

September 26, 1997

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President of the United States
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

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Sincerely,



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Member, HIV-Drug and Alcohol Task Force Client Committee

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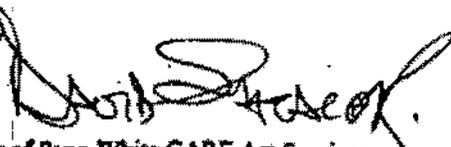
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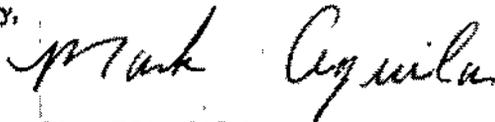
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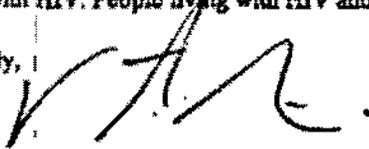
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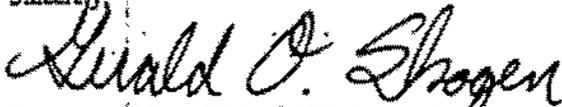
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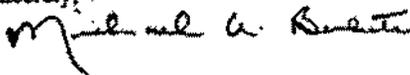
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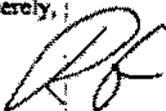
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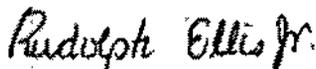
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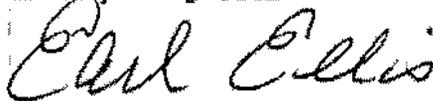
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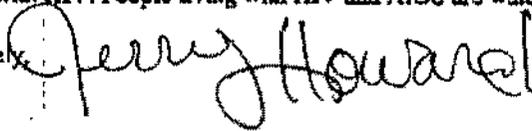
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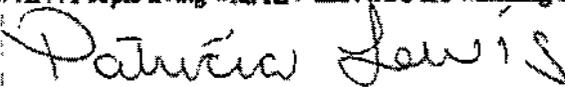
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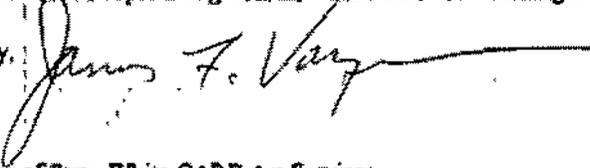
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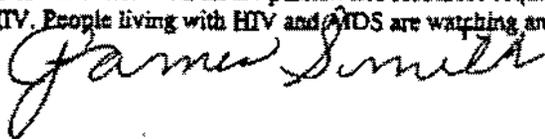
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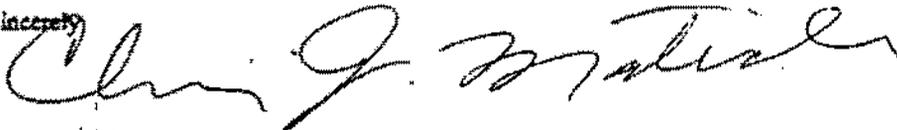
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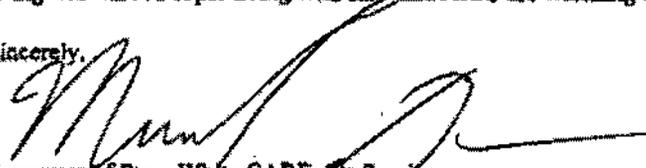
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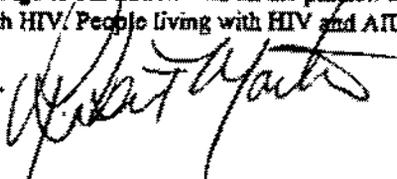
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Sincerely,



Consumer of Ryan White CARE Act Services
Member, HIV-Drug and Alcohol Task Force Client Committee

cc: Franklin Raines, Office of Management and Budget
Donna Shalala, Secretary of Health and Human Services
Bruce Reed, Assistant to the President
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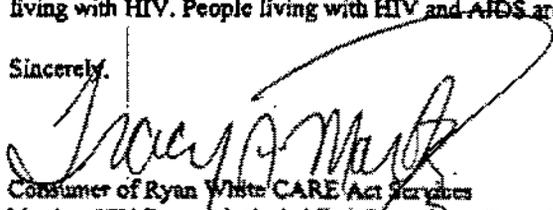
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Tracy A. Mark
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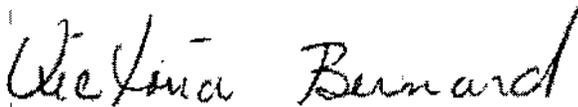
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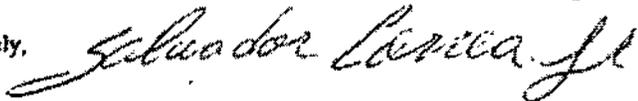
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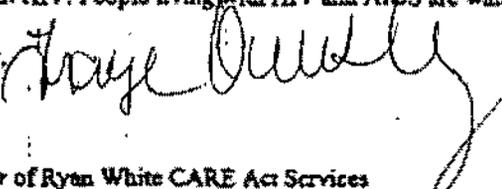
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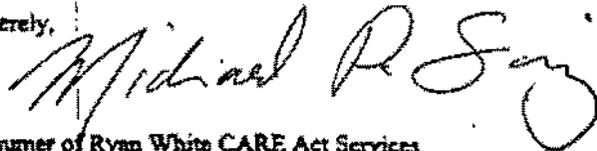
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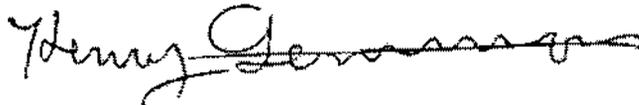
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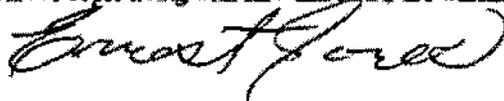
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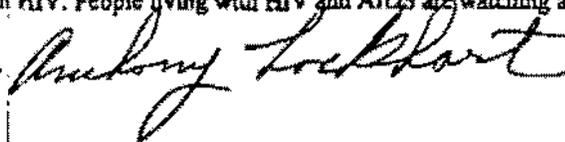
You have repeatedly stated that AIDS is a priority for your Administration. Despite the fact that AIDS, along with other critical domestic programs, was removed as a budget priority during the recent budget negotiations with Congress, we expect AIDS to remain a funding priority for your Administration. The good news will be short lived if we in any way retreat from our national commitment to providing the necessary resources for health care and the related support services needed to ensure that people living with HIV remain healthy, productive and contributing members of society.

Please support the highest possible funding for all Titles of the CARE Act in the House and Senate version of the FY '98 Labor, Health and Human Services and Education Appropriations bill, specifically the \$21.7 million request.

As you prepare your FY '99 budget request to Congress, we ask that you request Congress to provide increases for all Ryan White CARE Act programs. In particular, we strongly urge you to include a request for Title I funding for FY '99 in the amount of \$570 million. This would provide a \$120 million increase over the FY '97 Title I spending.

Your budget request is the tangible means of reassuring people living with HIV/AIDS that AIDS remains a priority for you and your Administration. I urge you and your administration to answer this challenge to our nation with all the passion and resources required to bring hope to Americans living with HIV. People living with HIV and AIDS are watching and waiting for your leadership.

Sincerely,



Consumer of Ryan White CARE Act Services
Member, HIV-Drug and Alcohol Task Force Client Committee

cc: Franklin Raines, Office of Management and Budget
Donna Shalala, Secretary of Health and Human Services
Bruce Reed, Assistant to the President
Sandra Thurman, Office of National AIDS Policy

MOTHERS' VOICES

United to end AIDS®

July 11, 1997

Mr. Bruce N. Reed
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20050

Dear Bruce,

I appreciate the time that you took yesterday to discuss issues surrounding the current ban against the use of federal funding for needle exchange programs. The meeting was both instructive and disturbing. It was helpful to hear your commitment to preserving Secretary Shalala's authority, and disturbing that you could not commit to exercising that authority.

We concur wholeheartedly with the community representatives who expressed outrage at the lack of progress toward a comprehensive plan for implementing the Secretary's waiver. Mothers' Voices believes that the Secretary should act immediately, and should expect a negative reaction from conservatives on Capitol Hill. If a proper roll out plan is arranged, this backlash could be minimized. The Secretary has science behind her as well as the support of the affected community, prominent health organizations, not the least of which is the American Medical Association, the U.S. Conference of Mayors and many major newspapers which have endorsed the lifting of the ban as an effective HIV prevention tool.

Enclosed is a copy of the paper that Mothers' Voices has been distributing on Capitol Hill. It outlines the debate and provides summary talking points in favor of lifting the ban. Mothers' Voices will continue to work diligently to protect Secretary Shalala's authority to exercise the waiver, as we try to educate both the skeptical and potentially dangerous opponents about the need for and effectiveness of needle exchange programs.

I appreciate your efforts, and hope that you will keep tens of thousands of people who stand to benefit from needle exchange programs in mind as you proceed with your decision making process about whether or not the Secretary should exercise her authority. Conservative scientific estimates are that 33 people a day become HIV infected due to transmission through dirty needles. These represent not only needless infections but missed opportunities to provide treatment to injection drug users.

Sincerely,

Amy Whitcomb Stemmer
Legislative Consultant

Ann Kurth,
Executive Director

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MOTHERS' VOICES

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MOTHERS' VOICES REPORT

Needle Exchange: An Effective Weapon in Our HIV Prevention Arsenal

July 1997

Mothers' Voices ■ 165 West 46th Street, Suite 701 ■ New York, NY 10036
telephone 212.730.2777 ■ *facsimile* 212.730.4378 ■ *internet* <http://www.mvoices.org>

MOTHERS' VOICES REPORT

NEEDLE EXCHANGE: An Effective Weapon in our HIV Prevention Arsenal

INTRODUCTION:

New AIDS treatments provide improved chances for long-term survival, and renewed hope for an ultimate cure. During this time of optimism, though, we must not lose sight of the need to continue to aggressively prevent the spread of AIDS. While the new drug combination therapies offer hope to those living with HIV (the virus that causes AIDS), we must remember that these medicines have not prevented one infection.

The public is increasingly familiar with many standard HIV prevention options. Education about the need for safer sex, including condom availability, seems to reach at least a portion of the intended audience, and healthcare workers know to practice universal precautions to avoid viral transmission.

However, one very important weapon in our prevention arsenal *that has been proven to work* remains stigmatized: i.e., providing access to clean needles to reduce the transmission of HIV when dirty needles are shared by injecting drug users. Even though the epidemic has been fueled by exposure to dirty needles, Congress has actually *prohibited* needle exchange programs from receiving federal funding. Without access to these funds, only a handful of such programs (around 100 or so) exist, operating on an ad-hoc basis with piecemeal funding, in an attempt by these communities to stem the tide of local HIV infection.

Because needle/syringe exchange programs have proven effective, there is now a growing call for a national strategy to increase the availability of these programs to reach more areas of the country. Citing an "urgent public health need," the American Medical Association recently called for a change in laws to allow injecting drug users to possess and have easy access to clean hypodermic needles. The AMA voted to work with Congress to develop legislation to revoke the nine-year-old ban on federal funding for needle exchange programs and to urge state medical groups to initiate state bills to relax their state's drug paraphernalia laws.¹

OVERVIEW:

Currently, the fastest growing cause of HIV transmission is injecting drug use (IDU), which is increasing at twice the rate of infections among gay men. The virus is spread through blood to blood contact among drug users who share dirty needles. HIV is then passed on to the sexual partners (many of whom are not injecting drug users themselves), or to their newborns via perinatal transmission (mother to baby). **It is estimated that one-third of all current HIV infections are due, either directly or indirectly, to injecting drug use.**

¹ Soelya, KQ. A.M.A. backs drug-user needle exchanges. *New York Times* 6/27/97: A15.

Researchers have found that nearly 10,000 HIV infections in the United States could have been prevented between 1987 and 1995 if needle exchange programs had been more widely available.²

As public health officials know, people who are addicted to drugs spread the virus because they have no access to clean needles or syringes, and because they are unaware of their HIV status. Surveys have found that injecting drug users are concerned about contracting HIV, but legal and other barriers to clean needles keep them from taking the necessary precautions to prevent transmission of the virus.

Mothers' Voices believes that access to clean needles can significantly reduce HIV infections among injecting drug users, their sex partners and children. We believe that well designed needle exchange programs enable substance users to avoid HIV infection, and provide encouragement to enroll in drug treatment programs and vital links to other important health services.

Thus, we support lifting the ban on federal funding for needle exchange programs³ and revoking or modifying state prescription and paraphernalia laws that limit access to sterile syringes.⁴

FACTS:

- One-third of all new HIV infections are attributable to injecting drug users and their sexual partners. Sixty-three percent of all AIDS cases among women are related to sharing needles and syringes for the injection of drugs or to sex with an injecting drug user, and 58 percent of all pediatric AIDS cases are due to the mother's use of injecting drugs or sex with an injecting drug user. Over one-half of all AIDS-related deaths for African-Americans and Latinos are injection-related.
- The lifetime cost of treating 25,500 cases of needle/syringe sharing related AIDS (the number treated in 1995) was more than \$3 billion. If the federal ban on needle exchange funding continues to the turn of the century, the United States will have failed to prevent 11,000 cases of AIDS at a cost of at least \$1.3 billion for medical care.
- **Needle exchange programs work.** Seven federally supported studies have concluded that needle exchange programs are an effective means of slowing the rate of HIV transmission, without increasing drug use.⁵ After instituting their needle exchange program, New Haven, Connecticut found an estimated 33% reduction in the rate of new HIV infections among their target population.

² Lurie P & Drucker E. *Lancet* 3/3/97

³ Federal law currently prohibits funding needle exchange until "the Surgeon General of the United States [determines] that such programs are effective in preventing the spread of HIV and do not encourage the use of illegal drugs."

⁴ Ten states and the District of Columbia prohibit the purchase of a syringe without a prescription. Paraphernalia laws exist in 46 states and the District of Columbia precluding the possession or distribution of syringes except for "legitimate medical purposes."

⁵ The National Commission on AIDS, 1991; University of California, 1993; The Centers for Disease Control, 1993; The National Academy of Sciences 1995; General Accounting Office, 1993; and Office of Technology Assessment, 1995; NIH Consensus Document on HIV Prevention Strategies, 1997.

- **Needle exchange programs do not increase the incidence of drug abuse.** A study of a San Francisco based needle exchange program found that the rate of daily injections was actually decreased among program participants.
- **Needle exchange programs provide a point of access** for injecting drug users into a broader range of healthcare services including drug treatment, AIDS education and traditional medical care. Most cities have long waiting lists of drug treatment services. In Seattle, Washington eight of ten participants who requested vouchers entered into addiction treatment programs.
- **Needle exchange programs are an inexpensive way to prevent HIV infection.** The median cost of running a needle exchange program is \$169,000, which breaks down to approximately \$0.71 to \$1.63 per syringe distributed. The lifetime cost of treating a person with AIDS is estimated to be approximately \$119,000.

FEDERAL FUNDING, LOCAL DESIGN:

Needle exchange programs cannot begin to solve the problems of those addicted to drugs, nor the larger constellation of problems faced in poor and disenfranchised communities. However, when properly designed and with community support, such programs can have a major impact on reducing HIV transmission among injecting drug users, thus creating an opportunity for many to live long enough to overcome their drug addiction.

One critical element necessary for the success of these programs is local planning and authority over the design of the needle exchange efforts. Mayors and local health officials who have encouraged the creation of needle exchange coalitions have found that cooperative efforts with the local affected population and the community at large have been critically important to the success of these programs. Local autonomy provides health officials with the opportunity to tailor their programs to the specific concerns and conditions of their community.

The ban against the use of federal money for needle exchange programs has been a barrier to increasing the number of local programs in existence. Public health and elected officials report that the federal ban has had a chilling effect on creating new programs. While these programs have proven to be effective, local officials interested in implementing needle exchange programs point to the lack of federal leadership and support as a primary impediment to initiating their own local efforts.

Thus far, the ban against the use of federal funding for needle exchange programs has been motivated by politics. Elected officials and Administration appointees are concerned about being seen as supporting the habits of injecting drug users. But studies have shown that a majority of the American public actually support needle exchange programs -- one recent survey from the Kaiser Family Foundation reveals that 55 percent of 1,000 voters surveyed were either strongly or somewhat in favor of needle-exchange programs to prevent the spread of HIV.⁶ Leaders from the Centers for Disease Control and the National Institutes of Health, numerous national public health organizations, drug treatment programs, law enforcement officials, religious leaders,

⁶ Reuters. Most US voters favor needle exchange. 6/13/97

and organizations involved in the daily battle to prevent the spread of AIDS, support funding needle exchange programs.

There is bipartisan support from elected officials, as well. In June 1997 the United States Conference of Mayors approved a bipartisan resolution urging immediate elimination of the current restriction on the use of federal funds for needle exchange. Legislators in California, Rhode Island, and Minnesota recently have passed bills supporting needle exchange programs.

Finally, the scientific evidence is in. The National Institutes of Health HIV Prevention Consensus report published in February 1997 found that needle exchange programs cause a 30 percent or greater reduction in HIV in injecting drug users and increase the likelihood that IDUs will enter drug treatment programs. The NIH found that needle exchange *does not* increase drug use or encourage non-drug users, especially youth, to use drugs; and does not lead to an increase in used needles discarded in public spaces.

CONCLUSION:

Needle exchange programs are a critical part of comprehensive HIV prevention. A commitment of funds and resources must be dedicated to these programs so that they will include additional services such as drug treatment programs and healthcare services that make effective intervention for the injecting drug user community possible.

Currently, all statutory conditions for lifting the ban have been met. In 1996 U.S. Secretary of Health and Human Services Shalala herself declared that these programs have been shown to reduce the rate of new HIV infections, and in 1997 she declared that needle exchange programs are "an effective component of a comprehensive strategy to prevent HIV and other blood borne infectious diseases."

The decision to lift the ban should be considered on the merits as a sound public health strategy.

The Clinton administration must exercise its ability to waive the ban, and the members of Congress must stand by Secretary Shalala's decision to do so.

