

FOIA MARKER

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Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member:

Subseries:

OA/ID Number: 19406

FolderID:

Folder Title:

Correspondence - SLT - Incoming - 11/97

Stack:

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6

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Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. form	re: Letter tracking (Personal) [partial] (1 page)	11/06/1997	b(6)
001b. letter	Concerned citizen to Sandra Thurman re: Wife with AIDS (Personal) [partial] (2 pages)	11/02/1997	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19406

FOLDER TITLE:

Correspondence - SLT - Incoming - 11/97

2018-0764-F

jm2055

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

COR Scheuler
11/92

Corr: SLT - Incoming 12/97

Corr: SLT - Incoming - 7/98

Corr: SLT - Declines 12/97

Corr: - SLT - Declines - 7/98

Corr: SLT - Incoming - 1/98

Corr: SLT - Incoming 8/98

Corr: SLT - Declines 1/98

Corr: SLT - Declines - 8/98

Corr: SLT - Incoming 2/98

Corr: SLT - Declines 2/98

Community Health Project

Corr: SLT - Incoming - 3/98

Corr: SLT - Declines - 3/98

ENCLOSURES FILED OVERSIZE ATTACHMENTS 19406

NARA # 1660

Corr: SLT - Incoming - 4/98

Corr: SLT - Declines 4/98

Corr: SLT - Incoming 5/98

Corr: SLT - Declines - 5/98



1790 BROADWAY
3rd FLOOR
NEW YORK, NY 10019
TEL 212 · 649 · 5000
FAX 212 · 649 · 5050

Jeff Kamen
Media Liaison
Office of National AIDS Policy
808 17th Street NW
Washington, DC 20006

November 20, 1997

Dear Mr. Kamen:

Thank you so much for your kind words about *Marie Claire* and for your offer to pass on a copy of our December issue to Sandy Thurman (enclosed).

Enclosed please also find a copy of the letter that we sent to President Clinton, detailing *Marie Claire's* joint AIDS campaign with Mary Fisher, along with an AIDS ribbon for him to wear on World AIDS Day. We very much hope the President will pledge his support for this extremely important issue.

We are hoping to publish some of the comments made by government officials in response to the issue and campaign, and would appreciate any remarks you would be willing to send us in writing.

Thank you again for your support. I look forward to hearing from you soon.

Sincerely,

A handwritten signature in black ink, which appears to read "Jenny Barnett". The signature is fluid and cursive, with a long, sweeping underline.

Jenny Barnett
Executive Editor



1790 BROADWAY
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FAX 212 • 649 • 5050

Sandra Thurman
Director
Office of National AIDS Policy
808 17th Street NW
Washington, DC 20006

November 20, 1997

Dear Ms. Thurman:

Per the suggestion of Jeff Kamen, I am enclosing a copy of the December 1997 issue of *Marie Claire*, featuring a 12-page special AIDS section. It is the culmination of a four-month initiative to raise funds for the AIDS cause and focuses on increasing awareness and providing readers with essential information. It also includes details of our campaign to bring the cause to the attention of those who have the power to effect change.

I have enclosed a copy of the letter that we sent to President Clinton, detailing *Marie Claire's* joint AIDS campaign with Mary Fisher, along with an AIDS ribbon for him to wear on World AIDS Day. We very much hope the President will pledge his support for this extremely important issue.

Sincerely,

Glenda Bailey
Glenda Bailey
Editor-in-Chief



1790 BROADWAY
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NEW YORK, NY 10019
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FAX 212 - 649 - 5050

AIDS is not over

President Bill Clinton
1600 Pennsylvania Avenue
Washington, DC 20500

November 3, 1997

Dear Mr. President:

In the December issue, *Marie Claire* is running a special health section to inform readers of the ongoing battle against AIDS. We ask you to show your support by wearing the enclosed ribbon bearing the slogan "AIDS is not over" on December 1, World AIDS Day. We are sending ribbons to all members of Congress and state Governors, and to President Clinton and the Cabinet. In an upcoming issue, we will publish the names of those pledging their support.

Despite developments in AIDS research and treatment, 36,280 Americans are expected to die this year of AIDS. And while the death rate is declining for the general population, it is increasing for women. More funds are needed to help those affected by AIDS, and we need to end the prejudice that plagues those infected with the disease. Americans with AIDS do not deserve their disease, but do deserve our assistance.

We hope you will join us in this campaign by signing the enclosed letter and mailing it back to: AIDS is not over, *Marie Claire*, Radio City Station, P.O. Box 1408, New York, NY 10101-1408.

Sincerely,

Glenda Bailey
Editor-in-Chief

Mary Fisher
Founder, Family AIDS Network

marie claire

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NEW YORK, NY 10019
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FAX 212 • 649 • 5050

"I am fully in support of World AIDS Day and *Marie Claire*'s campaign to raise AIDS awareness. I will wear my AIDS ribbon on December 1, World AIDS Day."

President Bill Clinton

While we are aware of the numerous requests for funds made of our public officials, *Marie Claire* would be honored to direct any contribution you might wish to make toward Mary Fisher's Family AIDS Network. As the nation's most famous woman with AIDS, she is providing national leadership on issues surrounding women and AIDS. *Marie Claire* would encourage you to join us in supporting her efforts. And if you do, we will ask her to share with you some of the exciting things they are doing in this area. If you wish to contribute, please make your check payable to Family AIDS Network, Inc. Thank you.

INTERNATIONAL BESTSELLERS

Fax Cover

To: Sandy Thurman

From: Rodney Snell

Date: November 10, 1997

Sandy, please find enclosed the correspondence sent to you on October 30, 1997. I look forward to talking to you at your earliest convenience. Rodney Snell

This fax is 4 pages.

P. O. BOX 607178, ORLANDO, FL 32860 (407) 647-2786

INTERNATIONAL BESTSELLERS

Memo

To: Sandy Thurman
From: Rodney Snell
Date: October 30, 1997

Dear Sandy,

I have called your office a couple of times over the last few weeks, but have not been able to reach you. Unfortunately, the time you tried to call me, I missed your call. Therefore, I am corresponding to you to introduce myself, and to explain the nature of my call.

Sandy, over the last few months, we have been researching for an individual to author a book for the mass market on AIDS. We have found that no book exists on the subject in the market, and yet, and as you well know, AIDS remains one of the greatest concerns of the general public, on a worldwide basis. To compound the problem, there still remains so much that the public is confused about, not knowing the difference between fact and myth. Furthermore, no other one area, has probably effected us more socially, than AIDS has over the last decade.

I know there are a lot of booklets published on the subject, and at times there is a wishful thinking with the public, that as long as they don't think about it, they will be immune. The recent episode with Nushawn Williams has brought back to the attention of the general public, how wide- spread AIDS is, and the impact it can have on anyone, and anywhere (the same as teenage pregnancy or drunk driving, as I've heard you say).

Sandy, we were hoping perhaps you would consider authoring this book on AIDS, which has created so much concern and fear to people all over the

P. O. BOX 607178, ORLANDO, FL 32860 (407) 647-2786

Sandy Thurman
Page Two

world. I believe the topic of AIDS would not only give the book excellent chances of achieving international BestSeller status, but there is also a tremendous opportunity for public service at hand, by educating the public, and therefore, greatly reducing the spread of AIDS. I also sincerely believe a mass market book of this type, would eliminate a great amount of fear and the many misconceptions that the public currently has of AIDS.

We would also be extremely interested in securing a book contract on your behalf, from a major publisher. Simultaneously, we would make sure the publisher would provide the appropriate amount of editors and staff writers to bring the book to fruition, without the project becoming overwhelming. These individuals are also extensively experienced in completing books that are "consumer friendly;" highly fascinating reading that is "hard to put down."

Sandy, for close to two years, I was the Vice-President of Marketing for John Gray, the author of *Men Are From Mars, Women Are From Venus*, (the current and all-time international bestseller has sold close to nine million hardcovers, worldwide, only to be outsold by the *Bible*, in the non-fiction category). Upon completing my projects with John Gray, I started my own company, to exclusively work with authors with mass market potential; negotiating their book contracts, and working on their behalf with publishers in marketing and distribution to ensure our authors' books have every possibility of achieving BestSeller status. We also create cross-promotions and national special events, and develop book related products and services to market, through partnerships with large companies.

Sandy, I look forward to speaking to you at your earliest convenience, regarding making this project a reality.

Sincerely,

A handwritten signature in black ink, appearing to read "Rodney K. Snell", with a long horizontal flourish extending to the right.

Rodney K. Snell

SEPTEMBER 22, 1997

PublishersWeekly

Now available on the
World Wide Web the Friday
before issue date at:
<http://www.bookwire.com>

HARDCOVER BESTSELLERS

FICTION

Last
Week
Weeks
on List

NONFICTION

Last
Week
Weeks
on List

1	The Best Laid Plans. <i>Sidney Sheldon.</i> Morrow, \$25 ISBN 0-688-14911-1	2	2	1	Angela's Ashes. <i>Frank McCourt.</i> Scribner, \$24 ISBN 0-684-87435-0	1	52
2	Cold Mountain. <i>Charles Frazier.</i> Atlantic Monthly, \$24 ISBN 0-87-113-679-1	1	3	2	Men Are from Mars, Women Are from Venus. <i>John Gray, Ph.D.</i> HarperCollins, \$23 ISBN 0-06-016848-X	10	217
3	The Angel of Darkness. <i>Caleb Carr.</i> Random House, \$25.95 ISBN 0-679-43532-8	—	1	3	The Man Who Listens to Horses. <i>Robert Roberts.</i> Random House, \$23 ISBN 0-679-43532-8	3	8
4	Plum Island. <i>Nelson DeMille.</i> Warner, \$25 ISBN 0-446-51506-X	4	17	4	The Perfect Storm. <i>Sebastian Junger.</i> Norton, \$23.95 ISBN 0-393-04016-X	2	13
5	The Partner. <i>John Grisham.</i> Doubleday, \$26.95 ISBN 0-385-47295-1	5	29	5	Into Thin Air. <i>Jon Krakauer.</i> Villard, \$24.95 ISBN 0-679-45752-6	5	21
6	Unnatural Exposure. <i>Patricia Cornwell.</i> Putnam, \$25.95 ISBN 0-399-14285-1	3	9	6	Babyhood. <i>Paul Reiser.</i> Morrow/Rob Weisbach, \$22 ISBN 0-688-14979-0	4	4
7	The Notebook. <i>Nicholas Sparks.</i> Warner, \$16.95 ISBN 0-446-52080-2	7	48	7	The Gift of Fear. <i>Gavin DeBecker.</i> Little, Brown, \$22.95 ISBN 0-316-23502-4	9	12
8	Special Delivery. <i>Danielle Steel.</i> Delacorte, \$16.95 ISBN 0-385-31691-7	8	12	8	Midnight in the Garden of Good & Evil. <i>John Berendt.</i> Random House, \$23 ISBN 0-679-42922-0	7	136
9	London. <i>Edward Rutherfurd.</i> Crown, \$25.95 ISBN 0-517-59181-2	9	17	9	Conversations with God, Book I. <i>Neale Donald Walsch.</i> Putnam, \$19.95 ISBN 0-399-14278-9	6	36
10	The God of Small Things. <i>Arundhati Roy.</i> Random House, \$23 ISBN 0-679-45731-3	10	7	10	The Millionaire Next Door. <i>Thomas J. Stanley and William D. Danko.</i> Longstreet, \$22 ISBN 1-56352-330-2	8	20
11	Dead in the Water. <i>Stuart Woods.</i> HarperCollins, \$25 ISBN 0-06-018368-3	—	5	11	Simple Abundance. <i>Sarah Ban Breathnach.</i> Warner, \$17.95 ISBN 0-446-51913-8	11	77
12	If This World Were Mine. <i>E. Lynn Harris.</i> Doubleday, \$23.95 ISBN 0-385-48655-3	6	9	12	Ten Stupid Things Men Do to Mess Up Their Lives. <i>Dr. Laura Schlessinger.</i> HarperCollins/Cliff Street \$24 ISBN 0-06-017308-4	—	1
13	Underworld. <i>Don DeLillo.</i> Scribner, \$27.50 ISBN 0-684-84269-6	—	1	13	The Bible Code. <i>Michael Drosnin.</i> Simon & Schuster, \$25 ISBN 0-684-81079-4	14	14
14	The Grilling Season. <i>Diane Mott Davidson.</i> Bantam, \$22.95 ISBN 0-553-10000-9	—	1	14	Even the Stars Look Lonesome. <i>Maya Angelou.</i> Random House, \$18 ISBN 0-375-50031-6	12	3
15	Here on Earth. <i>Alice Hoffman.</i> Putnam, \$23.95 ISBN 0-399-14313-0	14	2	15	8 Weeks to Optimum Health. <i>Andrew Weil, M.D.</i> Knopf, \$23 ISBN 0-679-44715-6	15	23

INTERNATIONAL BESTSELLERS**Fax Cover**

To: Sandy Thurman

From: Rodney Snell

F. 50

Date: November 24, 1997

This fax is 2 pages.

P. O. Box 607178, ORLANDO, FL 32860 (407) 647-2786

INTERNATIONAL BESTSELLERS

Memo

To: Sandy Thurman
From: Rodney Snell
Date: November 24, 1997

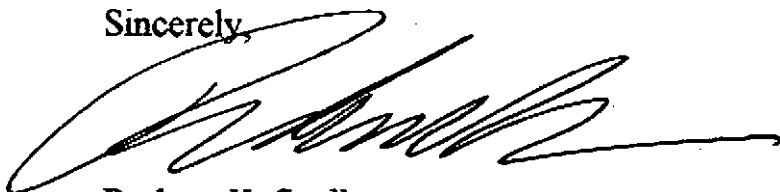
Dear Sandy,

Thank you for your time while I was in Washington. I thoroughly enjoyed our meeting.

Sandy, I am highly confident that we can make an incredible impact in the time period you had stated.

I look forward to speaking to you at your earliest convenience.

Sincerely,

A handwritten signature in black ink, appearing to read 'Rodney K. Snell', with a long horizontal flourish extending to the right.

Rodney K. Snell

P. O. BOX 607178, ORLANDO, FL 32860 (407) 647-2786

AIDS Foundation
OF CHICAGO

411 South Wells Street
Suite 300
Chicago, IL 60607

Tel (312) 922-2322
Fax (312) 922-2916
TDD (312) 922-2917

To: Sandy Thurman

From: Mark Ishaug

Re: Thank you notes

Date: November 14, 1997

Thanks again, Sandy, for coming to Chicago and doing such a fabulous job for us over two exhausting days. I loved touring the town with you. Next time I hope it's all pleasure and no business.

In terms of thank you notes, I'd do three:

1. Eileen Durkin, Executive Director
Howard Brown Health Center
4025 N. Sheridan
Chicago, IL 60613
2. Herschel Gamble, Executive Director
Community Supportive Living Systems
10837 S. Western, Suite #2
Chicago, IL 60643
3. Luule Vess, Executive Director
Project Vida
2659 S. Kedvale
Chicago, IL 60623

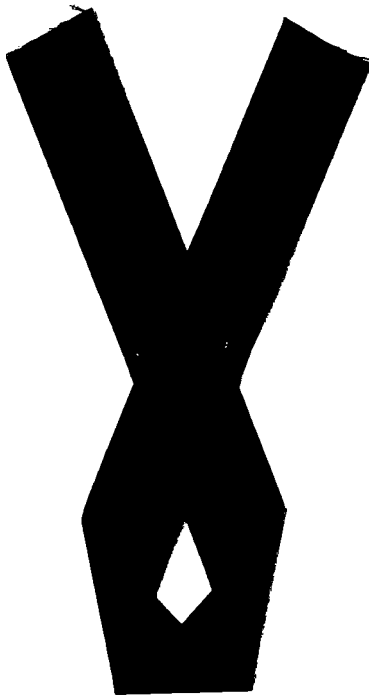
If you need anything else, let me know.

Hugs and kisses to you and Todd.

*little paper
to the friends
(at your site)*

Episcopal → little paper

*⊙ = good friends
(more
personal)*



***You are cordially invited to join
Management & Staff of the
National AIDS Hotline
in commemorating our
10th Anniversary
Monday, November 3, 1997
4:00 pm to 6:00 pm***



FAXED +
RECEIVED

(spoke to Ami Israel -
she knew it was on
its way)



The Honorable Sandra Thurman
Director, National AIDS Policy Office
808 17th Street, N.W. Suite 820
Washington, DC 20006

Dear Ms. Thurman:

On Monday, November 3, 1997 the management and staff of the CDC National AIDS Hotline will be commemorating it's 10th Anniversary in Research Triangle Park, NC. I am writing to personally invite you to join us at this important milestone. Our staff is well aware of the critical work of the National AIDS Policy Office and often refer callers to your office. Having you share in this commemoration would certainly add to the significance of the day.

Operated under contract with the Centers for Disease Control and Prevention by the American Social Health Association (ASHA), the hotline first opened in New York City in 1986. Since its move to North Carolina in 1987, our Information Specialists have answered more than 10 million calls. Information and referrals are available in English, Spanish, and via TTY to callers throughout the United States, Puerto Rico, and the U.S. Virgin Islands.

