FOIA Number: 2018-0764-F

FOIA MARKER

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Correspondence - Sandra L. Thurman - Outgoing - 10/97

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Withdrawal/Redaction Sheet
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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. letter	Sandra Thurman to Inmate living with HIV re: Advisory Council (Personal) [partial] (1 page)	10/14/1997	b(6)
001b. form	re: Correspondence routing slip (Personal) (1 page)	07/15/1997	b(6)
001c. letter	Inmate living with HIV to Sandra Thurman re: Advisory Council (Personal) [partial] (1 page)	07/06/1997	b(6)
001d. form	re: Correspondence routing slip (Personal) (1 page)	06/02/1997	b(6)
001e. letter	Inmate living witth HIV to Sandra Thurman re: Advisory Council (Personal) [partial] (1 page)	05/23/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

2018-0764-F
jm2100

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]

School of Nursing

UNIVERSITY OF MARYLAND
BALTIMORE

December 10, 1997

Ms. Sandra Thurman, Director
The White House Office of National AIDS Policy
808 17th St., NW, Suite 820
Washington, DC 20006

Dear Ms. Thurman,

This is a request to ask for a letter of support for the University of Maryland School of Nursing's exciting new project to provide primary health care and health promotion education for women in a residential drug treatment program on board the retired Naval Hospital Ship, The Sanctuary. The Ship will be permanently docked in the inner harbor. This project, designed by Project Life, is a new and innovative approach to "create a residential education program designed to keep the women addict clean by teaching her how to live a healthy, productive and law-abiding life." Project Life's goal is to help chemically dependent women to become employed, self-supporting providers who take responsibility for themselves, their families and the community at large. As you well know, the economic cost of untreated substance abuse is almost as alarming as the number of people who are chemically dependent. In Maryland, with a population of 5,046,050, ten percent (500,000 people) are reported to have a substance abuse problem according to Maryland's Department of Health and Mental Hygiene. Statistics from the Maryland's Alcohol and Drug Abuse Administration show that a minimum of 260,000 individuals are in need of addiction intervention services. With a limited amount of money available for drug treatment and a limited amount of publicly funded treatment slots, we would like to support this program by providing the primary health care needed for the women while in residence.

The School of Nursing would provide a dedicated team of health care professionals, including advanced practice nurses with training and experience in women's health care, adult care and mental health, to assume management of the primary health care needs of The Sanctuary residents. This program of care would include a complete initial health assessment, screening, history and physical examination for all potential Sanctuary residents, ongoing diagnostic, treatment and health maintenance services for Sanctuary residents which would be provided through regularly scheduled clinical hours on the ship and "on-call" availability for emergency consultation. The School of Nursing currently provides primary health care services through many of its own nurse-managed centers, as well as through contracts for services with prominent health care organization throughout the State.

685 West Baltimore Street
Baltimore, Maryland 21201
410 706 8195 TELEPHONE
410 706 0345 FAX

Phyllis Sharps, Ph.D, R.N.
Ruth Harris, " "
Univ. of MD S.O.N.
HSF, Rm. 134
685 W. Baltimore St.
Balt, MD 21201

Dear Ms. Sharps + Ms. Harris:

The Office of National AIDS Policy is pleased and proud to support University of Maryland School of Nursing's new sanctuary project. ~~board The Sanctuary~~ This exciting and innovative project ~~promises~~ offers hope and self-sufficiency for chemically-dependent women.

As the spread of HIV increased (related) to substance abuse, it is certainly encouraging to know the Sanctuary will be equipping women with not the only health care but skills to w/ quit drugs and lead healthy lives.

I wish you the best in undertaking a project with such ~~hopeful~~ and beneficial ~~repercussions~~ immense great proportions but also one of obvious immense rewards.
w/

Sincerely,

Sandra Thurman
Director
Office of Nat'l AIDS Policy.

Additionally, experienced faculty from the School of Nursing would develop a customized curriculum of women's health education to be delivered as an integral component of The Sanctuary program. This will include such topics as HIV/AIDS prevention, nutrition, parenting skills, family planning, human development, personal health care and promoting mental health/well being.

Not only will our faculty benefit by the experiences that the Sanctuary will provide, but there will be many exciting learning experiences for students in our nurse practitioner, clinical specialist, addiction, and community health graduate programs as well as students in our undergraduate program.

We are planning to submit a Special Projects grant to the Division of Nursing, NIH, in January as Steve Hammer, Director of Project Life, would like to start the program this spring.

We are very appreciative of the support you have provided the University of Maryland School of Nursing, in the past, and we are hoping that we can count on you to support our primary health care program on board the Sanctuary. We realize that we are asking for this letter to be written in a very short period of time and during a very busy time of the year, but we would appreciate it if we could have the letter by ~~January 9, 1998.~~ FAX 410-706-0345

Please address your letter to:
Phyllis Sharps, Ph.D., R.N.
Ruth M. Harris, Ph.D., R.N.
University of Maryland School of Nursing
Health Science Facility, Room 134
685 West Baltimore Street
Baltimore, MD 21201

Additional information about the Sanctuary Program is enclosed. If you should require more information, please contact us. Thank you for your support.