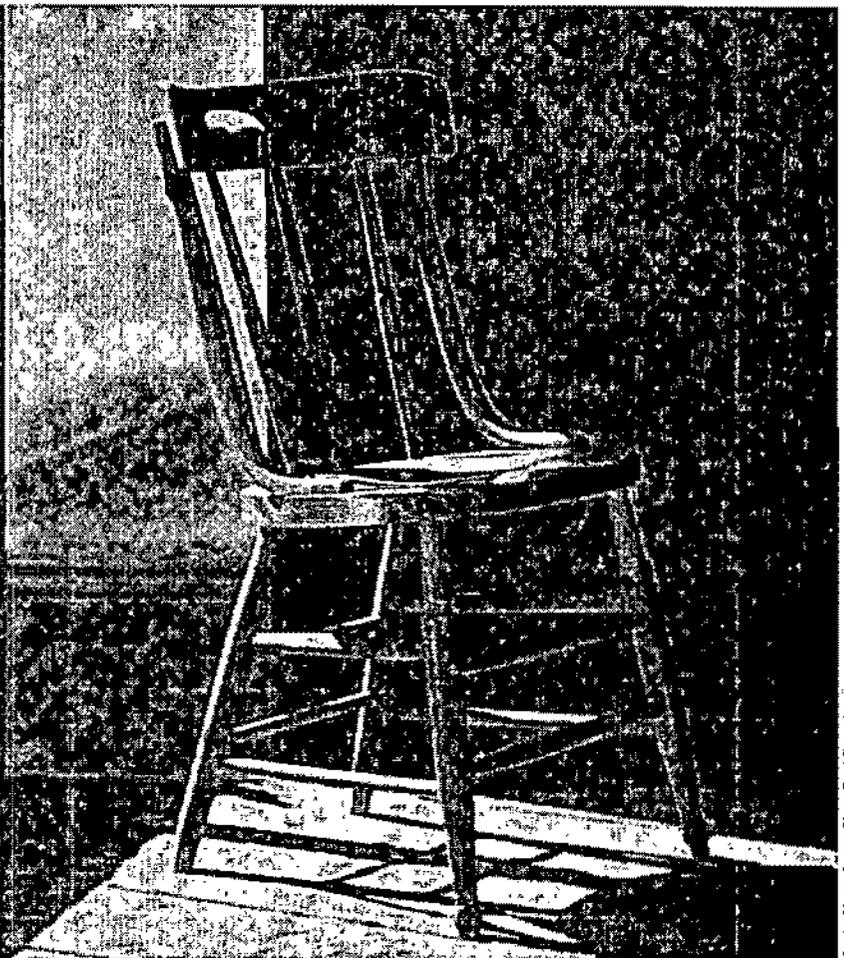
Every day the ban is in place is a day when new HIV infections will be spread -- unnecessarily -- to at least 33 American men, women, and children.



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You are more
likely to see
your grown
child die of
AIDS than
from any
other cause.



Public Media Center Photo Dept. P1234567

*S*ome people are living longer, but AIDS is still the biggest killer of American adults 25-44.

Tragically, not everyone can have their lives prolonged by the new treatments you've heard so much about. Nor do they prevent more and more U.S. teenagers from acquiring the virus that causes AIDS through unprotected sex and drug use.

And still there's no cure.

But we don't have to wait for the real answer to AIDS.

It can already be found in the hearts of parents who care enough to fight for honest, early education, research focused on vaccines and a cure, and support for those living with AIDS.

Parents like you, who truly understand the threat HIV/AIDS poses to all our children. A danger greater than any other disease or accidental cause of death in America.

Less than 20% of American parents know that AIDS is the most common killer of young adults. Now that you know, here's what to do:

Request your free Mother's Day information kit by calling toll-free 1-888-MVOICES (1-888-686-4237). Or contact Mothers' Voices, 165 West 46th Street, Suite 701, New York, NY 10036, website: <http://www.mvoices.org>





TAKE THE TEST

Take Control

maybe you think the epidemic is over

maybe you think no one is getting infected any more

maybe you think you can stop using condoms

maybe you think you're not positive for HIV-

maybe you think you are

On June 27, think again.

National HIV Testing Day is sponsored by the National Association of People with AIDS (NAPWA) in partnership with Mothers' Voices, the National Alliance of State and Territorial AIDS Directors, the National Lesbian and Gay Health Association, the Academy for Educational Development, Agouron Pharmaceuticals, the Centers for Disease Control and Prevention, the Pediatric AIDS Foundation, and Planned Parenthood Federation of America.

The 1997 campaign focuses on women, youth, and communities of color, populations that continue to see high rates of HIV infection, and has been endorsed by the American Red Cross, the National Council of La Raza, the National Council of Negro Women and the American Medical Association.

Voluntary HIV antibody counseling and testing is a critical step in taking control and responsibility over one's health. The campaign stresses the importance of pre-test and post-test counseling in conjunction with any form of testing. The earlier a person is diagnosed and begins to monitor her or his health, the greater the chance of remaining healthy. HIV counseling and testing is an excellent opportunity for professionals to establish direct dialogue with individuals who are not infected but at high risk, and this counseling can help to create and maintain the behavioral changes needed to prevent infection.

Receiving a positive diagnosis can be devastating. The many medical, social, and psychological components of HIV disease are often difficult to grasp when first diagnosed. However, HIV testing coupled with comprehensive education, protection of legal rights, early health monitoring and access to treatment options, offers people with HIV a real opportunity to take control and lead a longer and healthier life.

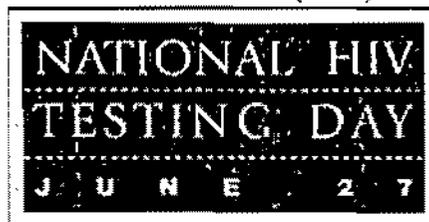
To learn more about voluntary HIV testing and counseling, contact the National AIDS Hotline, your physician, local health clinic, or an AIDS service provider in your area.

NATIONAL AIDS HOTLINE

1-800-342-AIDS (English)

1-800-344-7432 (Spanish)

1-800-243-7889 (TTY)



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MOTHERS' VOICES

United to end AIDS®



Mothers' Voices Mission Statement

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Executive Director

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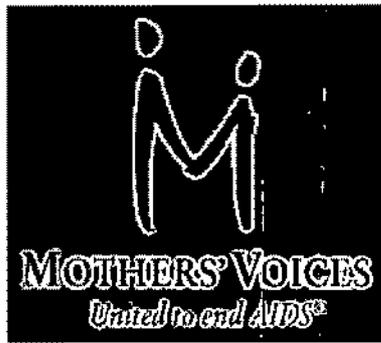
Elizabeth Glaser
Don Hall
Flo Spierce

Mothers' Voices believes that every child deserves the chance of a lifetime. Mothers' Voices will build a movement of mothers to create a public climate responsive to the urgency of the AIDS epidemic.

We recognize that public and private attitudes toward sexuality inhibit a successful response and threaten progress in the fight against AIDS. Therefore, through a national grassroots network of educated and empowered mothers, we will raise our voices and mobilize our moral authority to promote public policies that advance the efforts for AIDS education, prevention, research, treatment and ultimately, a cure.

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MV Accomplishments: What We Do

■ EDUCATION

- 1997 Card Campaign: 400,000 Cards, Sabbath Outreach Kit to 1000 congregations, Mother's Poll
- Tools for Parents: 120,000 "Talking To Your Children" brochures, award-winning internet site, PSA in People Magazine, National Resource Center, 'Parent's Project' video kit and MV Parents' Booklet, "Moms Curriculum" for use in homes & workplaces
- Founding partner in the United States Conference on AIDS

■ ADVOCACY

- Only organization at August political conventions
- Mothers' Platform to End AIDS - MothersVote 96 Voter education drive
- 'Hands Around the Capital' event at AIDS Quilt
- HIV Prevention research luncheon at the National Institutes of Health
- "Comprehensive Sex Ed" and "Access to Clean Needles" HIV prevention statements (grassroots strategies)

■ NATIONAL NETWORK

- Chapters: Atlanta, Chicago, Houston, Los Angeles, Miami
- "Next": Boston, Baltimore, Denver, Detroit, Minneapolis, Providence, Seattle

Comprehensive Sexuality Education as a Strategy to Foster Healthy Sexuality, and Reduce the Spread of HIV

Mothers' Voices believes that the rise of HIV and other sexually transmitted infections can best be stemmed in a climate of healthy sexuality. Research shows that children are strongly influenced by their parents, and Mothers' Voices acknowledges that mothers are primary educators to promote healthy sexuality and behavioral choices for children. Today, the AIDS epidemic poses an urgent challenge to mothers as they guide their children through this important aspect of human development.

Mothers' Voices believes that sexuality education need not be difficult if started early and as a natural part of parenting. By educating themselves, mothers can take the lead in developing a *positive* approach to communicating a healthy and responsible understanding of sexuality to their children and families.

We believe that sexuality education is a lifelong process and that mothers are in a singularly unique position to impart healthy sexuality by promoting values that positively support the child's understanding of their body, their gender, their sexual orientation, their social role, and their interactions with others.

Mothers' Voices recognizes that information alone is not sufficient to avoid the risks associated with sexual behavior, including HIV infection. To make responsible decisions, children also must be given support in developing self esteem, strong interpersonal skills, and a system of values consistent with personal acceptance of their own distinct gender identity and sexual orientation.

Outside of the home, mothers can be a voice of reason for policies and programs that promote healthy sexuality. Recognizing that development extends beyond the home environment, it is vital that schools, religious and community groups, media, business and government accept responsibility in reinforcing healthy attitudes.

Mothers' Voices supports HIV prevention programs that focus on decision making skills and that address the full spectrum of safer sexual behavior, including the postponing of sexual activity, abstinence, condom accessibility and skills for safer sex practices.

Mothers can have a powerful influence in shaping a public consensus in support of the values embodied in this statement.

Reducing HIV Transmission Among Injecting Drug Users, Their Sex Partners and Children

Drug addiction is a profoundly difficult challenge to society, and has a devastating impact on many communities. According to the U.S. Centers for Disease Control, in the year ending June 30, 1996, 26% of AIDS cases were due to injecting drug use. Approximately one third of all cases among heterosexuals were associated with injecting drug use, and 58% of pediatric cases were due to the mother's use of injecting drugs or sex with an injecting drug user.

Mothers' Voices believes that access to clean needles can significantly reduce HIV infections among injecting drug users, their sex partners and children. Six federally funded studies have concluded that needle exchange programs reduce HIV transmission rates without increasing the amount of drug use by program clients or changing overall community levels of drug use.¹ Nor do these programs increase the number of discarded syringes in the environment. Community based programs have been shown to reach injecting drug users with long histories of drug use and who remain at significant risk for HIV infection.

We believe that well designed needle exchange programs enable substance users to avoid HIV infection, while providing encouragement to enroll in drug treatment programs and links to other important health services.

Thus, we support lifting the ban on federal funding for needle exchange programs² and revoking or modifying state prescription and paraphernalia laws that limit access to sterile syringes.³

Programs providing clean needles are best when they offer comprehensive services, including referrals to addiction treatment. In too many instances, however, there are long waits for those who wish to enter programs. Mothers' Voices strongly advocates for increased investment in addiction prevention and treatment programs.

Needle exchange programs cannot begin to solve the problems of those addicted to drugs, nor the larger constellation of problems faced in poor and disenfranchised communities. However, when properly designed and when community support is forthcoming, such programs can have a major impact on reducing the leading cause of HIV transmission among injecting drug users, thus creating an opportunity for many to live long enough to overcome their addiction.

Mothers' Voices supports access to clean needles and expanded access to addiction treatment as important components of a comprehensive approach to reducing HIV infection among injection drug users, their sexual partners and children.

¹ The National Commission on AIDS, 1991; University of California, 1993; The Centers for Disease Control, 1993; The National Academy of Sciences 1995; General Accounting Office, 1993; and Office of Technology Assessment, 1995.

² Federal law currently prohibits funding needle exchange until "the Surgeon General of the United States [determines] that such programs are effective in preventing the spread of HIV and do not encourage the use of illegal drugs."

³ Ten states and the District of Columbia prohibit the purchase of a syringe without a prescription. Paraphernalia laws exist in 46 states and the District of Columbia precluding the possession or distribution of syringes except for "legitimate medical purposes."

Adopted November 16, 1995

Expanded Bio-Medical Research

Introduction

Mothers depend on scientific progress in all areas of child rearing. From the safety of fire-retardant infant clothes, to well designed and tested car seats, to the safety and effectiveness of vaccines and baby formulas, mothers expect full support and commitment from society. With AIDS threatening families everywhere, American mothers count on our nation to make its most solemn commitment to conquering this disease.

Recent estimates of HIV infection are alarming. The World Health Organization estimates that approximately 18.5 million adults and more than 1.5 million children worldwide are infected with HIV, the virus that is believed to cause AIDS. In North America, 1.1 million people may be infected with HIV.

The United States is recognized as a world leader in science and technology. In the field of bio-medical research, the U.S. has a vital role to play on behalf of its own citizens and for the benefit of the world community.

Mothers' Voices views biomedical research as an investment in the future of children everywhere. We seek to promote a better understanding of the scientific process, recognizing that the practical applications of science are best achieved through wide-ranging and imaginative inquiry. Progress depends on creative experimentation and does not always proceed in a direct manner. In fact, advances in one area often create unanticipated insight into other areas of investigation.

As mothers, we nurture our children, encouraging them to be cooperative and sharing with their brothers, sisters, classmates and friends. As women, we are often called upon to make peace in our families. We are deeply distressed when we see one disease pitted against another. There is nothing productive to be gained by comparing an infectious epidemic disease such as AIDS with other non-infectious diseases such as cancer, heart disease and diabetes. We oppose this divisive practice and we will rally all Americans to value and support the full range of bio-medical research. Increased support for research will advance the efforts against AIDS and provide a framework for dealing with other life threatening diseases. Expanded bio-medical research has the potential to prevent early deaths and prolong millions of lives.

In addition, since AIDS is a new and rapidly spreading infectious disease, the epidemic warrants specific expenditures for surveillance, infection control/prevention, and population and natural history studies not required of chronic, non-infectious, "endemic" diseases, such as cancer, heart disease, and diabetes.

Mothers' Voices supports the expansion of basic bio-medical research, clinical research, vaccine research and behavioral research. Basic research is needed to better understand the disease progression of AIDS. Expanded clinical research is needed to develop better treatments including the use of natural therapies and holistic approaches. Vaccine research and innovative behavioral research is needed to prevent HIV infection and other sexually transmitted diseases (STDs).

We believe that each of these areas warrant increased investment and we oppose any proposals to neglect one area in favor of another.

A Call to Action

Today, mothers are joining the ranks of AIDS activists, speaking up and demanding a voice in national policy decisions. Mothers' Voices will support and enhance this natural leadership.

While we expect the pharmaceutical industry to act responsibly by increasing its commitment to research and development, we also demand that our government act as a full partner by supporting innovative basic and clinical research.

AIDS will not be the last deadly virus to confront humanity. It is our goal to build a more profound appreciation for science and the scientific method. We will build on the past successes of the AIDS activist movement by adding a strong, clear and loving voice. By involving and supporting mothers, we will create a model for activism that will serve the health and well being of families now and in the future.

MOTHERS' VOICES PLATFORM TO DEFEAT AIDS

THE AIDS EPIDEMIC IS NOT OVER

As American mothers, we have renewed hope for an end to AIDS. The recent XI International Conference on AIDS affirmed investment in the campaign against AIDS:

- Prevention works: sustained efforts have led to stabilization of new infections in some groups in the U.S.
- A new class of antivirals have been able to reduce HIV levels in the blood and bears further investigation.

As mothers, we celebrate these advances even as we recognize that much work remains ahead. *The epidemic is far from over.* Too many Americans view AIDS as a disease affecting others. Difficulty in addressing sexuality, as well as substance abuse, inhibits a full and productive public dialogue on the most effective ways of preventing AIDS.

History shows that eradicating infectious diseases, such as tuberculosis, requires continuing vigilance, and that premature reduction of efforts can lead to unexpected resurgence of even more serious disease.

Today, AIDS is the leading killer of Americans aged 25-44, with one in four new HIV infections occurring in young people between the ages of 13 and 21. New infections in women continue to rise, and among young gay men the rate is as high as three percent - not seen since the early 80's.

We cannot accept this loss of productive life from AIDS. Mothers, knowing the impact of AIDS on the young, and the devastation that AIDS brings to families, are uniting across boundaries of race, class, and sexual orientation to bring an end to the AIDS epidemic.

For the sake of our children, our nation, and our world let us *now more than ever redouble the fight to end AIDS.* Since AIDS is a global pandemic, we call upon our nation to work with the G7 nations to combat AIDS in the developing world, and to make a substantial contribution to the United Nations AIDS Program.

Mothers, united to create a future without AIDS, hereby call upon all Presidential and Congressional candidates to:

1. Increase financial and political commitment to the eradication of AIDS.
2. Expand both biomedical and behavioral research; develop vaccines and microbicides for prevention.
3. Support the consolidated budget authority of the Office of AIDS Research and implementation of the NIH AIDS Research Program Evaluation Working Group recommendations (Levine panel).
4. Foster public and private sector collaboration to develop improved and accessible therapies.
5. Increase funding for AIDS-related research at the NIH by \$157 million for FY 1997.¹
6. Support sexuality education and prevention targeted for all communities, and all ages, including children, and increase the CDC budget by \$154 million for FY 1997.²
7. Support programs designed to reduce the risks of infection associated with drug addiction.
8. Support high quality health care and services for people with HIV/AIDS and end discrimination in housing, employment, insurance, and travel.

¹ Funding recommendation of the National Organizations Responding to AIDS (NORA), 1996

² NORA, 1996

*Aids
Policy*

Memo

To: Nancy-Ann Min DeParle
Associate Director for Health Policy
Office of Management and Budget

Bruce Vladeck
Administrator
Health Care Financing Administration

From: Robert Greenwald
Director of Public Policy and Legal Affairs
AIDS Action Committee (Boston)

Christine Lubinski
Deputy Executive Director for Programs
AIDS Action Council

Date: July 2, 1997

Re: Medicaid expansion for low-income HIV positive individuals

On behalf of AIDS Action Council and our community based organization (CBO) members, we thank you for your commitment to explore an expansion of Medicaid eligibility for low-income people living with HIV. The attached policy paper and literature review reflect our work and best thinking about the range of issues related to the development of a Medicaid expansion initiative. We conducted an extensive literature review of cost-effectiveness of early intervention. These studies and articles cull the best data and newest information available to demonstrate the cost-effectiveness of early treatment for HIV/AIDS. The literature review provides the necessary evidence supporting the arguments for moving forward on an early intervention Medicaid expansion. It is our hope and our expectation that this memo and accompanying materials will facilitate prompt action by appropriate Administration officials, AIDS organizations, community advocates, and state Medicaid officials to discuss the parameters and timing of this effort.

Three months have passed since Vice President Gore announced his support for an expansion of the Medicaid program for low-income HIV positive individuals. Indeed, Vice President Gore requested a report from the Health Care Financing Administration (HCFA) on the

implementation issues for an expansion. At this time, we have no evidence that there has been any progress toward implementation.

The recent introduction of a new standard of care for HIV/AIDS clearly demonstrates not only the need for early intervention but also the more pressing challenges to access. While the new standards justify the need to get people with HIV/AIDS early treatment, the administration made no commitments to expanding access to the new standard of care. The proposed Medicaid expansion has the potential to actually further the goal of the new standards; getting people into care early when the treatments have the greatest potential of delaying disease progression and maintaining health.

From our partners at the state level, we know that Medicaid officials are cynical about the feasibility of a Medicaid expansion and are unwilling to engage in discussions with community based health advocates about the expansion. To date, we are unaware of any leadership by HCFA to inform the state Medicaid agencies about the proposed expansion. HCFA must demonstrate leadership and, at the very least, communicate with the state Medicaid agencies about the Administration's commitment to the proposed expansion.

Every year, funding for HIV/AIDS programs has consistently fallen short of the actual need. This year promises to be no different. There is little chance that discretionary programs like the Ryan White CARE Act programs will receive adequate funding to meet the need. As we have stated before, an expansion of the Medicaid program for low-income HIV positive individuals can help ease the burden of these programs.

