

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: 19394

FolderID:

Folder Title:

Correspondence - SLT - Incoming - 8/97 [4]

Stack:

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Row:

66

Section:

6

Shelf:

6

Position:

2

Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. letter	Individual living with AIDS to Supervisors re: HIV Planning Commission (Personal) [partial] (2 pages)	08/01/1997	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19394

FOLDER TITLE:

Correspondence - SLT - Incoming - 8/97 [4]

2018-0764-F

jm2052

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]

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G 3940

Date Rcvd: 8-25-97

From: Saundra C. Gilbert to President

Via Sue J. Smith from W/House

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

To Support Staff: _____

Date of Response: 9/3/97

n:\corresli

Charles Muller
Social Security Administration
Office of Public Enquiries
5401 Security Blvd.
4100 Annex Bldg.
Baltimore, MD 21235-

Fax: 410-966-6166
P: 410-965-1720

THE WHITE HOUSE
WASHINGTON

SEP 3 - 1997

Ms. Sandra C. Gilbert
2807 32nd Street, S.E.
Washington, DC 20020

Dear Ms. Gilbert:

Your letter to President Clinton has been forwarded to this office for a reply. I am saddened to hear of the loss of your son to AIDS. I assure you that I am doing my best to increase public awareness of this epidemic, and to bring it to an end.

Since these issues you raised relate to the Social Security Administration, I am forwarding your letter by fax to: Mr. Charles Mullen, Office of Public Enquiries. He can also be reached at 410-965-1720.

Sincerely,

A handwritten signature in black ink, appearing to read "Sandra Thurman", written over the word "Sincerely,".

Sandra Thurman
Director
Office of National AIDS Policy

THE WHITE HOUSE
WASHINGTON

8. 22. 77
DATE

MEMORANDUM

FOR:

ON A PC

FROM:

SUE J. SMITH *SP*
DIRECTOR, AGENCY LIAISON

SUBJECT:

REFERRAL OF CASEWORK

I am forwarding the attached letter to your office for appropriate action. Please send us a copy of your written response or your telephone report along with the writer's original correspondence and envelope to the following address:

Ms. Sue J. Smith
Director, Agency Liaison
Room 6, OEOB
The White House
Washington, D.C. 20502

If you have any questions, call my office at 202/456-7486.

Thank you for your help.

18/49/175 (OAAPE) MR
R. T. ~ AID FOR EDUCATION
August
AUG 1997

July 27, 1997

President William Clinton
1600 Pennsylvania Ave. N.W.
Washington, DC 20500

Dear Mr. President:

I am Sandra C. Gilbert, a Mother/Grandmother, writing to you because I have had no success in finding a foundation that provides college grants/or scholarships for children whose parent's have died of Aids.

On October 19, 1994, my son Michael Jerome Gilbert, died of Aids leaving his daughter, Lauren, (at that time 14 years of age) for me to raise. Lauren is now a senior in high school and looking forward to attending college in fall of 1998. So far her dad's social security has helped to pay for part of her education. Because of Ronald Regan's Administrative law, she will no longer receive this money after she turns 18 on September 20, 1998. If all children could continue to receive this money during their college years, it would be of additional help.

Lauren attends Gerogetown Visitation Preparatory School being very active in the Black Women's Society, Dance Ensemble, Peer Ministry, Community services and Volleyball. At the same time, she is involved in her church Choir, Usher board and CYO organizations. She also had an opportunity to volunteer with the Children's Express Foundations, Inc. working on special projects pertaining to Violence (where she interviewed Senator Ted Kennedy) and traveled to several city shelters during 1995 Kids Count Project interviewing other teens about their lives which was published under Kids' Voices Count.

Lauren was also asked to appear on the National Public Radio to share her personal experiences of living with her single dad as well as being asked to sit on a special panel to discuss Teen Violence. At the present time, Lauren is interested in becoming a Veterinarian.

I have contacted several organizations (Ryan White Foundation, Aids Action Foundation, Whitman-Walker Clinic, Inc., National Association for People with Aids, Pediatric Aids Foundation, & Aids Education Foundation) to name a few with no success. Along with writing to you, I sent a letter to Elizabeth Taylor Aids Foundation, Magic Johnson, Darrell Green, and Oprah Winfrey.

Thanking you in advance for any assistance you can provide.

Sincerely,

Sandra C. Gilbert
Sandra C. Gilbert
Mother/Grandgrandmother

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

808 17th Street, N.W., Suite 820
Washington, DC 20006

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

FACSIMILE COVER SHEET

TO: *Charles Mullen*

FAX NUMBER: *410-966-6166*

FROM: *Sandra Thurman*

DATE: *9/3/97*

PAGES INCLUDING COVER SHEET: *3*

COMMENTS:

+ hard copy mailed 9/3/97

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G3931

Date Rcvd: 8-15-97

From: Mark Richard Yurkovich

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

no response needed (TS)

To Support Staff: _____

Date of Response: _____

n:\corresli

Sandra Thurman
Aids Csar
808 17 th Ste 820
Washington, D C N W 20006

1734 N Fuller AV # 208
Hollywood, CA 90046.3036

8.12.97

Dear Ms. Thurman,

RE: REQUEST FOR ASSISTANCE

Recently I had written to the LA County Board of Supervisors regarding the Manner in which Ryan White Title II and III monies are distributed in Los Angeles County and most disturbly the fact that the HIV INFECTION RATE IS INCREASING ABOVE THE NATIONAL AVERAGE in specific TARGET GROUPS including GAY MEN and WOMEN.

I would deeply appreciative and indebted to you is you could help me understand the reasons behind these hugh discrepancies in the HIV INFECTION rates in these groups.

Thank you so much.

Sincerely


MARK RICHARD YURKOVICH, MA

Encl.

Withdrawal/Redaction Marker

Clinton Library

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001. letter	Individual living with AIDS to Supervisors re: HIV Planning Commission (Personal) [partial] (2 pages)	08/01/1997	b(6)
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COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19394

FOLDER TITLE:

Correspondence - SLT - Incoming - 8/97 [4]

2018-0764-F

jm2052

RESTRICTION CODES

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

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

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purposes [(b)(7) of the FOIA]
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financial institutions [(b)(8) of the FOIA]
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concerning wells [(b)(9) of the FOIA]

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.

(b)(6)

[001]

Sup.

500 W. Temple St

RM

LA, CA 90012

8.1.92

Dear Supervisor

Re: revamping LA County's HIV
Planning Commission

I am a person affected By AIDS. would you
be willing To help revamp the way Federal
Ryan White Title II & III monies are distrib-
uted in LA County ?

Currently the Commission members
you helped appoint :

- vote for the Federal monies
for their own agencies and
organizations.

- Nationally, the HIV infection
rate is dropping for gay
men and women But
in LA County HIV infection
rates are increasing for these
groups in LA County.

- only ~ 45% of these Federal
funds is used for direct services to
HIV infected / AIDS individuals

Thank you for sincerely looking at this issue.

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10008	David A.	DuBois	8/18/97	
Sender's Organization				
Pride Institute				
Addressed To				
Thurman, Sandra				
Subject	Response Type		Response Date	Responder ID
request for meeting				
Responder Name	Action Promised	Action Complet	Action Date	
Notes				
no response needed - TS				



August 14, 1997

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

Dear Sandy:

I now know why my friend Bryan Freeman speaks so highly of you. Your speech to the National Lesbian and Gay Health Association was right on target. I was especially pleased that you mentioned "the other gay disease", chemical dependency. Your remarks regarding the correlation of HIV transmission and substance abuse were very appropriate.

Founded ten years and over 5,000 graduates ago, Pride Institute is the nation's only JCAHO accredited inpatient facility devoted exclusively to the treatment of alcohol and drug dependent lesbian, gay and bisexual persons. Approximately seventy percent of our patients have HIV/AIDS.

As I mentioned to you, Pride Institute would like to offer our assistance in any capacity you wish. I would like to accept your invitation to stop by your office and bring Pride Institute's President, Richard Kresch, MD, to meet you.

On behalf of my fellow NLGHA Board Members, thank you again for your speech in Atlanta. Please let me know a convenient date when we might stop by.

I remain

Sincerely yours,

A handwritten signature in black ink, appearing to read "David".

David A. DuBois
Chief Operating Officer

ONAP Letter Tracking

Letter ID: 10005 Writer First Name: David J. Writer Last Name: Mactas Received Date: 8/18/97

FILE COPY

Sender's Organization

Center for Substance Abuse Treatment

Addressed To

Thurman, Sandra

Subject

thank you

Response Type

NR

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

No response needed - TS

— August 14, 1997

Dear Sandy,

It was great getting the chance to spend some time together in your new digs. I hope you give me the opportunity to showcase the Center's programs and introduce you to some of our terrific staff.

All of us at CSAT are encouraged by your appointment, and invested in your success.

Thanks for your hospitality,
Sandy.

Best regards,
David



David J. Mactas
Director

SAHHA- CSAT
DEPARTMENT OF
HEALTH & HUMAN SERVICES
ROCKWALL II STE 615
Public Health Service
Substance Abuse and Mental Health Services Administration
Rockville MD 20857

Official Business
Penalty for Private Use \$300



PENALTY
FOR
PRIVATE
USE \$300
* *
PB METER
7250502



Ms. Sandy Thurman
Director
White House National AIDS Policy
808 17th Street - Suite 820
Washington, D.C. 20006

20006-3910 65



ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10014	Charles	Kaiser	8/18/97	
Sender's Organization				
Addressed To				
Thurman, Sandra				
Subject	Response Type		Response Date	Responder ID
forwarded from POTUS				
Responder Name	Action Promised	Action Complet	Action Date	
Notes				
no response needed TS				

THE WHITE HOUSE
WASHINGTON

DATE: August 15, 1997

NOTE FOR: Sandy Thurman

The President has reviewed the attached, and it is forwarded to you
for your:

Information ☒

Action ☐

Thank you.

Staff Secretary
(x6-2702)

cc:

Potus wants copy sent to
Sandy

Thurman

Gift Form Submitted

B

8-14-97

CHARLES KAISER
Apartment PHD
245 West 107th Street
NEW YORK CITY 10025
(212) 864-2457
Fax: (212) 864-1706
e-mail: cbrdgbk@interport.net

The President
The White House
Washington, D.C. 20502

August 12, 1997

Dear Mr. President,

Enclosed is a copy of the galley of The Gay Metropolis, 1940-1996, my history of gay life in New York City since 1940.

I believe my book is the first to give you the credit you deserve for doing so much to strengthen the gay movement in America (pages 330-339). As I write in Chapter 6, "It was Bill Clinton's success as a presidential candidate in 1992 which ratified a basic shift in American attitudes towards its gay citizens." (page 330)

One of the book's main characters is Tom Stoddard, who idolized you when you were together at Georgetown and who later became one of America's most thoughtful gay leaders (pages 248-253). The book ends with Stoddard's comments on the Supreme Court decision striking down the Colorado initiative. "I hope our people remember that this happened in part because a Democrat is holding the White House [and appointed two of the Justices who joined in the majority opinion]," Stoddard noted (pages 344-347).

The Gay Metropolis is a Book-of-the-Month Club selection and will be published in November by Houghton Mifflin.

My friendship with the Wexlers goes back a generation. In 1966, my uncle Jerry Kaiser worked with Anne Wexler to send anti-war delegates to the Democratic State Convention in Connecticut that year. He and Anne were also two of Gene McCarthy's earliest supporters. My uncle Jerry was my idol, and my role model.

I hope you enjoy The Gay Metropolis.

With Warm Good Wishes.

Sincerely,



P.S. The best gossip about one of your heroes appears on page 96.