The hotline is a confidential toll-free service which is available to the public 24 hours a day, 7 days a week. Only last year's Hurricane Fran had the ability to stop the hotline's service for more than a few hours. Although forced to close for a 29.5 hour period, when the phone lines finally went dead throughout Research Triangle Park, the staff rode out the height of the storm using candles and flashlights to look up information for callers.

Although worthy of commemoration, this 10th anniversary has a bittersweet quality considering that the battle against HIV/AIDS is far from won. We are however proud of the hard work that our staff has done to educate others about this disease, as well as the leadership that the hotline has provided within the HIV/AIDS education community.

I hope that you will consider this invitation. My office stands ready to assist your office with any necessary arrangements.

Kind regards,

Ami Israel
Director
CDC National AIDS Hotline

*American
Social
Health
Association*

P.O. Box 13827
Research Triangle Park
North Carolina 27709
(919) 361-8400
Fax (919) 361-8425

THE WHITE HOUSE
WASHINGTON

November 3, 1997

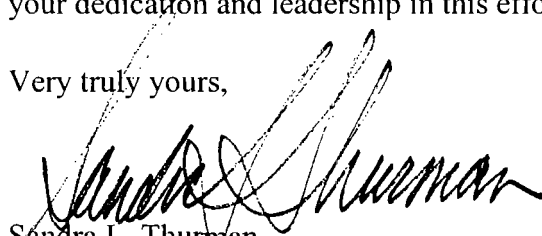
Dear Management & Staff of the CDC National AIDS Hotline:

I am pleased to have this opportunity to extend words of congratulations on the occasion of your 10th Anniversary commemoration. Truly, the work that each of you do is significant beyond measure. The service that you provide each hour of the day offers the public vital links to life-saving information and assistance.

So many strides have been made in dealing with HIV/AIDS, but, admittedly, we have a long way to go. Information and education have been and will continue to be the keys to prevention. Your ability to provide the information that is accurate, understandable and compassionate is critical.

The White House shares your commitment to AIDS education and prevention. Thank you for your dedication and leadership in this effort.

Very truly yours,



Sandra L. Thurman

Director

Office of National AIDS Policy

THE WHITE HOUSE

Sandy -

Excellent piece
By Tej's - good
to re-read after
the meeting with CDK.

He's updating it,
and I've asked for
him to send any
revisions.

Jodel



Daniel C. Montoya
11/05/97 04:40:47 PM

Record Type: Record

To: See the distribution list at the bottom of this message
cc: Sandra Thurman/OPD/EOP, Todd A. Summers/OPD/EOP
Subject: trying a different format - surveillance discussion papere

FYI -

dcm

----- Forwarded by Daniel C. Montoya/OPD/EOP on 11/05/97 04:38 PM -----



terje @ worldnet.att.net
11/05/97 11:54:00 AM

Record Type: Record

To: Daniel C. Montoya
cc:
Subject: trying a different format - surveillance discussion papere

HIV name reporting: the wrong debate

Increasingly a discussion within the AIDS community (and externally, witness Rep. Coburn's efforts) is focusing on the question of adoption of a names-based reporting system for HIV infection. A number of national organizations, including the Council of State and Territorial Epidemiologists (CSTE) and the National Association of State and Territorial AIDS Directors (NASTAD) have taken positions in favor of a national standard of named HIV reporting. There are indications that the Centers for Disease Control and Prevention (CDC) will soon undertake efforts to encourage named reporting in all 50 states. Perhaps not surprisingly, a polarized debate seems to be developing around the question, with many community based groups taking a hard line against any form of named reporting, arguing instead for HIV reporting using unique identifiers (if there is to be any HIV reporting at all).

I would submit that the polarized debate taking place is counter-productive and, moreover, misses the point about what it will really take to implement necessary steps to truly understand the extent, distribution and direction of the continuing HIV epidemic. To that end, I offer this (high opinionated) discussion paper to the debate.

Why the debate? What are the changes propelling it?

There is widespread agreement that our current national surveillance system woefully inadequate and uneven. Diagnosed AIDS is reportable by name in all 50 states, while HIV infection is currently reportable by name in slightly over half the states - although many of the largest states with high HIV prevalence (including California, New York, Massachusetts, etc) do not have HIV reporting.

While reliance on AIDS reporting was always inadequate (due to the long lag time between infection and clinical illness), recent developments in treatment which greatly delay disease progress accentuate these inadequacies. Reported numbers are falling significantly, but this is largely a result of changes in the treatment of HIV infection instead of real changes in incidence. The old case definition is increasingly meaningless in light of the changes in the reality of the disease itself. Our reliance on AIDS reports as the primary data about the epidemic has always been problematic - now it is so irrelevant that something must be done to improve it. Our ability to understand this epidemic and to make good decisions about the focus of prevention and care efforts relies on correcting this situation.

In 1993, an attempt to recognize the changes going on in the disease was made when the case definition was expanded to include low tell cell counts. Some would argue that HIV reporting is simply a recognition of the changes in the treatment field where treatment of HIV infection, rather than AIDS symptoms, is the new health paradigm.

There are three main arguments that are being cited by some advocates of named reporting (please note that not all advocates cite the all three arguments, or put the same spin on any of these arguments. My apologies to those whose arguments I have simplified, misstated, or bastardized - I am reflecting them as best I have heard them).

1.) Because of the inadequacy of current reporting systems, it is necessary to move to HIV named reporting in order to more fully capture the HIV epidemic. This includes the need for better data for service and prevention planning, as well to prevent the lower numbers from lulling the public and policy makers into false complacency. How can we retain and increase resources if the public thinks AIDS is going away? Whatever the drawbacks of HIV named reporting may be, the data we receive from it will undoubtedly be better than what we currently have.

2.) For too long, AIDS/HIV has been treated differently than other diseases of public health significance and this has, according to the argument, hampered our ability to effectively fight the epidemic using the best tools that public health has to offer. By treating it this way, we have heightened the stigma and fear, instead of mainstreaming and normalizing AIDS/HIV. While this may have been understandable in the beginning (where social stigma was much higher than it is today. Now that better treatment exists, it is time to break down that stigma by ending any kinds of "AIDS exceptionalism." A good place to start is by dealing with the way we treat issues of reporting

to public health officials. Lack of HIV reporting is a remnant of the paranoia (not always unjustified) of the early days of the epidemic - but now we have to move past policies made for and in 1985.

3.) Named reporting is important in order to ensure that all people with HIV are offered access to needed medical and social services. Now that potentially effective treatment exists, it is imperative that we contact all people with HIV to ensure they know about it and receive assistance in accessing the best services available. In addition, some argue that named reporting is essential to development of suitably aggressive programs to locate and bring into testing/treatment/prevention services the partners of those infected. Only by doing so will we be able to offer appropriate early intervention (possibly including PEP) to the newly infected, and thus stem the further spread of the epidemic and/or disease progression in the infected.

In addition, a fourth argument (with two variations) is likely to emerge in the near future..

4.) In light of the Chautauqua County and Ohio incidents and the surrounding publicity, there is likely to be a widespread public demand for increased reporting, testing and partner notification. Some would argue that we cannot ignore such public sentiment, and therefore should implement named reporting. Others in the public health community worry that if we do ignore the weight of public opinion, we only increase the gulf between a public health/AIDS elite and the community at large - an invitation to disaster with the adoption of even more restrictive legislation and bad policies. In such a scenario, named reporting is a necessary step (evil or good) to ward off far worse consequences.

HIV name/ unique identifier reporting - why neither gives us what we need

We must start with a basic understanding of a crucial difference between AIDS and HIV reporting. AIDS reporting was historically based on a single incident - the diagnosis of an AIDS defining condition, such as an opportunistic infection or (in recent years) a t-cell count under 200, indicative of immune system suppression. In most (but not all) cases, such a diagnosis is driven by a health occurrence that drives a person to seek out medical care. With a relative degree of predictability, a person experiencing health declines will seek out medical care (although questions of access to care and awareness of risk clearly delays the speed at which some people and populations have, in fact, entered systems of care, resulting in diagnosis and reporting delays for those individuals and populations). With a ton of caveats attached, it can be said that AIDS reports represent a group of people who have experienced a relatively similar health event - and therefore the number has (or had) some relatively uniform meaning. It could be predicted that a relatively high percentage of people who have experienced the health events will seek care and be reported to the local/state Department of Health.

Testing for HIV represents a much wider potential range of health events. Some positive tests take place when someone is entering an emergency room with PCP, while others take place in someone who is entirely asymptomatic but concerned about their past risk. Given the long time frame for disease progression, it is very difficult to accurately say what a positive test means about the health status of any individual. There is a wide range of acceptance of testing in different communities, and a wide range of precipitating events that may drive someone to testing. Unlike AIDS reports, which reflect a relatively defined and limited stage of illness, HIV reports have a much less specific meaning. The number of people testing positive therefore represents simply people who were aware of their own risk, connected to health care, and concerned enough to seek out or accept testing. These factors may be impacted by a variety of highly localized or individualized factors: local outreach or education efforts, health care provider attitudes, local media coverage, health insurance coverage, peer norms, and personal risk perception.

Because acceptance of testing is not universal, and because timing of testing is not uniform, it is far harder to state definitively what HIV reporting tells us, and severely limits how we can use the information.

HIV reporting does not tell us how many people are living with HIV - in the country or in any particular area. It only tells us how many people have taken the test and come back positive.

HIV reporting does not tell us which populations are experiencing new infections. Rather it tells us which infected populations are coming forward for testing. It does not state how recently they were infected or what percentage of a risk population is positive. It is highly subject to artifacts of testing systems - for example, if a clinic with testing outreach were to open in a previously under-served neighborhood with a particular ethnic concentration, it is likely that reports for that group would increase. (Similarly, a drop might be seen if that program lost funding). To presume that either situation reflects new infections would be erroneous..

HIV reporting tells us nothing about the extent or spread of HIV in populations that are not being tested. To rely on HIV data for decision making about prevention or care efforts is to risk being misguided by biases inherent in any voluntary system with uneven levels of testing acceptance. In the real world, HIV reporting is likely to bend decisions in favor of those populations that are already most aware of HIV and already accessing HIV services. Populations with inadequate access to treatment and prevention services will continue to be undercounted in HIV reporting, accentuating pre-existing inequities. Rather than serving as an early warning system, testing will only pick up any significant trend once people in a community are already aware enough of risk that they are seeking testing.

The arguments against named reporting (and some potential responses)

Those rallying around opposition to named reporting focus primary on the argument that named reporting will drive people away from systems of testing. According to this argument, people in affected communities have such strong distrust of government that the knowledge that their name might be put on a government list might keep them from getting tested or seeking medical care if they are infected. At a time when there is a huge imperative to encourage people to know their status and seek early treatment, anything that discourages these things is a problem.

(A second fear raised by many people is that once the names are collected, discrimination or punitive measures against those people will take place. I will discuss this potential concern in the next section, although it is important to note that this has not been born out by actual experience.)

The evidence of disincentive to testing is somewhat mixed and quite limited - experts on both sides of the question debate the meaning of one study versus another, but there has yet to be a conclusive examination of all of the data - for example, comparison of acceptance of testing among different populations in parallel states with and without named reporting. The MESH study results (mentioned in Atlanta as nearing completion) should be carefully examined. Based on the data that I have seen, it seems likely that the net effect of named reporting is a slight but measurable drop in testing, and that this drop is most likely to be seen among relatively well educated gay men who distrust the government.

It is important to remember that in nearly 30 states, people with HIV already live with named reporting. Quite simply, the sky has not fallen in those states.

Named based AIDS reporting has been widely accepted by the same advocacy community that so vigorously opposed HIV named reporting. It appears to be accepted by people living with AIDS, and there is little evidence that it is driving people away from care. Perhaps it can be argued that for symptomatic people, the option of not seeking care is less viable than it would be for asymptomatic HIV + people, but it seems someone absurd to believe that reporting drives one group away one group(HIV +) but not another (AIDS).

I also want to raise the question: does the loud opposition to reporting become a self- fulfilling prophecy? After hearing all kinds of dire warnings about how people at risk can't trust the government, doesn't that, in fact, contribute to the environment of distrust that exists. If we have a protracted national and state-by-state debate about reporting, will that debate itself serve to drive people further away from testing and care.

It is also important to recognize that in many other ways, people with HIV have no choice but to have their names reported to the government. Anyone who relies on Medicaid, Medicare, AIDS Drug Assistance Programs, public health clinics, federal and state disability

programs, insurance continuation programs, some Ryan White activities, etc., already has no choice but to have their HIV status made known to the government. The double standard of confidentiality for the well off and government access for the poor should not be forgotten.

The potential drawbacks and risks of named reporting

Having recently moved from a state (Vermont) without HIV named reporting to a state (Colorado) with a long established named reporting system, I have several concerns based on anecdotal observations about the different systems.

One of my greatest concerns is the way in which numbers are interpreted and presented. Quite simply, I am not impressed with the way these numbers are used.

I have repeatedly heard people who should know better (state and county health officials, AIDS service providers, community based organizations, consortium members, community planning group members) refer to the numbers reflected by HIV reports as representing the total number of HIV infected people within a jurisdiction, or as being reflective of new infections, or as a reliable predictor of future infections. Rarely, if ever, are the limitations or true meaning of the data discussed. Unfortunately, this does not contribute to enhanced public understanding of the epidemic, nor to better planning for services or prevention.

Similarly, I have been part of review panels for CDC prevention grants, HRSA Title I and SPNS grants, and a number of foundation grants. Unfortunately, in these settings I have seen little creative use of HIV data to guide decision making and priority setting. The data doesn't live up to the promises made for it.

I also have concerns that there are few safeguards about how the data may be used by those collecting it. For example, I was surprised at one local meeting when officials from the county Health Department indicated that they had matched arrest records from a local gay cruising area with HIV testing data. Although they had data on a small percentage (about 10%) of the arrestees, they announced that the seroprevalence in the park was a certain number. Quite simply, this is an epidemiologically invalid interpretation of these numbers, and certainly would not do much to engender trust among the risk population about the way their confidential data is used. The temptation to play with numbers must be recognized and tempered by strict guidelines about the uses of the data and the way it can and cannot be matched to other data sets.

Similarly, we must acknowledge that the potential exists for policy makers (especially legislators) to demand that the collected names be used in ways that many in the public health and AIDS communities would find inappropriate. This prospect cannot be dismissed out of hand - think, for example, of the success that Jesse Helms and others have had in inserting spousal notification, emergency responder

notification, sexual assault victim notification, and similar measures into federal legislation. How confident are we that we can successfully fight off mandatory partner notification, or legislation targeting particular professions (health care workers, child care providers, etc.)? While I do not consider these likely, it must be acknowledged that they are possible? Are we prepared to respond to them?

I believe the most damning argument against named reporting is simply that it will not produce what is promised in way of a better understanding of the epidemic.

While I believe that opponents of named reporting are sincere in their concerns, quite candidly it strikes me as a knee-jerk reaction based on old realities and exaggerated concerns about confidentiality and disincentives to testing/treatment. Similarly, I believe that advocates for named reporting are looking at a simplistic solution to a complex problem, and that they are not addressing the real question of what it will take to truly understand where the epidemic is going.

What would a comprehensive HIV surveillance system look like?

The CDC Advisory Committee on the Prevention of HIV Infection has stated that the goals of HIV/AIDS surveillance are:

- 1.) To target primary and secondary prevention
- 2.) To evaluate the efficacy of prevention activities
- 3.) To determine eligibility for government resources for services for HIV- infected persons
- 4.) To project resources needed to provide care and prevention interventions
- 5.) To educate the public about the scope and impact of the HIV/AIDS epidemic

I would argue that, in order to meet these goals, we need data far more than we need names. Case reporting (named or unique identifier) is the most traditional public health effort to monitor an epidemic. It is also the least imaginative and least well-suited for an on-going epidemic of the complexity of HIV/AIDS. I believe we must challenge the public health community to develop much more innovative methods to provide needed information.

I find it highly ironic that the CDC is prepared to push for named reporting at this point, when two years ago they rolled over and played dead when the Survey of Child Bearing Women, a blinded seroprevalence study done in 46 states, was taken away. It is precisely this kind of study that is needed to enhance our understanding of the epidemic for both care and prevention services. Reinstatement of the SCBW should be a major priority of enhanced surveillance activities.

While I am not a trained epidemiologist, I would like to offer some ideas (some close to what is being done, some much further out of the box) about what elements of an innovative national surveillance program might look like. I don't pretend that this is a comprehensive list, but rather one that gives some picture of the kind of activities

that would, taken together, provide decision-makers and communities with the information they need to make informed decisions about resource distribution. Some of the ideas I have suggested make the assumption that HIV reporting is in place.

As stated above, reinstatement of the SCBW should be a high priority for all of us. This population based study provided incredibly valuable information about the spread of HIV among women of child bearing age.