AIDS Action Council and its CBO members are eager to move forward on efforts to realize the expansion of Medicaid eligibility. We look forward to hearing from you at your earliest convenience.

cc: Don Gips, Office of the Vice President
Toby Donenfeld, Office of the Vice President
Sandy Thurman, Office of National AIDS Policy
Bruce Reed, White House
Chris Jennings, White House
Franklin Raines, OMB
Meg Murray, OMB
Donna Shalala, HHS
Marsha Martin, HHS
John Palenicek, HHS
Eric Goosby, HHS
Kathy King, HCFA
Lesley Hardy, HCFA

A Medicaid Expansion for Low-income HIV Positive Individuals: An Analysis of Key Issues

We appreciate the Administration's continuing commitment to actively pursue an expansion of Medicaid eligibility. Support for the demonstration/waiver authority for people living with HIV is clearly consistent with the Vice President's statement at AIDS Action's Leadership Awards Ceremony on April 9th. We are potentially on the threshold of a new era of HIV treatment, where disability can be prevented rather than simply treated. As the Vice President recognized, accomplishing this requires a rethinking of how our poverty-based Medicaid programs assure access to those in need.

We also recognize the complexity of the difficult policy decisions that go along with developing the criteria for a Medicaid expansion. We wish to use this memorandum to outline our position on many of these issues, in the hope that this can reopen a dialogue among the Administration, the community, and state and local officials. It is our view that it is critical that this dialogue occur *before* the Administration makes any firm decisions on any of these issues. We must assure that the best available evidence is before you so that the perspectives of those most directly affected (the community) and those responsible for implementation (the states) are fully considered.

Why an AIDS-specific expansion?

Perhaps the threshold policy question that must be addressed is why there should be a disease-based expansion of Medicaid eligibility, breaking with over thirty years of precedent, even in the form of a demonstration program. We believe that there are at least three compelling reasons that make the Medicaid expansion for people with HIV potentially unique:

There is a strong public health rationale for this expansion. HIV is a communicable disease. For similar communicable diseases -- STDs, TB, etc. -- the government has assured access to treatment. While we still do not have sufficient scientific data regarding the impact of new anti-HIV treatments on the infectiousness of people with HIV, it is plausible that reduced viral load may translate into reduced infectiousness. We do know that those who are in treatment are more likely to adhere to behavior changes that prevent HIV transmission.¹ Ongoing HIV primary care provides important opportunities to reinforce prevention messages. Substance abuse treatment, provided through Medicaid offers the promise of reducing or eliminating intravenous drug use and the needle sharing which continues to be a primary vehicle for HIV transmission in the United States. Thus, earlier and consistent access to care for people with HIV will contribute to the public health.

In addition, it is only through access to the comprehensive primary care services that Medicaid can provide that it will be possible to assure that those taking this new combination therapy will adhere to its complex regimen. While other programs, such as the AIDS Drug Assistance

¹Zenilman, John, et al., (title to follow), *Sexually Transmitted Diseases* 1966:23(5) 370-377.

Program of the Ryan White CARE Act, may increase access to pharmaceuticals, without associated monitoring and medical case management it is quite possible that individuals will not adhere to the appropriate regimen and might develop drug-resistant strains of HIV. This has the potential of compounding the public health challenge of HIV. This public health threat can be avoided by appropriate expansion of Medicaid.

This expansion provides an important opportunity to answer critical research questions about the new standard of care. Because of the speed with which these new treatments have been brought to market, we have left unanswered important questions about how to maximize the clinical effectiveness of these treatments: when is the best time to start a specific treatment regime, what is the optimal combination, when is it appropriate to switch or a specific treatment, etc. We have very little data on the impact and usefulness of this new approach on those who are treatment naïve. Most research has been done on those already with advanced HIV. Because this expansion is designed to bring individuals with HIV into care much earlier in their disease progression, it will be possible to design research studies on the impact and usefulness of new treatment approaches on persons living with HIV disease who are at varying stages of disease progress. Research studies designed in conjunction with the data collected through this expansion will help answer many questions regarding clinically- and cost-effective care.

The Federal government has an ethical obligation to assure access to these treatments. The release by HHS of clinical practice guidelines recommending combination antiviral therapy for a much larger class of individuals places a moral obligation on the government to help assure access to the standard of care for those who cannot afford it and do not have other sources of payment. It would be a tragic and ironic contradiction for HHS to issue model treatment guidelines and then not have them available to all in need through publicly funded programs.

Should the waiver/demonstration be required to be budget neutral?

We believe that the same reasons that make it compelling to have a disease-specific expansion of Medicaid eligibility through the waiver/demonstration authority also speak for moving forward *even if the demonstration is not budget neutral.* While we believe that budget neutrality should not be required, we are confident that an expansion of Medicaid eligibility to low-income HIV positive individuals will garner savings in Medicaid and in other federal entitlement programs. It is our belief that the potential additional cost associated with an expansion is balanced by the public health benefit (preventing new infections and preventing the development of drug resistant strains of HIV) and the research knowledge gained (about the best clinical and cost-effective use of these treatments). Indeed, it is therefore not unreasonable to expect fiscal support for this expansion from sources in addition to Medicaid.

What offsets should be considered in ascertaining the fiscal impact of an expansion?

Even though we believe that budget neutrality should not be required, we do believe that there will be a compelling set of fiscal offsets that dramatically reduce the potential cost to the Federal government of this undertaking. In this section we will define what we believe to be the parameters of some potential offsets within entitlement programs. While they go beyond what is

traditionally considered in calculating budget neutrality, we believe that because these savings are also from entitlement programs and because they are real and sufficiently large, they require consideration.

(1) *Medicaid.* We have reason to believe that early treatment with combination therapy will delay the development of disabling AIDS conditions,² thus delaying SSI eligibility and thus access to traditional Medicaid. Even without combination therapy, consistent HIV primary care and appropriate administration of prophylaxis medications will make a difference in improved health and fiscal savings.

We already know that prophylactic treatment for the opportunistic infection *Pneumocystis carinii* pneumonia (PCP) substantially reduces health care costs. Researchers at Johns Hopkins Hospital compared the outcomes of patients who received prophylactic treatment for 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.³ All too often, a bout of debilitating and costly PCP signals the transition from HIV to AIDS. The provision of comprehensive primary care and drug therapies, including low-cost PCP prophylaxis to HIV positive individuals will preserve health and save money.

Several studies have indicated that the cost of combination therapy is 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.⁴ The same study reported a 57 percent drop in the average number of days patients spent in the hospital, and a reduction in the average total monthly treatment cost per patient from \$2,772 to \$1,885 over two years.

Almost 70,000 new cases of CDC-defined AIDS were diagnosed in 1996. Half of those individuals will probably be eligible for Medicaid. If those costs are avoided or even delayed for a period of time, significant savings can accrue. Under the demonstration, many of these individuals would become eligible for Medicaid, thus partially offsetting the savings. However, it is safe to assume that not all of these individuals will become eligible under the waiver, since many will be able to continue working because they are not disabled and will not meet the financial eligibility requirements.

²Katzenstein, David A., Hammett, S.M., et al., "The relation of virologic and immunologic markers to clinical outcomes after nucleoside therapy in HIV-infected adults with 200 to 500 CD4 cells per cubic mm," *New England Journal of Medicine*, October 10, 1996, 335:15:1091-1098.

³J. Gallant, et. al., "The Impact of Prophylaxis on Outcome and Resource Utilization in *Pneumocystis carinii* Pneumonia," *Chest*, April 1995: 1018-1023.

⁴P. 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.

The effectiveness of these new combination therapies in reducing hospitalizations among those already diagnosed with CDC-defined AIDS has already been shown.⁵ Even if only a relatively small percentage of people currently on Medicaid reduce hospital utilization, there can be significant savings *above and beyond* the additional cost of combination therapy. For example, the medical costs associated with the last year of life for people with AIDS are the greatest. California Medi-Cal estimated that for those dying in 1994, costs for the last twelve months were \$39,995. This compares to an average of \$20,976 for those still living at the end of 1994.⁶ If those last year costs can be avoided for even some of those on Medicaid, we will see major savings. These savings represent potential resources for expanding eligibility to low-income individuals in the earlier stages of HIV disease.

(2) *Medicare.* Within Medicare, there will also be two types of savings: reduced costs for those already Medicare-eligible, and costs avoided for those who do not become disabled. First, most on Medicare gain eligibility by meeting the 29-month waiting period after becoming disabled. Their costs are much higher than the average person with HIV. Assuming access to combination therapy (either through Medigap coverage or dual eligibility for Medicaid), the average cost of \$25,000 per Medicare enrollee with AIDS could be dramatically reduced for those services traditionally covered by Medicare.

Second, there will also be costs avoided. If disability is prevented or delayed, then eligibility for SSDI (and later Medicare) will also be prevented or delayed. Again, at an annual average cost of \$25,000, if the growth rate is slowed or declines, then major savings can accrue to the system. The Medicare eligible population is also far less likely than the Medicaid population to become eligible for the Medicaid expansion, though we believe Medicare recipients should be eligible for the Medicaid expansion if they meet the income requirements. Most likely, that potential population would only include those who are over 65 or those who attained Medicare eligibility because of another disabling condition. Dual eligibility by Medicare recipients usually occurs after disability.

(3) *Supplemental Security Income.* If disability is prevented or delayed, there should be significant savings for the SSI program. These savings, at approximately \$6,000 per person per year, will be substantially greater than the costs associated with the Medicaid expansion. Indeed, the savings will be compounded, as disability is delayed for more and more individuals. Even if only a small fraction of those diagnosed each year with CDC-defined AIDS (70,000 in 1996) avoid that diagnosis and thus do not become SSI-eligible, significant savings would be achieved.

Further savings might be achieved if individuals now SSI-eligible became healthy enough to return to work.

⁵Mouton, Y.; Cartier, F., et al. "Dramatic cut in AIDS defining events and hospitalization for patients under protease inhibitors and tritherapies in 9 AIDS reference centers in France." Presentation at the 1997 Antiretroviral Conference in Washington, D.C.; and Torres, Ramon; Barr, M.R., "Impact of potent new antiretroviral therapies on in-patient and out-patient hospitalization utilization by HIV-infected patients." Presentation at the 1997 Antiretroviral Conference in Washington, DC.

⁶"Demographics and Expenditures for Persons with AIDS, 1980-94," *Medi-Cal Studies in AIDS*, No. 5, August 1996.

(4) *Social Security Disability Income.* As with SSI, costs can be avoided by preventing or delaying disability among those who would otherwise become eligible. Again, even if not eligible for the Medicaid expansion, it can be assumed that some portion of those who might have become SSDI eligible will have access to combination therapy and benefit from it. This would save about \$7,800 per person per year in SSDI benefits alone. Similarly, if some already on SSDI are able to return to work, additional savings could be achieved.

What other potential cost savings or alternative source of funding should be considered in assessing the overall implications of this demonstration/waiver?

(1) *The AIDS Drug Assistance Program.* While not part of the cost offsets considered above, any expansion of the Medicaid program would dramatically relieve pressure on the ADAP programs funded under the Ryan White CARE Act. It is believed that about 80 percent of people on ADAPs are at 200 percent or below the poverty level. If the financial eligibility standard for the Medicaid demonstration were similar, then the eligibility criteria for the ADAPs could be expanded and/or the funds saved could be redirected to other Ryan White programs that could provide wraparound supportive services for people in the Medicaid demonstration.

(2) *NIH could contribute research funds to support the expansion.* As discussed above, the expansion provides an opportunity to answer some important clinical research questions. If the demonstration is structured with that in mind, it would be appropriate for NIH to contribute some support for the research costs of the expansion.

Should there be a pre-determined limit on the size of the demonstration?

It would be wrong to cap the number of potential participants or the potential number of states permitted to apply. While this is meant to be a demonstration, it would be unethical to deny access to expanded treatment opportunities for people with HIV in any jurisdiction where a state is willing and able to participate. The distribution of AIDS cases across the country will determine incentives to participate in this program and will form a "natural" control group without having to set any predetermined limits on participation.

It should also be noted that an artificial cap in the number of clients permitted to enter the demonstration might be seen as a disincentive to participate by some states, who might be fearful that they would not be permitted to include all potential eligibles in their jurisdiction in the waiver. This would be especially true in some of the larger high-incidence states.

How can the standard of care be assured and continued treatment guaranteed during and beyond the demonstration?

Given the evolving nature of HIV treatment, there should be provisions in the demonstration that permit states to amend their waivers to accommodate new standards of care. Similarly, the federal government should retain the right to require changes in the demonstration should

medical research developments warrant.

Clearly, an ethical dilemma would arise at the end of the demonstration period if the experiment proved not to meet the cost effectiveness criteria established at the start of the project. Some provision should be made to assure continued access to treatment for those already enrolled in the program, while allowing states to discontinue eligibility for new enrollees.

What benefits should be covered as part of the demonstration?

It is our hope that there will be a standard, comprehensive benefits package that is consistent for all participating in the demonstration. While we can assume that certain services, on average, are highly unlikely to be used (e.g., nursing home care), we cannot predict the course of this disease for all who are taking combination therapy. Some may go on to develop AIDS and will meet the traditional Medicaid eligibility requirements, giving them access to the full Medicaid package. However, there should not be a gap in care when individuals transition from one eligibility category to another.

If HCFA opts to give states some flexibility in determining the benefits package, then a *minimum* benefits package should be defined at the outset, one that includes all the necessary components of comprehensive outpatient services: diagnostic testing, physician visits, drugs, medical case management, and outpatient substance abuse and mental health services. These would be necessary to assure the basic standard of care as defined by HHS and others. It would also be necessary to assure the comparability of the demonstrations across state lines for evaluation purposes.

What financial eligibility criteria should be used?

While some flexibility will be appropriate for the states, based on their underlying Medicaid program and what they can afford, the goal of this demonstration is to get as many people into care as early as possible. If the financial eligibility criteria are too stringent, many individuals without private third party coverage will be unable to afford combination therapy, thus undermining the public health goals of this demonstration. Delaying therapy will mean more costly Medicaid coverage in the near term, as well as lost prevention opportunities and diminished assurance that therapy once started will be adhered to through appropriate medical case management. Therefore, we propose starting the consideration of this demonstration at 200 percent of the federal poverty level.

What medical eligibility criteria should be used?

We believe that HIV infection should be the sole medical eligibility criterion. Current treatment guidelines suggest consideration of combination therapy very early in disease progression. While arbitrary cutoffs based on CD4 count and viral load could be made, they would be just that -- arbitrary. It is clear that different patients will opt for beginning therapy at different times, but the choice should be made by the patient and the clinician. Indeed, the full meaning of viral load levels and CD4 counts are evolving as our understanding of combination therapy evolves. (To

give a specific hypothetical example that shows the need for a broad-based medical eligibility standard: someone who begins combination therapy with his or her own resources could have a non-detectable viral load and a relatively high CD4 count. After exhausting personal resources for paying for these drugs, the individual might then meet the financial eligibility criteria for the demonstration; if the medical criteria were set by viral load or CD count, the individual would be forced to stop combination therapy until those criteria are met -- posing a personal and public health risk.)

In addition, early eligibility is also tied to the public health objectives of this demonstration, as discussed above: that access to primary care is associated with more likely adherence to prevention advice regarding HIV transmission.

How should this demonstration be evaluated?

It would be our hope, given the importance of this expansion and its potential to answer more than cost-effectiveness questions, that there will be a unified approach to evaluating all the demonstration sites, with standard criteria and data collection requirements.

What can be done to encourage states to participate in this demonstration?

It is critical to engage the state Medicaid programs in a dialogue about how this demonstration might best be constructed *during the development stage*. Within the limits discussed above, states will need a good deal of flexibility in designing this program given the tremendous variation in underlying costs, services, and current populations served by state Medicaid programs.

To the degree possible, states should be given financial incentives to participate: either through the identification of new federal resources or the sharing by the federal government with the states of some of the savings in federal-only entitlement programs that might result from this program (i.e., SSI, SSDI, and Medicare).

In addition, HCFA should support quick assessments of potential approaches to adopting this expansion that offer the possibility of limiting the financial exposure of the states. One example would be a capitated approach, which, if done with appropriate quality assurances, risk adjusters and the like, could result in additional savings to the state for the HIV population already in the Medicaid program while containing the cost of an expansion.

Next steps.

It is our hope that this memo has identified key areas of policy choices before you. We strongly believe that these issues require a full and frank discussion among the relevant federal officials, state Medicaid administrators, and AIDS community advocates. The complexities associated with this potential demonstration necessitate the most inclusive decision making process possible to assure full consideration of all information and options.

To that end, we propose the formation of a federal/state/community task force to work together in developing the parameters of this demonstration *as well as* to perform ongoing oversight as the demonstration is initiated. The challenges in developing the solicitation will not disappear once states have opted to participate. The evolving nature of the science of HIV and the associated public health and public policy questions will necessitate constant review and discussion to assure that the demonstration is as effective as possible. Creation of this task force would also send an important message to the states and the AIDS community about the Administration's seriousness in pursuing this initiative.

Appendix 1: Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents

Appendix 2: Documentation of the Cost-effectiveness of Early Intervention

THE WHITE HOUSE
WASHINGTON

*Aids
Policy*

MEMORANDUM FOR THE PRESIDENT

FROM: Bruce Reed, Assistant to the President for Domestic Policy
Sandra Thurman, Coordinator for National AIDS Policy

SUBJECT: International Studies on Reducing Maternal-Infant HIV Transmission

This memorandum will provide background on the controversy over an ongoing group of U.S.-supported international clinical trials studying options to reduce maternal transmission of HIV in developing countries. A brief overview of current knowledge, the rationale for further research, the World Health Organization position, concerns of domestic public interest groups, and the Department of Health and Human Services' position will be covered. Attached separately are talking points and Q&A's prepared by HHS on the issue.

Perinatal Transmission The World Health Organization (WHO) estimates over 1,000 HIV+ infants are born each day. Women with HIV disease have a 15%-40% risk of transmitting HIV to their baby with each pregnancy. The National Institutes of Health demonstrated that this transmission risk can be lowered to 8.3% by the administration of the drug AZT to women orally during pregnancy and intravenously during labor, and to their newborn infants orally for 6 weeks. This NIH study, known as ACTG 076 - comparing AZT with a placebo - was halted and published in 1994 when these dramatic results were evident. It has become the standard of care to offer all HIV+ pregnant women AZT therapy in the U.S.

An important unanswered research question is at what point during pregnancy or birth do women transmit HIV to their babies -- and if it is necessary to administer AZT over many months to prevent HIV infection in infants. Because many developing countries cannot afford expensive drug therapies for their citizens, pinpointing the critical period in which to administer AZT to prevent perinatal transmission is important so that the greatest number of women could be offered treatment.

Research Study Design Issues The public health leadership of several WHO member countries collaborated with the NIH and Centers for Disease Control and Prevention (CDC) to design and develop research studies to prevent perinatal HIV transmission in countries with limited health care infrastructure and resources. Each research study included an informed consent document outlining the research question, the randomization to an AZT or placebo group, and a detailed description of potential risks study participants may incur. All study protocols were reviewed and approved by the NIH and CDC Institutional Review Boards (IRBs) and the host countries. The political leadership of each host country were also fully informed of the study methodologies and concurred with their implementation. The first studies proposed by this international collaborative group began in 1993 with funding support from the U.S. (NIH, CDC) and France.