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G3934

Date Rcvd: 8-19-97

From: Arthur Amburst

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

no response needed TS

To Support Staff: _____

Date of Response: _____

n:\corresli

ZINC

RELATING ENERGY TO CANCER AND HEALTH

Investigation of all aspects of Zinc metabolism is urgent in cancer research. The biochemical roles of Zinc determine not only the cause of cancer but also its major role in AIDS. Zinc is ubiquitous to the human body. Along with the synthesis of DNA and cell cycles, its role of energy is dominate in all trace elements.

Of the seven or eight grams of trace metals in the human body four are Iron and two are Zinc, just enough to fill a teaspoon. Of the 60 trillion cells in the average body, the element Zinc is their catalyst for energy and communication necessary for life's function, its controversial performance, however, is influenced by the technique of obtainment and loss. Zinc is the only universal element related to all carcinogens, such as: Tobacco and Nuclear Fallout.

Conducting a basic epidemiology research program for the last 38 years, the conclusion is simple: There is not one aspect of Zinc metabolism that is not directly related to cancer. Research conducted on subjects such as estrogens, hormone, t-cells, enzymes, taste buds, growth, heating, energy, human milk, semen, hydrochloric acid and all forms of human physical science, is conclusive.

Zinc provides living cells energy for the vital process of necessary activities, its mechanism however is related to all cancers.

HUMAN POWER PACK & CANCER
(treatise available)

Arthur Armbrust



*111 E. Illinois Street
Wheaton, IL 60187*

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date	
10013	Michael	Imbroscio	8/18/97	
Sender's Organization				
Associate Counsel to the President				
Addressed To				
Thurman, Sandra				
Subject	Response Type		Response Date	Responder ID
request for documents			8/25/97	
Responder Name	Action Promised		Action Complet	Action Date
Notes				
forward to SLT for signature -TS				

THE WHITE HOUSE
WASHINGTON

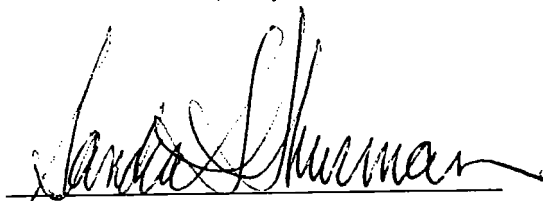
August 25, 1997

MEMORANDUM FOR: **MICHAEL IMBROSCIO**
Associate Counsel to the President

REGARDING: August 4, 1997 Request for Documents

This certification is in response to the memorandum from Charles F.C. Ruff, Counsel to the President, regarding the August 4, 1997 Document Request. By signing this document, I am certifying that I directed all individuals in my office to search their files as well as the office's files. To the best of my knowledge, these files have been reviewed and all responsive documents have been provided.

Office of National AIDS Policy:


Sandra L. Thurman
Director

THE WHITE HOUSE
WASHINGTON

August 18, 1997

MEMORANDUM FOR: SANDRA L. THURMAN

FROM: Michael Imbroscio
Associate Counsel to the President

REGARDING: August 4, 1997 Request for Documents

On August 4, 1997, Charles F.C. Ruff circulated to all Executive Office of the President staff a request for documents. The request sought a response by August 11, 1997. Please sign the attached certification as soon as possible so that we can establish that all appropriate files have been searched.

Thank you for your cooperation.

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G3933

Date Rcvd: 8-19-97

From: Laurence E. Suskind
MIT-Harvard Public Disputes Program

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

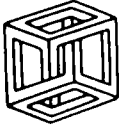
Recommendations/Instructions:

no response needed JD

To Support Staff: _____

Date of Response: _____

n:\corresli



THE PROGRAM ON NEGOTIATION

An Inter-University Consortium to Improve the Practice of Conflict Resolution

Harvard University • Massachusetts Institute of Technology • Tufts University

The MIT-Harvard Public Disputes Program

Professor Lawrence E. Susskind,
Director



Dispute Resolution Program

Professor Frank E. A. Sander and
Professor Michael Wheeler, Co-Directors

Harvard Negotiation Project

Professor Roger Fisher, Director

Harvard Negotiation Research Project

Professor Robert H. Mnookin, Director

Negotiation Roundtable

Professor James K. Sebenius, Director

The Project on Preventing War

William L. Ury, Director

Project on International Compliance and Dispute Settlement

Professor Abram J. Chayes and
Antonia Handler Chayes, Co-Directors

The Program on Negotiations in the Workplace

Professor Deborah M. Kolb and
Professor Joel Cutcher-Gershenfeld
Co-Directors

Project on the Psychological Processes of Negotiation

(Director to be named)

"Take the course. You'll use it again and again and again."

**Christopher Allen, Public Participation Coordinator, Pennsylvania
Department of Environmental Protection**

As a senior public official, how can you defuse public anger and restore confidence in your leadership when a crisis threatens your agency's ability to govern effectively? What specific steps can you take, whether you are dealing with:

- consumers who are dissatisfied because they think you lied or failed to treat them fairly;
- concerned interest groups who are attempting to block a license, rate increase or permit; or
- potential litigants who are seeking to assign liability or sue for damages?

At the MIT-Harvard Public Disputes Program, we have developed a powerful new negotiated approach to managing or avoiding public disputes that can turn potentially devastating threats into opportunities for gain for all parties. We would like to share it with you.

"As a public official, it is one of the most relevant and useful programs I've participated in."

Rick Staton, Chairman of Judiciary, West Virginia House of Delegates

Called "mutual gains," this innovative, proven approach will be the focus of a special executive program on "Dealing With an Angry Public," to be held in Cambridge November 13-14, 1997 and May 14-15, 1998. Please accept my personal invitation to attend.

I urge you to examine the enclosed prospectus, then to contact Elizabeth Walker, program coordinator, at 617-239-1111 (area code changes to "781" after 9/1/97) to confirm your participation.

Sincerely,

Lawrence E. Susskind
Director, MIT-Harvard Public Disputes Program

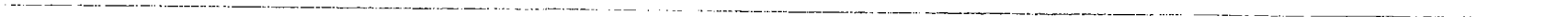
"Anyone who hopes to successfully navigate through controversial changes in public policy needs to understand and make use of the mutual gains approach."

Gloria Cousar, Deputy Assistant Secretary, U.S. Department of HUD

Ms. Elizabeth Walker
MIT-Harvard Public Disputes Program
Center for Management Research
55 William Street, Room 210
Wellesley, MA 02181-4094

]

IMPORTANT: Please Process Immediately. Registration Enclosed



Clinton Presidential Records Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

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

"This is a great seminar...These are techniques I will use daily."

The MIT-Harvard Public Disputes Program
Announces an Important Executive Briefing

Dealing With An Angry Public

*Protecting Your Reputation
and Your Market Share*

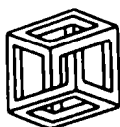


Strategies for Resolving Conflicts
& Disputes With Dissatisfied
Customers, Potential Litigants
And Concerned Interest Groups

In Cambridge, Massachusetts

November 13-14, 1997

May 14-15, 1998



A Project Of
THE PROGRAM ON NEGOTIATION AT HARVARD LAW SCHOOL
An Inter-University Consortium

Harvard University • Massachusetts Institute of Technology • Tufts University

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G 3939

Date Rcvd: 8-20-97

From: Edwin Celema

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

no response needed (CS)

To Support Staff: _____

Date of Response: _____

n:\corresli

As a member of the Democratic Party, and as a supporter of President Clinton, I am pleased that my party has taken the first step toward true campaign finance reform. The Democratic Party is now capping the amount an individual or corporation can contribute. But we need to go much further.

I challenge you, as a GOP leader, to do everything in your power to work with the Democratic Party toward real campaign finance reform. That includes pushing for passage of the bi-partisan McCain-Feingold Bill and agreeing to meet with Democratic Party leaders to reach a voluntary agreement that would end corporate contributions to both parties and place strict limits on the amount of money any individual can contribute.

We don't need more promises about campaign finance reform. We need both parties to act now to change the system for good.

Respectfully,

EDWIN COLEMAN

Mr. Edwin Coleman

STOP blocking the Democratic agenda for change. We need campaign finance reform, health care for children, expanded educational opportunity and a more secure retirement system.

STOP encouraging investigations with the sole purpose of embarrassing the President and Vice President. Let's get the truth, but do so in a fair and impartial way.

STOP the Republican agenda which will make abortion illegal, erode separation of Church and State and endanger our environment.

Sincerely,

EDWIN COLEMAN

Give Bill Clinton a Democratic House



Overall, how do you rate the 104th Congress?

☐ Excellent ☐ Good ☐ Fair ☒ Poor ☐ Undecided

What about Newt Gingrich's performance?

☐ Excellent ☐ Good ☐ Fair ☒ Poor ☐ Undecided

Do you think Newt Gingrich should remain as speaker?

☐ Yes ☒ No ☐ Undecided

/Gingrich agenda is extreme. As reflected in the intolerant language of their party platform adopted in August, Republicans want to pay for tax breaks by reducing spending on Medicaid, Medicare, and Social Security. They also want to cut spending on education and the environment.

In the world according to Newt Gingrich, political disagreement is the source of all evil. Here, for example, is what he had to say about the terrible Susan Smith murder case:

I think the mother killing her two children in South Carolina vividly reminds every American how sick the society is getting and how much we have to change. I think people want to change and the only way you get to change is to vote Republican.

Edwin W. Coleman
2215 Highland Dr.
Knoxville, Tenn. 37918



INSPEC
EX-1033
NEW
YEAR

Office of National AIDS Policy
(Executive Office of the President)
750 17th Street, NW #600
Washington, DC 20503

100-111111-111111

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G 3937

Date Rcvd: 8-20-97

From: Debra L. Peeney & Erin N. Barker
World Aids Day

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

no response needed TC

To Support Staff: _____

Date of Response: _____

n:\corresli



National Capital Area

August 12, 1997

Dear Friend
Office of National AIDS Policy
750 17th St., NW, Suite 600
Washington, DC 20503

Dear Dear Friend:

Every year on December 1, the world pauses for a moment to recognize the effect of AIDS. World AIDS Day was founded by The NAMES Project Foundation and The World Health Organization in order to educate the public to the impact of AIDS and to show the global scope of this pandemic. We want to help in your agency's recognition of this day, whose 1997 theme is **Children Living in a World with AIDS**. The most effective way to experience World AIDS Day is to display one or more 12' x 12' sections of the NAMES Project AIDS Memorial Quilt. The National Capital Area Chapter of the NAMES Project can help you secure sections of the Quilt for you agency's recognition of World AIDS Day.

The Quilt can reach into the human heart in ways that words often cannot. A quiet, dignified display provides both encounter and comfort to those who view it. We can help you with your display by providing up to four sections of the Quilt, literature about the Quilt, informational posters and suggestions for how to best display your section(s).

The cost for 1-4 sections of the Quilt, as well as the literature and posters, is \$200.00. This money helps to maintain the National Capital Area chapter of The NAMES Project as one of the most vibrant chapters in the United States. Our workshop and education center, located in downtown Washington DC, is open weekdays from 11:00 a.m. to 7:00 p.m. Visitors can drop in and receive everything from fabric to emotional support. Often times, panelmakers simply need someone to hear the story of their loved one in a caring and supportive atmosphere. We also host many outreach events, including discussions and presentations for students from middle schools, high schools, colleges and universities. Every year we answer the phone calls from thousands of people who call us for support, information and referral.

Our Center is an essential presence in the nation's Capital. By displaying one or more sections of the Quilt, you not only support our work, you also increase compassion for all those who are living and dying with AIDS as we work together to bring AIDS to an end.