Similarly, other blinded seroprevalence studies (part of the "family of surveys") that are currently conducted in sexually transmitted disease clinics and drug treatment facilities should be greatly expanded to reflect greater geographic scope and range. While economic consideration may limit how far it can be expanded, a system of near universal blinded screenings in these settings would provide a highly sensitive surveillance tool for the populations that use these resources. In addition, we should look for other settings where such blinded studies can appropriately be conducted.

Several years ago, there was serious discussion of a national door to door survey that involved blinded testing. This idea should be resurrected. Especially with the availability of newer, less intrusive collection techniques, there may be a higher rate of acceptance of testing than ever before. Such a survey could collect important data about the geographic, demographic and behavioral factors relating to infection. Oversampling could be used with key populations and in key localities. Repeating the survey on a regular basis would provide valuable information about incidence.

Sentinel studies should be strengthened in areas where there are particular concerns. Sites around the country serving important demographic or behavioral populations should be selected, and monitoring HIV infection rates by the clients of such facilities on an on- going basis provides valuable information. Outreach testing in key locals (shooting galleries, bars, bathhouses, homeless clinics, low income neighborhoods, migrant worker camps, etc.) should be enhanced and incorporated in these sentinel studies.

Increasingly, we need to use technology that allows some estimation of how recent or distant an infection is: measures such as CD4 counts and natural viral development markers can help "date" new infections among those testing positive.

Collection of data on all HIV testing, not just positive tests results. Knowing how many people in any particular population test positive without knowing how many people in that group were tested is of limited use. Being able to have data about the percentage of people in any particular population seeking testing who have tested positive would be valuable, but at the moment that data is only widely available for publicly funded alternative test sites (and, in some cases, other STD, prison and similar clinics). According to CDC, only 15% of positive tests come from the publicly funded ATS facilities, while 52% were in private physicians, clinics and hospitals. It would

not be necessary to collect names in order to obtain this kind of data.

Behavioral surveillance should be given greater emphasis, including greater use of the sexual behavioral elements in the BRFSS and the YRBS, increased use of the behavioral information being collected in countless local prevention and service products, and selective studies to measure the prevalence of HIV risk behaviors in key populations. These studies should be matched with local data about HIV prevalence/incidence and solid scientific information about transmission efficacy.

Priority should be given to development of mathematical modeling techniques that allow more accurate estimation of HIV in various communities, and assistance in applying these techniques in various environments. The CDC should commit itself to analyzing data annually and releasing estimates of HIV prevalence and incidence based on that data and these models.

Enhanced technical assistance programs for health departments, community planning groups, planning councils and consortia are sorely needed. Data is currently poorly used in most places, and much more effort needs to be made to help key players understand and effectively utilize this data.

This is by no means a comprehensive list, but instead serves, I hope, to stimulate thought and discussion on alternative or complements to HIV reporting that can help achieve our goal of having adequate information to shape our prevention and care efforts.



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Message Sent To:

Isbell @ hugheshubbard.com @ inet
harndc @ aol.com @ inet
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*Pierre Cardin
c/o 111 Lexington Avenue
New York, New York 10016*

*This event is organized to welcome Docteur Luc Montagnier
and to support his efforts in the field of AIDS research in the
USA and throughout the world.*

*Several eminent scientists will join him on this occasion as well as
political and academic figures and personalities from the worlds
of culture, entertainment, and fashion.*

*During the dinner, Dr. Montagnier will elaborate on his plans
to attack AIDS on a global level and on the efforts undertaken to
find a vaccine.*

Pierre Cardin

*requests the pleasure of your company
at a dinner in honor of*

Docteur Luc Montagnier

President of the World Foundation for AIDS Research and Prevention

and to welcome the co-discoverer of the HIV Virus to the United States as

*Bernard and Gloria Salick Distinguished Professor and
Director of the Center for Molecular and Cellular Biology
at Queens College of the City University of New York*

Wednesday, November 12, 1997, at eight o'clock

at Maxim's

680 Madison Avenue · New York

Reply Card Enclosed

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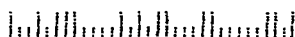
Sandra L. Thurman

Director

Office of National AIDS Policy

The White House

Washington, D.C. 20500



[Handwritten signature]



November 5, 1997

The Honorable Albert Gore, Jr.
Vice President of the United States
Old Executive Office Building
Washington, DC 20501

Dear Mr. Vice President:

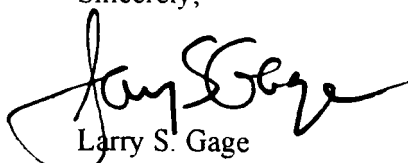
As the health facilities that serve many individuals with HIV and AIDS, the National Association of Public Hospitals and Health Systems (NAPH) thanks you for your endorsement of the AIDS Action Council's Re-Inventing Medicaid proposal which would provide Medicaid access for asymptomatic individuals with HIV. NAPH represents nearly 100 metropolitan hospitals and health systems nationwide which average 4.5 times the number of HIV/AIDS admissions at all hospitals. Our members also provide over 40% of all hospital outpatient HIV/AIDS care.

Under the current Medicaid program, low-income, HIV-positive Americans are denied access to drugs that prevent full-blown AIDS until they have already developed full-blown AIDS. This is the equivalent of installing air bags in cars that have already crashed. Meanwhile, we are spending Medicaid dollars treating the many opportunistic infections that require expensive life-saving treatment brought on by the lack of protease use. The fact that Medicaid provides access to the protease cocktail only for people with AIDS is also a direct contradiction to federal guidelines advocating earlier treatment.

Public hospitals and health clinics are often treatment centers for the HIV-positive individuals who need, but cannot get access to, protease inhibitors. To meet the needs of those who cannot afford protease inhibitors, our hospitals are either providing them to patients at little or no cost or are treating the opportunistic infections that result from lack of availability to these therapies. Because our members rely on Medicaid Disproportionate Share Hospital (DSH) funding to provide for 40% of its uncompensated care, the Medicaid program is already paying some of the cost for individuals who come to our facilities and cannot pay for care. Furthermore, recent cuts to the DSH program through the Balanced Budget Act will limit Medicaid resources designated to our facilities. When the resources of public hospitals are stretched, there may be nowhere else for many HIV-positive individuals to turn for treatment.

Expanding Medicaid to cover asymptomatic HIV-positive Americans would likely save lives and save money, and more efficiently direct existing Medicaid resources. Recent reports indicate that there is a crisis in providing needed drugs through the Ryan White program which is designed to meet the country's HIV/AIDS drug access needs. Meanwhile, we have already identified a logical solution and must move quickly toward its implementation.

Sincerely,



Larry S. Gage
President

bcc: Sandra Thurman, Office of National AIDS Policy

NATIONAL
ASSOCIATION
OF PUBLIC
HOSPITALS &
HEALTH
SYSTEMS

N A P H

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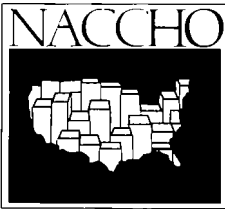
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NATIONAL
ASSOCIATION OF
COUNTY & CITY
HEALTH OFFICIALS

November 18, 1997

Sandra Thurman
Director
Office of National AIDS Policy
808 17th Street, NW, Ste. 820
Washington, DC 20006

Dear Ms. Thurman:

On behalf of the National Association of County and City Health Officials (NACCHO), I am delighted to confirm your participation in the December 9, 1997 NACCHO HIV/AIDS Advisory Committee meeting. The meeting will be held in NACCHO's offices at 440 First Street, NW, Room 450.

Enclosed please find an agenda for the December 9th meeting. You will note that we have allotted one hour for discussion with you, from 11:00 a.m. until 12:00 noon. Please feel free to join us for lunch at as well if you are available. If you have any questions, or if you need to modify the agenda in any way, please call Michael Meit at NACCHO at (202) 783-5550, ext. 202.

Sincerely,

Elaine O'Keefe /mm

Elaine O'Keefe
Chair, HIV/AIDS Advisory Committee

Enclosure

*8/14/97
For Co-Dir
JH/D
NACCHO
404-876-3194*

*404-876-1298
607-1209*



NACCHO HIV/AIDS ADVISORY COMMITTEE MEETING
DECEMBER 9, 1997
8:00 AM – 2:00 PM

AGENDA

- 8:00 Welcoming Remarks – Elaine O’Keefe and Michael Meit
- 8:10 Committee Member Introductions
- 8:30 Reflections on Our Mission & Discussion of Accomplishments
- 9:00 Review of NACCHO HIV Resolutions: Suggestions for New Position Statements on Contemporary HIV Issues
- 9:30 Discussion of Prominent HIV Issues for LHDs
- 10:15 Break
- 10:30 Hepatitis C Project Update
- 11:00 The National Perspective: Dialogue with Sandra Thurman, Director, Office of National AIDS Policy
- 12:00 Lunch
- 1:00 Next Steps: Ideas for Committee Direction



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

Assistant Secretary for Health
Office of Public Health and Science
Washington D.C. 20201

John Auerbach, M.D.
Director, HIV/AIDS Bureau
Massachusetts Department of Health
250 Washington Street, 3rd Floor
Boston, MA 02108-4619

NOV 24 1997

Dear Dr. Auerbach:

John :

Thank you for your forbearance as we have sought the clarifications you requested in your August 28, 1997 letter. Specifically, you inquired about the possibility of using federal funds to assist those Medicare-enrolled persons with HIV disease eligible for the HIV Drug Assistance Program to purchase Medigap insurance to cover the costs of HIV/AIDS pharmaceuticals.

The Office of General Counsel in the Department has provided us with the following information. There is no provision within the Public Health Service Act that would preclude the use of federal funds to purchase Medigap insurance for people with HIV/AIDS who are eligible for Medicare. Section 2615 of the PHS Act specifically provides for the use of State grant funds to purchase "medical benefits under a health insurance program." In addition, section 2616 which authorizes State AIDS Drug Assistance Programs could also be relied upon to support such activities.

You have specifically inquired as to whether section 1882(d)(3)(B)(iii)(III) of the Social Security Act, 42 U.S.C. section 1395ss(d)(3)(iii)(III), would prohibit the State from purchasing Medigap coverage. This section of the SSA is within the authority of the Department's Office of the Inspector General (OIG). The OIG has a separate legal office, and therefore a ruling on this issue would need to be requested directly from the OIG.

I hope this information will be helpful to you. Please do not hesitate to contact me if I can be of further assistance on this or other matters.

Best Regards,

Eric

Eric P. Goosby, M.D.
Director, Office of HIV/AIDS Policy

cc: Richard Riseberg
Joseph O'Neill, MD

The HIV Treatment Improvement Act of 1997

Representative Nancy Pelosi

The bill is designed to accomplish three basic objectives:

1) Have federally funded HIV treatment conform to new HIV Treatment Guidelines.

- The bill allows the Secretary of HHS to designate HIV treatment guidelines and establishes mechanisms to insure that federally funded programs conform to these guidelines.

2) Improve and expand HIV treatments under Medicaid.

- The bill establishes a limited benefit for people who are HIV-infected and meet the state income and resource requirements under Medicaid. The benefit would include primary care, therapeutic drugs, laboratory tests, and other services that may be necessary for compliance with optimum therapy, e.g. medical case-management, substance abuse and mental health treatment.
- Allows the Secretary to establish a formulary for therapeutic drugs consistent with recognized guidelines and requires that state Medicaid programs cover these drugs as a minimum. This list would supersede state Medicaid formularies but each state would have the option to cover additional therapeutic drugs.

3) Improve and expand HIV treatment under the AIDS Drug Assistance Program.

- Allows the Secretary to establish a formulary for therapeutic drugs consistent with recognized guidelines and requires that state ADAPs cover these drugs at a minimum.
- Prohibits states from adopting policies medically inconsistent with the recognized HIV treatment guidelines.
- Requires a minimum 20% state match for states receiving more than \$1 million in targeted ADAP funding.

HLC

105TH CONGRESS
1ST SESSION

H. R. _____

IN THE HOUSE OF REPRESENTATIVES

Ms. PELOSI introduced the following bill; which was referred to the Committee
on _____

A BILL

To amend title XIX of the Social Security Act and title XXVI of the Public Health Service Act with respect to treatments regarding infection with the virus commonly known as HIV.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the "HIV Treatment Im-
3 provement Act of 1997".

4 **SEC. 2. MEDICAID COVERAGE OF HIV-INFECTION-RELATED**
5 **DRUG TREATMENT FOR CERTAIN INDIVID-**
6 **UALS.**

7 (a) IN GENERAL.—Section 1902 of the Social Secu-
8 rity Act (42 U.S.C. 1396a) is amended—

9 (1) in subsection (a)(10)—

10 (A) by striking "and" at the end of sub-
11 paragraph (E);

12 (B) by adding "and" at the end of sub-
13 paragraph (F); and

14 (C) by inserting after subparagraph (F)
15 the following new subparagraph:

16 "(G) for making medical assistance avail-
17 able for HIV-infection-related drug treatment
18 (as defined in subsection (aa)(2)) for certain
19 HIV-infected individuals (as defined in sub-
20 section (aa)(1));"; and

21 (2) by adding at the end the following new sub-
22 section:

23 "(aa)(1) HIV-infected individuals described in this
24 paragraph are individuals not described in subsection
25 (a)(10)(A)(i)—

26 "(A) who have HIV infection;

1 “(B) whose income (as determined under the
2 State plan under this title with respect to disabled
3 individuals) does not exceed the maximum amount
4 of income a disabled individual described in sub-
5 section (a)(10)(A)(i) may have and obtain medical
6 assistance under the plan; and

7 “(C) whose resources (as determined under the
8 State plan under this title with respect to disabled
9 individuals) do not exceed the maximum amount of
10 resources a disabled individual described in sub-
11 section (a)(10)(A)(i) may have and obtain medical
12 assistance under the plan.

13 “(2) For purposes of subsection (a)(10), subject to
14 paragraph (3), the term ‘HIV-infection-related drug treat-
15 ment’ means each of the following services to monitor and
16 treat HIV infection through drug treatment:

17 “(A) Prescribed drugs.

18 “(B) Physicians’ services and services described
19 in section 1905(a)(2).

20 “(C) Diagnostic tests described in paragraphs
21 (3) and (13) of section 1905(a).

22 “(D) Services, such as substance abuse and
23 mental health treatment and medical case manage-
24 ment services, to the extent required in order to as-
25 sure compliance with a regimen of drug treatment.

1 “(3) HIV-infection-related drug treatment under a
2 State plan shall be such services described in paragraph
3 (2) as meet the needs of HIV-infected individuals, based
4 on the most current national guidelines that are recog-
5 nized by the Secretary and that relate to the treatment
6 of HIV infection through drug treatment and without re-
7 gard to any prescription drug formulary that would other-
8 wise be applied under the State plan.”.

9 (b) CONFORMING AMENDMENTS.—

10 (1) Section 1902(a)(10) of such Act (42 U.S.C.
11 1396a(a)(10)) is further amended, in the matter fol-
12 lowing subparagraph (G), as inserted by subsection
13 (a)(1)—

14 (A) by striking “and” before “(XIII)”, and

15 (B) by inserting before the semicolon at
16 the end the following: “and (XIV) the medical
17 assistance made available to an individual de-
18 scribed in subparagraph (G) who is eligible for
19 medical assistance only because of such sub-
20 paragraph shall be limited to medical assistance
21 for HIV-infection-related drug treatment (as
22 defined in subsection (aa)(2))”.

23 (2) Section 1905(a) of such Act (42 U.S.C.
24 1396d(a)) is amended, in the matter before para-
25 graph (1)—

1 (A) by striking "or" at the end of clause
2 (x),

3 (B) by adding "or" at the end of clause
4 (xi), and

5 (C) by inserting after clause (xii) the fol-
6 lowing new clause:

7 "(xii) individuals described in section
8 1902(aa)(1);".

9 (c) EFFECTIVE DATE.—(1) Except as provided in
10 paragraph (2), the amendments made by subsections (a)
11 and (b) shall apply to calendar quarters beginning on or
12 after the date of the enactment of this Act, without regard
13 to whether or not final regulations to carry out such
14 amendments have been promulgated by such date.

15 (2) In the case of a State plan for medical assistance
16 under title XIX of the Social Security Act which the Sec-
17 retary of Health and Human Services determines requires
18 State legislation (other than legislation appropriating
19 funds) in order for the plan to meet the additional require-
20 ments imposed by the amendments made by subsections
21 (a) and (b), the State plan shall not be regarded as failing
22 to comply with the requirements of such title solely on the
23 basis of its failure to meet these additional requirements
24 before the first day of the first calendar quarter beginning
25 after the close of the first regular session of the State leg-

1 islature that begins after the date of the enactment of this
2 Act. For purposes of the previous sentence, in the case
3 of a State that has a 2-year legislative session, each year
4 of such session shall be deemed to be a separate regular
5 session of the State legislature.