World Health Organization Activity In June 1994, the WHO hosted a meeting of researchers and public health practitioners from the U.S., Europe, and countries in Africa, Asia and the Caribbean which have a high incidence of HIV disease. The purpose of the meeting was to examine the results of the NIH ACTG 076 trial in terms of their applicability internationally. The following recommendations were issued from this meeting:

- 1) Encourage the use of AZT as outlined by the NIH ACTG 076 study in industrialized countries; and
- 2) Immediate exploration of alternative regimens that could be used to achieve prevention of perinatal HIV prevention in the developing world.

WHO participants established parameters for the conduct of research studies in developing countries. The studies supported by the U.S. and France were consistent with these parameters.

Concerns of Some U.S. Public Interest Groups Dr. Sidney Wolfe of the Public Citizen Health Research Group wrote a long critique of U.S. involvement and support for these international perinatal HIV prevention studies in a letter to Secretary Shalala. The letter was broadly distributed to the media. Key concerns raised were:

- o Some research designs include a placebo arm when AZT has proven benefit. Such a research design would never be allowed in the U.S.
- o The studies violate major international ethical guidelines, specifically: the World Medical Association's 1975 Declaration of Helsinki; four of the Nuremberg codes for human experimentation; and the International Ethical Guidelines for Biomedical Research Involving Human Subjects designed to address ethical issues in developing countries
- o There is no guarantee that women and infants in host countries will benefit from the research knowledge gained
- o The lack of appropriate care in host countries does not justify study designs with placebo arms that have no benefit. The standard of care in many countries does not include access to prenatal care, medications, hospital births or intravenous infusions
- o Comparison of these studies to the Tuskegee syphilis study; criticism that IRBs should ensure that risks to subjects are minimized and subjects are not unnecessarily exposed to risk; this is colonialism at its worst

Senator Carol Moseley-Braun (D-IL) has also voiced her concern regarding study designs with a placebo arm when there is a known effective treatment for HIV prevention. She is alarmed that such studies are supported with U.S. funds, and thinks it is inappropriate to continue such funding in face of the apology being offered to the Tuskegee survivors this Friday.

Department of Health and Human Services The Department of Health and Human Services has conducted a review of the U.S.-funded studies in question and continues to support both the study designs and public health importance of completing them. They are ongoing as of this date. HHS testified to this effect before the House Government Reform and Oversight Committee last week. There was very little discussion of the issue among Representatives present.

In brief, the HHS position maintains:

- o The studies address a pressing need in the global control of the spread of HIV, defining interventions that will result in reductions in maternal-infant transmission which can be safely and routinely implemented in the developing world;
- o The studies are based on the assumption that the NIH ACTG 076 regimen is not a feasible therapeutic intervention in developing countries due to lack of medical infrastructure and cost constraints; the research design examines options for treatment which are viable and affordable within the medical care delivery systems of the study countries
- o All ongoing studies are in full compliance with U.S. and in-country regulations and laws, have gone through extensive in-country and U.S. ethical review processes and an international ethical review, and all studies have strong in-country support; an independent Data and Safety Monitoring Board continues to provide oversight of research findings at regular intervals
- o Broadly accepted ethical principles for international research recognize a role for the local standard of care when testing the effectiveness of a new intervention. In the case of developing host countries, the local standard is minimal to no health care access. Studying new research options of AZT administration at specific times during pregnancy offers a new benefit to individuals who would not otherwise have had it, while defining research knowledge that may allow many individuals to benefit if shorter courses of AZT prove effective for HIV prevention. The placebo arm is equivalent to the local standard of care.

Attached are Q&As and talking points which support the HHS position on this issues.

THE WHITE HOUSE
WASHINGTON

QUESTIONS AND ANSWERS

Q. Did you know about the NIH supported clinical trials using AZT and placebos in HIV infected pregnant women in developing countries?

A. I am aware that NIH is funding some research into how to improve prevention of mother to infant transmission of HIV in some developing countries. I understand that AZT is the drug that is being used in these studies.

I have asked the Secretary of Health and Human Services to provide me with a report on these NIH studies. I also asked for an evaluation of how these studies will help the women and infants involved and how the studies are helping to curb maternal transmission of HIV in these countries.

Q. Some of the women in these studies are not receiving AZT, they are getting a placebo. How does this compare with the U.S. position that all HIV infected pregnant women and their infants should be offered AZT?

A. That question will be addressed in Secretary Shalala's report. Just let me say that in many developing countries no HIV treatment at all is available for pregnant women or their infants. It is totally different situation than what we have in this country where AZT is readily available.

Q. Some critics are saying that the NIH funded AZT studies in developing countries are not different from what happened in the Tuskegee study where treatment was withheld from some of the participants. How do you answer that?

A. Well, I will need to see the report from HHS before I can fully address that. But I must emphasize that in the Tuskegee study, treatment that was widely available in this country was deliberately withheld from some of the participants. In the AZT studies overseas, the only AZT treatment available is the treatment provided to participants in the study.

Q. Some critics are saying that there is an issue of violation of international ethical codes in the AZT studies. Is this true?

A. I will know more about the studies and the specific concerns surrounding it when I review Secretary Shalala's report. Until then, I can't say anything further on this. I can assure you that we will not support any studies where such violations occur.

TALKING POINTS

- * OUR GOAL IN SUPPORTING THESE STUDIES IS TO FIND EFFECTIVE WAYS TO PREVENT MOTHER-TO-CHILD TRANSMISSION OF HIV THAT CAN BE USED IN DEVELOPING COUNTRIES. THAT MEANS FINDING A REGIMEN THAT IS EFFECTIVE FOR THE SPECIFIC POPULATION AND AFFORDABLE IN THAT COUNTRY.
- * THE FULL AZT-076 REGIMEN, WHICH IS THE STANDARD OF CARE IN THE UNITED STATES, IS NOT FEASIBLE FOR THESE COUNTRIES. IT IS EXPENSIVE AND REQUIRES SOPHISTICATED MEDICAL MONITORING.
- * WE HAVE WORKED WITH THE WORLD HEALTH ORGANIZATION, UNAIDS AND THE HOST GOVERNMENTS TO DESIGN THESE TRIALS. THEY ARE FULLY SUPPORTED BY THE INTERNATIONAL BODIES AND BY THE HOST GOVERNMENTS
- * THESE TRIALS HAVE BEEN REVIEWED FROM AN ETHICAL STANDPOINT BY THE CDC AND NIH INSTITUTIONAL REVIEW BOARDS, AND BY REVIEW BOARDS IN THE HOST COUNTRIES. WE AGREE THAT THESE ARE DIFFICULT AND COMPLEX ISSUES, BUT THAT IS EXACTLY WHY WE WENT TO SOME LENGTHS TO ACHIEVE MEDICAL AND ETHICAL CONSENSUS ON THE RESEARCH NOT ONLY WITHIN HHS, BUT WITH INTERNATIONAL ORGANIZATIONS AND THE HOST COUNTRIES THEMSELVES.
- * WE ARE DEDICATED TO FINDING AN EFFECTIVE THERAPEUTIC INTERVENTION THAT CAN REALISTICALLY BE ADMINISTERED IN THE HOST COUNTRIES AND IS AFFORDABLE.

*Aids
policy*

QUESTIONS AND ANSWERS
MOTHER-INFANT TRANSMISSION OF HIV

Q. Why is the U.S. government supporting these studies around the world?

A. HHS has been criticized for conducting 9 studies in different parts of the developing world.

All nine were designed in cooperation with public health officials in the countries themselves.

All are aimed at finding ways to reduce mother-infant transmission of HIV in those specific countries. They were devised after completion of the AIDS Clinical Trial Group (ACTG) protocol 076 showed dramatic, positive results of an AZT treatment regimen in the U.S.

All nine were developed following a June 1994 WHO meeting in Geneva at which researchers and public health practitioners from around the world called for 1) use of the 076 regimen in the industrialized world where feasible and, 2) immediate exploration of alternative regimens that could be used in the developing world. They were designed in accord with guidelines developed at that meeting.

Q. Why can't the 076 regimen be used everywhere?

A. According to consensus among researchers and public health practitioners in all the cooperating countries, the 076 regimen is imply not feasible as a standard of prevention in much of the developing world. Let me explain:

- * The regimen requires that women be reached early in pregnancy and have blood drawn and tested for HIV. Once the woman knows she is positive for HIV she must take AZT three times daily for weeks, then receive AZT intravenously during labor and delivery. Once the baby is born the newborn must receive AZT in syrup for 6 weeks. In the developing world women are most often not seen in health care delivery systems before delivery.
- * Drug costs alone for the 076 AZT regimen are estimated to be \$800, an amount that is 80 times the annual health budget per person in many countries involved in these studies, and not available outside the research setting.
- * In addition, the 076 regimen simply cannot be assumed to work everywhere. The U.S. study looked at women with greater than 200 CD4 counts who were not breast feeding, while most of the women in host countries would breast feed their infants. In addition, the biology of the HIV virus itself (different strains) may be significantly different in other countries.

Q. Why do some of these studies use a placebo control arm? The Public Citizen groups says this is wrong.

A. The panel convened in Geneva recommended that since the 076 regimen is not applicable in the developing world, "placebo-controlled trials offer the best option for obtaining rapid and scientifically valid results."

They explained that in parts of the world where the 076 regimen is not applicable, the choice of a placebo for the control group in a trial would be appropriate as there is currently no available effective alternative for HIV-infected pregnant women in these countries. This is the quickest way to find appropriate interventions that can be used to benefit the people in these countries.

Although it has been argued that we could use a low dose of AZT in these studies, we believe that low dose AZT would not be an appropriate control because 1) it offers no known benefit to the individual (low dose AZT has not been prove useful anywhere) and 2) this type of study could fail to achieve useful results.

Q. Why is the placebo arm in some studies no intervention at all?

A. Unfortunately, the current standard of perinatal care in much of the developing world is no prevention intervention at all. That is a fact of life. Using this standard care as the placebo control in these studies will result in the most rapid, accurate, and reliable assessment of the value of the intervention being studied compared to the local standard of care.

Q. Are these studies ethically acceptable?

A. They are. The ethical dilemmas are complex and difficult. But the human subjects issues of these studies have been reviewed intensively since the 1994 Geneva meeting. These matters have been discussed in many formal meetings and at forums; reviews have been conducted in the U.S. and the countries where the clinical trials are being carried out (or where they will be carried out).

Q. Public Citizen says that it is unethical to conduct a trial unless it offers all participants a chance to receive an effective intervention if such is available anywhere in the world, not just at the site of the clinical trials. What is your response to that?

A. After thorough review, HHS, and WHO agree that to meet the standards of the World Medical Association Declaration of Helsinki, these studies must employ the best current diagnostic and therapeutic methods available in the country where they are to be performed. Holding other countries accountable to a standard of care unavailable

to its citizens and denying the opportunity for research advances that might benefit them raises another set of difficult ethical issues not addressed by advocacy groups.

Q. Are you going to have these studies re-reviewed or modified, as many have suggested?

A. No. The ethical review of these studies has been rigorous. It has included community and scientific participation in reviews by the relevant institutional review boards (IRBs) in the U.S. and the local IRBs in the countries where the trials are carried out. Support from local governments is obtained and review by an independent Data and Safety Monitoring Board is required when deemed appropriate.

Q. How are these studies any different than the Tuskegee study?

A. The fundamental difference is that the Tuskegee study withheld treatment of known benefit in a country where the treatment was widely available. The AZT trials are being conducted in certain developing countries where the standard of care for HIV+ pregnant women does not include treatment for HIV or any prevention options for perinatal transmission.



July 24, 1997

*Bill
Pae...*

The Honorable William Jefferson Clinton
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Organizations Responding to AIDS Coalition (NORA), we are writing to formalize our communication with members of your Administration regarding the need for the Secretary of Health and Human Services to exercise her waiver authority and allow for the use of federal funds for needle exchange.

NORA is a coalition of over 175 health, labor, religious, professional and advocacy groups. Together, we articulate the broadest possible consensus on issues concerning HIV/AIDS and advocate for fair and effective HIV/AIDS policy, legislation and funding.

On July 10th, we met with Bruce Reed, Sandy Thurman and Kevin Thurm to discuss the strategy and timeline for the Secretary of Health and Human Services to exercise her waiver authority, thereby removing the current restrictions that prohibit the use of federal funds for needle exchange. Much to our dismay, neither a commitment from the Secretary to exercise the waiver nor a clear plan for how the Administration would get to such a point was forthcoming.

In response to this news, we expressed our deep and continued concern that, despite the availability of sound scientific evidence which demonstrates the effectiveness of needle exchange, your Administration had yet to agree to exercise the waiver. We articulated our belief that continued delay will have serious public health consequences, and provided ample evidence -- including the recent adoption of resolutions in support of needle exchange by the U.S. Conference of Mayors and the American Medical Association -- that there is consensus in support of removing federal restrictions.

In the week following our meeting, several principals in your Administration took a number of important short-term actions to help fight off a negative amendment threat during the House appropriations process, which would have eliminated Secretary Shalala's waiver authority. While we are grateful for this assistance, we remain deeply concerned by your Administration's continued lack of a commitment to exercise the waiver authority and lack of a concrete strategy and timeline for so doing.

NORA

A coalition convened by
AIDS Action Council

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

At this time, we would like to request a meeting with you and senior members of your Administration to discuss this issue as soon as possible, preferably the week of July 28. The position of the HIV/AIDS community is clear -- your Administration must let science, and not politics, drive federal policy on this important public health issue. Your comments before the US Conference of Mayors, as well as those of your chief HIV/AIDS appointee, would indicate that you and your Administration concur. However, this continued delay, and the unwillingness of your Administration to make a firm commitment to exercise the waiver, suggest otherwise.

We look forward to an opportunity to speak with you and senior members of your Administration directly about this life-saving issue. Thank you for your consideration. Mike Shriver at (202-898-0414), will serve as the NORA contact to arrange this meeting.

Sincerely,

David Harvey, Co-Chair, NORA Coalition
Miguelina Maldonado, Co-Chair, NORA Coalition

cc: Vice President Al Gore
Erskine Bowles, Chief of Staff to the President
Donna Shalala, Secretary of Health and Human Services
Donald Gips, Chief Domestic Policy Advisor to the Vice President
Toby Donenfeld, Office of the Vice President
Bruce Reed, Assistant to the President for Domestic Policy
Chris Jennings, Special Assistant to the President on Health Policy
Sandy Thurman, Director, White House Office of National AIDS Policy
Franklin Raines, Director, Office of Management and Budget
Josh Gotbaum, Executive Associate Director, OMB
William Corr, HHS Chief of Staff
Kevin Thurm, HHS Deputy Secretary
Marsha Martin, Special Assistant to the Secretary, HHS
Eric Goosby, Director of HHS Office of HIV/AIDS Policy

*Aids Policy***MEMORANDUM FOR THE PRESIDENT**

From: Sandy Thurman

Date: July 21, 1997

Subject: Update on HIV/AIDS Issues for Your Meeting Tomorrow with Gay/Lesbian Leaders

This memorandum is to provide you with a quick update on current HIV/AIDS issues for your meeting tomorrow with gay and lesbian activists.

Background - While the AIDS groups are grateful for the support the Administration has given them in the past, there is considerable anxiety and doubt regarding our ongoing commitment to this issue. This concern began when AIDS programs (including the Ryan White CARE Act) were not included on a small list of discretionary programs that were listed as protected programs in the balanced budget agreement (neither were many other important programs). The community interprets this action to mean that the issue has been "de-prioritized." In addition, following the release of guidelines for AIDS treatment which advocated more aggressive use of triple drug combinations, the Administration did not request any additional dollars in the 1998 budget for AIDS Drug Assistance Programs (ADAP). (However, it should be noted that we have continually supported increases in ADAP, including 2 budget amendments last year and have always indicated our willingness to consider additional requests for this program.) All this, combined with delays in receiving the report the Vice President requested on Medicaid expansion to people with HIV (due to indications from HCFA that there is no way to make this budget neutral), and that little visible progress has been made on removing the restrictions on federal funding for needle exchange programs, has made the AIDS community a little irritated with us.

We have been working nonstop with the AIDS groups on these issues. The bottom line is, while we have pending issues, it has been a pretty extraordinary year so far for the AIDS community.

Decrease in the AIDS Death Rate -On July 14, the CDC released new figures showing a 19% decrease in the number of AIDS deaths in the first nine months of 1996, compared with the same period of 1995. In contrast with earlier data, the number of deaths due to AIDS among women decreased 7%, and mortality numbers dropped for all racial groups and categories of HIV transmission. The CDC attributed these findings to greater access to medical care and the development of effective therapies for HIV and associated opportunistic infections. AIDS advocates noted that as AIDS death rates drop, there are increasing numbers of individuals living with HIV who require access to these lifesaving interventions. Clearly, our investment in

the AIDS epidemic is beginning to pay off as a significant achievement, given increasing AIDS deaths and infections worldwide. *It is important to note, however, that there is no evidence that the number of new HIV infections is slowing indicating that prevention and education efforts must be reinforced.*

Funding Issues - In the House Appropriations subcommittee mark-up, the full \$40 million increase in the Administration's FY 1998 budget request for the Ryan White CARE Act programs was provided, with some reallocation of the increases among Ryan White programs. In addition, the mark up included a \$132 million increase for ADAP in the Chairman's mark. No formal budget amendment was sent forward by the Administration for this, given the size of the offset. You may want to take this opportunity to formally support this increase. OMB asserts that this increase is going to happen anyway, so we might as well take credit for it. The community will obviously appreciate your support.

The House subcommittee increased funds for AIDS prevention by \$5 million (\$12 million below budget request) and AIDS research by \$73 million (\$33 million above budget request). The Senate Labor/HHS subcommittee's 602B allocation is \$200 million below the House's, making it less likely that the Senate will fund AIDS programs at the House levels. In VA/HUD, the Housing Opportunities for People With AIDS (HOPWA) program has been funded at the budget request of \$204 million (an \$8 million increase).

Model Clinical Practice Guidelines for Treatment of HIV Infection - On June 19, an independent panel of experts convened by HHS and the Kaiser Family Foundation published treatment guidelines for antiretroviral therapy in adults and adolescents. The draft guidelines address a critical need among providers as to how to best to use new AIDS drugs most effectively. The guidelines recommend a more aggressive approach to treatment using triple drug combinations at earlier stages of HIV infection to avert immune system damage.

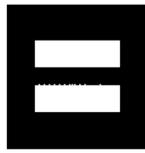
While the draft of these guidelines is not technically a government document, issues of payment for this new standard of care clearly confront us. HHS has stressed that the responsibility for HIV treatment is shared one by the federal government, states, private and non-profit sectors and individuals each playing an important role. The additional \$132 million in ADAP funding included in the House Appropriation's subcommittee is a good start towards trying to address expanding demand for these new therapies.