World AIDS Day, 1997

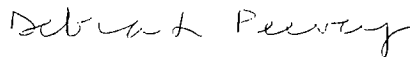
August 12, 1997

Page Two

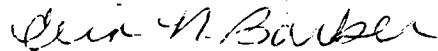
Enclosed is an article from the City Paper explaining the power of the Quilt as it was displayed in its entirety last Fall on the Mall. Also please find a response form and timetable to follow if you choose to request one or more sections of the Quilt.

We are poised to help you answer any questions you may have regarding your World AIDS Day display. We hope you will consider providing your organization with one or more sections of the Quilt as a means to bear witness to this global pandemic and for all the children represented in this year's theme. We can be contacted at the Center by calling (202) 296-2637.

Sincerely,



Debra L. Peevey
World AIDS Day Coordinators



Erin Barber

Enclosures



**THE NAMES
PROJECT**

AIDS Memorial Quilt
Workshop & Education Center
(202) 296-2637

World AIDS Day, 1997

Quilt Request Timeline

August 1, 1997 - September 1, 1997

Please submit all requests for Quilt, as well as any specific panel requests on enclosed form

October 1, 1997

While we will endeavor to fill post-deadline requests, these requests made after this date will be subject to a late fee

December 1, 1997

World AIDS Day—**Children Living in a World with AIDS**



Quilt Reservation Form

World AIDS Day 1997

Requested Date and Time of Display date _____ time _____

Name of Organization/School _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone: _____

Your name and/or name of contact person:

Name: _____ eve. phone _____

Name: _____ eve. phone _____

How many 12x12s or 3x6s? _____

Additional information: _____

Please complete & return this form to World AIDS Day Reservation, 1613 K Street, NW, Washington, DC 20006. If you prefer, FAX the completed form to us at 202/296-4121.



OCTOBER 11-13

The Quilt in the Capital

Although the NAMES Project Foundation states its mission as being "to use the AIDS Memorial Quilt to help bring an end to the AIDS epidemic," it's worth noting what the Quilt has already accomplished. The giant patchwork of cultural difference traverses every social boundary, uniting in memory a shadow populace whose scattered members have been made equal in death. Calling to mind both Mark Twain's 1:1 scale map and the modernist grid, the Quilt is the most successful public artwork of our age. It gains its authority not from a single Promethean maker, but from the people, and communicates universal truths to all but the truly hateful. A populist icon, the Quilt adapts an arena of American folk expression to the contemporary taste for personalized monuments (the latter a welcome trend for which we have Maya Lin to thank). Its very material connotes comfort at the same time that its perfectly literal expanse (How many sickbeds would its panels cover? How many corpses would they shroud?) conveys the horrible scale of the loss it enshrines. Most importantly, the Quilt has permitted mourning, particularly of a kind that not long ago was taboo, to enter the public sphere of a culture that had largely purged itself of open expressions of grief. That may seem a meager solace in the face of the continuing epidemic, but it's no small development, rather one to be proud of. The entire Quilt will be shown from 8 a.m.-5 p.m. on the National Mall Grounds. FREE. (202) 296-2637. (Glenn Dixon)

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G3935

Date Rcvd: 8-20-97

From: Thomas J. Gibson

Denver HIVNet Community Advisory Board

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

NO response needed - TS

To Support Staff: _____

Date of Response: _____

n:\corresli

DENVER HIVNET COMMUNITY ADVISORY BOARD

**605 Bannock Street, Suite 217
Denver, Colorado 80204-4507
(303) 436-7262**

August 15, 1997

VIA U.S. MAIL

Sandra L. Thurman
Director of the Office of
National HIV Policy
750 15th Street, N.W., Suite 600
Washington, D. C. 20503

RE: Thank You Again

Dear Sandra:

Thank you again for meeting with Steve Wakefield and me in July. I thought you would be interested in the enclosed article that appeared in the Denver Post this week. We're excited about the vaccine study moving forward.

Please do not hesitate to contact me if you have any questions or comments regarding any of the matters we discussed during our meeting, or if the Denver HIVNET Community Advisory Board can be of any assistance.

Very truly yours,

DENVER HIVNET COMMUNITY ADVISORY BOARD

By: Thomas J. Gibson
Thomas J. Gibson, Chairperson

TJG/dm

cc: Steve Wakefield

AIDS vaccines tested in Denver

By Renate Robey
Denver Post Staff Writer

Years of AIDS research on Tuesday came down to two small, routine-looking syringes: a yellow one for the right arm and a blue one for the left.

As a nurse emptied the syringes into Brett Hamblen's arms, the 25-year-old became part of a national research project that puts Denver at the front lines in the search for an AIDS vaccine.

Denver is one of 14 sites around the country testing the safety and effectiveness of two new experimental vaccines against the human immunodeficiency virus. Hamblen was one of the first to be in-

jected with the trial vaccine. "It's my small way (of helping)," said Hamblen, a Denver tanning salon manager.

Researchers first isolated the virus that causes AIDS in the mid-1980s, and there were expectations that a vaccine could be developed within two years, said Dr. Frank Judson, director of Denver Public Health.

"Then a period of pessimism followed," Judson said. Several vaccines were tested on humans in the early 1990s and didn't produce the kinds of immune system responses that researchers sought. Testing on humans slowed dramatically.

But with this new study, sponsored by the National Institutes of Health, "We're

beginning to get back on track," he said. Federal money for HIV vaccine research has increased by 33 percent in the past two years.

"A couple of years ago, there was not much hope in the (gay) community," said Tom Gibson, chairman of the Community Advisory Board that worked with Denver Health to recruit and screen participants for this and previous studies. "There wasn't anything in the pipeline . . . to look forward to. Although these vaccines may not be the miracle we're all hoping for, it does give us some hope."

Please see **VACCINE** on 4B

4B •

THE DENVER POST

AIDS vaccines tested in Denver

VACCINE from Page 1B

The Denver drug trial will last 18 months. Researchers selected 30 gay or bisexual men who tested negative for HIV. Nationally, there are 420 people in the trial.

Denver was chosen because of its previous work reaching out to people at high risk for AIDS and previous studies on the spread of hepatitis B and other diseases.

The thrust of this new study is combining two new vaccines.

One of the vaccines encourages the body to develop more antibodies to fight HIV if it is introduced into the body, but not yet into the cells. Judson said the antibodies help stop the virus before it gets established and acts to neutralize it.

The second vaccine works to stimulate the body's own immune system to kill the HIV that has made its way past the first line of defense and into the cells.

Researchers say that neither of the vaccines in the study can infect someone with the AIDS virus.

The 30 study participants were screened from a pool of 600 volunteers. They met with counselors at least three times before their first



The Denver Post / John Prieto

Barb Barth, Denver Public Health nurses coordinator, gives shots on Tuesday to Brett Hamblen, 25, who is among 30 volunteers testing a new AIDS vaccine in Denver, one of 14 national test sites.

shot. Counselors try to ensure that the men are practicing safer sex, and that they don't engage in high-risk sexual behavior because they think the vaccine will protect them. Men in the study will not

know if they've received one or both of the vaccines, or two placebos.

After this study is completed, a larger national test is planned of 3,000 to 5,000 people.

In Denver, all the participants are considered healthy but high-risk males.

But in other cities, women, intravenous drug users and low-risk people are also included.

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G 3938

Date Rcvd: 8-20-97

From: Theresa M. McGovern
The HIV Law Project

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

See G 3685 3925

To Support Staff: _____

Date of Response: _____

n:\corresli

HIV

*Theresa M. McGovern, Esq., Co-Executive Director

Bebe J. Anderson, Esq., Co-Executive Director

* Carol M. Suzuki, Esq.

Victoria F. Neilson, Esq.

Gretchen Morales, Esq.

Elizabeth Lopez-Martinez, Esq.

Carole Levy, Esq.

Eric Goosby

Office of National AIDS Policy Director,

750 17th St., NW 6th Floor

Washington, DC 20500

August 7, 1997

Dear Mr. Eric Goosby:

As you are undoubtedly well aware, New York Assemblymember Nettie Mayersohn has been circulating a letter among legislators and AIDS organizations, claiming that New York State's mandatory newborn HIV testing program-- the first such program in the United States-- has been an unmitigated success.

As the Director of the HIV Law Project, a nonprofit legal agency that administers a toll-free hotline designed to respond to questions, concerns or problems resulting from the mandatory newborn HIV testing program, I feel obligated to share with you my dramatically differing experiences with the program.

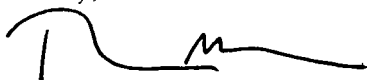
New York State implemented the first mandatory newborn testing program in the country on February 1, 1997. As you know, the test of the newborn is in fact a test of the mother: all babies born to HIV-positive mothers will test HIV-antibody-positive at birth, although 85% will eventually seroconvert to HIV-negative without any treatment intervention. According to the program regulations, hospitals must inform women of the test, counsel every woman about the test's significance, and inform women about how to obtain her and her infant's test results. If a woman tests HIV-positive, she is supposed to receive culturally sensitive counseling in her own language when she is given the results; she is supposed to be told of available treatments and, perhaps most importantly, she is supposed to be guaranteed health care for herself and her infant.

In many instances, these protections are being ignored. Providers are not informing women that they and their infants will be tested. Women who test HIV-positive often have no idea that they were tested, and are confused and alarmed when they are called and told to report to a hospital that may not even be their own. Doctors have abruptly, and totally inappropriately, informed women in public places when other people were present that their baby tested HIV-positive. Translators are not available and women receive inaccurate information or do not understand what they are being told. Women who test HIV-positive through their infants experience long delays-- in at least two instances up to six weeks-- in receiving test results, and because of failures in counseling, many of these women have breastfed their infants. Tracking down of women who test HIV-positive is being mishandled, resulting in repeated confidentiality violations. The program does not address important issues such as a special protocol related to adolescents and their infants.

The widespread, consistently recurring problems with the mandatory newborn HIV testing program compelled the HIV Law Project to respond; on July 18, 1997, we filed a class action lawsuit against the State of New York and two hospitals, claiming that the implementation of the mandatory HIV testing program has violated the constitutional rights of women and children due to the State's failure to protect the class. Women who are most vulnerable to abuses-- poor, homeless, substance users, immigrants, women who don't speak English, or who experience domestic violence-- and who have been most harmed by program violations, are most often too traumatized and too afraid to come forward. Unfortunately, Ms. Mayersohn's comment, "None of the dire predictions of an increase in suicides or domestic violence or women avoiding the health care system, appears to have any basis in reality," is inaccurate.

The HIV Law Project has a long history of fighting for care and access to treatment for HIV-positive women and children. We are committed to ensuring that the rights of HIV-affected women and children are safeguarded. Thank you for your attention.

Sincerely,



Theresa M. McGovern, Esq.

Director

841 Broadway Suite 608 • New York, New York 10003 • Phone (212)674.7590 Fax (212)674.7450

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: 63925

Date Rcvd: 8-14-97

From: Theresa M. McGovern

HIV Law Project

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

Copy ?

See G 3685, 3938

To Support Staff: _____

Date of Response: _____

n:\corresli

Theresa M. McGovern, Esq., Co-Executive Director

Bebe J. Anderson, Esq., Co-Executive Director

Carol M. Suzuki, Esq.

Victoria F. Neilson, Esq.

Gretchen Morales, Esq.

Elizabeth Lopez-Martinez, Esq.

Carole Levy, Esq.

Sandy Thurman

Director of National AIDS Policy

750 17th St., NW Suite 600

Washington, DC 20503

August 7, 1997

Dear Ms. Thurman:

As you are undoubtedly well aware, New York Assemblymember Nettie Mayersohn has been circulating a letter among legislators and AIDS organizations, claiming that New York State's mandatory newborn HIV testing program-- the first such program in the United States-- has been an unmitigated success.