6 **SEC. 3. PUBLIC HEALTH SERVICE ACT; MODIFICATIONS TO**
7 **PROGRAM OF TREATMENTS FOR HIV DIS-**
8 **EASE.**

9 (a) REQUIREMENTS REGARDING TYPES OF TREAT-
10 MENTS.—Section 2616(c) of the Public Health Service
11 Act (42 U.S.C. 300ff–26(c)) is amended—

12 (1) in the matter preceding paragraph (1), by
13 striking “the State shall—” and inserting “the
14 State—”;

15 (2) by redesignating paragraphs (3) through
16 (5) as paragraphs (5) through (7);

17 (3) by striking paragraphs (1) and (2); and

18 (4) by inserting before paragraph (5) (as redes-
19 ignated by paragraph (2)) the following paragraphs:

20 “(1) shall determine, in accordance with guide-
21 lines issued by the Secretary, which treatments and
22 which laboratory services are to be included in the
23 program under subsection (a);

24 “(2) shall provide for the medical administra-
25 tion of such drugs in accordance with guidelines is-

1 sued by the Secretary for treatments described in
2 subsection (a) (or in accordance with guidelines rec-
3 ognized by the Secretary as appropriate guidelines
4 for such treatment);

5 “(3) shall not for purposes of this section adopt
6 any policy medically inconsistent with the guidelines
7 of the Secretary that are referred to in paragraphs
8 (1) and (2);

9 “(4) shall provide assistance for the purchase of
10 treatments and laboratory services included in the
11 program, and the provision of such ancillary devices
12 as are essential to administer the treatments;”.

13 (b) NON-FEDERAL CONTRIBUTIONS AS CONDITION
14 FOR RECEIPT OF CERTAIN AMOUNTS.—Section
15 2618(b)(2)(H) of the Public Health Service Act (42
16 U.S.C. 300ff-28(b)(2)(H)) is amended to read as follows:

17 “(H) APPROPRIATIONS FOR TREATMENT
18 DRUG PROGRAM.—

19 “(i) With respect to the fiscal year in-
20 volved, if under section 2677 an appropria-
21 tions Act provides an amount exclusively
22 for carrying out section 2616, the portion
23 of such amount allocated to a State shall,
24 subject to clause (ii), be the product of—

1 equipment, or services. Amounts provided
2 by the Federal Government, and any por-
3 tion of any service subsidized by the Fed-
4 eral Government, may not be included in
5 determining the amount of such non-Fed-
6 eral contributions.”.

7 (c) TECHNICAL AND CONFORMING AMENDMENTS.—
8 Section 2616 of the Public Health Service Act (42 U.S.C.
9 300ff-26) is amended—

10 (1) in subsection (a)—

11 (A) by striking “to provide” and all that
12 follows through “prevent” and inserting “to
13 provide treatments for HIV disease and for the
14 prevention of”; and

15 (B) by inserting before the period “, and
16 to provide related laboratory services”; and

17 (2) in subsection (c)—

18 (A) in each of paragraphs (5) through (7)
19 (as redesignated by subsection (a)(2) of this
20 section), by inserting “shall” after the para-
21 graph designation; and

22 (B) in paragraph (7) (as so redesignated),
23 by striking “progress” and all that follows
24 through “subsection (a)” and inserting

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10

1 "progress made in making treatments described
2 in subsection (a)".

3 **SEC. 4. PUBLIC HEALTH SERVICE ACT; MINIMUM GRANT**
4 **UNDER CARE GRANT PROGRAM REGARDING**
5 **HIV DISEASE.**

6 Section 2618(b)(1)(A) of the Public Health Service
7 Act (42 U.S.C. 300ff-28(b)(1)(A)) is amended to read as
8 follows:

9 "(A) each of the several States and the
10 District of Columbia for a fiscal year shall be
11 the greater of—

12 "(i) \$250,000; or

13 "(ii) an amount determined under
14 paragraph (2); and".

ONAP Letter Tracking

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10332	Richard E.	Neal	11/19/97	
Addressed To				
Thurman, Sandra				
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House of Representatives				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
AIDS Funding/Massachusetts				
☒ Response Needed?	Response Type	Response Date	Responder ID	
	any help you can give			
Responder Name	Action Promised	Action Complet	Action Date	
Notes				

*Find Response at
House of Reps*

File Incoming



Congress of the United States
House of Representatives
Washington, DC 20515

November 17, 1997

Ms. Sandra Thurman
Director of National AIDS Policy
Executive Office of the President
Domestic Policy Council
Room 216
Old Executive Office Building
Washington, D.C. 20502

Dear Ms. Thurman:

Enclosed please find copies of correspondence that I have had with various local, state and federal officials regarding the incidence of AIDS in Western Massachusetts. I have worked for many months to assist in the procurement of additional funding for the Western Massachusetts region as a result of the latest increases in AIDS cases. It is my hope that you will be able to assist in this endeavor.

The Western Massachusetts region has experienced a dramatic and unfortunate increase in the reported incidence of AIDS. The citizens of this area have a dire need for increased funding to be allocated for preventative educational programs, as well as much needed treatment and counseling programs for those who are already afflicted with this devastating and merciless disease. The City of Springfield and the surrounding municipalities are struggling to serve a large population of infected individuals with scarce resources that are provided to them under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Currently, this area which encompasses the City of Springfield - rated as the 25th highest nation-wide incidence of AIDS per 100,000 residents - is in critical need of financial assistance in the fight against the spread of this disease.

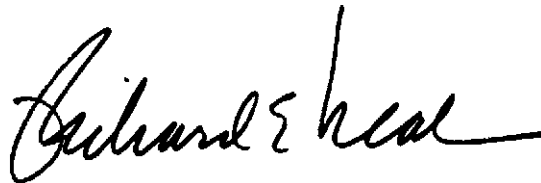
As a result of the funding criteria utilized by the Office of Management and Budget, the western portion of the state is ineligible for funds under Title I of the Ryan White CARE Act. It is absolutely necessary that the geographical areas that contain the highest number of cases of

Page Two
Ms. Sandra Thurman

AIDS and HIV be given adequate monies to further prevent and control the spread of this disease. I implore you to look into this disconcerting disparity in the allocation of funds for the treatment of AIDS and encourage you to work with Mr. Franklin Raines of the Office of Management and the Budget to reconcile this inherent incompatibility with the policy of the Clinton Administration and its dedication to the elimination of AIDS from our communities.

I would appreciate any assistance that you may be able to offer regarding this matter. It is imperative that our communities are given the greatest amount of assistance in the fight against AIDS, particularly those which have such a demonstrated need for increased attention and support. Thank you in advance for all of your dedication and hard work in this policy area. I look forward to working with you in the fight to prevent AIDS.

Very truly yours,

A handwritten signature in black ink, appearing to read "Richard E. Neal". The signature is fluid and cursive, with a long horizontal stroke at the end.

Richard E. Neal
MEMBER OF CONGRESS

REN/ab
Enclosures



SCOTT HARSHBARGER
ATTORNEY GENERAL

(617) 727-2200

The Commonwealth of Massachusetts
Office of the Attorney General
One Ashburton Place
Boston, MA 02108-1698

September 18, 1997

Mr. Franklin Raines, Director
Office of Management and Budget
725 17th Street, NW
Washington, D.C. 20503

Re: Ryan White CARE ACT Funding

Dear Mr. Raines:

A handwritten signature in cursive script that reads "Frank".

I am writing to express my strong support for a greater allocation of Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds than is currently available to municipalities in Franklin, Hampden, Berkshire and Hampshire Counties in Massachusetts. The share of funds that is provided to this region of the state -- which includes the City of Springfield, with the 25th highest nation-wide incidence of HIV/AIDS cases per 100,000 residents -- is deplorably inadequate to effectively meet the demands of controlling and preventing the spread of this epidemic.

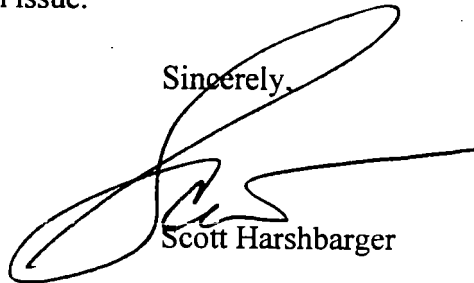
As you may know, the City of Springfield and the four western counties of Massachusetts are currently ineligible for Ryan White CARE Act Title I monies based on criteria determined by the Office of Management and Budget. While these areas are eligible for Ryan White Title II funds, subject to state allocation, the lack of any funding through the Title I program has left the City of Springfield in particular far behind in its efforts to prevent and stem the spread of HIV/AIDS. The neighboring areas of Hartford and New York State, however, are drawn within Title I eligible metropolitan areas.

Although recent advancements in the treatment of HIV/AIDS have brought promise to many infected individuals, there are still many more lives that may be saved through effective treatment and prevention programs. Therefore, available sources of funding for HIV/AIDS treatment, support services and education must be appropriately allocated to those areas hardest hit by this insidious disease. Given the dramatic increase in the rate of HIV infection in the City of Springfield and the western Massachusetts area, it is likely that this region will experience a further rise in the number of HIV/AIDS cases if an adequate portion of available federal funds is not allocated to these areas.

Franklin Raines, Director
Office of Management and Budget
September 18, 1997
Page 2

Please do not hesitate to contact me regarding this matter. Thank you for your commitment to this crucial public health issue.

Sincerely,

A handwritten signature in black ink, appearing to be 'SH', with a long horizontal line extending to the right.

Scott Harshbarger

cc: The Honorable Richard E. Neal
The Honorable Edward T. Kennedy
The Honorable John F. Kerry
Mayor Michael J. Albano
Anita Eichler, Director, Health Resources and Services Administration
Barry Clendenin, Deputy Associate Director of Health,
Office of Management and Budget
John Auerbach, Director, Massachusetts Department of Public Health,
HIV/AIDS Bureau
Joseph J. D'Amour, Esq.

Richard J. Kos
Mayor

COPY

October 22, 1997

Mr. Franklin Raines, Director
Office of Management and Budget
725 17th Street, NW
Washington, D.C. 20503

RE: Ryan White CARE ACT Funding

Dear Mr. Raines:

I am writing to express my strong support for a greater allocation of Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds that is currently available to municipalities in Franklin, Hampden, Berkshire and Hampshire Counties in Massachusetts. The share of funds that is provided to this region of the state is deplorably inadequate to effectively meet the demands of controlling and preventing the spread of this epidemic.

As you may know, the City of Chicopee and the four western counties of Massachusetts are currently ineligible for Ryan White CARE Act Title I monies based on criteria determined by the Office of Management and Budget. While these areas are eligible for Ryan White Title II funds, subject to state allocation, the lack of any funding through the Title I program has left the City of Chicopee in particular far behind in its efforts to prevent and stem the spread of HIV/AIDS. The neighboring areas of Hartford and New York State, however, are drawn within Title I eligible metropolitan areas.

Although recent advancements in the treatment of HIV/AIDS have brought promise to many infected individuals, there are still many more lives that may be saved through effective treatment and prevention programs.

CITY OF CHICOPEE



Mr. Franklin Raines, Director

October 22, 1997

Page 2

Please do not hesitate to contact me regarding this matter. Thank you for your commitment to this public health issue.

Very truly yours,

A handwritten signature in black ink, appearing to read "Rick Kos", with a long horizontal line extending to the right.

Richard J. Kos
Mayor

cc: The Honorable Richard E. Neal
The Honorable Edward T. Kennedy
The Honorable John F. Kerry
John Auerbach, Director, Massachusetts Department of Public Health,
HIV/AIDS Bureau
Joseph J. D'Amour, Esq.
Joseph P. O'Neil, M.D., M.P.H., Acting Associate Administrator
Bureau of Health Resources Development



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

HIV/AIDS Bureau

Health Resources and
Services Administration
Rockville MD 20857

AUG 28 1997

The Honorable Richard E. Neal
House of Representatives
Washington, DC 20515-4905

Dear Mr. Neal:

Thank you for your letter dated August 12 to Dr. James C. McCann, Project Officer, Eastern Services Branch, Division of Service Systems, HIV/AIDS Bureau, in which you asked for clarification as to whether the Department of Health and Human Services (DHHS) can disburse Title I Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds to localities outside the Boston Eligible Metropolitan Area (EMA) under mitigating circumstances, specifically the City of Springfield.

At the time Dr. McCann received your letter, he also received a phone call from a staff person in your office (Ms. Alison Bartlett) requesting clarification on the same issue addressed in your letter. She was referred to the letter of June 26 sent to your office which states that Title I dollars of the CARE Act are awarded to EMAs based on defined metropolitan statistical areas (MSAs), determined by the United States Office of Management and Budget. The Boston Title I EMA does not cover the geographic counties located within Western Massachusetts, including the City of Springfield, and the MSA including the City of Springfield does not meet eligibility criteria, as cited in CARE Act legislation for Title I funding. It was related that DHHS cannot change defined MSAs. Dr. McCann suggested that she contact the Title II Program Director in Massachusetts, Mr. John Auerbach at 617-624-5303, to discuss funding applicable to the City of Springfield.

Ms. Bartlett related that she would provide this information to you. We appreciate your interest in the provision of needed services to people living with HIV and AIDS in Massachusetts, and in particular to those residents residing in Springfield. If you need additional information please contact Dr. James C. McCann at 301 443-2937.

Sincerely,

A handwritten signature in dark ink, appearing to read "Joe O'Neill", is written over the typed name.

Joseph F. O'Neill, M.D., M.P.H.
Associate Administrator



Congress of the United States
House of Representatives

Washington, DC 20515

August 12, 1997

Mr. John Auerbach
Director
Massachusetts Department of Public Health
HIV/ AIDS Bureau
250 Washington Street
3rd Floor
Boston, Massachusetts 02108-4619

Dear Mr. Auerbach:

I am writing to you on behalf of the City of Springfield regarding the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. There is an imperative need for increased funding to be allocated statewide to those communities that are experiencing the greatest impact of the AIDS/ HIV epidemic. I am enclosing a copy of the letter that I had received earlier this year from Attorney Joseph D'Amour, Liaison to the Gay and Lesbian Community for the City of Springfield, for your review.

The City of Springfield has been working desperately to alleviate the incidence of AIDS and its affects on the community. The prevention and treatment of those who are unfortunate enough to have contracted this fatal and merciless disease must be a priority for the Department of Public Health and local community leaders. The grim and notorious distinction that has been given to Springfield, the rank of 25th highest city nationwide with incidence of full-blown AIDS per 100,000 individuals, makes it even more crucial that any available funds under Title II be distributed accordingly. The current formula used for the appropriation of funds under Title I dictates that a community must be within an eligible metropolitan area based on statistics determined by the U.S. Office of Management and Budget. Unfortunately, Springfield is precluded from this regional disbursement.

Mr. Auerbach, the current funding that Springfield and the Western Massachusetts region receives is woefully inadequate to effectively and proactively combat the impending spread of this fatal disease. I am positive that the latest reports from the Center for Disease Control and the disheartening statistics that have been compiled will give credence to the request for additional funds to be earmarked for Springfield. I am very concerned that the western region of the state will experience a further rise in the number of AIDS infections and cases if they are not given the opportunity to develop offensive strategies and coordinate efforts with community health organizations.

Page Two
Mr. John Auerbach

Springfield has an imperative need for funding that would make possible medical treatment for those patients who are stricken by poverty and otherwise unable to access adequate health services. I respectfully request that attention be given to the City of Springfield and Western Massachusetts when Title I CARE Act monies are appropriated.

Springfield has more than adequately demonstrated their need for financial assistance in combating AIDS. I believe there can be a positive resolution to the inadequacy of funding for the treatment and prevention of AIDS in Western Massachusetts. I understand that there are financial constraints on the ability to serve all communities, however, there must be a reallocation of funding to address the inherent and absolute need for individuals outside of the metropolitan Boston area to receive treatment. I look forward to hearing from you at your earliest convenience and to working with you to ensure that areas most in need of financial assistance receive their proportional share of federal funds. Thank you in advance for your time and attention to this most important matter.

Yours very truly,

A handwritten signature in cursive script, reading "Richard E. Neal".

Richard E. Neal
MEMBER OF CONGRESS

REN/ab
Enclosure



Congress of the United States
House of Representatives

Washington, DC 20515

August 12, 1997

Dr. James C. McCann
Bureau of Health Resources Development
Health Resources and Services Administration
Parklawn Building, Room 7A-39
5600 Fisher Lane
Rockville, Maryland 20857

Dear Dr. McCann:

I am writing to you in regards to Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and funds that are allocated under the parameters of this legislative action. I was referred to you by Dr. Joseph F. O'Neill, Acting Associate Administrator of the Bureau of Health Resources Development.

I previously corresponded with the Department of Health and Human Services to determine the specifications that are required under the CARE Act for communities to receive funding under Title I and Title II. I am enclosing with this letter a copy of the original correspondence that I received from Attorney Joe D'Amour, Liaison to the Gay and Lesbian Community for the City of Springfield. This letter I believe is self-explanatory and clearly enumerates the concerns of this local municipality in dealing with the AIDS epidemic.

The City of Springfield has experienced an dramatic increase in the incidence of AIDS, but because of the use of the eligible metropolitan area factor and statistical data therein, as a community that is not located within the metropolitan Boston area, it is not able to receive much needed funds. It has come to my attention that perhaps there is some discretion that may be given by DHHS in the disbursement of funds when mitigating circumstances, such as drastic and severe increases in reported cases of AIDS and HIV, necessitate a diversion from the established EMA. I would appreciate a determination as to the possibility of any alteration in this use of EMA's for the distribution of funds under Title I of the CARE Act. If you could forward such information to me at your earliest convenience, I would greatly appreciate it. Thank you in advance for your time and attention.