Sincerely,

Phyllis W. Sharps

Phyllis W. Sharps, Ph.D., R.N.
~~Principal~~ Investigator

Ruth M. Harris

Ruth M. Harris, Ph.D., R.N., A.N.P.-C
Principal Investigator

Second Draft

OK w/ changes RK Fuller 10/10/97

October 14, 1997

Mrs. Shirley Grey
President, Board of Directors
HIVCO
1471 Business Center Drive
Suite 500
Mount Prospect, IL 60056

Dear Mrs. Grey:

Congratulations on 10 ~~wonderful~~ years of ~~valued~~ exceptional service to the HIV community in the suburbs of Chicago. I would also like to extend well deserved praise and recognition to the Junior League of Evanston-North Shore and the Cook County Department of Public Health for their enduring commitment to persons with HIV/AIDS and to their pivotal roles in the founding of your fine organization.

It is with deep regret that I will be unable to attend your special event on Friday, October 17, due to a previous commitment. I greatly appreciate your invitation and wish all of you in the HIVCO family continued success.

Yours sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

C:\WORK\WP\HIVCO.WPD

October 14, 1997

Mrs. Shirley Grey
President, Board of Directors
HIVCO
1471 Business Center Drive
Suite 500
Mount Prospect, IL 60056

Dear Mrs. Grey:

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Yours sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

C:\WORK\WP\HIVCO.WPD

THE WHITE HOUSE

WASHINGTON

October 14, 1997

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1471 Business Center Drive
Suite 500
Mount Prospect, IL 60056

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Yours sincerely,

Sandra L. Thurman

Sandra L. Thurman
Director
Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

November 13, 1997

Linné Girouard, DIFFA
c/o Donna Barrett
Wortham Center
via fax: 713-237-9313

Dear Friends:

As a longtime friend and colleague of DIFFA's Executive Director, David Sheppard, I know how much he regrets not being able to celebrate this milestone with you. Long before President Clinton appointed me as National Director of AIDS Policy, I had the honor of chairing "Heart Strings" for DIFFA in Atlanta. David was singing DIFFA Houston's praises then and tangible proof of your continued success can be found today in the grants to local service providers which total over $2.5 million.

Today, we face new challenges brought on by the good news of combination therapies: complacency among donors who think we no longer need their help and among volunteers as well who are battle weary and want to believe that the good news is better than it may ultimately be. Your leadership is needed now more than ever before.

I join you in honoring the individuals and organizations who have fought so long and hard on behalf of your friends, families and neighbors and extend heartfelt gratitude to you, DIFFA Houston, for making a decade of difference in your community.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

DIFFA
DESIGN
INDUSTRIES
FOUNDATION
FIGHTING
AIDS

David Sheppard, Executive Director
Design Industries Foundation Fighting AIDS
150 West 26th Street, Suite 602
New York, New York 10001
Telephone•212-727-3100
Fax•212-727-2574

memo by fax

Date: November 13, 1997

Memo to: Sandy Thurman Fax: 202-632-1096

Sandy, thank you for helping me on this! I think you know that I love the way you put words together. The following text was done strictly to make this as easy as possible, so feel free to have your way with it. The DIFFA Houston Chair is Linné Girouard. Performance is tonite.

•••

I had the honor of Chairing

As a longtime friend and colleague of DIFFA's Executive Director, David Sheppard, I know how much he regrets not being able celebrate this milestone with you. Long before President Clinton appointed me National Director of AIDS Policy, I [redacted] "Heart Strings" for DIFFA in Atlanta. David was singing DIFFA Houston's praises then and tangible proof of your continued success can be found today in the grants to local service providers which total over $2.5 million.

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Sandy Thurman
National Director of AIDS Policy

Fax to: Linné Girouard, DIFFA
c/o Donna Barrett
Wortham Center
713-237-9313

Thank you!

150 West 26 Street
Suite 602
New York, NY 10001
212.727.3100
Fax 212.727.2574

THE WHITE HOUSE

WASHINGTON

October 29, 1997

Sandra E. Ritter
Cecil County AIDS Alliance
HERO Buddy Program
120-A W Main Street
Elkton, MD 21921

Dear Ms. Ritter:

Thank you for your letter sharing the wonderful work you've been doing in combating HIV/AIDS in your community. I am delighted that the First Annual Susquehanna AIDS Walk was such a success and I wish you continued achievement as you carry on in your efforts to fight this epidemic.

Your dedication in working toward the eventual control of the HIV/AIDS pandemic is important and your offer of support is greatly appreciated. It is only through working together that we will beat this disease.

Again, I congratulate you and encourage you to keep up the good work.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10203	Sandra	Ritter	10/1/97

Addressed To
Thurman, Sandra

Sender's Organization
Cecil County AIDS Alliance, HERO Buddy Program

Sender's Street1

Sender's Street2

Sender's City	Sender's State	Sender's Zip

Subject
Thank you letter

☐ Response Needed?

Response Type	Response Date	Responder ID
none		

Responder Name	Action Promised	Action Complet	Action Date

Notes

Thanks for writing
Congratulations
& keep up the good work

September 30, 1996

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

Dear Ms. Thruman,

On October 14, 1996, I met you at a HERO Appreciation Gala held at the Johns Hopkins University in Baltimore, Maryland. I must say I am very impressed with your committment, dedication and your genuine sincerity shown for this dreaded disease.

I mentioned our First Annual Susquehanna AIDS Walk to take place September 28, 1996 in the historic little town of Havre de Grace, Maryland. Remember I showed you our T-shirt and the gentleman took our picture? Well, Ms. Thruman it is with a swelled chest and watered eyes that I report the success of our event. Cecil County AIDS Alliance, Harford County AIDS Alliance, along with Recovery Friends Care worked most diligently to make this happen. First we raised enough money from local patrons to absorb the event costs so that all the pledge money from the walkers would benefit the HIV/AIDS population directly! Ryan White and HOPWA funds get exhausted so rapidly that we just thought our groups could help. Ms. Thruman we raised and estimated $20,000 just through pledges. I am so pleased and just wanted to share this with you.