As the Director of the HIV Law Project, a nonprofit legal agency that administers a toll-free hotline designed to respond to questions, concerns or problems resulting from the mandatory newborn HIV testing program, I feel obligated to share with you my dramatically differing experiences with the program.

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In many instances, these protections are being ignored. Providers are not informing women that they and their infants will be tested. Women who test HIV-positive often have no idea that they were tested, and are confused and alarmed when they are called and told to report to a hospital that may not even be their own. Doctors have abruptly, and totally inappropriately, informed women in public places when other people were present that their baby tested HIV-positive. Translators are not available and women receive inaccurate information or do not understand what they are being told. Women who test HIV-positive through their infants experience long delays-- in at least two instances up to six weeks-- in receiving test results, and because of failures in counseling, many of these women have breastfed their infants. Tracking down of women who test HIV-positive is being mishandled, resulting in repeated confidentiality violations. The program does not address important issues such as a special protocol related to adolescents and their infants.

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The HIV Law Project has a long history of fighting for care and access to treatment for HIV-positive women and children. We are committed to ensuring that the rights of HIV-affected women and children are safeguarded. Thank you for your attention.

Sincerely,



Theresa M. McGovern, Esq.

Director

841 Broadway Suite 608 • New York, New York 10003 • Phone (212)674.7590 Fax (212)674.7450

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: G3685

Date Rcvd: 04-25-97

From: Theresa McGovern
The HIV Law Project

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: Michael

RCVD: _____ DONE: 7/7

Recommendations/Instructions:

See G 3938, 3928

To Support Staff: _____

Date of Response: 7/7 6/16/97

- Needs a thoughtful answer
- Can't ignore her.
- Becoming aware of what's happening is very important
- Agree with the wide range of concerns when mandating strategies supervise working with women as individuals
- Important for all the lesson, the real implementation issues.
- Appropriate their advocates for women.

THE WHITE HOUSE
WASHINGTON

June 16, 1997

Theresa McGovern, Esq.
Co-Executive Director
The HIV Law Project
841 Broadway, Suite 608
New York, NY 10003

Dear Ms. McGovern:

Thank you for sharing with me some of the issues that have arisen with the implementation of New York State's new mandatory newborn HIV screening program. The problems you presented are of great concern.

I have long been a proponent of comprehensive, voluntary strategies for supporting pregnant women and women with children in obtaining adequate HIV-related information and care. Mandatory programs of screening and testing, particularly when they are not well designed or supported, can be ineffective and even counterproductive.

It is important for all of us to learn about the implementation issues for programs such as New York's because they are likely to be repeated elsewhere. I would appreciate the opportunity to utilize your expertise to become better informed on this issue. Would it be possible for me or someone from my staff to obtain a personal briefing? That might provide us with greater insight into the problem, which would in turn help us to support a meaningful and effective response.

You will appreciate that my office is still in transition, and the staff has not been fully developed. Please allow me a few more weeks to put things in order, and then I will have someone on my senior staff call to follow up on my briefing request. In the interim, I will broach the subject with our colleagues at HHS to learn about ways in which they are responding to the problems with mandatory programs like yours in New York.

I appreciate your taking the time to write and look forward to working with your agency and other advocates to help insure the care and protection of women and children living with HIV and AIDS in New York City.

Very truly yours,



Sandra Thurman

Director, Office of National AIDS Policy



- Theresa M. McGovern, Esq., Co-Executive Director
- Bebe J. Anderson, Esq., Co-Executive Director
- Carol M. Suzuki, Esq.
- Victoria F. Neilson, Esq.
- Gretchen Morales, Esq.

Sandy Thurman
Director
National AIDS Policy
750 17th Street, NW, Suite 600
Washington, D.C. 20503

April 16, 1997

Dear Ms. Thurman:

Congratulations on your appointment to the Office of National AIDS Policy.

I am writing to you to follow up on requests for a meeting with Secretary Donna Shalala that I made to your predecessor, Dr. Eric Goosby. I have enclosed copies of my correspondence with him for your review.

As stated in the enclosed letters, a mandatory newborn HIV screening program, the first in the U.S., began in New York State on February 1, 1997. The HIV Law Project administers a Mandatory HIV Testing Hotline designed to provide outreach and information to women subjected to the new policy and to educate health care providers on mandatory testing-related issues. During the past two months, we have learned of a wide range of problems with the newborn HIV screening program, including: forced administration of AZT to newborns under threat that their mothers will be charged with medical neglect; test results being sent to the wrong hospital; regulated prenatal care providers failing to provide HIV counseling and offers to test; hospitals discharging women without informing them that their newborns have been tested and what the consequences of a positive result will be; hospitals failing to counsel HIV-positive women not to breastfeed; women being misinformed or not informed of positive test results due to lack of interpreters; inadequate follow-up of women whose infants test HIV-positive or overly aggressive, invasive follow-up, such as counselors pursuing women by waiting outside their homes; and physical violence against women (e.g., the partner of a woman who tested HIV-positive beat up the woman in the hospital after he learned of her test results).

Clearly, these extremely troubling, unintended adverse consequences of the mandatory newborn HIV testing program must be addressed as soon as possible to prevent further harm to women and their children and to ensure that they receive the treatment and care that they need.

Thank you. I look forward to hearing from you.

Sincerely,

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

Theresa McGovern
Co-Executive Director

HIV

Theresa M. McGovern, Esq., Co-Executive Director

Bebe J. Anderson, Esq., Co-Executive Director

Carol M. Suzuki, Esq.

Victoria F. Neilson, Esq.

Gretchen Morales, Esq.

February 19, 1997

Dr. Eric Goosby
Acting Director
Office of National AIDS Policy
750 17th Street, N.W., Suite 600
Washington, D.C. 20503

Dear Dr. Goosby:

Congratulations on your appointment as Acting Director of the Office of National AIDS Policy, and thanks again for including me in the National Institutes of Health meeting on AZT carcinogenicity.

As I know you are well aware, most medical and public health experts support voluntary HIV counseling and testing as the most effective strategy for bringing HIV-infected and -affected women and children into care. Nevertheless, and despite consistent opposition to mandatory testing of pregnant and childbearing women by experts such as the Federal Centers for Disease Control, the American College of Obstetricians and Gynecologists, and the American Academy of Pediatrics, New York became the first state in the United States to require mandatory testing of all newborns, and therefore, of all pregnant women, beginning on February 1, 1997.

The HIV Law Project, along with over 160 other agencies and individuals, have formed a coalition (The Coalition for Women's Choice in HIV Testing and Care) to advocate for women's informed choice in testing and care. As a measure of its commitment to the Coalition, the HIV Law Project has hired a full-time Community Organizer, Chris Cynn, to focus primarily on organizing the group.

We have formulated a consensus statement and a "Statement of Principles" that I have enclosed; among our present concerns are proposals to unblind the newborn seroprevalence study on a national level. The proposals are particularly problematic considering that treatment alternatives for HIV-positive women are limited and not accurately conveyed to women. Although The National Cancer Institute study on mice pups established that mice pups exposed to AZT *in utero* developed cancer as adults, the New York State Department of Health is currently distributing materials that state: "There is no information at this time on any possible long-term health problems for babies whose mothers took AZT." We have requested meetings with Gus Birkhead and with Donna Shalala to discuss our concerns.

Any suggestions about how to proceed and any support in attempting to arrange the meetings would be much appreciated. For your reference, I have enclosed copies of the letters to Drs. Birkhead and Shalala.

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

Sincerely,



Theresa McGovern
Director of Litigation

Enclosures 841 Broadway Suite 608 • New York, New York 10003 • Phone (212)674.7590 Fax (212)674.7450

- Theresa M. McGovern, Esq., Co-Executive Director
- Bebe J. Anderson, Esq., Co-Executive Director
- Carol M. Suzuki, Esq.
- Victoria F. Neilson, Esq.
- Gretchen Morales, Esq.

March 24, 1997

Dr. Eric Goosby
Acting Director
Office of National AIDS Policy
750 17th Street, NW
Suite 600
Washington DC 20503

Dear Dr. Goosby,

I am writing to renew my request for a meeting with the Secretary to discuss any plans to fund and/or unblind the CDC's newborn seroprevalence study of childbearing women.

As you may know, the New York State Legislature awarded the HIV Law Project funds to administer a Newborn Testing Hotline. The Hotline is designed to respond to anyone who has questions, problems or concerns as a result of the State's implementation of the new mandatory newborn HIV testing program. Although the New York State Department of Health blocked the issuance of the funds for the hotline and refused to publicize the "800" number in state-funded facilities, we have nonetheless received some disturbing information, including reports of:

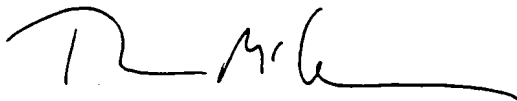
- Hospital personnel threatening to report women to the child welfare authorities if they refuse either to take AZT or consent to AZT administration to their infant. Most women are so afraid of a charge of medical neglect that they acquiesce.
- Newborns' positive test results being sent to the wrong hospital, resulting in repeated confidentiality violations of the mother and newborn.
- Regulated prenatal medical providers inadequately or completely failing to offer HIV testing and counseling.

- Women leaving the hospital without being told that their newborns were tested and what a positive result will mean; HIV counselors work only nine to five weekdays, and women who deliver over the weekend check out before counselors can see them.
- Because of a lack of interpreters, women's partners or other relatives serving as translators and withholding information, including an HIV positive test result, from the women.
- Inadequate and/or inaccurate information being given to women who test positive.
- Either a complete lack of follow up after a woman receives a certified letter asking her to return and she does not, or aggressive, inappropriate follow up, such as standing by a mother's doorway, etc.
- No guarantee of healthcare for women and children newly identified as HIV-positive.
- A woman's partner beating her up in the hospital after he was informed of her HIV status.

All of these reports violate the stated objectives of mandatory newborn testing and evidence a disturbing disregard for affected families. They further underscore the purely cosmetic value of unblinding the newborn seroprevalence study. Please urge the Secretary to meet with us to discuss these matters as soon as possible.

Thank you for your assistance.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Theresa McGovern', with a long horizontal flourish extending to the right.

Theresa McGovern
Legal Director

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10019	Benneville N.	Strohecker	8/21/97

Sender's Organization

Harbor Sweets

FILE COPY

Addressed To

Thurman, Sandra

Subject	Response Type	Response Date	Responder ID
update			
Responder Name	Action Promised	Action Complet	Action Date

Notes

called on 8/25 - asked him to re-send paper.

(TS)



Palmer Cove, 85 Leavitt Street, Salem, MA 01970
Tel. (508) 745-7648
Fax (508) 741-7811

Benneville N. Strohecker
Founder, C.E.O.

August 8, 1997

Sandra L. Thurman, Director
Office of National AIDS Policy
808 12th Street NW
Suite 820
Washington D.C. 20006

Dear Sandy,

June Osborne insisted I bring you up to date.

She and I had dinner together a few weeks ago, and discussed the results from my distribution of A New Challenge to Changing Behavior concept paper.

I told June that you were included in the original distribution last March but that we hadn't been able to connect for a response.

June said, "Don't give up...Sandy's input is important."

So-- attached is my update to those who made it clear that they wanted to be a part of the project.

I do hope you'll respond or at least give me a brief thumbs up (or down) on my direction.

