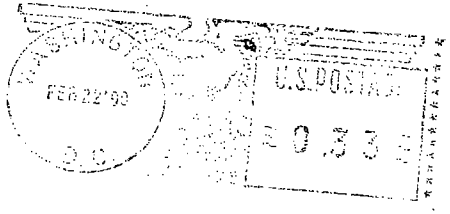


Ms. Sandy Thurman
Director
White House Office of
National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

URGENT FAX

RUSH TO: Sandra Thurman, White House, Office of the

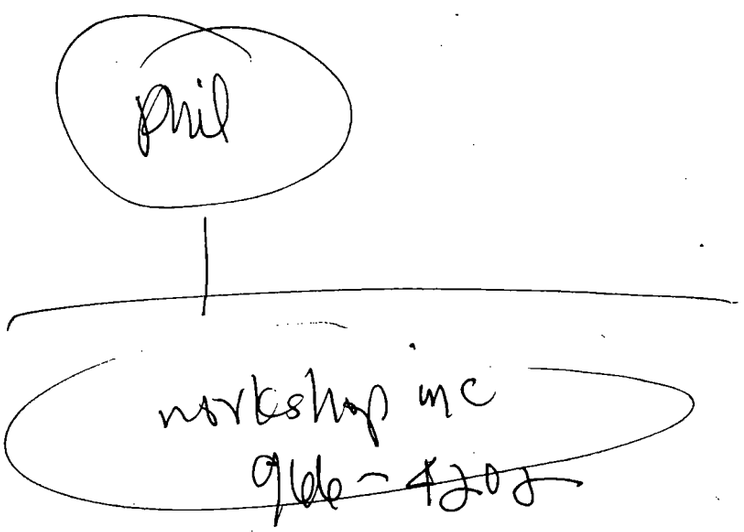
FAX: 456-2439

FROM: 1775 " T " St. NW DC Station.#2

PAGES (INCLUDING THIS COVER): 2

Example of SDtate level success on ADAP access. FYI. •Bill Arnold, T•H•C•A•N•N

Wednesday, February 17, 1999



shawn
2058806

Alice
(718) 9975143 (days)
(516) 883 3008 (weekend)

lee jackson
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~~trisha~~
224 9847

A Not for Profit 50.1(c)(3) Policy & Program Information Exchange &
Service Organization for AIDS/HIV Education, Advocacy, Support & Action.

T•II
C•A•N•N

The Title II Community
AIDS National Network
1775 "T" Street, NW
Washington, DC 20009

Ph: (202) 588-1775
FAX: (202) 588-8868
Web Site at:
www.t2cann.org
eMail: T2CANN@aol.com

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Kevin M. Finnegan
Herbert W. Perry, LPA/EA
Mabrey R. Whigham III

Service Projects:

CANAN
(Community AIDS National Alert Network)
Internet home page & National fax & eMail Alerts
CANAN_DC@AOL.com

The Title II T.A. Corps
Peer & Technical Assistance for Title II Community needs.
1. Hgh Risk Insurance Pools
2. Disability/Benefits & "Back to Work"

TAEP
(The Treatment Access Expansion Project.)
New Tools for needs projection and policy development.

The Voice of Title II
A newsletter for Ryan White funded service providers and their clients

Members: NORA (National Organizations Responding to AIDS)
The ADAP Working Group

Vice Chair/CEO:
William E. Arnold
Director Public Policy:
Gary R. Rose, JD
Chair/CFO:
Herbert W. Perry, LPA/EA

17 February 1999

STATE ADAP BULLETIN

The Colorado State Legislature has just passed a supplemental ADAP appropriation of $465,901.00.

The raises the current State ADAP funding available to a total of $1,171,670.00.

Therefore the Colorado ADAP will NOT be closing down next month as expected.

Pharmaceutical manufactures patient assistance programs will NOT be asked to pick up Colorado ADAP patients as has regularly happened in previous years.

It has taken 3 years of grassroots advocacy in coalition by AIDS activists, drug industry lobbyists, ASO personnel, People With AIDS, and other committed Coloradans (including newly elected members of the Legislature) and State government employees to finally end the annual program collapse of the Colorado ADAP program which threatened continuity of access to treatments for the ADAP Clientele.

The funds have already been made available to the ADAP program and should carry all clients until 1 April when the FY 1999 federal ADAP funds become available to all ADAP's.

The Colorado ADAP Coalitions are to be congratulated.