Every day is a challange with this disease and I do so hope you know I am doing my best to stay involved, promote awareness, education and prevention. Need me, just call. Again thank you for staying in and hanging on. Your "coming from the trenches" makes the understanding of the devistation more real. Please just know Cecil County is working to fight this dreaded HIV/AIDS disease. Your presentation on CNNBC in Miami was also wonderful!

Respectfully I remain,

Sandra E. Ritter
Cecil County Aids Alliance
HERO Buddy Program

October 2, 1997

Miss Dee Schneider
1460 NE 169th St., Apt. 108
North Miami Beach, FL 33162

Dear Miss Schneider:

Thank you for your recent letter. The President and I are sorry to hear about your cousin. We want you to know that we are trying to do everything within our power to make blood products safe.

We would like to assure you that we will continue to propose and support increases in funding for medicines for HIV/AIDS patients. Also, we would like to mention that money given to AIDS drugs through the Ryan White Care Act has tripled in the past year.

Thank you for taking time to write us during this difficult period.

Yours sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 20, 1997

W. Ron Allen
President
National Congress of American Indians
2010 Massachusetts Ave, NW
Second Floor
Washington, DC 20036

Dear Mr. Allen:

I apologize for the delay in responding to your letter dated July 2 which discusses the formation of an interagency working group on HIV/AIDS to further the recommendations of the American Indian/Alaska Natives/Native Hawaiians Policy Roundtable convened by this office in February.

As requested, I would be pleased to meet with you and appropriate members of your staff to discuss how we may more fully address this and other recommendations made during the Policy Roundtable. I will have my staff call to arrange this meeting in the near future.

This office understands the complexity of HIV/AIDS in Indian Country and looks forward to working with the National Congress of American Indians in meeting the needs of American Indians/Alaska Natives/Native Hawaiians.

Sincerely yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 24, 1997

To the attendees of the Association of Nurses in AIDS Care 10th Annual Conference:

This is an *extraordinarily* important time for everyone whose lives are touched by HIV and AIDS. Recently there has been a sense of great hope and optimism generated by new combination drug therapies. We know that these new therapies do in fact help some people for some time, often in miraculous ways. And for that we are enormously grateful.

But we also know that for millions of Americans these new drugs are still out of reach. We know that the blinding ignorance born of racism and homophobia still feeds this epidemic. And we know that the twin epidemics of HIV and drug abuse put many at risk for HIV and lead many to question proven prevention strategies like needle exchange.

So the reality of emerging new drug therapies keeps us optimistic, but it cannot make us complacent.

The epidemic is far from over. Yes, the number of deaths from AIDS has declined. That means that those *living* with HIV and AIDS are enjoying longer and better lives. However, we also know that the number of new HIV infections --- 40,000 per year in this country and 3 million per year across the globe --- has not slowed. In reality, there is every reason to believe that the misperception that we have a cure is leading many into a false sense of security that threatens prevention efforts and fuels public and political indifference.

It is our responsibility to temper hope with realism by sharing the reality that AIDS is still thriving here and, indeed, around the world. We must keep spreading the message of prevention. There may not be a cure to this disease yet, but the transmission of HIV is containable, so long as people are properly educated and equipped to protect themselves. We must also continue to offer care to those living with HIV and AIDS by ensuring access to adequate medical treatment, supportive services, as well as the best medicine of them all --- basic human kindness. A warm heart and attentive ear can still go a long way!

There are indeed many waves that we still must navigate before reaching our final destination, a day without AIDS. But none of us came into this work to get rich or to get home by 5! We came into it to keep people alive.

Most of us do not take the time to acknowledge how much pain and anguish we witness and experience, so let me thank you for your strength, your courage, and your perseverance. Nurses are the often unsung heroes who are there alongside patients with HIV and AIDS, holding their hands, giving them hope and offering them heartfelt compassion on a daily basis. Your tireless dedication deserves our utmost appreciation and tribute.

Together, in the words of Mother Jones, "we must pray for the dead and fight for the living!" So onward with our work.

Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 15, 1997

Carolyn Branson
HIV/AIDS Program Manager
American Red Cross
National Headquarters
Jefferson Park
8111 Gatehouse Road
Falls Church, VA 22042-1203

Dear Carolyn:

My thanks for sending along the Red Cross HIV/AIDS prevention materials and for taking time from your busy schedule to meet with me.

I also appreciate the offer to utilize your large network of chapters, military stations, staff and volunteers. They represent an extraordinary opportunity to extend the prevention message.

I look forward to working with you, Mark Robinson and others at the Red Cross as we seek an end to this terrible epidemic.

Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

October 15, 1997

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8111 Gatehouse Road
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Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

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ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10199	Carolyn	Branson	10/1/97

Addressed To

Thurman, Sandra

Sender's Organization

American Red Cross

Sender's Street1

Sender's Street2

Sender's City	Sender's State	Sender's Zip

Subject

thanks for meeting

☐ Response Needed?