Medicaid Expansion for HIV Infection - On April 9, the Vice President requested that HHS report to him on the feasibility of a Medicaid demonstration project expanding Medicaid eligibility to people with HIV infection prior to the onset of full-blown AIDS. Currently, over 50% of people with AIDS depend on Medicaid for their health care. New AIDS therapies like the protease inhibitor drugs have been effective in delaying disability and reducing hospital costs for many people. This has raised speculation about whether the question if earlier access to drug therapies and primary care would prove cost-effective for Medicaid as well as other public spending for services to people with HIV/AIDS.

HHS briefed the Vice President's office in late May/early June and is now working to address

budget concerns. HHS will likely submit a report to the Vice President in the next few weeks. The report will likely say that it would be feasible to do a demonstration program limited to several sites but with capped enrollment. This demonstration, however, would not be budget neutral, and thus would represent a break in our longstanding budget neutrality criteria in Medicaid waivers. There are some at HHS and OMB who believe that it would be preferable for the Administration to support full legislation to change the Medicaid program to cover this population earlier rather than break our budget neutrality standard. However, this proposal would be quite expensive.

Needle Exchange Programs - The House Appropriations subcommittee for Labor, Health and Human Services marked up their bill on July 15, preserving the authority of the Secretary of HHS to lift the restrictions on use of federal funds for needle exchange programs. HHS does not expect a challenge to this at full committee next week, it is pursuing a strategy of watchful waiting, maintaining a low profile for as long as possible. Most of the AIDS groups accept this strategy as long as the Secretary's authority is not endangered. We held a meeting at the White House last week with the AIDS groups and HHS to facilitate communication on this issue.



HUMAN
RIGHTS
CAMPAIGN

July 1, 1997

Mr. Bruce Reed
Assistant to the President for Domestic Policy
The White House
Washington, DC 20201

Dear Mr. Reed:

As the largest national gay and lesbian political organization and as a leading member of the National Organizations Responding to AIDS (NORA) Coalition, the Human Rights Campaign (HRC) is working on many issues impacting the HIV/AIDS community. These issues are outlined in the AIDS Issues briefing paper in the accompanying packet. The packet also includes individual fact sheets, which provide more detail and background on particular programs, including the polling data commissioned by HRC on AIDS related issues.

On June 19th, the Department of Health and Human Services and the National Institutes of Health issued new guidelines for the treatment of HIV disease. The guidelines call for early and aggressive treatment of people with HIV. They highlight the need to increase funding for treatment programs to ensure that combination therapies and the primary care services necessary to deliver them are accessible to all the men, women and children living with HIV and AIDS.

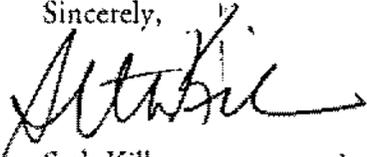
As the FY 1998 appropriations process gets underway, the Human Rights Campaign is urging members of Congress and the Administration to:

- Review the AIDS Budget fact sheet which details the need and specific funding levels for HIV/AIDS prevention, research and care programs. While the need is far greater, we are seeking support for *at least* the funding levels requested in the President's budget and an increase in funding for access to HIV and AIDS drug therapies.
- Preserve a strong Office of AIDS Research (OAR) at the National Institutes of Health and oppose efforts to pit one disease against another.
- Support funding for the Housing Opportunities for People with AIDS (HOPWA) program and drug and alcohol treatment programs. It is impossible for a person living with HIV disease to follow a treatment plan and maintain their health without stable housing and treatment for drug addiction.
- Maintain the authority of the Department of Health and Human Services to determine sound federal public health policy by opposing any efforts to repeal the Secretary's authority to allow the use of federal funds for needle exchange programs.
- Oppose efforts to impose federal mandates on state and local HIV prevention strategies.

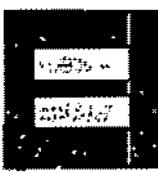
HRC
page 2

We are making progress in the fight against HIV and AIDS. To continue, we must maintain and expand our investment in these efforts. I look forward to working with you on all HIV and AIDS related issues in the 105th Congress. Please do not hesitate to call me at (202) 216 - 1526 if you have any questions regarding the enclosed material or if I can be of further assistance to you.

Sincerely,

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

Seth Kilbourn
Senior Health Policy Advocate



HUMAN
RIGHTS
CAMPAIGN

file: MDS

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AIDS ISSUES

AIDS ISSUES IN THE 105TH CONGRESS

The Human Rights Campaign as an organization and as a leading member of the National Organizations Responding to AIDS (NORA) Coalition is working on many issues impacting the HIV/AIDS community. These issues, which the 105th Congress and the Clinton Administration will need to address, are outlined below. The issues center around funding, Medicaid, research, prevention, Rep. Coburn's (R-Okla.) HIV Prevention Act, needle exchange, and the role of the new Director of the White House AIDS Policy Office. Accompanying this outline are fact sheets which provide more detail and background on particular programs, including a fact sheet on the polling data commissioned by HRC on AIDS related issues.

1. Funding

Budget Issues

As it was with the 104th Congress, the pressure to balance the budget remains the primary impediment to the necessary funding increases in the HIV/AIDS budget portfolio. The budget agreement between the Clinton Administration and Congressional leaders raises serious concerns about the degree to which HIV/AIDS programs will be prioritized in the FY 98 budget and appropriations process. While the budget agreement is not law, it does set forth the principles and understandings that guide the development of the budget resolution which, in turn, sets forth overall spending goals for the FY 98 fiscal year and for subsequent fiscal years through FY 2002.

The fact that no health program in general and no HIV/AIDS program specifically was listed as a protected program in the budget agreement is cause for concern. Further, domestic discretionary spending (which includes funding for AIDS programs like the CARE Act, NIH research and CDC prevention programs) is capped through FY 2002. Compared to a "baseline" level of funding, which assumes discretionary spending increases at the rate of inflation, these caps represent a \$61 billion cut to domestic discretionary programs over the next five years. These cuts are greatest in the "out years" of the five year budget plan which means that competition for increasingly scarce resources will be greatest in FY 2000 through FY 2002.

FY 1998 Appropriations

The accompanying AIDS Budget fact sheet outlines the elements of the HIV/AIDS portfolio, including the funding needs as identified by the NORA Coalition.

The budget resolution reflects the lack of protection for HIV/AIDS programs in its figures on health discretionary spending. For fiscal years 1998 through 2000 these spending levels are assumed to range between \$24.9 and \$24.2 billion, compared to the \$25 billion available in FY 97.

The FY 98 budget resolution cuts \$100 million from health programs compared to FY 97. Factoring in a 3% inflation rate, this cut represents an \$850 million (or 3.5%) cut in spending compared to FY 97. Given the costs of the newly developed protease inhibitors in treating HIV disease and the large unmet need for HIV/AIDS prevention, care and treatment, we are greatly concerned that there will not be enough funding available to support HIV/AIDS programs adequately across the board.

Need

HRC and the NORA Coalition will emphasize the inter-relatedness of the programs within the HIV/AIDS funding portfolio, and the benefits we are beginning to see as a result of sustained investment in prevention, research, and care/treatment.

Prevention funding increases are necessary to meet the need identified by the HIV Prevention Community Planning Process, established by the CDC in 1994.

We will also support increased funding for biomedical and behavioral research in general and AIDS research in particular at the National Institutes of Health (NIH). The Office of AIDS Research (OAR) which administers and coordinates AIDS research across the NIH is vital to this effort.

Access to quality care and treatment remains out of reach for many people with HIV and AIDS. It is vital that Congressional leaders understand the need for both increased funding for the CARE Act Title II AIDS Drug Assistance Programs (ADAP) and the primary care and support services offered through the other Titles of the CARE Act and other Federal programs (i.e., HOPWA, Drug and Alcohol Programs, etc.). This continuum of care, developed over the last ten years with these Federal funds, make it possible for people to access necessary treatment, follow the treatment regimens, and remain healthy for longer periods of time.

Guidelines on Antiretrovirals

The newest developments in drug treatment options offer hope to many people living with HIV and AIDS. The use of protease inhibitors, in combination with existing antiretroviral therapies, has led to dramatic reductions in the amount of HIV present in the body. This reduction, in turn, is associated with improvements in health status and other clinical outcomes.

While combination therapies appear to be effective for many people, they are not effective for all people and their long-term benefits are not known. In addition to being very expensive (\$10,000 - \$12,000 per year per patient), the treatment regimens are very complicated to follow.

The Department of Health and Human Services will soon issue for comment *Guidelines for the Use of Antiviral Agents in HIV-Infected Adults and Adolescents*. These guidelines will likely recommend use of combination therapies early in the disease progression which will very likely lead to a sharp increase in demand for them.

2. Medicaid

Overview

Discrimination, pre-existing condition exclusions, lifetime coverage limits, experience rating and other practices have all served to deny health care coverage to people with HIV disease. As a result, Medicaid has become the only form of health care coverage available to many people living with HIV/AIDS. More than half of people with AIDS and 90% of children with HIV rely on Medicaid for their health care.

In FY 1997, federal Medicaid costs for people with AIDS are estimated to be \$1.8 billion with approximately 104,000 people living with HIV and AIDS receiving benefits through the program. Most people with HIV and AIDS become eligible for Medicaid because they meet disability criteria or are considered "medically needy" in States which offer that eligibility standard.

Per Capita Caps

The President's budget originally included a per capita cap for Medicaid beneficiaries, which would cap the federal payment to states per beneficiary. The caps applicable to each state in a given year would be the sum of the individual caps for four groups of beneficiaries in the State: the aged, disabled, adults in families with children, and children. The caps would vary for each group to reflect differences in costs for care.

HRC worked actively to defeat the per capita cap provision. The cap did not reflect the high cost of treating people with HIV disease (especially with the costs of the new protease inhibitors), which could have put pressure on States to use the flexibility they have to limit eligibility (e.g., medically needy) and benefits categories (e.g., prescription drug coverage).

The budget resolution specifically states that per capita caps are not part of the assumptions that factor into Medicaid reform. However, the resolution assumes \$9.8 billion in cuts to the Disproportionate State Hospital (DSH) Program and unspecified measures to enhance state flexibility in administering the Medicaid program. These DSH cuts and flexibility options are designed to achieve a total savings of \$13.6 billion in the Medicaid program over the next five years.

Hospitals which provide large volumes of care to uninsured people and Medicaid beneficiaries receive DSH payments. DSH funding has provided crucial support to these hospitals, many of which provide a vital safety net for people living with HIV and AIDS. We are advocating for targeted DSH cuts which will spare hospitals that provide the highest levels of uncompensated care.

Proposals to enhance state flexibility must also be monitored carefully. Under the guise of state flexibility, Medicaid managed care plans could become too costly for people with HIV/AIDS (see next section) and payments to federally qualified health centers and rural health clinics could be reduced.

Managed Care

The formation of Medicaid managed care systems could threaten the AIDS care infrastructure that people living with HIV and their advocates have worked to build. Managed care has a very poor track record dealing with disabled and chronically ill people. Managed care has traditionally

provided care for healthy, employed populations. Mandatory enrollment of disabled Medicaid beneficiaries living with HIV/AIDS into managed care plans has made it difficult for many people with HIV/AIDS to obtain high-quality, comprehensive health care under the Medicaid program. In developing these systems, the Medicaid program must proceed cautiously and protect the existing AIDS care infrastructure.

Welfare Reform and Medicaid

Under the welfare reform plan passed last year States can deny Medicaid coverage to legal immigrants currently in the country. Refugees and asylees could be denied Medicaid benefits after 5 years. Legal immigrants entering the country after August 22, 1996 will be ineligible to receive Medicaid coverage for 5 years (with a State option to extend the ineligibility). Legal immigrants and refugees living with HIV/AIDS will be affected by these provisions, although their precise numbers are unknown.

The President's budget this year proposed to restore Medicaid benefits to legal immigrants who become disabled after they enter the country and to legal immigrant children. The budget also proposed to extend Medicaid eligibility for refugees and asylees from 5 to 7 years. These provisions are included in the assumptions governing the budget resolution. Medicaid eligibility will be restored for those people who entered the United States before August 23, 1996 and who are or become disabled. The exemption for refugees and asylees will be extended from 5 to 7 years.

Medicaid Expansion

On April 9, Vice President Gore announced that the Administration has asked the Health Care Financing Administration (HCFA) to find ways to implement a Medicaid expansion initiative that would extend Medicaid eligibility to more low-income people with HIV. Many individuals who are HIV positive and low income are not eligible for Medicaid unless they qualify for disability and have an AIDS diagnosis. This definition of disability precludes them from receiving new treatments and care that require early interventions. An expansion of Medicaid benefits to people with HIV earlier in their disease progression could save significant Medicaid resources by delaying the onset of full blown AIDS.

The most likely mechanism to create the Medicaid expansion is through the existing 1115 waiver process, whereby States can submit plans to the Health Care Financing Administration (HCFA) to expand Medicaid coverage to people not currently eligible. States must demonstrate that the expansion will not result in increased cost (i.e., it must be "budget neutral").

The Medicaid expansion proposal for people with HIV and AIDS must be designed such that States will be able and encouraged to actually participate in the expansion plan. This design will likely need to include a relaxation of the "budget neutrality" requirements, given that the long term savings from such an expansion is difficult to measure.

HRC will work with HCFA and others in the Administration to ensure that the Medicaid expansion is effective and will provide increased access to care for more people with HIV.

3. Research

Overview

AIDS research at the National Institutes of Health (NIH) has led to major advances in the understanding and treatment of HIV and related opportunistic infections. Because HIV disease affects so many systems of the body, AIDS research is conducted at all 24 Institutes, Centers and Divisions at the NIH. Success against AIDS and other diseases depends on national research as a whole. HRC and the NORA coalition are supporting funding increases for AIDS research specifically and NIH overall. This funding will support: epidemiology and natural history of the disease, basic science, development of AIDS treatments, AIDS vaccines and behavioral research.

Office of AIDS Research (OAR)

During consideration of FY 1997 research levels, the House eliminated the Office of AIDS Research consolidated budget. The final appropriations bill restored the OAR's role to plan, prioritize, and budget AIDS research at NIH but did not include a single line item, consolidated budget for the OAR. A strong OAR is essential to coordinate AIDS research efforts across the 24 Institutes, Centers, and Divisions at NIH. We remain concerned about the status of the OAR and will continue to work on enhancing its role and the authority granted to it in the appropriations process.

Comparisons to Other Diseases

Funding levels for AIDS research will likely be compared to funding levels for other diseases in the appropriations process. Comparisons of funding for different diseases are counterproductive and misleading. The health of the nation is dependent upon a strong national commitment to biomedical research across disciplines and diseases that benefits all Americans. Because the existing knowledge base, economic and human costs, and scientific opportunities of every disease are important it is inappropriate and unwise to pit research funding for one disease against another.

AIDS research enhances and stimulates research in other fields, with broad implications for other diseases such as cancer, heart disease, Alzheimer's disease, and others. NIH AIDS research has, for example, been a driving force in the emerging biotechnology industry, one of the most important U.S. scientific and commercial endeavors of the last decade. NIH AIDS research involving the blood/brain barrier has had valuable implications for research on Alzheimer's disease, dementia, multiple sclerosis, encephalitis and meningitis.

Scientific priority-setting should consider many factors. One of the most important factors is scientific opportunity. Scientists believe that the scientific opportunities presented by AIDS are enormous, similar to the opportunities that existed in cancer research during the 1970s, which eventually opened new avenues of research and are generally credited with providing the foundation for the molecular biological revolution of the late 1970s and 1980s.

4. Prevention

Overview

The community planning process instituted by the Centers for Disease Control and Prevention (CDC) over the last few years is proving to be effective. The process is similar to the CARE Act Title I planning council process through which providers, public health officials, professional health planners, community leaders, and people living with HIV work together to plan effective strategies and budgetary priorities.

Prevention interventions that are locally determined and controlled assure that those groups most at risk receive the most appropriate interventions. Money, as well as years of valuable, productive life can be saved by not only preventing initial infection, but also by ensuring access to voluntary testing and systems of care.

Studies show that by combining a variety of focused, sustained prevention techniques people do change their behavior. Such techniques include: teaching people the skills needed to negotiate difficult social situations; reinforcing techniques over time to enhance long-term behavior change; and promoting safer practices by ensuring access to condoms and sterile needles.

Rep. Coburn's HIV Prevention Act (see below for details) poses a serious threat to this community based approach. The cost to implement the testing and reporting provisions of his bill (estimated to be \$420 million) would decimate the already insufficient \$630 million the CDC spends on HIV prevention activities.

5. Coburn Bill

Overview

Rep. Tom Coburn (R-Okla.) introduced H.R. 1062, the HIV Prevention Act of 1997 in March. Sen. Don Nickles (R-Okla.) then introduced a companion bill in the Senate (S. 503). The bills are identical, except that the Nickles bill does not make states' participation in the federal Medicaid program contingent on enacting its provisions. The Coburn bill has 97 co-sponsors; the Nickles bill has 3 co-sponsors.

Two Members (Rep. Bilbray and Rep. Gibbons) signed on as co-sponsors but then removed their name after meeting with national groups, including HRC, and constituents. Similar meetings have occurred (and will continue) to urge other Members to lift their co-sponsorship. We are also working to ensure that no part of Coburn's bill will be attached to other pieces of legislation such as budget reconciliation and appropriations.

Cost

The estimated cost to implement the bill is \$420 million and it would require a minimum of 265 statutory or regulatory changes across the country. This cost and administrative burden would force States and localities to shift resources away from community-based, locally developed prevention strategies that respond to the unique needs in each community. These strategies have been proven to be effective in HIV prevention and any weakening of their effectiveness will cost lives.

Testing and Partner Notification

The bill mandates that States report the identities of people testing positive for HIV to be used by the CDC to set up a national partner notification program. The CDC has never called for such a system and every State currently must have a partner notification program in place in order to receive HIV/AIDS prevention funds from the CDC and funding under the Ryan White CARE Act.

Mandating HIV names reporting and the establishment of a national system of partner notification would lead to the elimination of anonymous HIV testing; including the newly approved HIV home sample collection kits. Limits on a broad range of testing options discourages people from coming forward to be tested both because of fear of breaches in confidentiality and lack of access to testing sites.

Supporters of these testing and reporting requirements are using the fact that more and better information is needed about HIV disease earlier in the disease progression. Using an AIDS diagnosis as the marker for studying the epidemic is indeed not as useful as it once was. People are living longer with AIDS which means that AIDS deaths are decreasing; but this decrease does not mean that infections are also decreasing. To understand the nature of the epidemic at the "front end" of the disease progression is therefore more important than it ever was in order to get people into treatment earlier, to identify barriers to care, and to accurately measure the course of the epidemic.

HRC and other advocacy groups will emphasize several points regarding the need for this data. First, mandatory testing, named reporting and coercive partner notification programs are not necessary to get this information. Second, state and local health departments are working with local communities on the best ways to measure the impact of the epidemic. Third, "one-size-fits-all", federal requirements should not impede local processes and authority. Local public health officials and affected communities at the local level must be allowed to decide on the best ways to move forward in dealing with a changing epidemic. This local determination has been the standard for other diseases and should remain so for HIV.

Other Provisions

The bill also calls for the mandatory testing of alleged sexual offenders. The Omnibus Crime Control Act of 1994 already allows a victim to request a court order to have the alleged perpetrator tested for HIV in federal sexual assault cases. In addition, 44 States and the District of Columbia mandate or authorize HIV testing for charged or convicted sex offenders.