Best,

BNS/hn

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Sweet Sloops® Marblehead Mints® Sand Dollars® Sweet Shells® Harbor Lights®
The Robert L. Strohecker Assorted Rabbit® Dark Horse Chocolates®

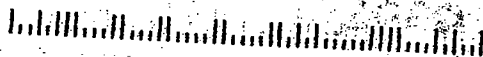


Palmer Cove, 85 Leavitt Street
Salem, MA 01970



SANDRA L. THURMAN, DIRECTOR
OFFICE OF NATIONAL AIDS POLICY
808 17TH STREET NW
8TH FLOOR, SUITE 820
WASHIN

200008/33



ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10018	Professor Luc	Montagnier	8/21/97
Sender's Organization			
World Foundation AIDS Research and Prevention			
Addressed To			
Thurman, Sandra			
Subject	Response Type	Response Date	Responder ID
praising Administration			
Responder Name	Action Promised	Action Complet	Action Date
Notes			
no response needed TS			



FONDATION MONDIALE RECHERCHE ET PREVENTION SIDA

WORLD FOUNDATION AIDS RESEARCH AND PREVENTION

1, rue Miollis 75732 Paris Cedex 15 - Téléphone : 01 45 68 38 41 - Fax : 01 42 73 37 45

Nos réf : SC/FMS/LM/EC/357
Paris, le 8 août 1997

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

Dear Ms. Thurman:

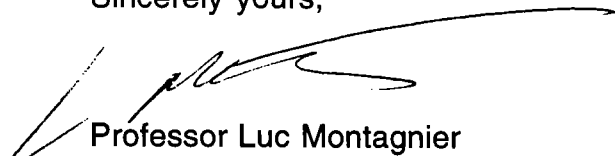
A copy of your letter of 19 July 1997, addressed to Dr. Hamid Shirvani, Vice President for Graduate Studies and Research at Queens College/CUNY, New York, was passed on to me.

May I take the opportunity to express my great admiration for the President's enthusiastic support of the medical and scientific community working on AIDS. His commitment to increased government funding for prevention, research and social programs, and his call for the creation of an AIDS vaccine research unit at the National Institutes of Health, are proof of his willingness to take bold action.

I embark on the new initiative at Queens College with tremendous confidence that the Administration will be a close and willing partner in the fight against the epidemic. It shall be a pleasure to work with you.

With my very best wishes, I am

Sincerely yours,



Professor Luc Montagnier
President

ONAP Letter Tracking

FILE COPY

Letter ID	Writer First Name	Writer Last Name	Received Date	
10024	Christine	Lubinski	8/22/97	
Sender's Organization				
AIDS Action Council				
Addressed To				
Thurman, Sandra				
Subject	Response Type		Response Date	Responder ID
Medicaid Expansion				
Responder Name	Action Promised	Action Complet	Action Date	
Notes				
no response needed (TS)				

cc: attach to Daniel + me



MEMORANDUM

TO: NORA coalition members

FR: NORA Executive Committee

DA: 21 August 1997

RE: Medicaid Expansion "White Paper"

Co-chairs

David Harvey
AIDS POLICY CENTER FOR
CHILDREN, YOUTH AND
FAMILIES

Miguelina Maldonado
NATIONAL MINORITY AIDS
COUNCIL

Executive Committee

Val Bias
NATIONAL HEMOPHILIA
FOUNDATION

Rose Gonzalez
AMERICAN NURSES
ASSOCIATION

Byron J. Harris
NATIONAL ALLIANCE OF
STATE AND TERRITORIAL
AIDS DIRECTORS

Christine Lubinski
AIDS ACTION COUNCIL

Mike Shriver
NATIONAL ASSOCIATION OF
PEOPLE WITH AIDS

Jane Silver
AMERICAN FOUNDATION FOR
AIDS RESEARCH

Winnie Stachelberg
HUMAN RIGHTS CAMPAIGN

AIDS Action Council has asked the NORA Executive Committee to distribute the enclosed "white paper" *Expanding Eligibility for Medicaid to Persons With HIV Disease* to the full coalition for review and possible endorsement. Please contact Christine Lubinski or Chad Lord at AIDS Action Council (202-986-1300) if you have any questions or would like to endorse this report (see enclosed fax-back form).

NORA

A coalition convened by
AIDS Action Council

1875 Connecticut Ave., NW
Suite 700
Washington, DC 20009
202 986 1300
202 986 1345 fax

"A coalition of over 175 organizations responding to AIDS with resolve and action."



"Our view is that getting these drugs to people earlier won't cost more in the long run. It may even save money. It will certainly save lives."

--Vice President Al Gore

April 9, 1997

Dear Colleague:

With these words, the Vice President endorsed an AIDS Action Council proposal to provide low-income people with HIV access to health care and promising new AIDS drugs through the Medicaid program. The Vice President's announcement in April sparked hope that the wide gap in access to care and treatment would be narrowed.



New combination drug therapies have prompted unprecedented hope in the long battle against AIDS. But with these new drugs have come the familiar problems of affordability and access to care. In response, AIDS Action Council and its community-based partners approached the Clinton administration earlier this year with a plan to expand Medicaid eligibility to cover low-income people with HIV from the date of diagnosis. Under the present Medicaid system, most HIV-positive poor people are not "sick enough" to qualify for coverage — they must wait until they develop full-blown AIDS before they can receive health care, which is then more expensive to provide.

Recognizing that the current approach is inhumane, not cost-effective, and in conflict with current treatment guidelines, Vice President Gore voiced his support for the AIDS Action Council proposal, and pledged that the administration would report on implementation of the Medicaid expansion within 30 days of his announcement on April 9. The 30 days have long since come and gone with no ensuing report from the Clinton administration, leaving this innovative proposal in bureaucratic limbo.

But AIDS Action Council and its community-based partners have continued to work on this issue. Enclosed is a copy of *Expanding Eligibility for Medicaid to Persons with HIV Disease*, a "white paper" analyzing the need for a Medicaid expansion and explaining the proposal.

We hope that you will review this document and consider endorsing this proposal by signing on to this document. In addition, we would ask that you call on Vice President Gore to take prompt action on this proposal. Should you have any questions or need more information, please feel free to call Christine Lubinski at (202) 986-1300 or Robert Greenwald at (617) 450-1257.

Sincerely,

A handwritten signature in cursive script, reading "Christine Lubinski".

Christine Lubinski
Deputy Executive Director
AIDS Action Council

A handwritten signature in cursive script, reading "Robert Greenwald".

Robert Greenwald
Director of Public Policy & Legal Affairs
AIDS Action Committee of Massachusetts

1997 Medicaid Expansion Initiative

Action and Response Form

Expanding Medicaid eligibility to low-income individuals living with HIV from the date of diagnosis may be the single most important action we can take to improve access to health care and life-prolonging drugs. If you support this initiative, please lend your organization's name as an endorser of the Medicaid expansion white paper. The position paper and the list of its endorsers will be presented to Vice President Gore.



Yes! Sign us on! Please add our name to the list of the initiative's endorsers that will be presented with the white paper – *Expanding Eligibility for Medicaid to Persons with HIV Disease* – to Vice President Gore.

To sign on as an official endorser of the white paper, complete and fax this form to Chad Lord at AIDS Action Council, (202) 986-1345 – or call (202) 986-1300, extension 3062.

RESPONSES ARE DUE NO LATER THAN MONDAY, SEPTEMBER 8.

NAME _____

TITLE _____

ORGANIZATION _____

ADDRESS _____

PHONE _____ FAX _____

E-MAIL _____

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

More information about this project can be obtained by contacting
Christine Lubinski, AIDS Action Council of Washington, D.C. at (202) 986-1300, or
Robert Greenwald, AIDS Action Committee of Massachusetts, at (617) 450-1257.

The duplication and distribution of this report is supported in part by a generous grant from The George Gund Foundation, Cleveland, Ohio.

EXPANDING ELIGIBILITY FOR MEDICAID TO PERSONS WITH HIV DISEASE

INTRODUCTION

Recent research has shown that a long-held assumption about AIDS was wrong—there is no initial dormant phase of HIV infection. Instead, the virus attacks the body's immune system from the outset. This improved understanding of how HIV functions, along with the advent of powerful new medications, has led to new recommendations for care and treatment. Specifically, experts now advise comprehensive care and treatment, often with combination drug therapy, from the earliest stages of HIV disease.

Despite the experts' recommendations for early treatment and the existence of effective drugs, significant obstacles to accessing care and medications remain for low income people living with HIV. Existing programs cannot meet the need for comprehensive health care and preventive services. The current Medicaid requirements force most HIV positive individuals to wait until they develop full-blown AIDS to become eligible for coverage, a model which is inconsistent with clinical standards, inhumane, and costly.

EARLY INTERVENTION WORKS, SAVING LIVES AND DOLLARS

The new standard of care for people with HIV emphasizes early clinical intervention, calling for both primary care and combination drug therapy, including protease inhibitors, at earlier stages of infection. The National Institutes of Health (NIH) report that "...it has been suggested that the best opportunity to eradicate HIV infection is provided by the initiation of potent combination antiretroviral therapy during primary infection."¹ According to Dr. David Ho, director of the Aaron Diamond AIDS Research Center, mathematical models suggest that patients caught early enough and treated with combination drug therapies could be free of HIV in two to three years.²

While complete eradication of the HIV virus from the body has not yet been demonstrated, combination drug therapies have proven effective for many, driving viral loads (the amount of virus in the blood) below detectable levels, and maintaining or dramatically improving overall health. Combination therapies can slow the progression from HIV to AIDS, and can help prevent opportunistic infections (OIs). For example, researchers at NIH's National Eye Institute recently discovered that a combination of protease inhibitors and other anti-HIV drugs can prevent or delay the progression of cytomegalovirus (CMV) retinitis, a common complication of AIDS which causes blindness without proper treatment.³ Some patients in

¹ C. Carpenter, et. al., "Report of the NIH Panel to Define Principals of Therapy of HIV Infection," June, 1997.

² L. Altman, "With AIDS Advance, More Disappointment," *New York Times*, January 19, 1997.

³ NIH News Release, "Combination Drug Therapy for AIDS Found to Control Blinding

the study were able to stop standard CMV retinitis treatment, which can be cumbersome, toxic, and extremely costly (between \$50-100,000 per patient per year), without advancement of their disease.⁴

Combination drug therapies including protease inhibitors are expensive, with costs ranging from \$8,000 to \$10,000 per year. But several studies have indicated that the dollars spent “up front” on these medications are offset by later savings on hospitalizations and other expensive care and treatment for AIDS-related illnesses. A study by Dr. Peter Ruane of the Tower Infectious Disease Medical Associates in Los Angeles found that each dollar spent on combination drug therapies resulted in at least two dollars of savings on overall treatment costs, which declined 23 percent.⁵ The same study reported a 57 percent drop in the average number of days patients spent in the hospital. Data from Saint Vincent’s Hospital in New York support the conclusions of the Tower study, showing a significant decrease in inpatient care, both in terms of the number of people hospitalized and the average length of stay.⁶

The findings of the protease inhibitor studies—that early intervention and treatment can prolong health and reduce the need for more expensive treatment later—are consistent with earlier studies on the cost-effectiveness and beneficial impact of preventive treatment. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) with those who did not receive such treatment. The patients not taking prophylaxis accounted for all of the deaths attributed to PCP, 85 percent of the hospital days, 100 percent of the Intensive Care Unit days, and 89 percent of the inpatient charges. The study concluded that those “who developed PCP despite prophylaxis had a better outcome and used fewer resources than patients not receiving preventive therapy.”⁷ Another study examining preventive treatment for PCP found that prophylaxis resulted in longer life and a savings of \$16,503 for each patient, as compared with no prophylaxis.⁸

Comprehensive care and treatment which prevents or delays the progression from HIV infection to AIDS can both improve quality of life and save money. A survey of the costs of care for

Eye Infection,” May 20, 1997 (reporting study results published in the *Journal of the American Medical Association*, May 21, 1997).