Response Type	Response Date	Responder ID
none	10/15/97	

Responder Name	Action Promised	Action Complet	Action Date

Notes

American Red Cross

National Headquarters
Jefferson Park
8111 Gatehouse Road
Falls Church, VA 22042-1203

September 23, 1997

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

Dear Sandy:

Belated thank you for taking time to meet with Susan Livingstone and me. We appreciated having the chance to update you on American Red Cross HIV/AIDS prevention education efforts around the country and to offer our assistance in any way we can help.

Our 1400 chapters and military stations, our Statewide HIV/AIDS Networks (SWANs), and our thousands of volunteer and paid staff provide multiple grass roots possibilities. So, please let us know what we can do.

Unfortunately, Susan Livingstone is no longer with the Red Cross. We miss her greatly, but look forward to working with our new vice president, Mark Robinson.

As promised, we are sending several Red Cross HIV/AIDS materials for your library under separate cover. At your request, an extra copy of our *Facts Book* is included for your personal library. (We are updating the *Facts Book* this year, and will forward a revised copy when it is available.)

We also would love to brief all your staff at your convenience as we discussed, either here in Falls Church or at your office. I will be the contact person [(703) 206-7429] to arrange for the briefing. Again, our thanks for meeting with us.

Sincerely,

Carolyn

Carolyn Branson
HIV/AIDS Program
Manager

THE WHITE HOUSE

WASHINGTON

October 15, 1997

Alex Weinerman
Senior Vice President
Director of Scientific Affairs
McCann HealthCare, Inc.
515 North State Street, Suite 2400
Chicago, IL 60610

Dear Mr. Weinerman:

Thank you for sending along a copy of your letter to the President regarding his AIDS Vaccine Initiative. I also appreciate the information you forwarded regarding your suggestion for an AIDS vaccine.

I have forwarded a copy of your letter to Dr. David Baltimore, who is heading up an advisory committee on AIDS vaccines for the National Institutes of Health. They are a more appropriate body to evaluate the merits of your recommendation.

Again, thank you for your work to find a vaccine against AIDS.

Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

October 15, 1997

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Senior Vice President
Director of Scientific Affairs
McCann HealthCare, Inc.
515 North State Street, Suite 2400
Chicago, IL 60610

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Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

N:\THURMAN\LETTERS\97OCT\WEINERMA.WPD

AIDS Action council

October 27, 1997

Helene Gayle
Director, Center on HIV/AIDS, STD, and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333

Dear Dr. Gayle:

AIDS *Action*, representing over 2,000 community-based organizations, is writing to express concern over the Centers for Disease Control and Prevention's (CDC) efforts to modify the nation's current AIDS/HIV surveillance system by moving to a names based system for HIV reporting. AIDS *Action* recently resolved to support HIV reporting by unique identifiers (UI) and other non-names based surveillance systems (see enclosure).

Given our community's long-standing history of working together to resolve difficult issues and implement sound public health policies, we are concerned about the method and speed by which CDC is moving to implement a new HIV names reporting system. **AIDS *Action* urges the CDC to reconsider the rapid implementation of a new HIV surveillance system based on names.** Instead, we propose that the CDC continue to work with community, health, and state advocates in developing a new HIV surveillance system that will gather the data we need to have a more accurate picture of the epidemic.

1875
Connecticut Ave NW
Suite 700
Washington DC
20009
Fax 202 986 1345
Tel 202 986 1300

Although all states conduct AIDS surveillance based on names, the prospect of adopting this system for HIV is significantly different and potentially more devastating. We are deeply concerned that the CDC's new system will not take into consideration a myriad of complex issues such as:

- removing barriers to testing including increasing the availability of anonymous testing;
- confidentiality and privacy concerns;
- linkages to care and new treatments; and
- development of sophisticated non-names based HIV surveillance systems.

These issues are critical to the success of any new HIV surveillance system that is developed. For example, we believe the CDC needs to be more vigilant about encouraging HIV testing, ensuring confidentiality, and removing obstacles that discourage testing. The collection of names on central HIV registries will serve as a serious deterrent to HIV testing, particularly for individuals in high-risk groups. The absence of anonymous testing in a number of states is disturbing and also

serves as a deterrent to individuals seeking testing. **AIDS *Action* recommends that CDC encourage all states to provide anonymous testing to ensure that individuals are not deterred from seeking HIV testing.** Reversing the trend exemplified by the ten states that do not offer anonymous testing, but have HIV names reporting, is essential.

In the area of confidentiality and privacy, it is important to consider that HIV names registries are likely to be kept for 20-30 years instead of the 20-30 months that the registries were kept for individuals with end stage AIDS diagnoses. People with HIV infection are still working, applying for insurance and loans, all of which could be jeopardized by the mishandling of these registries. In light of these circumstances and recent court decisions which suggest that asymptomatic HIV positive individuals may not be afforded discrimination protections under the Americans with Disabilities Act, we have grave concerns about a names based system.

Linkages to care and access to early interventions are essential to help HIV infected individuals stay healthy. However, the proposed new system would do little to help HIV infected populations access our medical care system and the promising new treatments that are now available. Individuals with AIDS who are now reported are eligible for disability income support programs and Medicare and Medicaid. We believe that before any new system is adopted, we need to further explore the relationship a new CDC initiated HIV surveillance system would have with the programs at the Health Resources Services Administration (HRSA), and the Health Care Financing Administration (HCFA).