The bill would allow health care providers to withhold medical procedures unless the patient is tested for HIV and the provider is notified of the results. A patient's life may be placed in jeopardy if the health care provider waits for test results before providing the necessary care. Guidelines from the CDC and OSHA on universal precautions are accepted practice to prevent HIV transmission in health care settings.

Opposition

The National Governor's Association has expressed strong opposition to H.R. 1062, indicating that it "places Medicaid funding at risk in order to advance testing requirements of dubious

merit...Governors oppose the bill and would object to inclusion of its provisions in a reconciliation package or any other appropriations or authorization bill." The bills are also opposed by the Association of State and Territorial Health Officials, the National Alliance of State and Territorial AIDS Directors, the American Public Health Association, and the American Nurses Association.

6. Needle Exchange

Need for Programs

Over 30% of new HIV infections in 1994 and 1995 were among drug users. Over 50% of pediatric AIDS cases and 66% of AIDS cases among women can be linked to drug use. Unlike other population groups, in which recent data show a 13% decline in AIDS deaths, AIDS deaths in women have increased by 3%. Needle exchange programs target a difficult-to-reach population for whom HIV prevention and access to drug treatment is vital in order to save the lives of drug users themselves, their sexual partners and their children.

According to a June 1996 study, the number of HIV infections that could have been prevented between 1987 and 1995 in the U.S. if needle exchange programs were widely available is between 4,400 and 9,700. Had these HIV cases been prevented, up to \$500 million in health care expenditures could have been avoided. The study also found that an additional 11,300 cases among injection drug users, their sexual partners, and children could be prevented by access to needle exchange programs through the year 2000.

DHHS Report

The FY 1997 Appropriations bill prohibits States and communities from using Federal funds for needle exchange programs unless the Secretary of the Department of Health and Human Services affirms that needle exchange programs reduce HIV transmission and do not increase drug use. In response to Senator Specter's request, the Secretary released a report on February 18 stating that needle exchange programs are effective in reducing HIV transmission as part of an overall prevention program. The report did not explicitly state that needle exchange programs do not increase drug use, although there is no evidence that needle exchange programs lead to increased drug use by exchange clients or in the wider community. In fact, exchange programs have been effective links to drug treatment programs.

HRC is one of the leading organizations working on removing the prohibition on use of federal funds for needle exchange programs. Working with the Administration, Members of Congress, and national and local groups, we are educating key decision makers on the necessity of needle exchange and on the need to lift the federal funding restrictions. HRC's recently commissioned poll by the Tarrance Group and Lake Research indicates that a majority of people (53%) support needle exchange programs to prevent the spread of HIV.

Research and Support

Numerous organizations have reviewed the research on needle exchange programs and concluded that needle exchange programs are effective. These organizations include the Congressional Office of Technology Assessment, the U.S. General Accounting Office, the National Commission on AIDS, the National Academy of Sciences, and most recently, the National Institutes of Health. In addition, leading professional organizations have voiced support for needle exchange programs as an

important HIV prevention strategy. They include the American Medical Association, the American Public Health Association, and the Association of State and Territorial Health Officials.

7. Voters, Polling and AIDS

Overview

Public opinion research shows clearly that America is united across party lines when it comes to the fight against AIDS. Voters of all political backgrounds -- including swing voters and traditional GOP voters -- support strong efforts against AIDS. Voters believe that the federal government has a responsibility to address this national health crisis, and taxpayers are willing to pay for it.

HRC commissions extensive and ongoing studies about voters' attitudes toward HIV/AIDS issues and policies. The research is conducted by Democratic and Republican research firms, including Lake Research, The Tarrance Group and Bailey, Deardourff & Associates.

Voters of all political stripes support a strong federal effort against AIDS. Data from a February 1995 study shows that AIDS transcends partisan affiliation, personal ideology or religious beliefs. GOP men and Republicans over age 45 support funding for the care of men, women and children with AIDS, as do 83 percent of Clinton voters, 62 percent of Bush voters and 70 percent of Perot voters.

Care

Voters support maintaining or increasing federal funding for the care of people with AIDS. While there is public support for putting the government's fiscal house in order, 72 percent of voters favor maintaining or increasing funding for the Ryan White CARE Act.

Important groups of voters feel strongly about caring for people with AIDS. Swing voters favored maintaining or increasing AIDS care funding by a margin of 72 percent. This included 70 percent of Perot voters, 72 percent of Western voters, 70 percent of Midwestern voters and 81 percent of women with no college education.

Government's Role

American voters think the federal government is not doing enough about AIDS. Fully 45 percent of the electorate thinks the federal government is not doing enough to address the AIDS crisis. That includes 48 percent of Baptists and 44 percent of Perot voters.

AIDS Education Programs

Parents want schools to teach their kids how to prevent AIDS. Despite efforts by political extremist groups to distort the purpose of AIDS education programs, a strong majority of parents -- fully 59 percent -- are more concerned that their kids receive adequate information about AIDS than they worry about "exposing children to information about homosexuality."

Discrimination

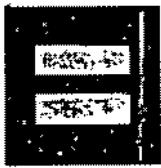
Voters oppose discrimination against people with HIV and AIDS. Independent voters were strongly opposed to anti-gay language proposed in federal AIDS legislation, with 62 percent of independents saying they were against such language in the Ryan White CARE Act. 56 percent of all voters opposed this discriminatory language.

Needle Exchange

HRC recently commissioned a poll by the Tarrance Group and Lake Research on needle exchange. The poll results indicate that a majority of people (53%) support needle exchange programs to prevent the spread of HIV.

8. Office of AIDS Policy Director

In April, the President appointed Sandy Thurman as the Director of the White House Office on AIDS. She brings a healthy mix of leadership, political skills and commitment to the fight against HIV and AIDS. Among Thurman's biggest challenges will be to build support within the White House, Department of Health and Human Services and the Congress for needle exchange programs (NEPs). We expect that she will be able to provide needed coordination within the Administration and a point of contact for the community on all HIV and AIDS issues.



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AIDS Budget

In the first six months of 1996, AIDS deaths in the United States decreased by 13%, marking the first such decline since the epidemic began in 1981. This decrease is the result of the sustained investment this country has made to HIV/AIDS research, prevention and care. This federal investment is working and must be expanded to meet the demand for new services in light of the recent advances in HIV/AIDS treatments. The facts are¹:

- As of February 28, 1997, 581,429 Americans have been diagnosed with AIDS since 1981: 488,300 (84%) men; 85,500 (15%) women; and 7,629 (1%) children
- 365,000 American lives have been lost to AIDS since 1981; an average of 100 Americans are diagnosed with AIDS daily
- An average of 100 to 150 men, women and children become infected with HIV every 24 hours
- HIV infection remains the leading cause of death among 25-44 year olds, accounting for 19% of deaths in this age group
- One-quarter of new HIV infections in the United States occur among young people under age 21
- In the first six months of 1996, women accounted for 20% of newly reported AIDS cases; in the first six months of 1996, there was a 3% increase in AIDS deaths among women²
- In 1985, 233 children were left without parents due to AIDS; in 1995, there were 30,000 children orphaned by AIDS; by the year 2000, this figure is expected to exceed 85,000 children²
- Over 76% of women infected with HIV are women of color
- In 1996, people of color accounted for over half (62%) of all adult AIDS cases reported in the United States; African Americans accounted for a larger proportion (41%) of adult AIDS cases than whites (38%) for the first time in the epidemic

¹Source: Centers for Disease Control and Prevention, 1996

²Source: AIDS Project Los Angeles

FY 1998 HIV / AIDS PORTEFOLIO

	FY '96 (Actual)	FY '97 (Actual)	President's Request '98	FY '98 Need *(1)
Prevention /Centers for Disease Control	\$585.4M	\$617.0 M	\$634.3 M (+17.3 M)	\$829 M (+212 M)
Ryan White (Total)* (2)	\$757.7 M	\$996.3 M	\$1,036.2 M (+40 M)	\$1,390 M (+393.9 M)
Ryan White Title I	\$391.7 M	\$449.9 M	\$454.9 M (+5 M)	\$546 M (+96.1 M)
Ryan White Title II: CARE Services	\$208.8 M	\$250.0 M	\$265 M (+15 M)	\$340 M (+90 M)
Ryan White Title II: ADAP earmark	\$52.0 M	\$167.0 M	\$167 M (-0-)	\$297.6 M (+130.6M)
Ryan White Title III(b)	\$56.9 M	\$69.6 M	\$84.6 M (+15 M)	\$113.6 M (+44 M)
Ryan White Title IV	\$29.0 M	\$36.0 M	\$40.0 M (+4 M)	\$61 M (+25 M)
Title V(a) - AIDS Education Training Centers	\$12.3 M	\$16.3 M	\$17.3 M (+1 M)	\$23 M (+6.7 M)
Ryan White Title V(b)-Dental	\$6.9 M	\$7.5 M	\$7.5 M (-0-)	\$9 M (+1.5 M)
NIH Research	\$1,431.9 M	\$1,501.1 M	\$1,540.8 M (+39.7 M)	\$1,636.2 M (+134.5 M)
Agency for Health Care Policy Research *(3)	\$125 M	\$144 M	\$149 M (+5 M)	\$160 M (+16 M)
Housing Opportunities for People With AIDS	\$171.0 M	\$196.0 M	\$204.0 M (+8 M)	\$250 M (+54 M)
Substance Abuse & Mental Health Services Administration *(3)	\$1,885 M	\$2,135 M	\$2,150 M (+15 M)	\$2,335 M (+200 M)
Indian Health Services	\$3 M	\$3.6 M	\$3.8 M (+.2 M)	\$3.3 M *(3)
Food & Drug Administration	\$72.7 M	\$72.7 M	\$72.7 M (-0-)	\$74 M (+1.3 M)
Total	\$5,031.6 M	\$5,665.7 M	\$5,790.9 M (+125.2 M)	\$6,677.7 M (+1,012 M)

(1) Need figures are supported by the NORA Coalition and represent the resources needed to respond to growing caseloads, unmet needs and unfunded research opportunities.

(2) Funding for Special Projects of National Significance is included in CARE Act total funding, based on a 3% tap on the amounts appropriated for Titles I-IV, not to exceed \$25 M.

(3) Figures for AHCPR and SAMHSA are total figures for the agencies. Funding levels for AIDS-specific programs are unavailable.

(4) Need solely for the purchase of AIDS drugs for patients of the Indian Health Service. The FY '96, FY '97 and President's FY '98 budget request are total funding levels for services within IHS.



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Medicaid & AIDS

Discrimination, pre-existing condition exclusion, lifetime coverage limits, experience rating and other practices have all served to deny health care coverage to people with HIV disease. As a result, Medicaid is the single largest source of health insurance for people living with AIDS, providing access to physician visits, hospitalization, prescription drugs, home health care and long-term care. Over half of people with AIDS and 90% of children with HIV rely on Medicaid benefits for their health care.

WHAT IS MEDICAID?

- Authorized under Title XIX of the Social Security Act, Medicaid is the nation's primary federal/state program for providing health and long-term care coverage to about 36.8 million elderly, disabled and low-income Americans in 1996.
- The Medicaid program is the single largest form of federal assistance to the states, accounting for 40% of federal funding to the states. The Medicaid program is jointly funded by the federal and state governments. By law, the federal payment cannot be lower than 50% nor greater than 83%. States with lower per-capita incomes will receive a higher federal "match". The federal share of Medicaid funding varies by state - poorer states receive a higher federal share.
- 8.7 million blind, elderly, and disabled Americans receive their health care coverage from Medicaid.
- As of August 1995, adolescents up to age 19 and in families with incomes not exceeding the poverty level were guaranteed Medicaid coverage in only 11 states.
- In 1993, AIDS killed more young people than any other infectious disease. It is probable that many young adults were infected with HIV as adolescents with no guarantee of Medicaid eligibility.
- Medicaid expenditures have recently slowed to record low rates of growth. The growth rate from 1995 to 1996 was only 3%. Even with rises in Medicaid enrollment and the increase in the rate of health care inflation, the Medicaid growth rate has slowed down.

CRITICAL IMPORTANCE OF MEDICAID

Medicaid's historical role of providing comprehensive health care for eligible individuals must be protected.

- The current Medicaid statute (Title XIX of the Social Security Act) must remain intact, including the guarantee that all currently eligible persons will receive the care they need.

- The federal government must retain responsibility and oversight of state Medicaid programs and for ensuring basic standards for access and quality of care, as well as meaningful consumer participation in the planning, implementation and monitoring of Medicaid managed care plans.
- The formation of Medicaid managed care systems threatens to severely undermine the AIDS care infrastructure that people living with HIV and their advocates have worked for years to build. In developing managed care systems, the Medicaid program must proceed cautiously and protect the existing AIDS care infrastructure.

MEDICAID AND THE RYAN WHITE CARE ACT

Medicaid and the Ryan White CARE Act are distinct and complementary programs. Medicaid provides health care coverage to low-income people. The health services available under Medicaid vary state by state. The CARE Act augments Medicaid services by providing primary health care, including dental care, home health care and drug reimbursement services, as well as enabling services like child care and transportation to people living with HIV disease.

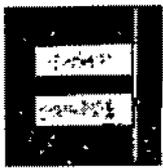
Cuts to the Medicaid program cannot be alleviated through the use of CARE Act funds. The CARE Act has never been adequately funded and cannot begin to replace Medicaid as the fundamental health care safety net for low-income Americans. Many AIDS service providers offer comprehensive services to people with HIV disease in their area through funding from both the Medicaid and CARE Act programs.

MEDICAID REFORM AND FUNDING

President Clinton originally proposed a per-capita cap in his FY 1998 budget, which would limit federal payments to States for the Medicaid program to a certain amount per beneficiary. For people with high treatment costs, including people with AIDS, the cap would not be sufficient. The budget pressure created by the per capita cap at the State level would likely result in the elimination of optional eligibility categories like the "medically needy" program and optional benefits like prescription drug services. Many people with AIDS rely on these options to access the Medicaid program and the newly developed treatments that have given hope to so many people living with this disease.

People living with HIV and other advocates successfully challenged the President's proposal which was dropped from the current budget agreement. That agreement, however, includes cuts of \$15 - \$17 billion in the Medicaid program, primarily focussed on payments to hospitals which serve a significant number of low-income and uninsured individuals.

Last month, the administration proposed a Medicaid expansion pilot project to provide access to the Medicaid program to more people living with HIV. This welcomed proposal could allow eligible individuals to receive health care earlier in their disease progression, thus reducing the costs of treating opportunistic infections and providing long term care.



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AIDS Research

The new regimes of combined antiretroviral therapies have been remarkably successful in slowing progression to disease and death in thousands of patients with HIV/AIDS. These breakthroughs in AIDS treatment are the result of over a decade of Congressional support for AIDS research at the National Institutes of Health (NIH). Success against AIDS and other diseases is only possible with a vital national research effort. Support for AIDS research specifically and NIH research overall is essential.

AIDS RESEARCH AT NIH

AIDS research occurs at all 24 institutes, centers and divisions at the National Institutes of Health (NIH) and is managed and coordinated through the Office of AIDS Research. The FY 1997 NIH AIDS research budget is \$1.501 billion. This funding supports: epidemiology and natural history of the disease, basic science, development of AIDS treatments, AIDS vaccines and behavioral research.

THE LEVINE REPORT

In March 1996, NIH released the Report of the NIH AIDS Research Program Evaluation Working Group of the Office of AIDS Research Advisory Council. The report, developed by an independent cross disciplinary panel and chaired by Dr. Arnold Levine of Princeton University, is the first comprehensive review of AIDS research at NIH. There are 14 major points to the blueprint including increased support for investigator-initiated research, more emphasis on vaccine development and the need to preserve a strong Office of AIDS Research.

FINDING EFFECTIVE TREATMENTS

AIDS research at the NIH has advanced the knowledge and treatment of HIV/AIDS, improving and lengthening the lives of people with AIDS. NIH AIDS research has:

- doubled the survival time of a person with AIDS, and improved their quality of life.
- produced the four FDA-approved drugs for the treatment of HIV infection: AZT, ddI, ddC, and d4T. The discovery and development of these drugs are major accomplishments of the National Cancer Institute (NCI) and the National Institute of Allergy and Infectious Diseases (NAID).
- led to tremendous advances in the treatment and prevention of AIDS-related opportunistic infections, including CMV retinitis, Pneumocystis carinii pneumonia, and toxoplasmosis.
- demonstrated that AZT, when administered during pregnancy, may dramatically reduce HIV transmission from mother to fetus.

BROAD BENEFITS OF AIDS RESEARCH

AIDS research enhances and stimulates research in other fields, with broad implications for other diseases such as cancer, heart disease, Alzheimer's disease, and others. NIH AIDS research has:

- been the main source of funds for immunological research and has accelerated study of the human immune system. (Several drugs that first received approval for the treatment of AIDS-related conditions, including fluconazole, clarithromycin, and EPO, have important uses in cancer and organ transplant patients.)
- accelerated investigation into viruses, particularly retro viruses. NIH AIDS research has enhanced scientific understanding of all retro viruses, some of which may have important roles in other human diseases.
- been a driving force in the emerging biotechnology industry, one of the most important U.S. scientific and commercial endeavors of the last decade.
- led to research involving the blood/brain barrier which has valuable implications for research on Alzheimer's disease, dementia, multiple sclerosis, encephalitis and meningitis.

OFFICE OF AIDS RESEARCH

The NIH Revitalization Act of 1993 strengthened the authority of the Office of AIDS Research to develop an annual research plan and a consolidated bypass budget for all NIH AIDS research. With AIDS research underway at all 24 ICDS at NIH, the Office of AIDS Research is essential to the planning of NIH's AIDS research resources. Through this strategic planning process linked with the annual budget process, the OAR Director has the coordinating and fiscal authority to coordinate the NIH-wide AIDS research program.

The OAR's role is limited strictly to planning, prioritization and budgeting under a system that reduces bureaucracy and eliminates duplication of effort. The OAR neither reviews grants nor conducts research programs. These efforts continue to occur, appropriately, by the scientists at the NIH institutes. The multi-disciplinary nature of AIDS research makes the OAR structure more efficient, and more scientifically sound, than a single AIDS institute or uncoordinated efforts across the 24 ICDS.

COMPARISONS ARE COUNTERPRODUCTIVE

Comparisons of funding for different diseases are counterproductive and misleading. The health of the nation is dependent upon a strong national commitment to biomedical research across disciplines and diseases that benefits all Americans. Because the existing knowledge base, economic and human costs, and scientific opportunities of every disease are important it is inappropriate and unwise to pit research funding for one disease against another.

Scientific priority-setting should consider many factors. One of the most important factors is scientific opportunity. Scientists believe that the scientific opportunities presented by AIDS are enormous, similar to the opportunities that existed in cancer research during the 1970s, which eventually opened new avenues of research and are generally credited with providing the foundation for the molecular biological revolution of the late 1970s and 1980s.



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HIV Prevention

During the past four years AIDS cases have more than doubled, and AIDS is now the leading cause of death of all Americans aged 25 to 44. Currently, prevention is the only cure for stopping HIV transmission. Increased prevention funding is needed to ensure that effective, well-funded and well-documented prevention programs targeting populations at risk can be implemented. By reducing the number of new HIV infections, we can reduce the demand for expensive care services in the future.