⁴ *Id*

⁵ P. Ruane, “Dramatic Reductions in Use of Healthcare Services by Patients with HIV Result from Use of Combination Therapy with a Protease Inhibitor,” Tower Infectious Disease Medical Associates, Inc., January 23, 1997.

⁶ R. Torres, “Impact of Potent New Antiretroviral Therapies on In-Patient and Out-Patient Hospital Utilization by HIV-Infected Persons,” Saint Vincent’s Hospital and Medical Center, January 23, 1997.

⁷ J. Gallant, et. al., “The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia,” *Chest*, April 1995: 1018-1023.

⁸ A. Castellano and M. Nettleman, “Cost and Benefit of Secondary Prophylaxis for *Pneumocystis carinii* Pneumonia,” *Journal of the American Medical Association*, August 14, 1991: 820-824.

Medicaid patients with HIV in Baltimore found that monthly costs for people with CD4+ T-cell counts under 50 (generally a sign of more advanced HIV disease) were more than twice those of people with more than 500 T-cells.⁹ Stated simply, providing care for those who are seriously ill costs more than caring for healthier people. Yet under the present Medicaid system, many living with HIV must wait for their T-cells to drop and their illness to worsen before they can receive coverage and access care.

GAPS IN HEALTH CARE COVERAGE REMAIN

The advances in overall health care and drug treatments have brought renewed health and unprecedented hope to many people living with HIV disease. For the first time in the 15 years of the AIDS epidemic, there has been a decrease in the numbers of Americans dying from AIDS. The U.S. Centers for Disease Control (CDC) reported a 13 percent decline in the number of AIDS deaths for the first six months of 1996, as compared to the same period in 1995, and attributed this decline to improved medical care, prophylaxis for OIs, and the use of combination therapies.¹⁰

In the same report, however, the CDC noted that AIDS continues to be the leading cause of death of Americans aged 25 to 44, and that the “increased prevalence of AIDS [in the U.S.] indicates the need for medical and other services for persons with HIV infection.” While the new medications make obtaining care more important than ever, challenges in expanding access to primary care and treatment remain.

Medicaid provides access to health care coverage for low income, uninsured, disabled people. Individuals who are HIV positive but have not been diagnosed with AIDS, however, are often not eligible for Medicaid, because they do not meet the program’s disability standards or other categorical eligibility requirements. To qualify for Medicaid, people must meet income requirements and the disability criteria of the federal Supplemental Security Income (SSI) program. The Social Security Administration uses the CDC’s definition of AIDS, along with evidence of functional impairments, as proof of disability.¹¹ **Despite the fact that early clinical intervention—including primary care, preventive services, and medication therapies—has been shown to improve health and delay the onset of expensive opportunistic infections, most HIV positive individuals must wait until they “get sicker” and develop AIDS before they can receive Medicaid.**

⁹ R. Moore and R. Chaisson, “Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland,” *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1997, 14:223-231.

¹⁰ Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173. For the first nine months of 1996, AIDS deaths declined even more dramatically, by 19 percent over the same period in 1995.

¹¹ The CDC definition of AIDS for surveillance purposes is: documented CD4+ T-lymphocyte counts <200 per microliter or percent of total lymphocytes <14 percent or a variety of opportunistic infections.

This is particularly devastating because the populations in which HIV infection is increasing are the ones likely to enroll in Medicaid once their HIV infection becomes full-blown AIDS. The epidemic is growing fastest among groups which have traditionally been socioeconomically disenfranchised, including racial and ethnic minorities, injection drug users, and women. In 1996, for the first time, blacks accounted for more AIDS cases than whites (41 percent versus 38 percent).¹² Women represented 20 percent of new AIDS cases in 1996, up from seven percent in 1985. While overall AIDS deaths declined 19 percent in the first nine months of 1996, deaths among blacks decreased 10 percent and deaths among women, only seven percent.¹³

These populations are also the groups less likely to have health insurance and access to treatments, and more likely to face barriers in obtaining health care, according to a survey by the Agency for Health Care Policy and Research.¹⁴ People who are uninsured or underinsured not only lack access to expensive combination therapies, but also to basic primary care and preventive services.

Additionally, current Medicaid requirements undermine public health efforts by preventing many people with HIV from receiving care earlier in their disease. Under the present system, we are often not reaching these people to teach and reinforce behavior changes which can prevent HIV transmission. Even if people are able to obtain the new combination therapies, they may lack access to the primary care and medical case management needed to ensure that the prescribed treatment regimen is appropriate and effective, and to support them in following complex treatment plans. If patients do not strictly comply with their combination therapy regimens, they are likely to develop drug-resistant strains of HIV. The existence of such drug-resistant HIV mutations may further complicate public health efforts to combat AIDS.

Despite the existence of federal AIDS programs, such as the AIDS Drug Assistance Programs (ADAPs) and the other components of the Ryan White CARE Act, Medicaid serves as the foundation of AIDS care through its provision of both comprehensive health care and drug therapies. ADAPs provide limited prescription drug coverage for some uninsured and underinsured people with HIV and AIDS. But these programs cannot (and are not designed to) meet the need for comprehensive primary care and diagnostic services. In spite of their limited mission—to provide access to a limited formulary of proven AIDS medications—ADAPs face severe financial pressure in many states, and often cannot meet the growing demand for new combination therapies. In some states, ADAPs do not even cover protease inhibitors, and many offer a very limited formulary of antiretroviral and OI drugs. In other states, there are lotteries, long waiting lists, and increasingly restrictive eligibility criteria for ADAP participation.

While other Ryan White CARE Act programs pay for some primary care and drug

¹² Centers for Disease Control, *Morbidity and Mortality Weekly Report*, February 28, 1997, 46: 165-173.

¹³ B. Seitz, "AIDS Sufferers Living Longer," ABC News.com, July 15, 1997.

¹⁴ P. Mohr, Patterns of Health Care Use Among HIV-Infected Adults: Preliminary Results," *AIDS Cost and Services Utilization Survey*, Agency for Health Care Policy and Research, September 1994: 3.

reimbursement, they are not intended to provide widespread comprehensive health care. Ryan White funding is used for a range of care and services, including food, transportation, and case management for people living with AIDS. Additionally, many ADAPs and Ryan White-funded primary care programs have eligibility criteria which exclude people in the earlier stages of HIV disease. These programs lack the financial resources to broaden their eligibility criteria to cover such individuals.

The Medicaid eligibility framework—requiring total disability to qualify for coverage—is at odds with current clinical and public health knowledge. Many low income HIV positive individuals with relatively intact immune systems are not presently eligible for Medicaid, but will eventually qualify for Medicaid after developing AIDS. Unable to afford adequate treatment early in their HIV disease, they cannot obtain the health care services necessary to manage the disease, and will be more ill when they do enroll in Medicaid. Ironically, earlier access to these medical services and treatments would enable them to preserve their health, learn how to prevent transmission of HIV to others, and avoid more costly care such as inpatient hospitalization. For humane, financial, and public health reasons, it is time to make Medicaid's eligibility requirements consistent with the clinical realities of HIV disease.

A COLLABORATIVE RESPONSE

In response to the contradictions between current Medicaid disability criteria and AIDS clinical evidence and care standards, which call for early treatment of HIV disease, representatives from the AIDS Action Council, community-based AIDS service organizations, the Health Care Financing Administration (HCFA) and the Office of Management and Budget (OMB) have begun to work collaboratively to address these issues. Response from the administration has been unequivocally supportive, culminating in an endorsement from Vice President Al Gore, who has asked HCFA to find ways in which to expand Medicaid and allow more low-income Americans with HIV to access care and therapies. Gore is quoted as saying “[Medicaid expansion] can ease suffering, it can increase hope, and it can get new drug therapies into the hands of people who need them.” As a result of these collaborations, we are all working together under HCFA's leadership to develop a plan for expanding eligibility to Medicaid for persons who are HIV positive.

AN AIDS-SPECIFIC EXPANSION

As participants in these discussions, we have recognized several reasons for an AIDS-specific expansion of Medicaid. We believe that it serves the interests of public health, scientific knowledge, and fairness to broaden Medicaid coverage to include people with HIV.

Public health: With earlier health care and treatment, as mentioned above, people living with HIV are more likely to avoid behaviors which can spread the virus, and are more likely to adhere to complex treatment plans, which can both prolong health and prevent development of drug-resistant strains of HIV. Earlier access to care can also serve as an incentive for people to learn their serostatus for the first time, and then take steps to avoid either contracting or transmitting HIV.

Scientific knowledge: Protease inhibitors and other new medications received rapid FDA approval, have not yet been in long-term use, and have been researched mainly by studying people in more advanced stages of HIV disease. There are many remaining questions about the benefits, risks, and best way to use combination therapies in people who are HIV positive, but do not have AIDS. A Medicaid expansion demonstration project which brings people with HIV into care provides the opportunity to gather data and conduct research studies designed to answer these questions.

Fairness: The current Medicaid system requires most low-income people with HIV to develop AIDS in order to gain access to health care and new combination therapies. This is in conflict with principles and guidelines recently released by the Department of Health and Human Services and the NIH, which call for earlier intervention with combination drug therapies as the standard of care for the treatment of HIV in most cases. The government should ensure that this standard of care, endorsed by its own agencies, is accessible to those who have no other way to obtain it. Our federal government has always recognized the importance of ensuring access to treatment for other communicable diseases, such as sexually transmitted diseases and tuberculosis—it is unfair and inhumane to deny such treatment to people with HIV.

PROPOSAL DESIGN

The objective of this program is to expand Medicaid eligibility to low-income individuals who have tested positive for the presence of HIV and who would otherwise be eligible for Medicaid once their health status met an AIDS-defining diagnosis. States participating in this initiative will demonstrate that the provision of earlier access to care and treatment will extend the period of time that a person who is HIV positive remains asymptomatic, defer the onset of opportunistic infection, and delay hospitalization, all of which will result in significant cost savings and life-enhancing benefits. The following section describes what we believe are the core components of this initiative.

Eligibility

Any and all individuals who meet the following criteria will be eligible under this program:

- test positive for the presence of HIV; and
- have income at or below 200 percent of the federal poverty level.

State demonstrations will coordinate resources with other private, state, and federal programs. Individuals with private insurance can apply for and become eligible for Medicaid as a “wrap-around benefit” thereby maximizing private insurance participation. State proposals will specify the state specific eligibility guidelines and coordination of other state and federal programs.

Covered Benefits

Ideally, states will provide the full benefit package (i.e., mandatory and optional Medicaid services) to individuals eligible through this program. In any case, benefit packages must be flexible to accommodate new treatment advances and changes in standards of care that become available during the course of the demonstration. Through this project, states, at a minimum, must provide:

- primary care,
- prescription drugs,
- diagnostic and laboratory services,
- mental health services, and
- substance abuse treatment services.

Options to Participate in the Demonstration Projects

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to grant waivers from the usual federal Medicaid requirements¹⁵ to states which want to create demonstration projects to test new approaches to Medicaid. These demonstration projects must be designed to promote the objectives of Medicaid,¹⁶ and must include a research and evaluation component. Generally, demonstration projects created under a Section 1115 waiver are supposed to be “budget neutral” over the life of the project, meaning that costs under the demonstration project do not exceed what costs would have been without the waiver in place. Section 1115 also authorizes matching federal funds for certain expenditures.

This initiative will be designed to provide states with the maximum flexibility possible in participating in a Medicaid expansion demonstration project. The project does not necessarily need to meet the traditional definition of “budget neutrality,” since there can be federal and/or state subsidies. Also, budget neutrality should be measured within a time frame which is appropriate for assessing the clinical impact and cost-effectiveness of the new combination therapies (e.g., over a period of five to ten years).