Sincerely,

Richard E. Neal
MEMBER OF CONGRESS

REN/ab
Enclosure



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Bureau of Health Resources Development

Office of the Assistant Secretary
for Health
Washington DC 20201

The Honorable Richard E. Neal
House of Representatives
Washington, DC 20515-4905

Dear Mr. Neal:

Thank you for your letter dated June 5 to Mr. Robert Baitty, Branch Chief, Survey Documentation and Quality Assurance Branch, Division of HIV Services (DHS), in which you expressed concern over the allocation of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds in the State of Massachusetts. You had a particular concern regarding the inequities in the allocation of funding to certain regions within Western Massachusetts, specifically to the City of Springfield.

You indicated that monies appropriated through Title I of the CARE Act are not proportionately disbursed to communities in Western Massachusetts. Title I dollars of the CARE Act are awarded to eligible metropolitan areas (EMAs) based on defined metropolitan statistical areas (MSAs), determined by the United States Office of Management and Budget. The Boston Title I EMA does not cover the geographic counties located within western Massachusetts, including the City of Springfield, and the MSA including the City of Springfield does not meet eligibility criteria, as cited in CARE Act legislation for Title I funding.

The Title II program of the CARE Act allocates funding to states and territories that provide health care and support services for people living with HIV disease. In fiscal year (FY) 1997, Massachusetts received a Title II grant award of \$7,528,256. This amount specifically includes an AIDS Drug Assistance Program (ADAP) earmark of \$3,310,714. As you are aware, Title II funds may be spent for HIV services through consortia or direct contracting, home and community-based care, continuation of health insurance coverage, and ADAP. The CARE Act specifies that decisions regarding the allocation of funds to these various categories be determined by the State, not the Federal funding agency.

The Massachusetts Department of Public Health, which administers the Title II program, is in the process of conducting a competitive Request for Proposals (RFPs) to determine funding allocations throughout Massachusetts. A variety of community based AIDS service organizations in Springfield have submitted RFPs to the Department of Public

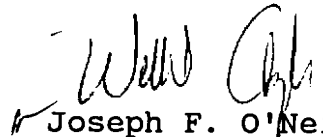
Health for AIDS funding (both Federal and State), and will be notified of their FY 98 HIV funding level sometime in early fall, effective October 1.

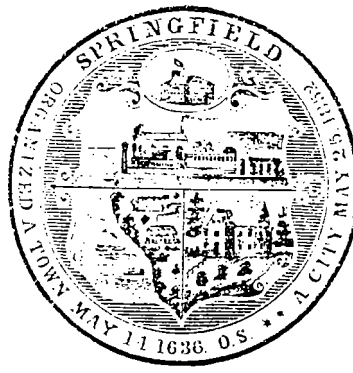
The DHS Project Officer for the Massachusetts Title II grant is Dr. James C. McCann. Dr. McCann is in contact with the grantee on a regular basis, and is continuously informed of Title II funding activities within the State.

The Title II grant is administered by the Massachusetts Department of Public Health, HIV/AIDS Bureau, 250 Washington Street, 3rd Floor, Boston, MA, 02108-4619. The Program Director is Mr. John Auerbach. Mr. Auerbach can be contacted at 617-624-5303.

We appreciate your interest in the provision of needed services to people living with HIV and AIDS in Massachusetts, and in particular to those residents residing in Springfield. We are pleased to inform you that the state and local administration of the Title II grant is in compliance with the legislation and the intent of the CARE Act. If you need additional information please contact Dr. James C. McCann at 301 443-2937.

Sincerely,


Joseph F. O'Neill, M.D., M.P.H.
Acting Associate Administrator



THE CITY OF SPRINGFIELD, MASSACHUSETTS

MAYOR MICHAEL J. ALBANO

JOSEPH J. D'AMOUR, Esq.

Liaison to the Gay Community

MAY 12, 1997

U.S. REP. RICHARD NEAL
FEDERAL BUILDING
1550 MAIN STREET
SPRINGFIELD, MA 01105

MAY 16 1997

DEAR CONGRESSMAN NEAL:

I WRITE ON BEHALF OF MAYOR MICHAEL J. ALBANO TO REQUEST YOUR HELP IN SECURING OUR FAIR SHARE OF FEDERAL FUNDING FOR AIDS TREATMENT UNDER THE RYAN WHITE CARE REAUTHORIZATION ACT.

THE CDC HAS RECENTLY REPORTED (APRIL 1997) THAT SPRINGFIELD HAS THE GRIM DISTINCTION OF HAVING THE 25TH HIGHEST INCIDENCE OF FULL-BLOWN AIDS PER 100,000 IN THE NATION; BOSTON RANKS 48TH. NEVERTHELESS, THE BOSTON METROPOLITAN REGION (INCLUDING SOUTHER NEW HAMPSHIRE) RECEIVES \$8.5 MILLION IN RYAN WHITE TITLE 1 MONEY WHILE SPRINGFIELD/ HOLYOKE/ NORTHAMPTON AND THE FOUR WESTERN COUNTIES RECEIVE NOTHING UNDER THAT TITLE.

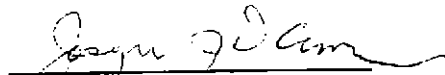
FROM ALL SOURCES COMBINED, SPRINGFIELD CURRENTLY RECEIVES \$ 1.2 MILLION FOR AIDS TREATMENT/PREVENTION ACCORDING TO THE MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH. DPH COMMISSIONER DAVID MULLIGAN ACKNOWLEDGES THAT CURRENT FUNDING IS WOEFULLY INADEQUATE TO THE TASK OF FIGHTING OUR CITY'S NO. 1 PUBLIC HEALTH ENEMY.

IT IS ALSO MY UNDERSTANDING THAT THERE EXISTS A TITLE I PLANNING COUNCIL IN BOSTON WHICH SETS THE GEOGRAPHIC BOUNDARIES FOR TITLE I APPROPRIATIONS. THE DISTRIBUTION OF TITLE I FUNDS SHOULD BE BASED PRIMARILY ON ACTUAL NEED RATHER THAN THE CURRENT ARTIFICIAL MEASURE.

WE WOULD RESPECTFULLY ASK THAT YOU CALL FOR AN INVESTIGATION INTO THESE APPARENT INEQUITIES IN RYAN WHITE TITLE I ALLOCATION AND HELP TO SECURE OUR FAIR SHARE OF U.S. FUNDS FOR THE TREATMENT OF THIS GROWING EPIDEMIC IN THE CITY OF SPRINGFIELD AND THE FOUR WESTERN COUNTIES.

PLEASE FEEL FREE TO CALL ME OR MAYOR ALBANO IF YOU SHOULD NEED ANY FURTHER INFORMATION.

SINCERELY,


JOSEPH J. D'AMOUR

ENCLOSURES

Sarah Meehan
Daniel

*FEDERAL AIDS FUNDING FROM RYAN WHITE CARE ACT
FOR SPRINGFIELD, MA*

TITLE 1: NOT AVAILABLE: \$8.5 M OF TITLE 1 FEDERAL FUNDS
FROM "RYAN WHITE CARE REAUTHORIZATION ACT"; THAT
MONEY GOES DIRECTLY FROM THE U.S. GOVT. TO THE CITY
OF BOSTON AND IS DISTRIBUTED TO 60% OF
MASSACHUSETTS AND EVEN SOUTHERN NEW HAMPSHIRE
BUT NO FUNDS AT ALL FOR THE FOUR WESTERN COUNTIES
OF MASS.

TITLE 2 : \$6 M U.S. FUNDS DISTRIBUTED BY MASS DPH
THREE FUNDING AREAS-----

1. PRESCRIPTION REIMBURSEMENT: 1,600 PERSONS
THROUGHOUT THE COMMONWEALTH "MASS DRUG
ASSISTANCE PLAN". (70% OF THE \$6 M).
2. HOME CARE FOR AIDS PATIENTS:
\$112,000 FOR GREATER SPRINGFIELD: CONTRACT:
PIONEER VALLEY VISITING NURSES ASSOCIATION.
3. AIDS CONSORTIA: \$552,000 THIS YEAR, \$689,000 FOR
YEAR BEGINNING NEXT OCTOBER: CONTRACT:
LEAD AGENCY-RIVER VALLEY AIDS CONSORTIUM.

TITLE 3: FUNDS DISTRIBUTED DIRECTLY BY U.S. TO CITIES
PRIMARY CARE FUNDS: GREATER SPRINGFIELD
RECEIVES \$290,000 CONTRACT: FAMILY PLANNING OF
WESTERN MASS. WHICH DISTRIBUTES TO BAYSTATE
MEDICAL AND HOLYOKE HEALTH CENTER.

MISCELLANEOUS:

TITLE 4 : PEDIATRIC AIDS: FUNDED TO BAYSTATE MEDICAL.

TITLE 5: AIDS EDUCATION: FUNDED TO AHAP AT U. MASS/AMHERST

###

Violence Project present
**Violence
Relationships**

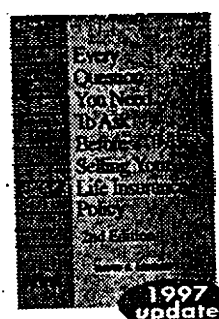


male relationships?
difficulty leaving their
male victim?
relationships?
abusive relationship?
Bisexual/Gay Community and
Department; Robb Johnson,
Berounsky, AIDS Action
Domestic Violence Project

7 7-9PM
Cafe
, Boston
THE GAY MEN'S
DOMESTIC VIOLENCE
PROJECT

Protease Inhibitors
Timing
New Tax Laws
Pricing
SGLI/VGLI
Confidentiality

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Regional

New AIDS statistic, money for Springfield

by Ed Boyce

SPRINGFIELD — According to a recent report by the U.S. Center for Disease Control, the city of Springfield now has the 25th highest per capita rate of HIV infection in the nation, with 33.5 cases per 100,000, compared with 19 cases 100,000 grand for Boston, ranking the Hub at 48th highest in the country.

Partly in response to this new statistic released in a CDC report dated April 17, which reflects all cases, newly diagnosed and old as of the end of 1996, Springfield politicians are scrambling to find new funding to stem the rapidly rising tide of new infections in that city.

"While Boston is making great progress, we're falling behind and that concerns [Mayor Michael Albano] and everyone else around here," said Joe D'Amour, Mayor Albano's liaison to the lesbian and gay community.

Springfield's per capita rate of HIV infection is approximately the same as some much larger cities, such as New Haven and Philadelphia.

"It's true, and that's alarming," Millie Rivas, assistant executive director of Springfield's Gandara Center, a treatment clinic for people living with HIV/AIDS, told the *Morning Union and Daily News* of Springfield.

"The real shocking part is people don't view themselves here as being like those in an inner city with places like Chicago," Rivas said.

Hartford has a slightly higher infection rate than Springfield, with

34.1 cases per 100,000 residents, making it the 23rd highest. New York City has the ignominious honor of being first ranking, with 120 cases per 100,000.

At a Springfield City Hall news conference last Wednesday, Mass. Department of Public Health Commissioner, David Mulligan, said Springfield already receives nearly \$1.2 million a year. But the various scattered treatment programs need better coordination, he said, and the city could use more money.

"You have an incredibly serious problem here," Mulligan said. "This issue is not going away."

State Rep Dennis Murphy, (D-Springfield) recently introduced a line item in the fiscal year '98 state budget earmarking an additional \$300,000 for Springfield's fight against HIV/AIDS.

The allocation apparently survived the House appropriations process and is now up for consideration by the State Senate where Minority Leader Brian Lees (R-Springfield) has pledged to work for its passage, according to D'Amour.

"The gay community of Springfield is profoundly grateful to our State Rep. Dennis Murphy for this unprecedented appropriation," said D'Amour.

"The city has to make a more affirmative outreach to all of the communities affected by AIDS, including the gay community and communities of color," said D'Amour.

"Hopefully the \$300,000 will provide the resources for that."

Material from the Associated Press contributed to this report.

RALPH REED, con'tinues from cover

certain that softening the message would not be sufficient to motivate the Coalition's hard core of donors and workers, they would trickle away to inactivity or to other groups that maintained their stridency. Tafel thought the

The 1992 Republican Convention will be seen as the high water mark of the religious right, that point when the infection of their bigotry flared most visibly upon the American scene. And it set in motion the immune system of the American body politic

DU READY IE BEACH?



Union News.

1860 Main Street, Springfield, Mass. 01101

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AIDS rate signals need for political courage

The news that Greater Springfield's per-capita AIDS rate is higher than that of cities like Boston, Chicago and Detroit may, finally, force elected officials into taking action to prevent the spread of the disease here.

We hope it does. Officials cannot say they were unaware of the magnitude of the problem, because the rising numbers of people infected with the HIV virus — which causes AIDS has been reported regularly — often on Page 1 — over the past several years.

And as the number of people infected with this deadly disease has grown, we have repeatedly urged action, such as clean-needle exchange programs and safer-sex education programs.

But little has been done, and today 33.5 people out of every 100,000 in the metropolitan Springfield area have been diagnosed with AIDS — far in excess of Boston's rate of 19 per 100,000, for example.

The latest figures from the National Centers for Disease Control and Prevention in Atlanta put the Springfield region in the same category with other hard-hit cities such as Hartford, Philadelphia, Dallas and Oakland.

David Mulligan, state public health commissioner, terms it "an incredibly serious problem." At a press conference last week at City Hall, he warned, "This issue is not going away."

It hasn't gone away during the years that public officials ignored it. Instead it has worsened.

Springfield is already receiving \$1.2

million for AIDS treatment programs, but Mulligan said the city could clearly use more money.

Treatment of those living with HIV or AIDS is expensive, and often must be paid by taxpayers since patients may be unable to work and may not have medical coverage. Treatment is essential, even in early stages, since it can extend life expectancy significantly. Infected pregnant women can, with treatment, reduce by two-thirds the chance that their babies will be born HIV-positive.

But funding must also go to prevention. State figures show that about a third of all AIDS cases were transmitted by intravenous drug users sharing needles. That figure could be significantly reduced by needle exchange programs.

AIDS infection remains highest among homosexuals and drug users, and public attitudes toward such behavior lead to an emotionally charged atmosphere when it comes to public spending on prevention. Thus most public officials are much more eager to fill potholes than insist on AIDS treatment and prevention.

But the spread of AIDS cannot be allowed to continue.

While homosexual males and IV-drug users are still the primary victims of AIDS, the infection has also crossed over into the non-drug-using heterosexual population.

And nearly two out of every three persons so far infected with AIDS in Massachusetts have already died of it.

It is time to act.

① TO: M. Albano

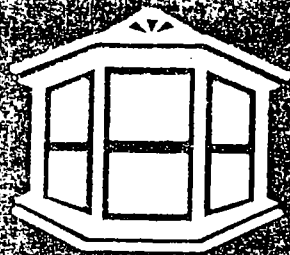
② TO: B. Lees

③ TO: L. Melconig

From:

J.D. Amou

4-28-97



Bay Windows

This Week:

Boston's Bayard Rustin Breakfast enters its 8th year — p. 3

East Boston transplant may have first case under New York City's anti-bias law — p. 5

April 17 - April 23, 1997

New England's Largest Gay and Lesbian Newspaper

Vol. 15, No. 17

50 cents at newsstands

Menino's city AIDS budget rankles service providers

No new dollars for AIDS in Boston's fiscal year 1998 budget proposal

by Fred Kuhr
Bay Windows staff

Boston Mayor Thomas Menino released his fiscal year 1998 budget on April 9, leaving some AIDS advocates angry.

The AIDS Action Committee of Massachusetts blasted Menino two days after his budget proposal was released, stating that his budget failed to increase funding for AIDS prevention, care and treatment services.

Although the Mayor included \$1.5 million for AIDS services, the group noted that the figure has increased by only 10 percent over the last six years while the number of AIDS cases has gone up by 50 percent.

"We are not seeing any decrease in the number of infected people," said Larry Kessler, AIDS Action's executive director. "A level funding of AIDS programs is, in effect,

Continued on page 15

Suit: Anti-gay pundit made passes at male worker

Former employee of right-wing radio host alleges same-sex sexual harassment by boss

by Jeff Epperly
Bay Windows staff

Allen Ginsberg, Adieu

Lesléa Newman remembers a friend, mentor and confidante

by Lesléa Newman
Special to Bay Windows

town of Boulder, Colorado and more like my Uncle Irving as he ring the doorbell of America's most famous (and infamous) poet in baggy grey pants and rolled up





Ms.
Sandra Thurman
Director
OFFICE OF NATIONAL
AIDS POLICY
808 17th Street N.W., Suite 820
Washington DC - 20006

Caracas, November 25th, 1.997

Dear Ms. Thurman,

It was a great pleasure to have had the opportunity to meet you at the Healthcare Resource Allocation Conference in Washington DC. I was really grateful to Luigi Buitrago-Ho for introducing us.