Further, AIDS *Action* is especially disappointed that the CDC has not adequately invested resources in the development of non-names based HIV surveillance systems such as Maryland's UI system. States should be encouraged to develop non-names based systems and they should be provided with adequate resources necessary to start-up and perfect these systems. Since non-names systems such as UI's are new to the United States, states choosing this option should be given time to modify and adjust their operations in order to insure maximum effectiveness and reliability of data. Options regarding surveillance systems can only be effectively evaluated if properly funded and all investments including start-up costs are evenly distributed to states (e.g., New Jersey received dollars for creating a name based system whereas Maryland received only evaluation money). **AIDS *Action* recommends that the CDC provide the necessary resources to support the efforts of states to create and improve UI reporting systems and other non names-based surveillance systems without reducing the funding available for prevention programs.**

We are also concerned about your expected endorsement of HIV reporting by name in the November issue of the Morbidity and Mortality Weekly Report (MMWR) coupled with the publication of a study evaluating the UI systems in Maryland and Texas. **AIDS *Action* urges that you reconsider the publication of a CDC**

editorial position at this time. We are also concerned about the publication of the UI evaluation study given CDC's lack of investment in the development of these systems and demonstrated bias regarding support of states that implement HIV surveillance by name.

AIDS *Action* welcomes the opportunity to work with you on this important issue and we will contact you in the next few weeks to set up a meeting. Thank you for your consideration of our views.

Sincerely,

Daniel Zingale
Executive Director

cc: Mr. Kevin DeCock
Ms. Nancy Ann-Min DePearle
Mr. Don Gips
Mr. Josh Gotbaum
Mr. Chris Jennings
Hon. Nancy Pelosi
Mr. David Satcher
Hon. Donna Shalala
Mr. Richard Socarides
Mr. Kevin Thurm
Ms. Sandy Thurman
Mr. John Ward

AIDS ACTION RESOLUTION IN SUPPORT OF HIV REPORTING BY UNIQUE IDENTIFIER AND OTHER NON NAME-BASED SURVEILLANCE SYSTEMS

WHEREAS, AIDS surveillance and AIDS case reporting do not provide an accurate view of the extent of the epidemic nor give a timely and complete indication of trends in the epidemic; and

WHEREAS, generating data which is more representative of the scope of the epidemic can help us better allocate limited resources, target and evaluate prevention efforts, educate the public about the epidemic, and project where the epidemic is going; and

WHEREAS, HIV names reporting may discourage individuals from seeking HIV testing and treatment and the implementation of HIV names reporting is not currently accompanied by guaranteed access to care and treatment; and

WHEREAS, no strong federal privacy law governing health information currently exists and state privacy protections are inadequate; and

WHEREAS, recent court decisions suggest limited or no discrimination protections for asymptomatic HIV positive individuals under the Americans with Disabilities Act (ADA); and

WHEREAS, the negative aspects of name reporting, in the absence of guaranteed access to health care and strong privacy protections, outweigh the potential benefits of this approach; and

WHEREAS, non name-based surveillance systems, such as unique identifier reporting and population based sampling, will support the public health goals of providing data which can help us allocate limited resources, targeting and evaluating prevention efforts, educating the public about the epidemic and projecting where the epidemic is going, while protecting confidentiality and not discouraging people from seeking HIV testing.

BE IT RESOLVED:

That AIDS Action supports the development of non name-based HIV surveillance systems, including unique identifiers, to achieve the public health goals of HIV surveillance.

That AIDS Action opposes name based HIV surveillance.

That AIDS Action calls on the federal government to provide the resources necessary to support the efforts of states to create and improve unique identifier reporting systems and other non name-based surveillance systems without reducing the funding available for prevention programs.

That AIDS Action calls on the federal government to require states which have adopted or may adopt a names reporting system to provide and/or continue a publicly-funded anonymous testing option to ensure that individuals are not deterred from seeking HIV testing.

That AIDS Action calls on the Clinton Administration and the United States Congress to move forward expeditiously to enact and implement a strong federal confidentiality law which serves as a minimum standard for protecting the privacy of all health-related information.

That AIDS Action calls on the federal government to initiate efforts to guarantee access to care and treatment for all HIV positive individuals.

Adopted by the Board of Directors of the AIDS Action Council, October 18, 1997

ONAP Letter Tracking

Letter ID	Writer First Name	Writer Last Name	Received Date
10124	alex	weinerman	9/16/97

Addressed To

Thurman, Sandra

Sender's Organization

mcCann healthcare, inc.

Sender's Street1

Sender's Street2

Sender's City	Sender's State	Sender's Zip

Subject

aids vaccine

☑ Response Needed?

Response Type	Response Date	Responder ID
thanks		

Responder Name	Action Promised	Action Complet	Action Date
intern			

Notes

McCANN HEALTHCARE, INC.

September 9, 1997

Ms. Sandra Thurman
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Ms. Thurman:

I was very interested in learning of your position as a leader in the effort to combat AIDS. You might be interested in a communication I sent to the President (copy enclosed). I received a reply thanking me for my interest, but was very disappointed that no mention was made of my suggestion for an AIDS vaccine.

There is much general comment on the need for an AIDS vaccine, and how unfortunate it is that the search has been unsuccessful. My suggestion for use of an HIV epitope has actually been reported to be successful. (See enclosed abstract of a report published in Nat. Med.) This type of vaccine can also be used as a therapeutic agent. It can result in destruction of HIV-invaded cells. That effect is due to the cytotoxic T cells that propagate with use of the vaccine.

Perhaps such an agent could prove very effective if used alone. However, it should provide significant complementary action to the specific anti-HIV drugs. It should have few, if any, side effects. If by its use the expensive drugs could be administered in much-reduced dosage, cost and side effects could substantially be reduced.