Options for participation include the creation of a free-standing demonstration program or new or amended 1115 waivers. New 1115 waivers could provide the vehicle to expand Medicaid eligibility and/or allow a Medicaid buy-in option for those individuals otherwise ineligible for coverage. Amending an approved or pending 1115 waiver could also be used to expand eligibility. In addition, states could increase the income standards for their Medicaid buy-in programs, allowing more persons who are HIV positive to qualify. For example, states could set the income standard at 200 percent of the federal poverty level or they could use a graduated system to make more individuals eligible.

¹⁵ As defined in Section 1902 of the Social Security Act, and other provisions incorporated through Section 1902.

¹⁶ As set out in Title XIX of the Social Security Act.

NEXT STEPS

Over the next several months, the AIDS Action Council will work with HCFA to develop and refine a solicitation process for states to successfully participate in the HIV Expanded Eligibility Demonstration Initiative. It is important for community-based AIDS service organizations to urge their state governors and Medicaid directors to advocate for this initiative with HHS and HCFA. While we expect that this initiative will offer states tremendous opportunities to provide cost-effective access and coverage to its most vulnerable populations, we also recognize the range of development and design issues that need to be resolved. Over the next several months, the AIDS Action Council will work with states and HCFA to complete the following tasks:

- Continue to work with HCFA to design a program that includes adequate incentives for state participation in this initiative.
- Build consensus among federal and state leadership, elected officials, and government staff, including representatives from Medicaid programs, Departments of Health, and Departments of HIV Services.
- Work with HCFA to develop a process that allows states to efficiently design and implement a vehicle for eligibility expansion that responds to the unique environment and situations of each state (waiver amendment or new waiver submission).
- Design a process to solicit input from consumers, AIDS service organizations, primary care and other health care providers, and health care agencies regarding program design and program effectiveness, on an ongoing basis.
- Work with HCFA to develop a methodology that allows states maximum flexibility in measuring cost effectiveness. The goal will be to have HCFA resolve methodology issues related to baseline measurements, the measurement of savings in other government programs, and evaluation time frames.
- Work with HCFA to identify and develop data bases that provide the information needed to estimate current expenditures and projected costs for the purposes of assessment and future planning. Necessary data includes the number of newly eligible individuals by state and service area (persons who are HIV positive with incomes below state defined eligibility criteria), utilization of services, and cost.

ONAP Letter Tracking

Letter ID Writer First Name Writer Last Name Received Date

10023

M. Susan

Beasley

8/22/97

Sender's Organization

FILE COPY

Addressed To

Thurman, Sandra

Subject

job positions

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Complet

Action Date

Notes

Thank you - keep on file ... TS

M. Susan Beasley
1410 N. Scott Street, #865
Arlington, VA 22209
Phone: (703) 525-2470
e-mail: beasleys@gwis2.circ.gwu.edu

August 21, 1997

Sandy Thurman
Office of AIDS Policy
808 17th Street, Suite 820
Washington, DC 20006

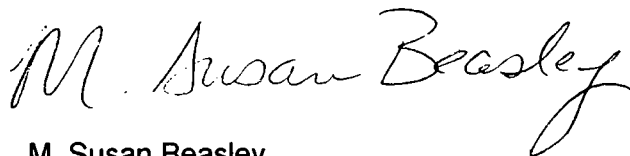
Dear Sandy:

Thank you for answering my questions about open positions in your office. I will contact Dr. O'Neill at HRSA to follow up on detail positions.

I have enclosed a copy of my resume as well as a writing sample. Please feel free to forward this information to others.

Thanks again for your help!

Sincerely,

A handwritten signature in cursive script that reads "M. Susan Beasley". The signature is fluid and elegant, with the first letters of the first and last names being capitalized and prominent.

M. Susan Beasley

M. Susan Beasley
1410 North Scott Street, #865
Arlington, VA 22209
(703) 525-2470

EDUCATION

The George Washington University School of Public Health and Health Services, Washington, DC

Master of Public Health, 1997

Maternal and Child Health track

Additional course concentrations in International Health/Women's Health in Africa

Hendrix College, Conway, Arkansas

Bachelor of Arts in Biology, 1995

Additional course concentrations in English

Czech Republic/Slovakia Environmental Health Exchange Program, 1992

University of Austria at Innsbruck

Summer study in German language and literature, 1993

EXPERIENCE

The National Committee for Quality Assurance (NCQA), Washington, DC

Research Assistant/Intern, 10/96-7/97

Organized and managed a database of potential health plan performance measures submitted to NCQA for inclusion in future versions of HEDIS (Health plan Employer Data and Information Set). Categorized proposed and existing HEDIS measures according to population, clinical condition, and type of care.

Reported results to facilitate the work of Measure Advisory Panels (MAPs) in the measure development process. Independently investigated the representation of women's health issues in HEDIS to capture the current state of health plan performance and quality assessment pertaining to women. Wrote summaries, developed agendas, and provided updates for Vice President of Collaborative Research, Director of HEDIS Development, and MAP Directors.

Arkansas Department of Health, Little Rock

Intern, Office of Chronic Disease and Disability Prevention, 9/94-12/94

Researched prevention of secondary conditions among individuals with spinal cord injury. Used Medline and other health databases to collect information for a position paper. Participated in activities to support a bill which would direct cigarette tax money to breast cancer research. Contributed to development and implementation of a tobacco control program targeting adolescents in local junior high and high schools.

Arkansas Department of Health, Little Rock

Intern, Office of Public Health Programs/Maternal and Child Health, 1/95-6/95

Assisted in a needs assessment of low-income mothers and children in all county and school-based health clinics in Arkansas. Collected data from vital statistics and other on-site sources. Served on multi-disciplinary committee which designed surveys for statewide distribution to providers and consumers. Gained experience in proposal writing and other activities related to grant applications.

Anesthesia Associates, Conway, Arkansas

Office Assistant, Summers 1993 and 1994

Prepared billing statements, processed patient payments, and filed insurance claims for public and private insurance. Counseled Medicaid enrollees on payment issues and conducted telephone surveys to assess patient satisfaction with anesthesia services.

SKILLS

Proficient in Microsoft Word 97, Microsoft Excel, Power Point, QuattroPro, Internet, and electronic mail. Strong writing and editing skills.

M. Susan Beasley
1410 North Scott Street, #865
Arlington, VA 22209
(703) 525-2470

REFERENCES

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Director, Maternal and Child Health Track
The George Washington University School of Public Health and Health Services
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Washington, DC 20037
Phone: (202) 994-3255
e-mail: mohandes@gwis2.circ.gwu.edu

Nancy Kim, MPP
Health Care Analyst, Women's Health Measure Advisory Panel (MAP) Manager
National Committee for Quality Assurance (NCQA)
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Washington, DC 20036
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e-mail: Kim@ncqa.org

Emily Schiffrin, MS
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National Committee for Quality Assurance (NCQA)
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e-mail: Thompson@ncqa.org

ONAP Letter Tracking

FILE COPY

Letter ID	Writer First Name	Writer Last Name	Received Date
10027	G. Cajetan	Luna	8/25/97
Addressed To			
Thurman, Sandra			
Sender's Organization			
San Joaquin AIDS Foundation			
Sender's Street1			
4410 N. Pershing Avenue, Suite C4			
Sender's Street2			
Sender's City	Sender's State	Sender's Zip	
Stockton	CA	95207	
Subject			
Rural HIV			
☒ Response Needed?	Response Type	Response Date	Responder ID
		8/25/97	
Responder Name	Action Promised	Action Complet	Action Date
			8/25/97
Notes			
Copy response letter and attachments to DCM other copy of attached report to me. Todd 8/25			

THE WHITE HOUSE
WASHINGTON

August 25, 1997

G. Cejatan Luna
San Joaquin AIDS Foundation
4410 N. Pershing Avenue, Suite C4
Stockton, CA 95207

Dear Mr. Luna:

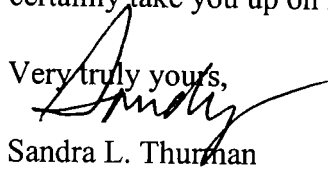
Thank you for sending along information on the California conference on AIDS issues in rural areas..

I wanted to correct a misunderstanding you might have about my comments in Atlanta. I suggested that we put together a group of people to assist the President's Advisory Council on HIV/AIDS in understanding and developing recommendations on rural AIDS issues (not a National Advisory Panel, which is a formally constituted body).

This is an issue of great importance to me. You can't do AIDS work in Atlanta for as long as I have and not have a good perspective on issues facing those in the rural south!

I am very appreciative of your offer to help. I will certainly take you up on it!

Very truly yours,


Sandra L. Thurman
Director
Office of National AIDS Policy

San Joaquin AIDS Foundation

le

SJAF

4410 N. Pershing Ave., Suite C4 • Stockton, CA 95207 • (209) 476-8533 • FAX (209) 476-8142

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August 20, 1997

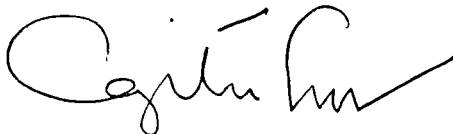
Ms. Sandy Thurman
Director of National HIV Policy
Executive Office of the President
808 17th Street, N.W., 8th Floor
Washington, D.C. 20006

Dear Ms. Thurman:

It was brought to my attention that at a recent meeting in Atlanta you emphasized that little focus has been given to the rural HIV/AIDS issue and that a National Advisory Panel may soon be instituted. I hope that this information is true, and that attention to rural HIV/AIDS will soon be forthcoming. The specific issues surrounding HIV and AIDS in rural California were the focus of **The First Invitational Conference on AIDS in Rural California** held in February 1997 at the University of the Pacific. Two copies of the **Consensus Statement and Recommendations** printed by the State of California Office on AIDS and the California AIDS Clearinghouse are enclosed for your perusal.

Targeted HIV/AIDS programs and interventions addressing the needs of women and seasonal or migrant farmworkers are particularly necessary! Please let me know if we can provide any further information or assistance in combating AIDS in rural America, and continued success in your important work.

Sincerely,



G. Cajetan Luna
Executive Director

"Knowing the facts, making a difference."

ONAP Letter Tracking

FILE COPY

Letter ID	Writer First Name	Writer Last Name	Received Date	
10031	DARIN	JOHNSON	8/26/97	
Addressed To				
Thurman, Sandra				
Sender's Organization				
NATIONAL RURAL HEALTH ASSOCIATION				
Sender's Street1				
1320 19TH ST. NW. SUITE 350				
Sender's Street2				
Sender's City		Sender's State	Sender's Zip	
WASHINGTON DC			20036	
Subject				
THANK YOU				
☐ Response Needed?		Response Type	Response Date	Responder ID
Responder Name		Action Promised	Action Complet	Action Date
Notes				
No response needed - (TD)				

8/26



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August 25, 1997

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Ms. Sandy Thurman
Office of National AIDS Policy
808 17th Street, NW
Suite 820
Washington, D.C. 20006

Dear Sandy,

Thank you so much for taking the time out of your busy schedule to speak at the National Rural Health Association's "Southeastern Conference on Rural HIV/AIDS: Issues in Prevention and Treatment." Your presence demonstrated a strong commitment by the Clinton Administration to focus its attention and resources on rural HIV/AIDS treatment and prevention efforts.

I am very excited to work with you and Scott in spearheading a task force that would be charged with making formal recommendations to your office and to the Presidential Advisory Council on rural HIV and AIDS policy. A nationally-recognized rural HIV/AIDS task force would allow us to build upon what was learned and shared at the Atlanta conference through the development of a national rural HIV/AIDS policy agenda developed by rural practitioners, caregivers, public health workers, and persons living with HIV and AIDS. As we discussed at the conference, I will be in touch with you later this week about meeting for lunch so that we can have an opportunity to discuss the rural task force.