The Conference was very enriching and it helped me come back to Venezuela with a different perspective on our HIV/AIDS work for next year. To give you a general idea about our organization, I have enclosed the two articles published in the Journal of the International Association of Physicians in AIDS Care. The one published in the November issue was also picked up by the CDC AIDS Daily News Update dated November 24th. I founded Accion Solidaria only two years ago and it is really motivating to see that they have been very fruitful.

As you will read in the articles, the venezuelan government has not yet recognized AIDS as a priority issue and most of the support services to those affected are being provided by NGO's and private individuals. As well, prevention on a large scale has been undertaken by the NGO's. We are already working on both the first National HIV/AIDS awareness and information ad campaign and the first HIV/AIDS Hotline. After almost 18 years...

I will be in Washington DC from the 5th until the 11th of January and it would be really interesting to meet with you. I will be calling your office to make an appointment, but I can also be contacted in Venezuela at 1-800-379-9676 during office hours or at 1-800-379-9668 at home.

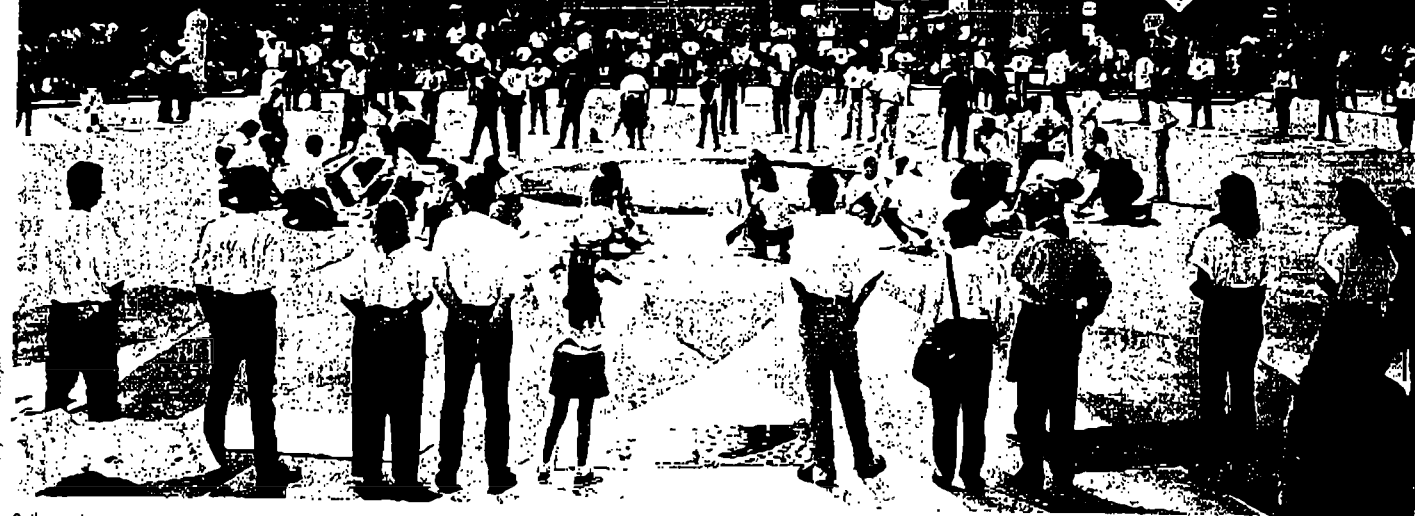
Thanking you in advance for your kind attention and looking forward to meeting with you, I remain,

Yours very truly,


Feliciano Reyna
President

Acción Solidaria

photo courtesy Feliciano Reyna



Quilt panels commemorating Venezuelans lost to AIDS were displayed on World AIDS Day last December in Caracas's Plaza de los Museos. The display was organized by Red MetSIDA, a network of 14 community agencies that work to combat AIDS in Venezuela.

A Venezuelan NGO confronts the Herculean task of providing drug access

Shawn Dougherty

There is no government funding of AIDS services in Venezuela. As in New York City in the early 1980s, it has fallen to committed private individuals to do the best that they can to begin to provide needed services and information to the people around them.

Feliciano Reyna is one of three co-founders of Acción Solidaria (Action for Solidarity), a nongovernmental organization (NGO) founded in late 1995 in Caracas whose purpose is to improve access to medications by procuring them at discounted prices or providing them outright.

"AIDS is not recognized yet as a priority in our country as a health problem, so it's not mentioned at all," says Reyna. The official lack of recognition of AIDS as a public health concern does not correlate with an actual lack of cases. The Pan American Health Organization officially recognized 6000 cases of AIDS in Venezuela at the end of 1996. There is widespread acknowledgment, even within that organization, that the actual num-

ber may be three times as high. The World Health Organization estimates that a country with Venezuela's social and cultural characteristics probably has 10 cases of HIV infection per actual case of AIDS. If these projections are correct, there are currently over a quarter million HIV-infected Venezuelans.

The silence surrounding AIDS is not just a function of lack of governmental interest. The PWA community itself is not outspoken. At a rally held in Caracas in observance of World AIDS Day last December, only one person would take to the microphone and identify himself as someone living with HIV. "They don't feel protected by the system, I guess" remarked Reyna. "Even though by law you're protected—you can't be knocked out of a job for example—still they say, 'we can be harassed.'"

"You don't have families who have lost kids talking about it—mothers, husbands, wives. We're slowly working through that. It's not happening yet. It's really sad when you have families talking about somebody being ill—they talk about cancer, whatever—they *never* talk about AIDS. I have a cousin who is positive. In his house they talk about *eso que él tiene* (that thing that he has)."

Acción Solidaria was founded by Reyna, a graduate of Cornell University and general manager of a textile company; José Medina, a nurse who specializes in caring for AIDS patients; and Armando Grisanti, an investment banker. Reyna was largely motivated by the death from AIDS of his personal and business partner, Rafael, in the summer of 1995. The two men had sufficient financial resources to have Rafael treated in Washington, DC. During Rafael's illness, Reyna made many connections abroad, and these international connections are central to the manner in which Acción Solidaria carries out its mission.

The first service that the organization provided was a "medicine bridge." Reyna and other volunteers traveled to Miami or elsewhere in the United States to purchase medications that were either unavailable in Venezuela or simply much less expensive in the US. Reyna had arranged to buy medications in bulk from Steven Schaefer's APP Pharmacy in North Miami, sometimes paying half of what he would have to pay in Venezuela. "Nobody has given us better prices than Steve," said Reyna. "It's unbelievable what he's done for us."

Likewise, with the help of Shedrick

Boren and Corklin Steinhart, MD, PhD, of Mercy Hospital in Miami, a special "group rate" was established for all Venezuelans who could travel to the hospital for viral load and other laboratory testing. This enabled Venezuelans to obtain the tests for less than half of their normal cost.

In these two cases, Acción Solidaria was merely acting as a broker and/or courier service. Reyna and other volunteers would be given money to purchase medications, and the medications would be transported back to Venezuela in the volunteer's luggage. Although the group has tax-exempt status in Venezuela, these shipments were, at first, not entirely "official." "We counted on the help of angels," Reyna remarked. "There was one time I had \$14,000 worth of medicine—75 bottles. My luggage sounded like a rattle. When I went to walk through customs, someone I know from the National Guard came up and talked to me and I got waved on."

In October 1996, lamivudine, stavudine, indinavir, and zidovudine were approved in Venezuela. Saquinavir had been approved just prior to this. With these approvals, Reyna now seeks out fewer drugs for purchase in the US. "Nevirapine is not even being prescribed yet in Venezuela, but when it and zalcitabine are then I will try to get those two. Then there are drugs which, for some reason, are much cheaper in the US, such as Cytovene."

Acción Solidaria does not merely act as a buyers club for people who can afford to purchase medications. The group brings medications to Venezuela that have been donated by charitable groups in the United States.

One such organization is United Against AIDS International, founded by Hugh Ward in 1995. Ward, an Irishman now living in New York City, felt that there was a surplus of medicine and medical supplies in the US—goods that for one reason or another would not be used in the US but could be used abroad.

Ward gathers an assortment of medications from various community-based agencies in New York. When patients switch drugs or die, medications that might simply be discarded become available. These drugs are an invaluable commodity in developing countries where they are generally not affordable.

Ward had friends in Venezuela and had started vacationing there in the early

1980s. When friends started succumbing to AIDS it was a natural choice to focus his efforts on that country. Ward set up a medicine bank at another Caracas organization, Acción Ecuénica, an NGO working with various health issues that had sufficient facilities to process and store the drugs. An attempt is made to register patients receiving antivirals and to secure at least a six-month supply of drug. This allows time to gather more medicine for that patient in an attempt to achieve continuity of treatment.

Ward decries the fact that there is simply not enough medicine to go around. He laments that "If people don't have access to a particular medicine, they just die," and calls the waste of short-dated medicine (medications that are discarded because they will reach their expiration date in three to six months) "more than a crime."

Two catholic priests, Fr. Kike Cordero and Fr. Pedro Corces, both located in Miami, have been helpful in procuring financial and material support. Fr. Corces has set up a repository for donated items at Prince of Peace Parish. Corces also introduced Reyna to a group of women, some of whom are active in the organization Mothers' Voices. With the help of these volunteers in Miami, Reyna is registering a not-for-profit organization in the United States. This registration will allow residents of the US to make contributions that are tax-deductible in the United States.

The next, logical, and most ambitious step for Acción Solidaria was to provide

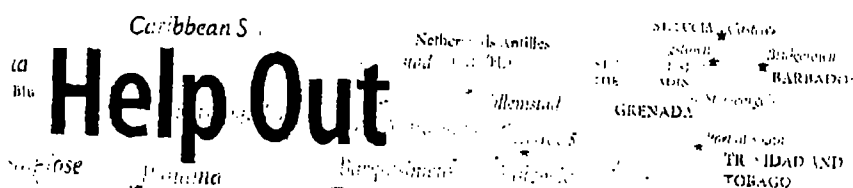
direct funding of the purchases of medications for people who could not afford them. The group now receives monthly donations from 41 people whose contributions are charged to their credit cards. These contributions allow Acción Solidaria to purchase all of the medicines taken by five children and five adults with HIV disease.

Given that Acción Solidaria has no staff, but is run by people who contribute the time that they have outside of their full-time jobs, the ability to fully fund the purchase of medicine for even 10 people is a major achievement. These efforts have been hindered by two successive devaluations of the Bolívar, the Venezuelan currency. In 1996 alone, the exchange rate fell from 170 to 470 Bolívares to the dollar.

Acción Solidaria has recently secured the assistance of the Venezuelan division of the advertising agency J. Walter Thompson, and Vivianne Matos, the wife of Venezuela's Secretary of the Treasury. Reyna hopes to launch the first well-coordinated national HIV prevention and education campaign in Venezuela.

"There is still a lot more to do," remarks Reyna. "But even on the smallest of scales, we cannot elude our responsibility to try to do something to help those in need. We welcome and are thankful for everyone's contribution, no matter how small—even if only one person benefits from it." ■

Shawn Dougherty is assistant editor of the Journal.



The following contact information is provided for those wishing to make financial contributions or arrange donations of materials or medications:

Acción Solidaria
Feliciano J. Reyna
Aerocav #1019
7801 NW 37th St.
Miami, FL 33166-6559
(800) 379-9676 office hours
(800) 379-9668 all other times
E-mail: Reygan@ibm.net

Prince of Peace Parish
Father Pedro Corces
275 NW 130th Avenue
Miami, FL 33182

United Against AIDS International
Hugh Ward
43-22 49th St.
Sunnyside, New York, NY 11104
(718) 639-5696



Breaking the silence

Shawn Dougherty

Six months after it was profiled in the *Journal* (May 1997), Acción Solidaria and its fellow NGOs are poised to launch Venezuela's first national AIDS prevention and education campaign.

The \$7 million campaign represents one front in a battle against the silence that surrounds both HIV disease and people living with the disease in Venezuela. Activists have recently had successes on various fronts:

- Acción Ciudadana Contra el SIDA [ACCSI], Venezuela's first AIDS organization, successfully represented 37 HIV-positive people in a suit against the Venezuelan social security system. These patients will now receive triple-drug therapy including protease inhibitors at government expense.
- The First National Venezuelan Meeting of People Living with HIV and AIDS was held on October 16-19.
- Acción Solidaria has incorporated a nonprofit organization in the United States, "Action of Solidarity." The organization will facilitate the receipt of donations from the United States and aid in forming an international support network.*
- Red MetSIDA, an umbrella organization for Venezuelan AIDS organizations, will initiate the nation's first AIDS hotline. The hotline will serve as an adjunct to the national education and prevention campaign.

"Every day all the NGOs are approached by anguished individuals,

Venezuela's activist community begins to reap the fruit of its labors

families, parents, friends who are confronted with this virus that, to them, came out of nowhere, as if it had not been among us for almost 17 years," remarked Feliciano Reyna, cofounder of Acción Solidaria. With the help of the Venezuelan division of the advertising agency J. Walter Thompson, the country will now have an organized, high-profile media campaign to bring prevention messages to the general population and dispel the misinformation that circulates throughout the country. J. Walter Thompson has designed the campaign at no cost. Other Venezuelan advertising agencies will ask their clients to donate television and radio air time and billboard space.

The British Embassy in Venezuela has donated a switchboard for Red MetSIDA's new AIDS hotline. Health Crisis Network in Miami will help to provide training for hotline workers. Both the ad campaign and the hotline may be in place by late November. "The hotline is absolutely necessary," stated Reyna. "Having an ad campaign will make no sense without the hotline." The need to dispel misinformation and stigma is illustrated by Reyna's experiences in trying to rent an office for the hotline. "I found a great space, but they did not want to rent it to us because we might have 'gente con eso' (people with that [HIV/AIDS])."

Human Rights activists and ACCSI founders Edgar Carrasco and Renate Koch orchestrated the successful lawsuit against the Venezuelan social security system (Instituto Venezolano de los Seguros Sociales [IVSS]). According to Venezuelan law, IVSS is obliged to cover the costs of

medicines and medical treatments of registered workers. Some HIV-positive workers were receiving ZDV and 3TC on an irregular basis. Though doctors were aware of effectiveness of triple-drug regimens, these were not being prescribed. The lawsuit, based on complaints of an initial group of five HIV-positive patients, argued that the patients constitutional rights to life, health, social security, nondiscrimination, and access to advances in science and technology were being violated. The 37 patients represented in the suit are now receiving three-drug cocktails and ACCSI is presently preparing a new suit representing 60 patients.

The decision handed down by the Venezuelan court seems to mirror two decisions recently made by the Costa Rican Supreme Court. On September 23 and 25, the Costa Rican Supreme Court ruled in two cases that the nation's social security system (Caja Costarricense de Seguro Social [CCSS]) was required to immediately provide combination antiviral therapy to the HIV-positive plaintiffs. The lawyer who filed both petitions, gay activist Marco Castillo, indicated that the decision opens the door for all patients with severely compromised immune systems to apply directly to the CCSS to receive the medications. However, he also predicted that the CCSS is likely to seek strategies to avoid providing the medications to persons who have not actually filed suits.

Commenting on the Venezuelan lawsuit, Reyna remarked, "It was not easy to get HIV-positive patients to join the suit because of their lack of trust in the legal system, as well as their fear of having their names publicly exposed. But the more people come out to defend their rights, the more outspoken the HIV-positive community and the better the chance for a permanent solution to this issue." ■

Shawn Dougherty is assistant editor of the *Journal*. His original report on Acción Solidaria appeared in the May 1997 issue.

*Until Action of Solidarity's application for tax-exempt status is approved, donations that are tax-deductible in the United States may be made to the organization through Health Crisis Network in Miami. Contact Marc Lichtman at (305) 751-7775.

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. form	re: Letter tracking (Personal) [partial] (1 page)	11/06/1997	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19406

FOLDER TITLE:

Correspondence - SI.T - Incoming - 11/97

2018-0764-F

jm2055

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10296	(b)(6)		11/6/97
Addressed To			
Thurman, Sandra			
Sender's Organization			
Sender's Street1			
Sender's Street2			
Sender's City	Sender's State	Sender's Zip	
Subject			
disability benefits help			
☒ Response Needed?	Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date
Notes			
What should we do?			

TAS referred matter to:
Susan H. Mather, MD
Asst Chief Medical Director
Environmental Medicine & Public Health
assistance & response?
on 11/20/97

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001b. letter	Concerned citizen to Sandra Thurman re: Wife with AIDS (Personal) [partial] (2 pages)	11/02/1997	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19406

FOLDER TITLE:

Correspondence - SLT - Incoming - 11/97

2018-0764-F

jm2055

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

11-2-97

Ms. Sandra L. Thurman
Director - National AIDS Policy Office
808 17th Street, 8th Floor
Washington, DC 20006

[0016]

Dear Ms. Thurman,

Please help, We don't know where else to turn, to find an advocate for our problem. My wife, (b)(6) has aids, and is being refused disability benefits from the Federal Veterans Administration.