William E. Arnold
T•II•C•A•N•N

Data Entry Form

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11305	Regina	Aragon	2/22/99	

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Response Type	Response Date	Responder ID	Responder Name	Action Promised

Action Completed	Action Date	Addressed To
		Sandy

Notes

Sender's Organization	Sender's Street1	Sender's Street2
SF AIDS Foundations	995 Market St. Ste. # 200	

Sender's City	Sender's State	Sender's Zip
San Francisco	CA	94103

SAN FRANCISCO AIDS FOUNDATION
995 MARKET STREET, SUITE 200, SAN FRANCISCO, CALIFORNIA 94103
VISITORS' ENTRANCE: ONE 6TH STREET AT MARKET

February 16, 1999

Sandra Thurman
Director
Office of National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

Dear Ms. Thurman:

The San Francisco AIDS Foundation is pleased to provide you with the enclosed copy of our new report, *Toward 2000: An HIV/AIDS Policy Agenda for California.* It describes the AIDS Foundation's major state policy and budget priorities for the coming year and we hope it will serve as a useful reference tool for you.

Continued state support for HIV/AIDS programs is critical to improving the quality of life for the approximately 100,000 individuals living with HIV in California. In recent years, deaths from AIDS have declined, but HIV infection rates continue unabated and more Californians are therefore living with HIV/AIDS than ever before. Because these individuals face numerous challenges (such as the need for adequate housing, appropriate health and mental health care, substance abuse treatment and other services), state policy makers face increasingly complex challenges in addressing this epidemic as the new century approaches.

Toward 2000 provides a brief overview of the HIV epidemic in California, as well as recommendations on a range of important issues affecting people living with HIV/AIDS and those at risk for infection, including: ensuring adequate state funding for HIV/AIDS programs, enactment of a non-names based HIV reporting system in California, reforming Medi-Cal and other programs providing access to adequate health care, and guaranteeing legal protection for local needle exchange programs.

We look forward to working with you in the coming year. If we can be of further assistance, please feel free to contact the San Francisco AIDS Foundation's Public Policy Department at 415/487-3080 or Fred Dillon directly at 415/487-3081.

Sincerely,

Regina Aragón
Public Policy Director

Fred Dillon
State Policy Director

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11299			2/18/99	

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Action Completed	Action Date	Addressed To
		Sandy

Notes

HIV/AIDS Prevention and Care Department

Sender's Organization	Sender's Street1	Sender's Street2
Family Health International	2101 Wilson Boulevard-St. 70	

Sender's City	Sender's State	Sender's Zip
Arlington	VA	22201

Lambda Legal Defense and Education Fund, Inc.

National Headquarters
120 Wall Street, Suite 1500
New York, NY 10005-3904
212-809-8585 phone
212-809-0055 fax

A national organization committed to achieving full recognition of the civil rights of lesbians, gay men, and people with HIV/AIDS through impact litigation, education, and public policy work.

Facsimile Transmission

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Open Letter to Public Health Officials Regarding Names-Based HIV Reporting

February 1999

Dear Health Official:

As service providers, members, and leaders in communities that have felt the impact of the AIDS epidemic, we are extremely concerned about the aggressive push to require the gathering of names of people who test positive for HIV.

The Centers for Disease Control and Prevention, in its proposed national guidelines urging all 50 states to adopt names-based HIV reporting systems, ignores or mischaracterizes the existing data against such systems. The federal agency fails to see how collecting names actually will produce inaccurate data about the extent of HIV infection in this country rather than serve the legitimate public health goal of securing a truly useful picture of the epidemic's reach.

Moreover, while misstating the value of names-reporting, the CDC has trivialized the serious concerns raised by community members regarding the harmful impact of names reporting on populations disproportionately affected by the epidemic. Without adequate services or legal protections, names reporting imperils the civil rights of people with HIV without benefits to balance the risks.

Regretfully, a number of states have already adopted names-reporting systems under pressure from CDC officials, fearing failure to adopt such a system will result in the loss of federal funds. This is a warning to the CDC and others responsible for the public's health that the concerns outlined in this letter must be addressed if the scope of the HIV epidemic is to be measured more accurately, and most importantly, to protect the vulnerable members of our communities affected by HIV.

Ignoring these problems will only increase the suffering and loss of human life in this country.

Names reporting will yield faulty data and cannot be relied upon to measure the HIV epidemic. We support gathering better epidemiological information through other HIV reporting methods so that prevention and treatment resources can be allocated where they are needed most.

- There are *no* data to support the assertion that collection of the number and names of persons who voluntarily test for HIV will provide an accurate, or even representative, picture of the reach or prevalence of HIV.
- Studies show that those who take HIV tests (and many don't) typically delay testing until they become sick and are no more than a few years from an AIDS diagnosis. As a result, names-based HIV reporting will always leave significant numbers of people uncounted.
- In New Jersey, for example, a state which has had a mandatory name reporting system in place since 1992, the number of HIV cases reported is less than one-third of the CDC's own conservative estimates of how many people in the state are infected.
- Other available methods of HIV surveillance must be explored that will yield more accurate information without compromising the privacy rights of people with HIV. These include the use of blinded seroprevalence studies and statistical sampling.
- The ability to do "look-back" studies, or to track individual cases, can be accomplished without collecting the names of people with HIV. In any event, the ability to do "look-backs" with particular individuals increasingly is unnecessary in a well-constructed surveillance system.