I hope you have great success in your assignment.

Sincerely yours,

Alex Weinerman
Senior Vice President
Director of Scientific Affairs

Suite 2400, 515 North State Street, Chicago IL 60610 Phone 312-836-9870 Fax 312-832-1360

McCANN HEALTHCARE, INC.

May 20, 1997

President Clinton
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Sir:

Your support for further research for an AIDS vaccine is most encouraging.

You may be interested to learn that there has been some encouraging work already done in this area. Enclosed please find the abstract of a report indicating a successful effort with a vaccine for preventing the infection[1]. The vaccine consists of a part of an HIV protein, called an epitope, that when administered produces a significant increase in so-called cytotoxic T lymphocytes which destroy HIV invaded cells.

An epitope is a small part of an antigen protein. It is an immune reactive part that is a key factor in the production of an immune response. Since it consists only of about 8 to 10 amino acids, it may be conserved intact if there is a mutation that results in a change in the structure of the protein.

You can see from my enclosed correspondence with Merck and Genentech[2] that I have been trying to develop interest in this concept. The enclosed reply from Merck is rather astonishing[3]. They did use the epitope technique in studies with monkeys. They used an epitope of a simian immunodeficiency virus (SIV). They got an encouraging immune response, an increase in cytotoxic T lymphocytes. But then they misapplied it. They tested it for protection against infection with a cell-free virus. Cytotoxic T lymphocytes will not work against a cell-free virus. The African study cited above involved natural infection in which most of the virus is present in invaded cells. The vaccine could, and in this case did, work to prevent infection.

Much of the vaccine work, so far, has been with attempts to develop an antibody response to the virus. Since most of the viral particles are present in blood cells, it is unlikely that such a vaccine can have much of an effect.

Of course, there is still much work to be done to determine the best conditions for use of an epitope vaccine. However, at least there is already some evidence that such a vaccine might work.

This type of vaccine may not only be an effective preventative, it may also be an effective therapy since it produces destruction of HIV-invaded cells.

It probably could work effectively in combination with one or more of the anti-HIV drugs now available.

Sincerely yours,

Alex Weinerman

Alex Weinerman
Senior Vice President
Director of Scientific Affairs

Suite 2400, 515 North State Street, Chicago IL 60610 Phone 312-836-9870 Fax 312-832-1360

(Continued from p 1160 d.)

Hepatitis B Virus Strains With Mutations in the Core Promoter in Patients With Fulminant Hepatitis

Objective: Fulminant hepatitis B can be induced by hepatitis B virus (HBV) strains with mutations in the precore region that cannot encode hepatitis B e antigen (HBeAg). Such mutations are rarely seen in HBV DNA clones from patients with fulminant hepatitis B in the United States and France. Thus, the other mutations in HBV strains causing fulminant hepatitis B need to be identified.

Design: Retrospective clinical, serologic, and molecular biological studies of patients with fulminant hepatitis B.

Setting: University and city hospitals in Japan.

Patients: 43 patients with fulminant hepatitis B.

Measurements: The precore region coding for a part of the HBeAg precursor and the core promoter regulating the transcription of precore messenger RNA were sequenced in HBV DNA clones.

Results: A point mutation from G to A at nucleotide 1896 in the precore region was detected in 519 (98%) of 529 HBV DNA clones from 38 patients. Two point mutations in the core promoter, from A to T at nucleotide 1762 and from G to A at nucleotide 1764, were detected in all 130 clones from the remaining 5 patients, who did not have mutations in the precore region, and in 20 (63%) of 32 clones from a patient with chronic hepatitis B who had transmitted HBV to 1 of these other 6 patients. Mutations in the core promoter were also detected in clones from 26 (68%) of the 38 patients with the precore mutation at nucleotide 1896. Neither HBeAg nor antibody to HBeAg was detected in 37 (90%) of the 41 patients tested.

Conclusions: In Japan, fulminant hepatitis B is closely associated with HBV strains that do not produce HBeAg because of mutations in the precore region, which affect translation of HBeAg, or because of mutations in the core promoter, which affect transcription of the HBeAg coding region.

(1995;122:241-248) Shunichi Sato et al. Reprint requests to Makoto Mayumi, Immunology Division, Jichi Medical School, Tochigi-Ken 329-04, Japan.

HIV-Specific Cytotoxic T-Cells in HIV-Exposed but Uninfected Gambian Women

A crucial requirement in the rational design of a prophylactic vaccine against the human immunodeficiency virus (HIV) is to establish whether or not protective immunity can occur following natural infection. The immune response to HIV infection is characterized by very vigorous HIV-specific cytotoxic T-lymphocyte (CTL) activity. We have identified four HIV-1 and HIV-2 cross-reactive peptide epitopes, presented to CTL from HIV-infected Gambians by HLA-B35 (the most common Gambian class I HLA molecule). These peptides were used to elicit HIV-specific CTLs from three out of six repeatedly exposed but HIV-seronegative female prostitutes with HLA-B35. These women remain seronegative with no evidence of HIV infection by polymerase chain reaction or viral culture. Their CTL activity may represent protective immunity against HIV infection.

(1995;1:59-64) Sarah Rowland-Jones et al. Molecular Immunology Group, Institute of Molecular Medicine, John Radcliffe Hospital, Headington, Oxford, England OX3 9DU.