(b)(6)

(b)(6) In the spring of 1995 Betty's health had gotten to the point where her energy only lasted for a few hours in the morning, per the advise of her doctor and counselor, Betty resigned from The V.A. hospital. The Director of Personnel knew of Betty's health condition before she resigned, and yet when she was processed out for her final check and balance of vacation and sick time, there was no mention of anything in regards to disability. About 2 years later when Betty did decide to file for disability, she was

informed that there was a one year window of opportunity in which she would have had to apply, or she was ineligible for benefits. As I stated, in the meeting that I attended with Betty, on her last day, there was not a word mentioned about any time restraints on disability benefits! Nor was there any in all of the paperwork that was issued that day. Isn't there some accountability somewhere? You may ask, why didn't Betty apply for disability right away? There are a couple of reasons, mentally she didn't want to admit that the disease had progressed to that point, and she thought that there were other people that were entitled, and when and if her health got to it, she could apply then!

We have sent numerous E-mails to the following individuals: Bill Clinton, Al Gore, Donna Shalala, Senator Russ Feingold, Senator Herb Kohl, Senator Ben Knighthorse, Senator Fred Thompson, Oprah Winfrey (Betty & I ended up on her show once, before we were married) and others that I can't remember. Some of these people even had regular snail mail sent to them. and some had phone calls made to them. The E-mails came back as form letters- even after sending as many as 4 replies, some said to include your mailing address

and we will write to get details- that was a year ago. It finally got to the point where the stress and frustration that was setting in wasn't worth what it was doing to Betty's health. It is very frustrating to have the government CLAIM that they want to help you (seat belts-tobacco wars, ADA, EPA, FDA, etc.) and when the time comes that you need one of their programs, excuses and loopholes are made. Betty isn't asking for anything that isn't due to her. God gave her more than enough to deal with already! It's ironic that those things and people you love the most are the most fragile and unsure!

(b)(6)

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10301	Charles W.	Mercer, MD	11/7/97

Addressed To

Thurman, Sandra

Sender's Organization

University of Tennessee Medical Center at Knoxville

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

invite to speak 1/98 in TN

☒ Response Needed?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

THE UNIVERSITY OF TENNESSEE
MEDICAL CENTER AT KNOXVILLE



- University Memorial Hospital
- Graduate School of Medicine

1924 Alcoa Highway
Knoxville, TN 37920-6999
(423) 544-9000

October 24, 1997

Sandra L. Thurman, Director
Office of National AIDS Policy
808 17th St. N.W.
Suite 820
Washington, D.C. 20006

Dear Ms. Thurman:

In follow-up to my previous letter and conversations with your office, The University of Tennessee Medical Center at Knoxville would like to invite you to be the key note speaker at the second annual AIDS Conference at the hospital in January. The following dates of January 20, 23, 26, 27 are available in our facility. The planning committee is anxious to work with your office to secure a mutually agreeable date.

As I mentioned in my last letter, The Medical Center administers the Tom Weaver AIDS Education Fund and last fall we sponsored a full day conference on all care aspects of HIV/AIDS. By the terms of the fund, it must be used for health care and caregiver education. This year we plan to invite doctors, residents, interns, as well as, nurses. We are especially interested in knowing the thrust of the Clinton Administration and the Office of National AIDS Policy. We are anxious to expand our knowledge in understanding the long range national goals and what is being done to implement them.

Pamela Michelson, RN, Assistant Director, of our Nursing Education Department is coordinating the specifics of this conference. Please contact her office if you require additional information related to the conference plans (423-544-9813).

I am enclosing information on the Tom Weaver Fund, as well as, The University of Tennessee Medical Center at Knoxville. I hope to have a favorable response from you at your earliest convenience.

Thank you.

Sincerely Yours,

A handwritten signature in cursive script that reads 'Charles W. Mercer'.

Charles W. Mercer, M.D.
Executive Vice Chancellor
Associate Professor, Medicine
The University of Tennessee Medical Center at Knoxville

Administrative Provisions
For the Establishment of

THE THOMAS J. WEAVER AIDS EDUCATION
ENDOWMENT AND GIFT FUND

at

The University of Tennessee Medical Center at Knoxville

The Thomas J. Weaver AIDS Education Endowment Fund has been established at The University of Tennessee Medical Center at Knoxville by friends, colleagues, students, and family of the late Thomas J. Weaver. This endowment will fund AIDS education programs at the University Medical Center and serve as a perpetual memorial honoring Tom for his many years of dedicated service to the University of Tennessee. The Endowment will provide ongoing education for nurses, residents, dentists, physicians, and other health care professionals and health care students associated with the University Medical Center.

Annual income from the endowment will support the Tom Weaver AIDS Gift Fund. Listed below are the types of expenditures which may be made from the fund:

1. Primary use of the fund shall be to cover travel, lodging, honoraria, and other appropriate costs in conjunction with an annual AIDS education program.
2. For other purposes in furtherance of the Medical Center's objectives of excellence in patient care, education, and research related to AIDS consistent with University policy.

The Chief Executive Officer of The University of Tennessee Medical Center at Knoxville will serve as Principal Investigator and appoint an annual Program Chairman. A Selection Committee (consisting of the Associate Administrator of Nursing, the Director of Pastoral Care and a representative of the Dean of the Graduate School of Medicine) will recommend speakers, materials and an appropriate format for the Thomas J. Weaver AIDS Education Program and also advise the Program Chairman of other appropriate expenditures. The Assistant Vice Chancellor for Development and Alumni Relations at the University Medical Center will serve as Responsible Person. All expenditures must be processed through customary University channels.

At the discretion of the University up to one-third of the annual income may be added to the principal to enhance the continued growth of the endowed fund. The actual portion of income to be reinvested will be determined annually in accordance with University policies in effect at that time.

Additional monies, securities, or other assets, if accepted by The University of Tennessee, shall become subject to all the covenants, terms and conditions of the Agreement.

If at any time in the future the need does not exist for this fund as stated in the Administrative Provisions of this Agreement or should this Agreement conflict with any federal, state, or local laws, statutes, regulations, or ordinances, the governing body of The University of Tennessee shall have the authority to select an appropriate educational use for this fund that closely approximates the original intent of the donors.

11/23/93

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10309	Larry	Biddle	11/12/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
Planning Works				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
thanks and 4/24/98 invite				
☒ Response Needed?		Response Type	Response Date	Responder ID
		rsvp		
Responder Name	Action Promised	Action Complet	Action Date	
Notes				

Planning Works

November 10, 1997

White House Office of National AIDS Policy
Ms. Sandra L. Thurman
Assistant to the President for National AIDS Policy
808 17th Street NW 8th Floor
Washington, DC 20006

Dear Sandy:

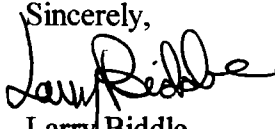
It was good to see you at the NEAC Board meeting last month. As I mentioned to you then, I am eager for you to attend our 1998 National AIDS Fundraising Conference. I believe it would be enjoyable, informative and inspiring to have you speak at the Conference's first event. This is our opening breakfast at 8 a.m. on April 24th.

The conference takes place from April 23 - 25, 1998. The 1998 conference theme is "Adapting to the Changing Face of AIDS." I would like you to set the stage by telling us (in a presentation of approximately 15 minutes) where we are as a nation regarding HIV disease -- especially from the White House perspective. Having led a local AIDS service organization, you understand that future funding issues will be of special interest for this audience.

Last year, we had almost 250 people attending -- both staff and volunteers -- from local AIDS service organizations located in 37 states and Canada. Now in its sixth year, the National AIDS Fundraising Conference is the largest gathering of staff and volunteers committed to increasing the resources needed to serve men, women and children living with HIV disease.

I hope you can attend. I know the conferees would benefit from your presence. We are planning to honor Tim Gil of the Gil Foundation (CEO of Quark) at the awards dinner. If you can also attend the awards dinner, that would be wonderful.

Thank you for your good works and leadership.

Sincerely,

Larry Biddle
Co-Director, National AIDS Fundraising Conference

DC
1925 K Street NW, Suite 220
Washington, DC 20006
1.202.887.1944 (phone)
1.202.872.1511 (fax)

PHILADELPHIA
417 North 15th Street, Suite 402
Philadelphia, PA 19102
1.215.496.8001 (phone)
1.215.405.0076 (fax)

PHILADELPHIA
planwrks@aol.com (e-mail)

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10312	Ginny	Apuzzo	11/13/97

Addressed To

Thurman, Sandra

Sender's Organization

White House

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

thanks for use of OEOB office

☐ Response Needed?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

THE WHITE HOUSE

WASHINGTON

November 12, 1997

Sandy,

I truly appreciate your generosity in providing your OEOB office for two weeks for a special White House project. It is refreshing to encounter such a hospitable disposition as yours, but then I am from New York!

Keep up the great work in the fight against AIDS!
Please do not hesitate to contact me if I can be of assistance in anyway. Thanks again for your help.

Many thanks!
Jimmy Carter

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10314	Esther	Walter	11/13/97

Addressed To

Thurman, Sandra

Sender's Organization

National Episcopal AIDS Coalition

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

invite to Miami 1/16-18/98

☐ Response Needed?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

**National Episcopal AIDS Coalition
January Meeting**

November 10, 1997

From: Esther Walter

The Executive Committee has reviewed plane fares and other expenses and determined that **Miami** is the most cost efficient location for the January Board meeting. We will consider Birmingham and San Francisco for our other meeting sites for 1998, and hope to confirm those plans before the January meeting. Houston had too many logistical problems to consider at this time.

The meeting in Miami will be at the Days Inn Civic Center, and the adjacent hospital where Carlos has his office. Details about housing, local travel, etc. will follow. It will be held on **Friday, January 16 through Sunday noon, January 18, 1998.**

In order to ensure the lowest possible cost, the Executive Committee has determined that all Board members must book their travel no later than December 15, 1997. If you wait until after that date to book your flight and the fares have risen, NEAC will pay only that part of your fare that would have been in force on December 15.

You can book your flight with Research Travel, 1-800-446-4200. They will bill NEAC directly for your ticket. If, after checking with them, you can get a better rate locally, please do so, but let me know so that the Treasurer can plan expenses.

If your plans will not permit you to attend this meeting, please let me know as soon as possible.

Esther Walter
1650 Mar Ella Trail
Des Moines IA 50310-3820

515-279-2936
ewalter@ecity.net

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10315	Ronnie	Mealy	11/13/97

Addressed To

Thurman, Sandra

Sender's Organization

Carl Vogel Center

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

invite to speak 4/24/98 night

☒ Response Needed?

Response Type

rsvp

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes



CARL VOGEL CENTER

HIV/AIDS Nutrition & Treatment Information

1012 14th Street, N.W. Suite 707, Washington, DC 20005

Phone: 202/638-0750

Fax: 202/638-0749

November 6, 1997

Ms. Sandra Thurman
Director
The White House Office of National AIDS Policy
808 Seventeenth Street, NW
Suite 820
Washington, DC 20006

Dear Ms. Thurman:

It was a great pleasure to meet you at the United States Conference on AIDS in Miami. Unfortunately I was unable to attend the reception held in your honor at the conference. However, after speaking with you, I know that I am not alone in believing that your appointment as Director of the White House Office of National AIDS Policy is a positive step in dealing with an epidemic whose face is ever-changing.

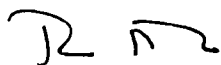
For this reason, the Carl Vogel Center, a non-profit HIV/AIDS nutrition and treatment information organization, is requesting the honor of your presence as Keynote Speaker at our Spring Gala Fundraiser on the evening of Friday, April 24, 1998. We would like you to speak on the Administration's plan for safeguarding funding of HIV/AIDS programs against possible reductions by Congress or a future administration.

In addition to Keynote Speaker, we would be honored to have you serve as Honorary Co-Chair of the event. The Chair will be shared with Miss Katherine Shindle, Miss America 1998.

The Gala, which will be held on the *Odyssey*, a boat on the Potomac River, will support our efforts to provide potentially life-saving information and support services for uninsured and underinsured people living with HIV and AIDS in the D.C. metropolitan area. The *Odyssey* boards at 7:00 p.m. and cruises from 8:00 until 11:00.

We would be most pleased to have you as the Keynote Speaker and Honorary Co-Chair of this event. We thank you in advance for your consideration and hope for a positive answer to our request.

Yours sincerely,



Ronnie M. Mealy
Executive Director

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10316	Verna W.	Hensley	11/13/97

Addressed To

Thurman, Sandra

Sender's Organization

Office of Senator William V. Roth, Jr.

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

thanks & informal invite

☐ Response Needed?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

United States Senate

WASHINGTON, DC 20510

November 7, 1997

Ms. Sandra Thurman
Director
Office of National AIDS Policy
The White House
Washington, D.C. 20500

Dear Sandra,

First, I want to thank you again on behalf of Senator Roth for taking the time from your busy schedule to come to Delaware to speak at the HIV Consortium conference on AIDS. I know the Consortium was absolutely thrilled to have you as their featured speaker and feel your contribution was essential to the overall success of the two-day conference.

Secondly, I wanted to follow up with you to give you an official invitation to come back to Delaware and enjoy many of our beautiful and historically significant sites. I have taken the liberty of sending you several brochures on some of our more interesting attractions. A few of our notable sites actually are located just across the line in Pennsylvania, but we claim them for our own. I'm sure you will find several activities that could fill a day, a weekend or even longer! I would recommend you consider the Brandywine River Museum, Winterthur and Longwood Gardens. Also, the tiny town of New Castle is delightful to visit and is still "undiscovered" for the most part.

As far as accommodations, it's hard to top the Hotel DuPont, as I think you know. However, there is also a Sheraton and Marriott Courtyard which are both very nice. I would be happy to follow up with additional information when you have an opportunity to plan a trip. Christmas at Longwood Gardens is beautiful, but so is Spring.

I enjoyed the opportunity to meet you and hope you will let me know if you decide to visit.

Sincerely,



Verna W. Hensley
New Castle County Director
Office of Senator William V. Roth, Jr.

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10330	Christopher	Krejci	11/17/97

Addressed To

Thurman, Sandra

Sender's Organization

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

public inquiry

☒ Response Needed?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

11/11/97

Director Sandy Thurman
Office of National Aids Policy
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Director Thurman:

I have a few questions to ask of you, if you have the time to respond I would be most grateful.

As we move into the next millennium, what we must we do to prevent the spread of AIDS?

What are your goals for this office as we finish out this century?

How long do you think it will be till a cure is found?

The last thing I would like to ask, could you send me a biography on yourself?

Thank you very much for your time, I look forward to hearing from you.

Sincerely,



Christopher Krejci
14907 Straub Hill Lane
Chesterfield, Missouri 63017

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10331	Bob	Tracy	11/18/97
Addressed To			
Thurman, Sandra			
Sender's Organization			
Minnesota AIDS Project			
Sender's Street1			
Sender's Street2			
Sender's City	Sender's State	Sender's Zip	
Subject			
invite to MN, 2/5/98			
☒ Response Needed?		Response Type	Response Date
Responder Name	Action Promised	Action Complet	Action Date
Notes			



November 10, 1997

Minnesota AIDS Project

Ms. Sandy Thurman
Office of National AIDS Policy
808 17th Street NW
Washington, D.C. 20006

Re: Request for Appearance
February 5, 1998 - AIDS Action Day at the Minnesota State Capitol

Dear Ms. Thurman:

The Minnesota AIDS Project requests you to consider scheduling a visit to Minnesota to be part of AIDS Action Day at the State Capitol on Thursday, February 5, 1998. This will be MAP's fourth annual AIDS lobby day at the State Capitol in Saint Paul. In addition to attracting 200 citizen advocates to engage in face-to-face meetings with legislators, we expect this lobby day will also feature a joint House/Senate health committees hearing on the impact of recent research and new treatments on HIV care, services, prevention and fair treatment of people affected by HIV. We are particularly interested in arranging for you to provide the lead testimony for this unprecedented hearing.

We are trying to pull together several complicated scheduling situations. We request at this time to learn of your interest and potential availability to be in Minnesota on February 5.

The one thing that is fixed at this point is the date for AIDS Action day. We are working on finalizing plans for the joint hearing. The chair of the Senate Health and Family Security Committee has verbally agreed to call a hearing, though we are working on finalizing matters with his staff. An unknown at this time is whether the chair of the House Health and Human Services Committee will agree to the joint hearing proposal. We have made the request and are fairly confident that we will get a positive response, particularly since the chair of that committee's budget subcommittee has agreed to support the request.

We requested the hearing for several reasons. First, as you are well aware, HIV prevention and treatment have changed dramatically within the past 18 months. Our experience at the Capitol suggests that far too many decision-makers seem to feel they learned all there is about HIV in 1988, which was the last time either legislative body attempted to look at the issue outside of the context of a particular legislative initiative. Second, the hearing presents an opportunity to again draw public attention to the impact of new research and treatments, but to do so in a way that counters the "AIDS is over" soundbites. Finally, we have trained a solid core of citizen advocates who know how to handle face-to-face meetings with legislators. By scheduling a hearing as part of this year's lobby day, we plan to introduce them to another important part of the legislative process.