PREVENTION WORKS

Studies show that by combining a variety of focused, sustained prevention techniques, people do change their behavior. Such techniques include: teaching people the skills needed to negotiate difficult social situations; reinforcing techniques over time to enhance long-term behavior change; and promoting safer practices by ensuring access to condoms and sterile needles.

HIV prevention interventions can change behaviors in a broad range of populations including: injection drug users in treatment, gay men at risk and homeless/runaway youth. Simple informational materials and programs are not enough. To be effective, prevention programs must:

- reach people in a variety of settings (schools, churches, the workplace, clinics and neighborhoods);
- be culturally specific;
- be intensive and long-term; and
- provide populations at risk with the information, support and skills to change high-risk behavior.

COMMUNITY INVOLVEMENT LEADS TO BETTER PREVENTION

The Centers for Disease Control and Prevention (CDC) has instituted a process to increase community participation and better targeting of HIV prevention efforts to ensure that limited prevention funds reach populations most at risk for HIV/AIDS.

HIV Prevention Community Planning is a collaborative process which includes state and local health departments, social service agencies, nongovernmental agencies, representatives impacted or affected by HIV, and representatives of communities and groups at risk for HIV infection. These groups work in partnership to plan and prioritize HIV prevention programs that are responsive to community-identified needs within specific target populations.

PREVENTION IS COST EFFECTIVE

Preventing AIDS will not only eliminate needless suffering and death but will also reduce expensive health care and other economic costs. The lifetime medical cost of treating a person with HIV from the time that he or she becomes infected until death is approximately \$119,000. People with AIDS who stop working can no longer generate income and pay taxes and are often forced to draw upon entitlement programs.

There continue to be urgent, underfunded priorities in HIV prevention as the virus continues to move into communities of color, women, and adolescents. Potential cuts in HIV prevention programs may reduce federal spending in the short term, but will only lead to increased costs in the future.

ADMINISTRATION REFORM

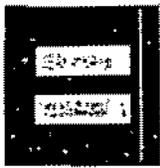
Administrative and legislative efforts to reform HIV prevention must have as their primary goal the strengthening of HIV prevention efforts, not the reduction of funding. Communities at risk for HIV infection have long advocated for significant reforms in federally-funded HIV prevention programs and for the need to design and implement effective prevention strategies in partnership with communities at risk.

MONITORING AND EVALUATION

The federal government, in partnership with state and local health departments, and representatives of communities at risk for HIV infection, should be responsible for developing, implementing, and evaluating a national prevention strategy. Infectious diseases, such as HIV are not confined to state borders. Decisions about whether or not to undertake HIV prevention activities must not be left solely to state health officials. While HIV Prevention Community Planning ensures broader participation at the local level, it does not diminish the need for federal oversight. The federal government must monitor the spending of federal funds and ensure the federally-funded prevention programs undertake scientifically sound HIV prevention activities that are supported by populations at risk for HIV. Current funding for HIV prevention programs must not be reduced by administrative changes or consolidation of categorical programs.

RESTRICTIONS ON CONTENT OF PREVENTION PROGRAMS

The federal government must not interfere with local decision making and priority setting by placing restrictions or mandates on the content of HIV prevention programs. Communities are best equipped to set priorities and develop and implement effective programs. Programs must not be restricted from using federal, state or local funds for prevention activities that they deem appropriate and consistent with public health.



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RYAN WHITE CARE ACT

Next to the Medicaid program, the Ryan White CARE Act is the largest federal investment in the care and treatment of people living with HIV/AIDS in the United States. The CARE Act supports a wide range of community based services, including primary and home health care, case management, substance abuse treatment and mental health services, and nutritional and housing services. The CARE Act also supports the AIDS Drug Assistance Program which provides HIV-related prescription drugs to those without access to basic HIV treatment.

CARE ACT TITLE I - EMERGENCY ASSISTANCE IN 49 AMERICAN CITIES

Title I of the CARE Act provides grants to cities and urban counties hardest hit by the AIDS epidemic. Five years ago, Title I provided assistance to 16 communities. This year 49 American communities receive funding under Title I, in which 74 percent of all reported AIDS cases in America have been reported.

The AIDS epidemic impacts particular communities in different ways. For this reason, Title I of the CARE Act empowers local Planning Councils to prioritize the services that are necessary to effectively respond to specific local needs. Planning Councils ensure community control of scarce resources and the participation of a diverse cross-section of public health experts, care providers, community leaders, and most important consumers of services and people living with HIV/AIDS.

CARE ACT TITLE II - GRANTS TO STATES/AIDS DRUG ASSISTANCE PROGRAMS

Title II of the CARE Act provides grants to states for the provision of comprehensive AIDS services, which may be provided through HIV Care Consortia. Consortia are associations of care providers and community based organizations operating in areas determined by the State to be particularly impacted by the HIV epidemic. States may also use Title II funds for home care services, health insurance continuation programs, and AIDS Drug Assistance Programs (ADAP). Allocation of funds to particular program areas is based on state and local needs assessments, availability of private health insurance, and the capacity of the state's Medicaid programs to provide access to necessary services.

Title II AIDS Drug Assistance Programs are a primary access point for medications for low income individuals living with HIV who are not covered by Medicaid or who do not receive prescription drug coverage through other third party payers.

CARE ACT TITLE III(B) - EARLY INTERVENTION

Title III of the CARE Act supports outpatient early intervention services for people with HIV and AIDS. Grants are made directly to public or nonprofit private organizations which currently provide comprehensive primary care services to populations at risk for HIV infection. Title III community health providers are the primary "point of access" to comprehensive health care for historically underserved populations and medically indigent individuals.

CARE ACT TITLE IV

Title IV of the CARE Act provides support for HIV comprehensive services and coordinated access to clinical research programs for children, youth, women and families. Community health centers and other appropriate private entities which serve a significant number of women and children can receive Title IV funds if they agree to coordinate the client's care with participation in research efforts.

CARE ACT TITLE V - SPECIAL PROJECTS, DENTAL SERVICES AND TRAINING

Title V of the CARE Act funds the Special Projects for National Significance (SPNS) program. The SPNS program assesses the effectiveness of new or innovative models of care and treatment that might be replicated elsewhere in the country.

Title V also includes the Dental Reimbursement Program which funds partnerships that provide quality oral health care to people living with HIV and AIDS while training future providers to effectively and safely administer such care.

Title V also funds the AIDS Education and Training Center (AETC) Program. The AETC program trains health care professionals to better counsel, diagnose, and treat people with HIV/AIDS and to keep health professionals up to date with new advances in HIV treatments and new standards of care.

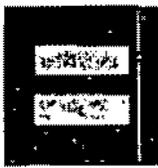
FUNDING IN FY 1997

Title I HIV Emergency Relief Grant Program	\$449.9 million
Title II HIV Care Grants to States	\$417 million
Title IIIB AIDS Early Intervention Service Grants to Clinics	\$69.6 million
Title IV Services for Children, Youth, Women and Families	\$36 million
Title V (Dental Reimbursement, AETCs)	<u>\$23.8 million</u>
TOTAL	\$996.6 million

In FY 1998, AIDS advocates are requesting a \$393.6 million increase in overall funding for the CARE Act in order to keep up with the growth in the HIV epidemic and the increasing costs of new HIV therapies and diagnostic testing.

LOCAL CONTROL ALLOWS TARGETED LOCAL RESPONSE

The CARE Act provides maximum flexibility to cities and states, allowing them to develop local systems of care based on the specific service needs of people living with HIV/AIDS in their area. Title I of the CARE Act requires that each local HIV services planning council-comprised of local public health, community - based service providers and people living with HIV/AIDS - assess local needs and make recommendations as to which services are needed. Similarly, through Title II, each state is given maximum flexibility to craft a service mix that is responsive to the specific service needs in that state. The CARE Act rejects a one-size-fits-all approach to AIDS care, recognizing that the AIDS epidemic nationally is really the combination of many local epidemics.



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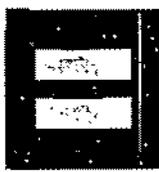
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Fact Sheet

OPPOSE THE COBURN HIV PREVENTION ACT OF 1997 (H.R. 1062/S. 503)

- The HIV Prevention Act of 1997, introduced by Rep. Tom Coburn (R-OK) and Sen. Don Nickles (R-OK), imposes one-size-fits-all "solutions" from Washington that tie the hands of State and local health departments. The provisions of the bill impose costly and ineffective testing mandates at the expense of proven HIV prevention strategies.
- Rep. Coburn's bill would make states' participation in the federal Medicaid program contingent on enacting its provisions. State Medicaid funds, when pooled with federal Medicaid funding, finance basic health care services for more than 37 million Americans, including over half of all people living with HIV/AIDS and 90 percent of children living with HIV/AIDS.
- H.R. 1062 and S. 503 would impose an estimated cost of \$420 million on States and localities and necessitate a minimum of 265 statutory or regulatory changes across the country. This cost and administrative burden would force States and localities to shift resources away from community-based, locally developed prevention strategies that respond to the unique needs in each community. These strategies have been proven to be effective in HIV prevention and any weakening of their effectiveness will cost lives.
- The bills mandate that States report the identities of people testing positive for HIV to be used by the CDC to set up a national partner notification program. The CDC has never called for such a system and every State currently must have a partner notification program in place in order to receive HIV/AIDS prevention funds from the CDC and funding under the Ryan White CARE Act.
- Mandating HIV names reporting and the establishment of a national system of partner notification would lead to the elimination of anonymous HIV testing, including the newly approved HIV home sample collection kits. Limits on a broad range of testing options discourages people from coming forward to be tested both because of fear of breaches in confidentiality and lack of access to testing sites.

- The bills also call for the mandatory testing of alleged sexual offenders. Testing a defendant in a sexual assault case may provide a false sense of security -- or alarm -- to the victim. If a defendant tests negative, it might only mean that antibodies to the virus have not yet developed in his body. If the defendant tests positive, it does not mean that the virus has been transmitted. The Omnibus Crime Control Act of 1994 already allows a victim to request a court order to have the alleged perpetrator to be tested for HIV in federal sexual assault cases. In addition, 44 States and the District of Columbia mandate or authorize HIV testing for charged or convicted sex offenders.
- The bills allow health care providers to withhold medical procedures unless the patient is tested for HIV and the provider is notified of the results. In addition to constituting a non-consensual procedure, a patient's life may be placed in jeopardy if the health care provider waits for test results before providing the necessary care. Guidelines from the CDC and OSHA on universal precautions are accepted practice to prevent HIV transmission in health care settings.
- The National Governor's Association has expressed strong opposition to H.R. 1062, indicating that it "places Medicaid funding at risk in order to advance testing requirements of dubious merit...Governors oppose the bill and would object to inclusion of its provisions in a reconciliation package or any other appropriations or authorization bill." Both bills are also opposed by the Association of State and Territorial Health Officials, the National Alliance of State and Territorial AIDS Directors, the American Public Health Association, and the American Nurses Association.



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Saving Lives Through Syringe Availability

An estimated 1-2 million Americans inject illegal drugs and the sharing of needles among injection drug users (IDUs) is a leading cause of HIV transmission. In "A Physician's Guide to HIV Prevention," the American Medical Association states that "primary care physicians can help their patients reduce HIV risk from injecting drugs by encouraging patients to...use a new needle each time drugs are injected." The scarcity of clean syringes is the result of federal, state and local laws restricting the sale, distribution and possession of syringes. Lowering the rate of injection-related HIV infections requires increasing the availability of drug treatment and increasing access to clean needles through changes in federal, state and local laws and broad implementation of needle exchange programs.

DRUG USE AND AIDS

- Approximately one-third of reported AIDS cases are related to injection drug use.
- Sixty-six percent of AIDS cases reported among women are related to injection drug use.
- More than half of all AIDS cases among children are related to injection drug use.
- In 1994 and 1995, seventy-five percent of all new HIV infections were among drug users.

NEEDLE EXCHANGE PROGRAMS IN THE U.S.

Needle exchange programs exchange sterile needles or syringes for used ones to prevent the sharing of injection equipment and the accompanying risk of transmission of HIV and other blood-borne diseases. The programs dispose safely of the used needles and offer a variety of related services to participants, including referrals to drug treatment and HIV counseling and testing.

Needle exchange programs have not been widely established because forty-seven states and two territories have laws that criminalize the sale or distribution of needles and syringes used to inject controlled substances. Eight states and the District of Columbia require a prescription for the purchase of a syringe. Most paraphernalia and prescription laws, adopted to combat illicit drug use, were enacted prior to the HIV/AIDS epidemic.

Through a variety of legal and tolerated mechanisms, including exceptions to state statutes, health department waivers, and local states of emergency, over 100 needle exchange programs operate in 40 U.S. cities in 28 states. In 1994, approximately 8 million needles/syringes were exchanged through these programs.

FEDERAL FUNDING BAN

Since 1988, Congress has enacted bans on using federal funds for needle exchange programs. The most recent federal ban is included in the Fiscal Year 1997 Omnibus Consolidated Appropriations Act. The ban prevents the use of federal funds for needle exchange programs unless the Secretary of Health and Human Services determines that such programs are effective in preventing the spread of HIV and do not encourage the use of illegal drugs.

In addition to prohibiting the direct expenditure of federal funds, state public health officials report that the federal ban has made states less inclined to fund needle exchange programs.

SCIENCE SUPPORTS NEEDLE EXCHANGE

Numerous respected organizations have reviewed the research on needle exchange programs and concluded that needle exchanges are effective. Those organizations include: the Congressional Office of Technology Assessment; National Academy of Sciences; National Commission on AIDS; University of California, San Francisco, in a study for the Centers for Disease Control and Prevention; U.S. General Accounting Office.

Several major studies show that the needle exchange programs lower the rate of new HIV infections among IDUs. One recent study conducted by Beth Israel Medical Center showed a two-thirds decrease in HIV infections among participants in five New York City needle exchanges. In addition, exchanges have reduced significantly the rates of hepatitis B and C.

There is no evidence that needle exchange programs lead to increased drug use by exchange clients or in the wider community. In fact, exchanges have been effective links to drug treatment.

AMERICANS SUPPORT NEEDLE EXCHANGE

In March 1996, the Kaiser Survey on Americans and AIDS/HIV found that 66% of respondents favored "having clinics make clean needles available to IV drug users to help stop the spread of AIDS."

An April 1997 poll by the Tarrance Group and Lake Research indicates that a majority of people (53%) support needle exchange programs to prevent the spread of HIV.

After reviewing the facts, numerous leading professional organizations have voiced their support for needle exchange as an important HIV prevention strategy. They include the: American Medical Association, American Public Health Association, Association of State and Territorial Health Officials, National Academy of Sciences, and the National Black Caucus of State Legislators.

SUCCESS IN CONNECTICUT

Connecticut partially repealed its state prescription and paraphernalia requirements in 1992. Prior to the repeal, 74% of injection drug users obtained syringes on the street. Following the repeal, 78% obtained syringes through pharmacies. According to the Connecticut Department of Public Health, needle sharing among IDUs fell from 52 to 32% following the repeal.

THE COST OF NOT ACTING

According to a June 1996 University of California study, the number of HIV infections that could have been prevented between 1987 and 1995 in the U.S. had needle exchange programs been widely established is between 4,400 and 9,700. In addition, up to half a billion dollars in health care expenditures could have been avoided. The study also found that an additional 11,300 cases among IDUs, their sexual partners and children could be prevented by access to needle exchange programs through the year 2000.

Date: April 29, 1997

To: The Human Rights Campaign

From: Lori Gudermuth
The Tarrance Group (R)

Celinda Lake, Jennifer Sosin and Dana Stanley
Lake Sosin Snell & Associates (D)

Re: **AMERICANS SUPPORT NEEDLE EXCHANGE**

A new national poll by the Tarrance Group (R) and Lake Sosin Snell & Associates (D) shows that a majority (55%) of the American public favors needle exchange programs:

Some local communities have adopted "needle exchange" programs as a way to curb the spread of AIDS and HIV. "Needle exchange" programs allow drug users to trade in USED needles for CLEAN needles. Generally speaking, do you FAVOR or OPPOSE these kinds of "needle exchange" programs?

[FOLLOW-UP:] Is that STRONGLY (favor/oppose), or SOMEWHAT (favor/oppose)?

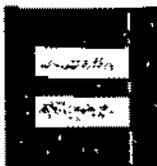
<i>strongly favor</i>	32	55
<i>somewhat favor</i>	23	
<i>somewhat oppose</i>	9	
<i>strongly oppose</i>	29	37
<i>(don't know)</i>	8	

Republicans are split evenly on this issue (45% favor, 48% oppose, 7% don't know), and moderate-liberal Republicans favor needle exchange by 17 percentage points (57% favor, 40% oppose, 3% don't know). Strong majorities of both independents (58% favor, 33% oppose, 9% don't know) and Democrats (64% favor, 29% oppose, 7% don't know) are in favor. Needle exchange also finds support in every region of the country: 60%-32% in the Northeast, 49%-44% in the Midwest, 51%-40% in the South, and 64%-30% in the West.

This memorandum reports the findings from a national survey of 1,000 adults who indicated they are registered to vote, conducted April 8-10, 1997, by The Tarrance Group and Lake Sosin Snell & Associates. The overall margin of error is ±3.1 percent.

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Voters & AIDS

Public opinion research shows clearly that America is united across party lines when it comes to the fight against AIDS. Voters of all political backgrounds – including swing voters and traditional GOP voters -- support strong efforts against AIDS. Voters believe that the federal government has a responsibility to address this national health crisis, and taxpayers are willing to pay for it.

This consensus has emerged due to the deepening impact of the epidemic on American families. In 1995, AIDS became the leading cause of death for all Americans aged 25-44. Over half a million American men, women and children have been diagnosed with AIDS, and more than 300,000 have already died from this disease. AIDS strikes hardest against younger people, robbing the country of valuable energy, talent and promise for the future.

The Human Rights Campaign commissions extensive and ongoing studies about voters' attitudes toward HIV/AIDS issues and policies. The research is conducted by Democratic and Republican research firms, including Lake Research, The Tarrance Group, Bailey, Deardourff & Associates, and Greenberg Research, Inc.

The following findings illustrate the broad, nonpartisan consensus around strong policies against HIV and AIDS in the areas of research, prevention, care and treatment.

WHAT AMERICA THINKS ABOUT AIDS

Voters of all political stripes support a strong federal effort against AIDS. Data from a February 1995 study shows that AIDS transcends partisan affiliation, personal ideology or religious beliefs. GOP men and Republicans over age 45 support funding for the care of men, women and children with AIDS.

Voters support maintaining or increasing federal funding for the care of people with AIDS. While there is public support for putting the government's fiscal house in order, 72 percent of voters favor maintaining or increasing funding for the Ryan White CARE Act.

Voters support funding for AIDS and the provision of drugs to patients who cannot afford them. A majority, 56 percent, is less likely to support a member of Congress who votes against continuing funding for AIDS research. Perhaps most encouraging is the clear evidence of support for the notion of government providing AIDS drugs to patients who cannot afford them, 69 percent, and even a broad majority of devout evangelicals support this proposal.