Liposome-Mediated *CFTR* Gene Transfer to the Nasal Epithelium of Patients With Cystic Fibrosis

We report the results of a double-blind, placebo-controlled trial in nine cystic fibrosis (CF) subjects receiving cationic liposome complexed with a complementary DNA encoding the CF transmembrane conductance regulator (CFTR), and six CF subjects receiving only liposome to the nasal epithelium. No adverse clinical effects were seen and nasal biopsies showed no histological or immuno-histological changes. A partial restoration of the deficit between CF and non-CF subjects of 20% was seen for the response to low Cl^- perfusion following *CFTR* cDNA administration. This was maximal around day three and had reverted to pretreatment values by day seven. In some cases the response to low Cl^- was within the range for non-CF subjects. Plasmid DNA and transgene-derived RNA were detected in the majority of treated subjects. Although these data are encouraging, it is likely that transfection efficiency and the duration of expression will need to be increased for therapeutic benefit.

(1995;1:39-46) Natasha J. Caplen et al. Department of Biochemistry and Molecular Genetics, St. Mary's Hospital Medical School, Norfolk Place, London, England W2 1PG.

Prognostic Factors Predictive of Survival for Truncal and Retroperitoneal Soft-Tissue Sarcoma

Objective The authors identified prognostic factors relevant to clinical outcomes (especially survival) in truncal and retroperitoneal soft-tissue sarcoma.

Summary Background Data These results can be used to optimize surgical management and select patients most likely to benefit from novel therapeutic strategies in future trials.

Methods A retrospective analysis was performed of a prospectively compiled database of 183 consecutive patients with truncal and retroperitoneal sarcomas seen at the Brigham and Women's Hospital and the Dana Farber Cancer Institute between 1970 to 1994.

Results For truncal sarcoma, multivariate analysis showed that high-grade histology was associated with an eightfold increased risk of death compared with low-grade histology ($p = 0.001$). In addition to grade, gross positive margin of resection ($p = 0.001$), microscopic positive margin ($p = 0.023$), and tumors greater than 5 cm in size ($p = 0.018$) were important independent prognostic factors for survival. In this series, postoperative radiation therapy for truncal sarcoma was associated with a 2.4-fold decreased risk of death compared with truncal sarcoma patients receiving no adjuvant radiation therapy, having adjusted for the other prognostic factors ($p = 0.030$).

In contrast, for retroperitoneal sarcoma, multivariate analysis showed that high-grade and intermediate-grade histology were associated with a five- to sixfold increased risk of death compared with low-grade histology ($p = 0.009$). In addition to grade, gross positive margin of resection ($p = 0.001$) and microscopic positive margin ($p = 0.004$) were important independent prognostic factors for survival in retroperitoneal sarcoma. Patients who received either preoperative or postoperative chemotherapy for retroperitoneal sarcoma had a 4.6-fold ($p = 0.002$) and 3-fold ($p = 0.010$) increased risk of death, respectively, compared with patients receiving no adjuvant chemotherapy, having adjusted for the other prognostic factors.

Conclusions The histologic grade and the margin of resection are prognostic for survival in both truncal and retroperitoneal soft-tissue sarcoma. Tumor size was an independent prognostic factor for truncal sarcoma, but not for retroperitoneal sarcoma. Postoperative adjuvant radiation was beneficial to overall survival for truncal sarcoma. In this series of patients receiving a heterogeneous mixture of chemotherapeutic regimens—either as preoperative "neoadjuvant" therapy or as postoperative "adjuvant" therapy, there were no beneficial effects on survival compared with nonrandomized patients not receiving chemotherapy.

(1995;221:185-195) Samuel Singer et al. Division of Surgical Oncology, Brigham and Women's Hospital, 75 Francis St., Boston, MA 02115.

Numbers and Ratios of Visual Pigment Genes for Normal Red-Green Color Vision

Red-green color vision is based on middle-wavelength– and long-wavelength–sensitive visual pigments encoded by an array of genes on the X chromosome. The numbers and ratios of genes in this cluster were reexamined in men with normal color vision by means of newly refined methods. These methods revealed that many men had more pigment genes on the X chromosome than had previously been suggested and that many had more than one long-wave pigment gene. These discoveries challenge accepted ideas that are the foundation for theories of normal and anomalous color vision.

(1995;267:1013-1016) Maureen Neitz and Jay Neitz, Departments of Ophthalmology and Cellular Biology and Anatomy, Medical College of Wisconsin, 8701 Watertown Plank Rd., Milwaukee, WI 53226.

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. letter	Sandra Thurman to Inmate living with HIV re: Advisory Council (Personal) [partial] (1 page)	10/14/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

2018-0764-F
jm2100

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]

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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)]

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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]
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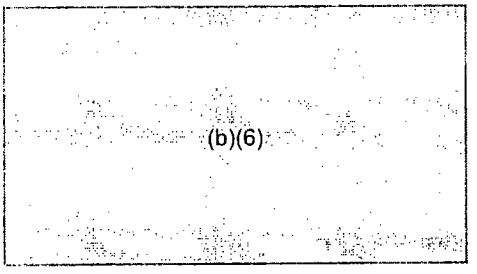
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

THE WHITE HOUSE

WASHINGTON

October 14, 1997



[0019]

Thank you for your interest in becoming a member of the Presidential Advisory Council on HIV and AIDS. I have forwarded your letter to Presidential Personnel in order that it receives proper attention and consideration.