Thank you again, Sandy, for joining us at the conference. Much of the success of the event can be attributed to the involvement of you, Scott and Joe. I very much look forward to working with you on the task force so that we can begin to work more collaboratively in addressing the issue of HIV and AIDS in rural America.

Sincerely,

Darin E. Johnson
Government Affairs Director

Sandy, Thank you so much for joining us in Atlanta - I look forward to lunch and to the beginning of a new friendship.

Donna M. Williams
Executive
Vice President

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10032

Robert

Sharpe

8/26/97

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Thurman, Sandra

Sender's Organization

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Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip

Subject

Newsletter

☐ Response Needed?

Response Type

none

Response Date

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Discard - (TS)

Office of
National AIDS Policy

Correspondence Routing Slip

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Tracking Number: G3914

Date Rcvd: 8-14-97

From: Miguelina Maldonado
National Minority AIDS Council

Staff Action:

Reviewed By Sandy: _____ Reviewed By: _____

Assigned To: _____

RCVD: _____ DONE: _____

Recommendations/Instructions:

no response needed - TS

To Support Staff: _____

Date of Response: _____

n:\corresli



July 24, 1997

Sandra Thurman
White House Office of National AIDS Policy
750 17th Street, NW
Washington DC 20503

Dear Ms. Thurman:

Thank you for participating in the NMAC conference: *Our Place at the Table: The National Meeting and Congressional Dinner*. The conference was a tremendous success, and I want to thank you for your support.

Our Place at the Table provided an update on key federal legislative and administrative measures and policies which affect communities of color. The conference also gave us an opportunity to explore the role of communities of color in laying a foundation of inclusion, parity, and access for the bridge to the 21st century. Through the different presentations and panel discussions, *Our Place at the Table* reached its goal of educating members of the community.

I would like to thank you specifically for presenting the session entitled "A Dialogue with Key National HIV/AIDS Policymakers." The time and effort you devoted to your presentation was invaluable to the success of the conference.

Once again, thank you for your support. I hope you enjoyed the conference, and I look forward to working with you again in the future.

Sincerely,

Miguelina Maldonado

Miguelina Maldonado
Director of Government
Relations and Policy

1931 13TH STREET NW
WASHINGTON, DC
20009-4432
TEL 202-483-NMAC (6623)
FAX 202-483-1135
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EXECUTIVE DIRECTOR
PAUL AKIO KAWAIA

ADAP

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Assistance Program
Advocacy Coalition

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Washington, DC 20009

Fax: 202/462-0446

Tel: 202/462-0260

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Agouron Pharmaceuticals, Inc.

AIDS Action Council

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AIDS Project Los Angeles

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Title II Community AIDS

National Network

Treatment Action Group

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31/7/97

Co-Chairs

William E. Arnold

Dorothy A. Keville

2 August, 1997

TO: Sandy Thurman

From: Bill Arnold

Subject: Meeting

Just a note to say personal "thank you" for last Thursday's
ADAP meeting.

In addition I remind you that I'm available to meet with you any
time you feel it's helpful.

Meetings can be on, or off, the record. I can wear this hat,
other AIDS hats, or no hat.

Best regards,

Bill
no response needed *TD*

ZUCKERMAN, SPAEDER, GOLDSTEIN, TAYLOR & KOLKER, LLP.

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RONALD H. WEICH
(202) 778-1818

October 29, 1997

The Honorable Sandy Thurman
Director
White House Office on National AIDS Policy
Old Executive Office Building
Washington, D.C. 20500

Dear Ms. Thurman:

I have been asked for my legal opinion on the question of whether existing state criminal laws can be utilized to prosecute an individual for knowingly transmitting or attempting to transmit the AIDS virus to another individual through sexual intercourse.

I render this opinion based upon the following professional experiences: (1) from 1983 to 1987 I served as an Assistant District Attorney in New York County, during which time I prosecuted hundreds of defendants for assault, rape and other violent crimes; (2) from 1987 to 1989 I served as Special Counsel to the United States Sentencing Commission; (3) from 1990 to 1996 I served as Counsel to two Senate committees, during which time I specialized in health law and criminal justice issues; and (4) since the beginning of this year I have been a partner in a law firm specializing in the defense of complex criminal investigations.

My view is that existing criminal laws provide ample authority to prosecutors to vigorously prosecute individuals who knowingly transmit the AIDS virus. While I have not, at this time, conducted a detailed survey of all fifty state penal codes, I am aware that approximately 20 states specifically criminalize the deliberate transmission of AIDS or other infectious diseases. In those states that have chosen not to enact specific statutes to address this conduct, prosecutors would still have authority to charge an individual who engaged in such conduct with one or more of the following crimes: *assault* (intentionally or, in some cases, recklessly causing physical injury to another individual); *reckless endangerment* (engaging in conduct that creates a substantial likelihood of physical injury to another individual); *attempted murder* (intentionally or, in some cases, recklessly attempting to cause the death of another individual).

There are some minor differences in the way different states define the elements of these crimes. In addition, most state penal codes contain gradations of each of the above described offenses depending upon the intent of the defendant, the degree of harm actually caused, and whether the course of conduct was merely attempted or actually completed. These differences

ZUCKERMAN, SPARDER, GOLDSTEIN, TAYLOR & KOLKER, LLP.

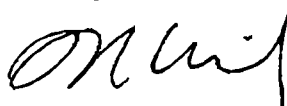
Page 2

among state criminal laws are a function of our system of federalism, under which the criminal law, especially as it applies to violent crimes, has traditionally been within the purview of state legislatures. As a result, state legislatures have considerable expertise in crafting criminal statutes based upon the needs and special circumstances of each state.

But despite these technical differences among state criminal laws, there is no doubt that in every state within the United States, it is a criminal act to knowingly transmit or attempt to transmit the AIDS virus to another individual through sexual intercourse. It is also undoubtedly true that heinous conduct of this kind exposes a defendant to substantial periods of incarceration in every state of the Union.

Please feel free to contact me if I may provide additional information on this important subject.

Sincerely,

A handwritten signature in black ink, appearing to read 'Ronald Weich', written in a cursive style.

Ronald Weich

HIV NEWSLINE

REPORTING RECENT ADVANCES IN THE DIAGNOSIS AND TREATMENT OF PATIENTS WITH HIV INFECTION

1 August 1997

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Director, AIDS Program
San Francisco General Hospital

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EXECUTIVE EDITOR

EDWIN BAYRD

Sandra Thurman, Director
Office of National AIDS Policy
808 17th Street, N.W.
8th Floor
Washington, D.C. 20006

Dear Ms. Thurman:

As Cathy Wilfert notes in the lead editorial in this issue of *HIV Newsline*—an issue devoted to the treatment of HIV infection in women and children—we have minimal data on the efficacy and safety of any antiretroviral agents other than ZDV in pregnant women and their offspring. This is a very unfortunate situation, because common sense and medical ethics both tell us that seropositive women who become pregnant should receive optimal antiretroviral therapy despite their pregnancy. And so, of course, should infants born to HIV-infected mothers.

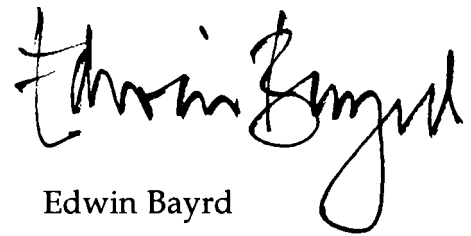
This paucity of information reflects medicine's traditional proscription against including pregnant women in clinical studies. To address this situation we have assembled, in this issue, all of the current clinical data on antiretroviral therapy for women and children—including the newest U.S. Public Health Service guidelines for the use of these drugs during pregnancy, guidelines released just before we went to press.

In a sense, the current issue of *AIDS Care* is also a special issue. This time the subject is pain, and we offer readers two approaches to the subject: one involves the use of standard analgesics, the other involves the use of a non-traditional remedy, acupuncture—which seems especially effective against peripheral neuropathies.

I encourage you to read Paul Volberding's editorial in the enclosed issue of *AIDS Care*. In it, he makes a strong case for expunging the term "alternative therapy" from our vocabulary. What we should call such non-traditional techniques, Paul declares, is complementary or concurrent therapies—because if they work for the patient, then they work. We don't know *why* they work, but then we don't know why ZDV is so successful in reducing perinatal HIV transmission rates either.

Our good work continues, and Paul and I will have news about an exciting new project to report to you next month.

Cordially,

A handwritten signature in black ink, appearing to read "Edwin Bayrd". The signature is fluid and cursive, with a large, sweeping loop at the end of the last name.

Edwin Bayrd

EB:ek
Encls.



National Council for International Health

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Washington, DC 20006-1503 USA
Tel: 202-833-5900 - Fax: 202-833-0075
E-mail: <ncihids@ncihids.org>

FAX TRANSMITTAL

To: Sarah

Fax: 4122-732-7359 202-632-1096

At: ONAP

Tel: _____

From: Ron MacInnis / Helen Cornman

Date: 8/15/97

At: Global AIDS Program

No of Pages: 1

MEMORANDUM

Dear Sarah,

Attached are our bios. Its strange to write a one paragraph bio of yourself - try it. We sound so capusulized and dry. Please let Ms. Thurman know that we're really a lot of fun and pretty easy-going, despite the stodgy sounding, obituary-like, paragraphs attached.

We think Patsy Fleming will be joining us for the meeting on Tuesday. Patsy is working with us as a consultant for a project we're working on with UNAIDS to enhance domestic ASO awareness of / and interaction with, global AIDS issues. Our President, Frank Lostumbo, will not be available to attend the meeting, but will make arrangements to meet with Sandra at a later time.

Let us know if you need any further information from us before our meeting on Tuesday. We look forward to meeting you and the rest of the staff.

Once again, thank you for your kind efforts on our behalf.

Helen and Ron.

Helen Cornman is a program officer in the Global AIDS Program of the National Council for International Health (NCIH). Prior to joining NCIH, Helen worked for The Guatemalan Association for the Prevention and Control of AIDS (AGPCS) for two years. Her responsibilities with AGPCS included pre and post test counseling, coordination of the only two HIV clinics in Guatemala and the development and coordination of a clinic/HIV prevention project for sex workers in Guatemala City, "La Sala". Helen's previous work experience is in project development, coordination and evaluation, grant writing, HIV education, counseling and care, training facilitation and community organizing. She has participated in several international workshops and recently served as a presenter at the XI International Conference on AIDS in Vancouver, July 1996. She has a Master's Degree from Boston University and has been working in the field of HIV/AIDS since 1987. She is currently coordinating efforts to provide nutritional supplements and treatment medications to HIV/AIDS clinics in Guatemala. She is fluent in Spanish.

Ron MacInnis is a program officer in the Global AIDS Program of the National Council for International Health (NCIH). Ron's prior work experience includes 5 years as a trainer and health policy technical adviser with World Vision International, USAID, and US Peace Corps for health, development, and HIV/AIDS projects in Zaire, Rwanda, Senegal, and Mali. In addition to his skills as a training coordinator and community organizer, he is experienced in project development, grant writing, and program evaluation. He has also worked as a journalist and communications specialist both domestically and internationally, and is currently editor of the NCIH publication, *AIDSLink*. In addition to his undergraduate studies in politics and journalism, he attended the international MPH program at the Boston University's School of Public Health. He is a member of the Global Network of People Living with HIV/AIDS (GNP+) and is a board member of the Centre d'Assistance Socio-Medicale (CASM) HIV/AIDS clinic in Abidjan, Cote d'Ivoire. He is a native of Sudbury, Massachusetts and has lived in Washington, DC since last year. He is fluent in French.