Ms. Sandy Thurman
November 10, 1998
Page Two

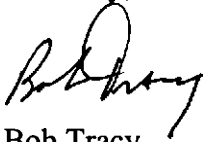
We propose that the hearing feature the following:

- o "Keynote" testimony from you representing the Office of National AIDS Policy.
- o A panel of four of Minnesota's prominent HIV physicians to report on significant new research and treatment developments, and to discuss their implications for HIV prevention, care and fair treatment of people affected by HIV.
- o Presentation of the Minnesota AIDS Project's 1998 State of AIDS Report by MAP's Executive Director, Lorraine Teel.
- o Written testimony from the Minnesota HIV Services Planning Council, the HIV/STD Prevention Task Force, and Minnesota HIV Housing Coalition.

We are prepared to support your visit through effective media relations, coordination of visits with other government and community groups involved with HIV care and prevention, introductions to representatives of groups you may want to communicate with during your visit, and financial assistance with travel.

I look forward to speaking with you or a representative of your staff in response to any questions you might have about AIDS Action Day at the State Capitol and your potential involvement. I can be reached at 612-373-2459.

Sincerely,

A handwritten signature in black ink, appearing to read "Bob Tracy", with a stylized, cursive script.

Bob Tracy
Public Policy Director

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10308	Jim	Martin	11/12/97
Addressed To			
Thurman, Sandra			
Sender's Organization			
House of Representatives			
Sender's Street1			
Sender's Street2			
Sender's City	Sender's State	Sender's Zip	
Subject			
Keep up the good work!			
☐ Response Needed?	Response Type	Response Date	Responder ID
	no response needed		
Responder Name	Action Promised	Action Complet	Action Date
Notes			

Dear Jim,

Thanks so much for
sending ~~me~~ the article from
the Chicago Tribune to me.

It makes me feel so old
when my godchildren and
Friends Children are ~~sending~~
@ reading articles and sending
them us. Weren't they just
reading Dr. Seuss?

Hope to see you soon.

Best Regards, Sandy



House of Representatives

JIM MARTIN
REPRESENTATIVE, DISTRICT 47
44 BROAD STREET, N.W., SUITE 500
ATLANTA, GEORGIA 30303
(404) 522-0400 (O)
(404) 657-8277 (FAX)

STATE CAPITOL, ROOM 132
ATLANTA, GEORGIA 30334
(404) 656-5125

STANDING
COMMITTEES:

APPROPRIATIONS
INDUSTRIAL RELATIONS
ETHICS
JUDICIARY, CHAIRMAN

October 31, 1997

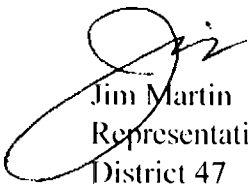
Ms. Sandy Thurman, Director
White House National Aids Policy
808 Seventeen Street, NW
Washington, D. C. 20500

Dear Sandy:

I am glad to be able to say that I knew you before you became famous. My daughter, Morgan, who works in Chicago sent me the enclosed article that appeared in the Chicago Tribune.

Keep up the good work!!

Sincerely,


Jim Martin
Representative
District 47

jm:cm

Enclosure

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10339	Keith	Cherry	11/24/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
Delaware HIV Consortium				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
thank you				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date	
Notes				

DELAWARE
HIV
CONSORTIUM

Dear Sandy:

Thank you so much for coming to Delaware for our annual conference. Your participation went far to increase public awareness about HIV in our state. I appreciate your flexibility in meeting with reporters, DuPont March, and presenting a keynote all in one morning. Folks here are still talking about how great they think you are. Again, thanks and I hope to see you again soon.

all the best,
Keith Cherry

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10337	Sophia	Chang	11/24/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
Kaiser Family Foundation				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
thanks/info for 1/98 forum				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date	
Notes				



SOPHIA W. CHANG, M.D., M.P.H.
DIRECTOR, HIV/AIDS PROGRAMS

November 20, 1997

Sandra A. Thurman
Director
White House Office of National AIDS Policy
808 17th Street, NW 8th Floor
Washington D.C. 20006

Dear Ms. Thurman:

Sandy

Thank you for agreeing to attend the Kaiser Family Foundation Forum on Understanding the Impact of New Treatments on HIV Testing to be held on January 28-30, 1998. We very much look forward to your participation.

Attached please find a copy of the draft agenda, with the inclusion of all participants who have confirmed their attendance. The agenda is in definite flux and more names are pending. As you see, you are being asked to participate by providing some introductory words/thoughts in the importance of HIV testing in our current era of more effective therapies. I will be happy to discuss any specifics with you as the date of the forum approaches. At any time prior to the Forum, please feel free to contact me at (650) 854-9400, or Tim Westmoreland, our Senior Advisor on HIV Programs, at (202) 662-9595.

Enclosed please also find a FAX-back form to make your appropriate travel arrangements. The contact person is Sue at Hunter Travel, she can be reached at (650) 328-6133. Hotel arrangements should be made through Martha Blandon, here at the Foundation, at (650) 854-9400.

Again, we look forward to facilitating a worthwhile discussion on the goals of HIV testing. I very much look forward to seeing you in January and thank you in advance for taking the time to participate.

Sincerely,

Sophia W. Chang
Sophia W. Chang, MD, MPH

SWC:mb
Enclosures

*Hope you had a wonderful Africa trip.
Looking forward to hearing about your successful World AIDS Day events!
Talk with you soon...*

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10338	B.J.	Stiles	11/24/97
Addressed To			
Thurman, Sandra			
Sender's Organization			
National AIDS Fund			
Sender's Street1			
Sender's Street2			
Sender's City	Sender's State	Sender's Zip	
Subject			
hello/suggested SLT letter			
☐ Response Needed?	Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date
Notes			

November 21, 1997

Sandy Thurman
Office of National AIDS Policy
808 17th Street NW, #Ste. 820
Washington, DC 20006

Dear Sandy:

Welcome home. I'm eager to hear about Africa. Perhaps we can "do lunch" after I return from Lima, which is December 6th.

We missed you at the several Board functions which Enoch so graciously hosted. We did entertain Kate Shindle, who impresses me more and more each time I hear her.

I'm enclosed suggested letter from you to John Creedon,

I enjoyed substituting for you/Todd Summers at the EAP conference in Baltimore. The event felt like "old home week," since there were so many presenters who've been allies in the epidemic for over a decade.

Hope you're recovering from jet lag.

Cordially,



B.J. Stiles
President & CEO

Draft

John J. Creedon
Retired President & CEO
MetLife Insurance Company
200 Park Avenue, Suite 5700
New York, NY 10166

Dear Mr. Creedon:

I'm sorry that my trip to Africa displaced my plans to attend the luncheon hosted by Enoch and NationsBank which honored you as this year's recipient of the Edward N. Brandt, Jr. Award. I hear that this was a splendid occasion, and that Ed himself was able to be in Washington for the occasion.

Your many contributions in response to the complex challenges associated with HIV/AIDS have provided benchmarking standards for other corporate leaders. I recall with special appreciation the first-ever nationwide TV program on AIDS, which your company sponsored, not only because it contained very important information but because you demonstrated the powerful message that AIDS was and is a challenge which requires corporate leadership.

That you've provided such splendid leadership as a Trustee of the National AIDS Fund also stands as a model of volunteer commitments in support of one of the nation's most respected and successful national AIDS groups. On behalf of President and Mrs. Clinton, I want to extend our thanks and appreciation for all that you've done to help reduce the incidence and impact of HIV/AIDS.

Sincerely,

Sandra Thurman

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10340	Tracy	Fischman	11/25/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
Cook County HIV Primary Care Center				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
thanks				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date	
Notes				



Cook County Hospital

1835 W. Harrison St., Chicago, Illinois 60612-9985, Telephone 312/633-6000

Cook County HIV Primary Care Center

1900 W. Polk St. Rm. 1239 • Chicago, IL 60612 • ph: 312-633-5081 • fax: 312-633-3002 • E-mail: TFisch7@aol.com

Ms. Sandy Thurman, Director
Office of National AIDS Policy
808 17th Street, NW
Washington, D.C. 20503

November 13, 1997

Dear Ms. Thurman,

I just wanted to drop you a note to thank you and express my appreciation for your hard work on behalf of people with HIV/AIDS -- I know at times it must be quite a challenge. I enjoyed meeting with you during your recent trip to Chicago -- I am happy to know that my good friend Mark is so influential that you did not think twice about missing the AFC Annual meeting. I hope you enjoyed your visit to our fare city -- while it's not as large as Los Angeles (a place I lived before moving to Chicago), I hear you got to experience its vastness and magnitude throughout the couple of days you were in town.

During our brief discussion at the Planning Council's Steering Committee meeting, as well as during our CAEAR Coalition meeting with you last September, you reiterated many of the concerns I and many others are feeling about the future of the health care delivery system for people with HIV/AIDS. This includes such things as future funding for and Reauthorization of the CARE Act; general funding beyond primary medical care and ADAP; the improbability of Medicaid expansion due to its lack of budget neutrality; the increasing trends towards Medicaid/Managed Care; etc. To top this all off, the "us vs. them" mentality with other diseases, as well as the media hype/discourse that indicates the end of HIV as we know it, makes our jobs extremely challenging and trying (I'm sure you saw the recent article in the New York Times about the "special treatment" of HIV -- I've enclosed a copy just in case). All of these issues define the challenges which lie ahead, and I hope we can work closely with you to strategically and effectively prepare for them within our current political and social climate.

While much of what we discussed with you was both daunting and distressing, I was pleased to hear that you are taking a strong stand against mandatory name reporting for all of the right reasons (at least until "you are convinced otherwise"). I am quite sure you discussed this issue in depth with Mark, for we, like many others, have been preparing to deal with it both locally and nationally.

The importance of your support and leadership within the Administration cannot be overstated. Since I'm writing you this thank-you note, I would also like to take the time to briefly tell you about the Cook County HIV Primary Care Center. As you might know, the HIV Center is the largest provider of HIV/AIDS services in the Midwest. Our patient load is reflective of the epidemic across the country -- populations that have traditionally lacked access to health care services, such as poor people of color, women, children and adolescents -- all of whom require a full range of services beyond primary medical care, such as housing, case management, child care, mental health counseling and treatment, substance abuse treatment, nutritional services, etc.

We strive to address these myriad issues to ensure our patients receive all of the services they need. We are a "one-stop shopping" model program that successfully, creatively and efficiently utilizes all of its available resources. We are especially excited about the opening of our new facility in the Spring of 1998 called the CORE Center. The CORE Center will become the nation's first free-standing, specialized out-patient clinic for people with HIV/AIDS and related infectious diseases. CORE is a unique collaborative between Cook County, the state's only public hospital, and Rush-Presbyterian-St. Luke's Medical Center, Illinois' largest private hospital. The Center will offer an array of ambulatory services which will allow patients to receive medical procedures that presently require costly inpatient hospital stays. The Center also will provide access to the clinical research trials, prevention and psychosocial support services which we have successfully provided throughout the years. In addition, it will be a resource and referral center for specialized care for people who are receiving their primary health care services elsewhere in the community.

As we strive to put an end to the HIV/AIDS epidemic that is devastating far too many of our communities, we feel extremely fortunate to have your support, and we look forward to working closely with you to promote positive, constructive public health and social policy. I hope you will call on me at any time -- I certainly know I'll be calling on you! You can reach me at 312-633-5081/312-495-2960 (pager). I look forward to working with you in the future, and hope to see you again soon -- perhaps when I'm in D.C. for a CAEAR Coalition meeting or AIDSWatch. Thank you again, and stay strong!

Sincerely,

A handwritten signature in black ink that reads "Tracy Fischman". The signature is written in a cursive, flowing style.

Tracy Fischman

Public Health Administrator of Policy, Planning and Public Affairs

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10341	Joseph A.	McCormack	11/25/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
McCormack & Associates				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
thanks re: Ashok				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date	
Notes				

MCCORMACK & ASSOCIATES

• EXECUTIVE SEARCH CONSULTANTS •

November 12, 1997

Sandra Thurman
Directors Office of National AIDS Policy
750 17th Street, NW, Suite 600
Washington, DC 20503

Dear Sandy,

It was a pleasure to meet you at last, and I sincerely appreciate your warm reception and kindness to Ashok. Since you have been to India, you can appreciate the magnitude of the challenges he faces in Bombay.

We have been busy lining up appointments with as many funders as we can, and I expect Ashok will have a busy week here in Los Angeles. Unfortunately, not everyone has a strong interest in the international dimension of the HIV epidemic.

Please keep Ashok and the Humsafar Trust in mind when you talk to others about AIDS prevention and treatment in Asia. Thanks so much for your encouragement.

Sincerely yours,



Joseph A. McCormack

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10342	Alan F.	Holmer	11/25/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
Pharmaceutical Research and Manufacturers of America				
Sender's Street1				
Sender's Street2				
Sender's City	Sender's State	Sender's Zip		
Subject				
newsletter				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name	Action Promised	Action Complet	Action Date	
Notes				

Alan F. Holmer
PRESIDENT



November 19, 1997

Ms. Sandra L. Thurman
Director, National AIDS Policy
Office of National AIDS Policy
750 17th Street, N.W.
Washington, D.C. 20503

Dear Ms. Thurman:

Enclosed is a copy of our 1997 report on *New Medicines in Development for AIDS*. The report shows the research-based pharmaceutical industry is continuing its commitment to finding better treatments and hopefully a cure for the hundreds of thousands Americans suffering from AIDS and AIDS-related conditions. The 124 medicines, vaccines, and gene therapies in development by 84 companies and the 50 medicines already approved for HIV infection and related conditions reflect that commitment.

Considering that the AIDS virus was identified only 14 years ago, the progress already made against the AIDS virus is a remarkable achievement. According to the Centers for Disease Control, AIDS deaths dropped 26 percent in 1996 and new cases of reported AIDS dropped for the first time in 16 years. But, despite this good news, the disease is still a major killer in the United States.

Pharmaceutical companies are building on the knowledge gained during the past decade and are intensifying the search for more effective treatments, a cure and a preventive vaccine for AIDS. I hope you will share this report with your colleagues; please do not hesitate to call if I can provide you with further information.

Sincerely,

A handwritten signature in black ink that reads "Alan Holmer". The signature is fluid and cursive, with the first and last names being clearly legible.

Alan F. Holmer

Enclosure

Pharmaceutical Research and Manufacturers of America

1100 Fifteenth Street, NW, Washington, DC 20005 • Tel: 202-835-3420 • FAX: 202-835-3429

November 14, 1997

TO: Sandy Thurman

FROM: Helen Miramontes

RE: Participants for Preliminary Meeting on PACHA's Vaccine Report/Recommendations

This is a follow up memo of our discussion this week on the tentative meeting with DHHS representatives and representatives from outside the Federal government to discuss PACHA's vaccine report and recommendations from the December meeting. Per our discussion we will limit the meeting participants to approximately 20 people:

External:

- 1) Don Francis - Vaxigen
- 2) Don Burke - John Hopkins
- 3) Pasteur - Stanley Plotkin
- 4) Seth Berkely - IAVI
- 5) Mary Lou Clements-Mann - John Hopkins
- 6) Bob Belshe - St. Louis University
- 7) Cathy Wilfert - Duke (or her husband Sam Katz - but she is the one that has been working on AIDS)
- 8) Jerald Sadoff - Merck
- 9) Max Essex - Harvard

Internal:

- 1) DOD - Deborah Birx
- 2) FDA - Karen Goldenthal
- 3) CDC -
- 4) NIH -

ONAP:

- 1) Sandra Thurman

PACHA:

- 1) Helen Miramontes
- 2) Daniel Montoya
- 3) Alexandra Levine ?
- 4) Scott Hitt ?

n:\vaccine meeting
11/14/97

TOTAL P.01

PLEASE TYPE THE INSCRIPTION LINE OF THIS FORM

TO: STEPHEN NOLET, RM 94, EXT. 67610

fax 62461

From: _____ Room: _____ Ext. _____ Date _____

Photo is attached ☒ or choose from: The President _____
First Lady _____ First Couple _____Is a lithograph, less expensive photo, okay for this request?
Yes _____ No ☒To be signed by: President ☒ First Lady ☒Return to originating office ☒
Mail (MUST ATTACH TYPED MAILING LABEL) _____For records purposes, please provide the name and address of who
this photo is to be inscribed to:Name MR and MRS Thomas Stillitano
Organization _____
Address 9504 Lynnhell Place
City/State/Zip Alexandria VA 22309Inscribe to: (PLEASE TYPE) Photos ARE INSCRIBED Ready for SIGNATURE
Message: Best Wishes _____ With Appreciation _____ Congratulations _____

THE WHITE HOUSE
WASHINGTON

November 12, 1997

Sandy,

I truly appreciate your generosity in providing your OEOB office for two weeks for a special White House project. It is refreshing to encounter such a hospitable disposition as yours, but then I am from New York!

Keep up the great work in the fight against AIDS!
Please do not hesitate to contact me if I can be of assistance in anyway. Thanks again for your help.

*Many thanks!
Jimmy Carter*