The Council's Subcommittee on Prison Issues has been and will continue to work closely with the Justice Department and the Federal Bureau of Prisons in its commitment to effectively address the needs of the HIV-positive prison population. Your own contributions in working toward the eventual control of this epidemic are truly appreciated.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001b. form	re: Correspondence routing slip (Personal) (1 page)	07/15/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

2018-0764-F
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RESTRICTION CODES

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001c. letter	Inmate living with HIV to Sandra Thurman re: Advisory Council (Personal) [partial] (1 page)	07/06/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

2018-0764-F
jm2100

RESTRICTION CODES

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

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RR. Document will be reviewed upon request.

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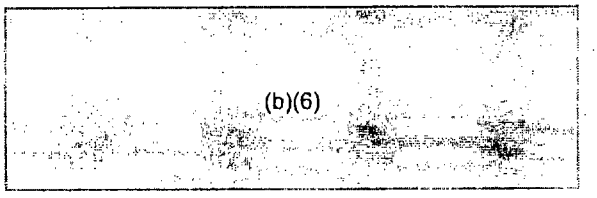
[001e]

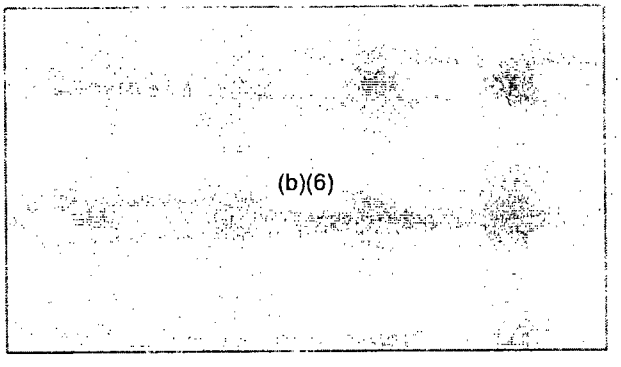


July 6, 1997

Director Sandy Thurman
Office of National AIDS Policy
750 17TH St. NW Ste 600
Washington, DC. 20503

Dear Sandy Thurman:

I am interested in your decision about the vacancies on the President's Advisory Council. I am extremly interested in filling one of the openings. Please let me know. Thank you!



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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001d. form	re: Correspondence routing slip (Personal) (1 page)	06/02/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

2018-0764-F
jm2100

RESTRICTION CODES

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May 23, 1997

Sandy Thurman, Director
Office of National AIDS Policy
750 17th Street, N.W., Suite 600
Washington, D.C. 20503

Dear Ms. Thurman,

I am aware of the vacancies in the President's advisory council on the HIV-positive population of federal incarceration facilities, and the policies which govern their care under federal law and regulation.

I respectfully request your consideration of me a member of this advisory council.

It is my understanding that the current criteria for appointment to this important panel does not include present incarceration of an HIV-positive inmate. I strongly disagree with such criteria because of my personal experience, and hope that you will consider appointment of at least one currently incarcerated individual who has experienced first-hand the administration of treatment for such federal prisoners.

If this advisory council is to be at all meaningful and successful, it is paramount that it include one who knows how prescription medication, counseling and in-confinement experiences are affected by the policies and implementation of those policies as determined by the federal government.

Frankly, my personal experience has not been altogether positive under what I admit are difficult circumstances which do not easily reconcile themselves with diverse societal judgment. However, I believe it is important to and consistent with this Administration's policy and claim of compassion that those of us who are suffering from HIV be treated fairly and humanely.

My experience here has lacked some fairness and some compassion. I have tried to understand that those acts which brought me to this facility cause me to bear some significant burden, but I still believe there is a better and more positive way for all of us to address the HIV issues which confront us.

I ask you not so much for myself but for all of those who share my diagnosis of HIV-positive what you set forth a policy within federal facilities which at the very least allows an opportunity for relief of suffering if not an opportunity for development of cures, remission or recovery.

It seems to me that a person like myself, who has experienced both an inconsistency in administration of treatment and an unreliable implementation of spoken policy, would be an asset and a source of important input to the advisory council you are posed to appoint.

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001e. letter	Inmate living witth HIV to Sandra Thurman re: Advisory Council (Personal) [partial] (1 page)	05/23/1997	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19399

FOLDER TITLE:
Correspondence - Sandra L. Thurman - Outgoing - 10/97

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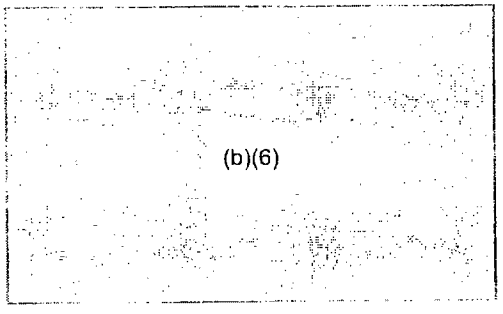
I offer myself not for personal gain or personal well-being, but for the long-term treatment of HIV-positive inmates who at minimum deserve humane treatment, access to available and experimental therapies and the ability to teach others about the transmission of the virus and what preventive steps can be taken to avoid exposure.

Again, I am respectfully requesting that you consider me for appointment to your council because of my experience as an inmate who is HIV-positive. I hope that my very positive record during incarceration would speak in my favor. But should you choose not to appoint me, I hope that you will keep in mind the importance of appointing one who has experienced first-hand the administration of policies toward HIV-positive federal inmates, which has been inconsistent and inconsiderate at best.



[0016]