Names reporting engenders fear that discourages testing and creates more barriers to health care. Options for anonymous testing must be truly available.

- The overwhelming weight of evidence shows that significant numbers of people avoid testing if their names will be reported. Even a CDC-sponsored study, cited to show otherwise, demonstrated that nearly 20% of people interviewed identify names reporting as a factor preventing people from getting HIV tests.
- The failure of the CDC and many state health departments to appreciate the impact of race, class, sexual orientation, and other differences on people's views of name-based reporting is a fatal flaw to names-based HIV surveillance systems.

- Communities of color and other marginalized groups, which are hard hit by both the epidemic and lack of access to health care, historically have good reasons to mistrust the government and its enthusiasm for protecting them. For the poor, the young, gay men of all races, undocumented immigrants and many people of color, reassurances about confidentiality are unpersuasive.

- Twenty-nine states currently have laws criminalizing the sexual activity of people with HIV, and there is a continued political push to use HIV-surveillance data for more punitive measures targeting people with HIV. Without federal prohibitions on the misuse of testing information for non-epidemiological purposes, names-reporting systems create additional risks for those who decide to learn their HIV status.

Government support for HIV education and prevention programs must increase among communities known to have high rates of infection; public health officials at both the state and federal levels must become vocal and visible in opposing government restrictions on effective school and community-based prevention programs.

- The federal and state governments do not act upon information about HIV prevalence that already is available. It is hypocritical to cry for better data while ignoring those basic findings.

- Data regarding increased infection rates among young adults and women and the efficacy of syringe exchange programs in slowing transmission among intravenous drug users have not resulted in adequate prevention or treatment efforts.

The interests of public health and the perceptions and privacy concerns of people with HIV are closely linked. If accurate information about the extent of the HIV epidemic is to be gathered, the needs of those with HIV must be taken into serious consideration. We urge all public health officials to reject HIV surveillance systems that rely on names-based case reporting of those who test positive for HIV.

Signed,

Adolescent HIV Clinic/SUNY Health Science Center
Brooklyn

AIDS and Adolescents Network of New York
New York

AIDS Action
Washington, D.C.

AIDS Action Committee of Massachusetts
Boston

AIDS Foundation of Chicago
Chicago

AIDS Legal Council of Chicago
Chicago

AIDS Legal Referral Panel
San Francisco

AIDS Project Los Angeles
Los Angeles

AIDS Services of Dallas
Dallas

AIDS Survival Project
Atlanta

American Civil Liberties Union/AIDS Project
New York

Asian and Pacific Islander Coalition on HIV/AIDS (APICHA)
New York

Asian and Pacific Islander Wellness Center
San Francisco

Audre Lorde Project
New York

Birmingham AIDS Outreach
Birmingham, Alabama

California Prison Focus/HIV in Prison Committee
San Francisco

Callen-Lorde Community Health Center
New York

Coalición de Inmigrantes Positivos
New York

Colombian Lesbian and Gay Association
New York

Community AIDS Resource and Education Services of Southwest Michigan
Kalamazoo, Michigan

The GALAEI Project (Gay and Lesbian Latino AIDS Education Initiative)
Philadelphia

Gay & Lesbian Advocates & Defenders/AIDS Law Project
Boston

Gay and Lesbian Activists Alliance
Washington, D.C.

Gay Men's Health Crisis
New York

Harm Reduction Coalition
New York

Harvard AIDS Institute/Leading for Life
Boston

HomoVISIÓNES
New York

Illinois Federation for Human Rights
Chicago

International Association of Physicians in AIDS Care (IAPAC)
Chicago

Lambda Legal Defense and Education Fund
New York

Latino Commission on AIDS
New York

Latino Gay Men of New York
New York

Lesbian/Gay Community Center (Affirmations)
Ferndale, Michigan

Lesbian and Gay Immigration Rights Task Force
New York

Lower East Side Family Union
New York

Mano a Mano
New York

Mason County HIV/AIDS Advisory Council
Shelton, Washington

National Black Lesbian & Gay Leadership Forum
Washington, D.C.

National Latina/o Lesbian, Gay, Bisexual & Transgender Organization (LLEGO)
Washington, D.C.

National Minority AIDS Council
Washington, D.C.

Northwest AIDS Foundation
Seattle

Resist the List
Seattle

Pilsen-Little Village Community Mental Health Center
Chicago

People With AIDS Coalition of New York
New York

Positive Voice Washington
Seattle

Privacy Rights Education Project
St. Louis

PWA Health Group
New York

San Francisco AIDS Foundation
San Francisco

San Francisco Department of Public Health/AIDS Office
San Francisco

Triangle Foundation
Detroit

United Federation of Teachers
New York

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Richard N. Gottfried, Chairperson, New York State Assembly Health Committee

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Ellen M. Tedaldi, MD, Temple University Hospital

** *Organizations listed for identification purposes only.*