Important groups of voters feel strongly about caring for people with AIDS. Swing voters favored maintaining or increasing AIDS care funding by a margin of 72 percent. This included 70 percent of Perot voters, 72 percent of Western voters, 70 percent of Midwestern voters and 81 percent of women with no college education.

American voters think the federal government is not doing enough about AIDS. Fully 45 percent of the electorate thinks the federal government is not doing enough to address the AIDS crisis. That includes 48 percent of Baptists and 44 percent of Perot voters.

Parents want schools to teach their kids how to prevent AIDS. Despite efforts by political extremist groups to distort the purpose of AIDS education programs, a strong majority of parents -- fully 59 percent -- are more concerned that their kids receive adequate information about AIDS than they worry about "exposing children to information about homosexuality."

Voters oppose discrimination against people with HIV and AIDS. Independent voters were strongly opposed to anti-gay language proposed in federal AIDS legislation, with 62 percent of independents saying they were against such language in the Ryan White CARE Act. 56 percent of all voters opposed this discriminatory language.

THIS IS NO TIME TO RETREAT ON HIV/AIDS

The Centers for Disease Control and Prevention has reported that AIDS is the leading killer of all Americans aged 25-44. The federal government has a responsibility to address this national health crisis.

Cities and states cannot be saddled with the enormous costs of addressing a national epidemic. AIDS is a unique area of leadership for the federal government, with high public approval of all federal efforts in AIDS research, prevention and care. Congress should continue to invest in America's health in these three critical areas.

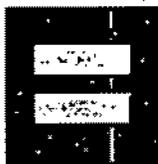
Congress should fully fund the Ryan White CARE Act. The Ryan White CARE Act provides necessary federal support while allowing local communities to decide how dollars are best spent. As the need for the CARE Act grows, so too does the recognition of its effectiveness. Through its support of community-based health and social services, including preventive AIDS drugs and therapies, the CARE Act prevents unnecessary and costly hospitalizations and reduces significantly overcrowding in hospital emergency rooms.

HIV/AIDS prevention programs save lives. Supported by the Centers for Disease Control and Prevention, and conducted by non-profit organizations like the American Red Cross, AIDS education programs are proven effective in keeping Americans safe and healthy. For this reason, 81 percent of voters -- and 72 percent of Republican voters -- support maintaining or increasing federal funds for AIDS education and prevention. Rep. Tom Coburn (R-OK), on the other hand, introduced a bill with provisions that are highly inefficient and have been demonstrated to discourage individuals at risk for HIV from seeking counseling and testing.

AIDS research remains a top priority. The search for a cure must not end until a cure is found. HIV/AIDS research has produced enormous benefits for people living with HIV/AIDS and has greatly expanded scientific understanding of the immune system and many diseases.

The American people strongly support federal efforts against AIDS. A bipartisan poll jointly conducted by leading Republican and Democratic polling firms has found unique public support for the federal government's efforts to fight HIV/AIDS. The Tarrance Group, a Republican polling firm, and Lake Research, a Democratic polling firm, surveyed 800 registered voters Feb. 25-26, 1995, in the first-ever bipartisan study of national voter attitudes on AIDS funding:

- 77 percent favor maintaining or increasing federal help for the care of people with AIDS.
- Voters are more likely to say the government is doing too little to deal with AIDS.
- A majority would be less likely to vote for a Member who opposes funding AIDS care.



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Housing & AIDS

Rates of communicable diseases such as HIV/AIDS and tuberculosis are higher among homeless people than in the general population. Often it is the disease that causes homelessness and poverty. Affordable, appropriate housing, such as that funded by the Housing Opportunities for People With AIDS (HOPWA) program is an essential element in any treatment plan for HIV/AIDS. It is almost impossible for an individual to follow a treatment plan, to store medications and maintain a healthy lifestyle without stable housing.

HOMELESSNESS AND AIDS

- 60% of people with HIV/AIDS will require housing assistance at some point during their illness.
- One-third to one-half of all people with AIDS are either homeless or in imminent danger of losing their homes.
- In 1992 the National Commission on AIDS estimated that 15% of homeless people are HIV positive.
- The Centers for Disease Control and Prevention (CDC) found an HIV infection rate of up to 21.4% in selected homeless populations.
- People living with HIV/AIDS have historically had difficulty accessing federal housing programs. Many have waiting lists that are longer than the average life span of a person with AIDS.

HOUSING OPPORTUNITIES FOR PEOPLE WITH AIDS (HOPWA)

The Department of Housing and Urban Development (HUD) has taken the position that housing programs for people with disabilities generally cannot be used to create AIDS-specific housing. To address AIDS-specific needs, Congress enacted the Housing Opportunities for People With AIDS (HOPWA) program in 1990. HOPWA is the only federal housing program that provides comprehensive, community-based HIV-specific housing programs.

Ninety percent of HOPWA funding is distributed by HUD directly to cities and states with high AIDS caseloads, through a formula grant. The remaining ten percent is awarded on a competitive basis to projects of national significance.

LOCAL CONTROL AND FLEXIBILITY

HOPWA gives local communities hardest hit by the AIDS epidemic desperately needed resources and local control over the use of those resources to meet the local housing needs of people with AIDS. Communities may use HOPWA funds to develop a broad range of housing and support services including short-term supported housing, rental assistance for low income persons with HIV/AIDS, community residences, or coordinated home care services.

COST EFFECTIVE

Cities and states control the use and administration of HOPWA funds. To ensure funds are used for housing activities, administrative costs are capped by law at 3 percent for formula grantees who administer the funds and 7 percent for the community-based "project sponsors" who actually provide the housing assistance.

At any given time, approximately 30% of people living with HIV disease in acute-care hospitals are there only because there is no other community-based residential alternative, at an average cost of \$1,085 per person, per day. The cost of providing housing and services at a HOPWA-funded residential facility is between one-tenth and one-twentieth of that amount. HOPWA reduces the use of emergency health care services by an estimated \$47,000 per person, per year.

DON'T DESTROY HOPWA

States and localities across the nation face severe funding shortfalls which reduce their ability to address the growing housing needs of their citizens with HIV/AIDS. As the number of AIDS cases continues to grow, the number of jurisdictions eligible for HOPWA funding grows as well. Each year, 10 to 13 new jurisdictions become eligible for formula grants based on increases in caseload. If HOPWA funding remains level, jurisdictions actually see cuts in the funding despite increasing need, because newly eligible jurisdictions must be accommodated. HOPWA is one of the few existing HUD programs that already provides the supposed benefits of block grants: formula funding to cities and states based on need, and funding that cities and states decide how to spend.

OTHER PROGRAMS CAN'T REPLACE HOPWA

Congress created the HOPWA program in 1990 because other programs failed to respond to the housing needs of cities and states. Other programs also failed to provide the specific resources and flexibility that enable jurisdictions to address the housing crisis that the AIDS epidemic poses locally.

Simply listing AIDS housing as an eligible activity for funding under a block grant will neither ensure that needs are addressed on the local level nor provide sufficient resources and guidance to enable localities to address those needs. Eliminating HOPWA will reduce resources to cities and states and increase local competition for those resources, while undoing years of local planning and development.

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Thurman
CO's

5-20-97

AIDS

Africa testing

THE WHITE HOUSE
WASHINGTON

197 MAY 16 09:53

MEMORANDUM FOR THE PRESIDENT

and
return

FROM: Bruce Reed, Assistant to the President for Domestic Policy
Sandra Thurman, Coordinator for National AIDS Policy

SUBJECT: International Studies on Reducing Maternal-Infant HIV Transmission

opportunity. I think this letter Eric E-mailed us
about will provide it. Elena

This memorandum will provide background on the controversy over an ongoing group of U.S.-supported international clinical trials studying options to reduce maternal transmission of HIV in developing countries. A brief overview of current knowledge, the rationale for further research, the World Health Organization position, concerns of domestic public interest groups, and the Department of Health and Human Services' position will be covered. Attached separately are talking points and Q&A's prepared by HHS on the issue.

Perinatal Transmission The World Health Organization (WHO) estimates over 1,000 HIV+ infants are born each day. Women with HIV disease have a 15%-40% risk of transmitting HIV to their baby with each pregnancy. The National Institutes of Health demonstrated that this transmission risk can be lowered to 8.3% by the administration of the drug AZT to women orally during pregnancy and intravenously during labor, and to their newborn infants orally for 6 weeks. This NIH study, known as ACTG 076 - comparing AZT with a placebo - was ~~tried and published in 1994 when these dramatic results were evident.~~ It has become the standard of care to offer all HIV+ pregnant women AZT therapy in the U.S.

An important unanswered research question is at what point during pregnancy or birth do women transmit HIV to their babies -- and if it is necessary to administer AZT over many months to prevent HIV infection in infants. Because many developing countries cannot afford expensive drug therapies for their citizens, pinpointing the critical period in which to administer AZT to prevent perinatal transmission is important so that the greatest number of women could be offered treatment.

Research Study Design Issues The public health leadership of several WHO member countries collaborated with the NIH and Centers for Disease Control and Prevention (CDC) to design and develop research studies to prevent perinatal HIV transmission in countries with limited health care infrastructure and resources. Each research study included an informed consent document outlining the research question, the randomization to an AZT or placebo group, and a detailed description of potential risks study participants may incur.

All study protocols were reviewed and approved by the NIH and CDC Institutional Review Boards (IRBs) and the host countries. The political leadership of each host country were also fully informed of the study methodologies and concurred with their implementation. The first studies proposed by this international collaborative group began in 1993 with funding support from the U.S. (NIH, CDC) and France.

Study - what I don't understand is agency mission
Womens Placebo Option - why not just study
study was in 1993
AIDS
Africa testing

World Health Organization Activity In June 1994, the WHO hosted a meeting of researchers and public health practitioners from the U.S., Europe, and countries in Africa, Asia and the Caribbean which have a high incidence of HIV disease. The purpose of the meeting was to examine the results of the NIH ACTG 076 trial in terms of their applicability internationally. The following recommendations were issued from this meeting:

- 1) Encourage the use of AZT as outlined by the NIH ACTG 076 study in industrialized countries; and
- 2) Immediate exploration of alternative regimens that could be used to achieve prevention of perinatal HIV prevention in the developing world.

WHO participants established parameters for the conduct of research studies in developing countries. The studies supported by the U.S. and France were consistent with these parameters.

Concerns of Some U.S. Public Interest Groups Dr. Sidney Wolfe of the Public Citizen Health Research Group wrote a long critique of U.S. involvement and support for these international perinatal HIV prevention studies in a letter to Secretary Shalala. The letter was broadly distributed to the media. Key concerns raised were:

- o Some research designs include a placebo arm when AZT has proven benefit. Such a research design would never be allowed in the U.S.
- o The studies violate major international ethical guidelines, specifically: the World Medical Association's 1975 Declaration of Helsinki; four of the Nuremberg codes for human experimentation; and the International Ethical Guidelines for Biomedical Research Involving Human Subjects designed to address ethical issues in developing countries
- o There is no guarantee that women and infants in host countries will benefit from the research knowledge gained
- o The lack of appropriate care in host countries does not justify study designs with placebo arms that have no benefit. The standard of care in many countries does not include access to prenatal care, medications, hospital births or intravenous infusions
- o Comparison of these studies to the Tuskegee syphilis study; criticism that IRBs should ensure that risks to subjects are minimized and subjects are not unnecessarily exposed to risk; this is colonialism at its worst

Senator Carol Moseley-Braun (D-IL) has also voiced her concern regarding study designs with a placebo arm when there is a known effective treatment for HIV prevention. She is alarmed that such studies are supported with U.S. funds, and thinks it is inappropriate to continue such funding in face of the apology being offered to the Tuskegee survivors this Friday.

Department of Health and Human Services The Department of Health and Human Services has conducted a review of the U.S.-funded studies in question and continues to support both the study designs and public health importance of completing them. They are ongoing as of this date. HHS testified to this effect before the House Government Reform and Oversight Committee last week. There was very little discussion of the issue among Representatives present.

In brief, the HHS position maintains:

- o The studies address a pressing need in the global control of the spread of HIV, defining interventions that will result in reductions in maternal-infant transmission which can be safely and routinely implemented in the developing world;
- o The studies are based on the assumption that the NIH ACTG 076 regimen is not a feasible therapeutic intervention in developing countries due to lack of medical infrastructure and cost constraints; the research design examines options for treatment which are viable and affordable within the medical care delivery systems of the study countries
- o All ongoing studies are in full compliance with U.S. and in-country regulations and laws, have gone through extensive in-country and U.S. ethical review processes and an international ethical review, and all studies have strong in-country support; an independent Data and Safety Monitoring Board continues to provide oversight of research findings at regular intervals
- o Broadly accepted ethical principles for international research recognize a role for the local standard of care when testing the effectiveness of a new intervention. In the case of developing host countries, the local standard is minimal to no health care access. Studying new research options of AZT administration at specific times during pregnancy offers a new benefit to individuals who would not otherwise have had it, while defining research knowledge that may allow many individuals to benefit if shorter courses of AZT prove effective for HIV prevention. The placebo arm is equivalent to the local standard of care.

Attached are Q&As and talking points which support the HHS position on this issues.

THE WHITE HOUSE

WASHINGTON

QUESTIONS AND ANSWERS

Q. Did you know about the NIH supported clinical trials using AZT and placebos in HIV infected pregnant women in developing countries?

A. I am aware that NIH is funding some research into how to improve prevention of mother to infant transmission of HIV in some developing countries. I understand that AZT is the drug that is being used in these studies.

I have asked the Secretary of Health and Human Services to provide me with a report on these NIH studies. I also asked for an evaluation of how these studies will help the women and infants involved and how the studies are helping to curb maternal transmission of HIV in these countries.

Q. Some of the women in these studies are not receiving AZT, they are getting a placebo. How does this compare with the U.S. position that all HIV infected pregnant women and their infants should be offered AZT?

A. That question will be addressed in Secretary Shalala's report. Just let me say that in many developing countries no HIV treatment at all is available for pregnant women or their infants. It is totally different situation than what we have in this country where AZT is readily available.

Q. Some critics are saying that the NIH funded AZT studies in developing countries are not different from what happened in the Tuskegee study where treatment was withheld from some of the participants. How do you answer that?

A. Well, I will need to see the report from HHS before I can fully address that. But I must emphasize that in the Tuskegee study, treatment that was widely available in this country was deliberately withheld from some of the participants. In the AZT studies overseas, the only AZT treatment available is the treatment provided to participants in the study.

Q. Some critics are saying that there is an issue of violation of international ethical codes in the AZT studies. Is this true?

A. I will know more about the studies and the specific concerns surrounding it when I review Secretary Shalala's report. Until then, I can't say anything further on this. I can assure you that we will not support any studies where such violations occur.

TALKING POINTS

- * OUR GOAL IN SUPPORTING THESE STUDIES IS TO FIND EFFECTIVE WAYS TO PREVENT MOTHER-TO-CHILD TRANSMISSION OF HIV THAT CAN BE USED IN DEVELOPING COUNTRIES. THAT MEANS FINDING A REGIMEN THAT IS EFFECTIVE FOR THE SPECIFIC POPULATION AND AFFORDABLE IN THAT COUNTRY.
- * THE FULL AZT-076 REGIMEN, WHICH IS THE STANDARD OF CARE IN THE UNITED STATES, IS NOT FEASIBLE FOR THESE COUNTRIES. IT IS EXPENSIVE AND REQUIRES SOPHISTICATED MEDICAL MONITORING.
- * WE HAVE WORKED WITH THE WORLD HEALTH ORGANIZATION, UNAIDS AND THE HOST GOVERNMENTS TO DESIGN THESE TRIALS. THEY ARE FULLY SUPPORTED BY THE INTERNATIONAL BODIES AND BY THE HOST GOVERNMENTS
- * THESE TRIALS HAVE BEEN REVIEWED FROM AN ETHICAL STANDPOINT BY THE CDC AND NIH INSTITUTIONAL REVIEW BOARDS, AND BY REVIEW BOARDS IN THE HOST COUNTRIES. WE AGREE THAT THESE ARE DIFFICULT AND COMPLEX ISSUES, BUT THAT IS EXACTLY WHY WE WENT TO SOME LENGTHS TO ACHIEVE MEDICAL AND ETHICAL CONSENSUS ON THE RESEARCH NOT ONLY WITHIN HHS, BUT WITH INTERNATIONAL ORGANIZATIONS AND THE HOST COUNTRIES THEMSELVES.
- * WE ARE DEDICATED TO FINDING AN EFFECTIVE THERAPEUTIC INTERVENTION THAT CAN REALISTICALLY BE ADMINISTERED IN THE HOST COUNTRIES AND IS AFFORDABLE.



The Honorable William J. Clinton
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear President Clinton:

June 4, 1997

On behalf of the Northwest AIDS Foundation and the thousands of individuals living with HIV and AIDS in Washington state, we urge you to support a \$68 million amendment to the AIDS Drug Assistance Program (ADAP) in Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. In the past year, new drug therapies have offered hope to individuals living with HIV and AIDS. This hope, however, comes at a high price, and many individuals cannot afford to access these new treatments.

The ADAP program augments state AIDS drug assistance programs that help pay the high cost of protease inhibitors and other drugs for many low-income, HIV-positive individuals. The high cost of these therapies has driven some state programs to the brink of bankruptcy and forced other to institute draconian cuts and dangerous limitation of services. In Washington, the state's AIDS Prescription Drug Program (APDP) was forced to close enrollment in July 1996 due to projected budget shortfalls. Due to hard work by AIDS advocates and former Governor Mike Lowry, the program was reopened and access was restored, despite a burgeoning deficit. Although the Washington State Legislature provided \$6.7 million new dollars for the APDP over the next two fiscal years, this sum is \$2 million short of projected need estimates by state health department officials. Across the nation, many states face similar funding shortages and have been unsuccessful in securing adequate funds through state legislators. Without a supplemental FY 1997 ADAP appropriations, individuals in need will be denied access to care.

Mr. President, we ask you to demonstrate ongoing leadership in supporting a \$68 million amendment to the FY 1997 ADAP budget. This proposal has received strong bi-partisan support in Congress, yet members have indicated that they are waiting for leadership from the Administration before moving forward with a proposal. Your support for an increased ADAP budget can help make a difference in the lives of tens of thousands of individuals across the country who rely on access to these life-saving drugs.

Sincerely,

A handwritten signature in black ink, appearing to read "Terry M. Stone".

Terry M. Stone
Executive Director

A handwritten signature in black ink, appearing to read "Steven B. Johnson".

Steven B. Johnson
Director of Public Policy

cc: The Honorable Albert Gore, Jr., Vice President of the United States
Washington state Congressional delegation
Erskine Bowles, Chief of Staff
Donna Shalala, Secretary of Health and Human Services
Sandy Thurman, National AIDS Policy Director

Bruce Reed, Assistant to the President for Domestic Policy
Marsha Scott, Deputy Assistant to the President for Political Affairs
Richard Soearides, Special Assistant to the Deputy Chief of Staff
Franklin Raines, Office of Management and Budget, Director
Nancy Ann Min, Office of Management and Budget, Director of Health and Personnel
Kevin Thurm, Deputy Secretary of Health and Human Services
William V. Corr, Department of Health and Human Services, Counselor to the Secretary
Eric P. Gossby, Office of HIV/AIDS Policy, Director
Deborah Von Zinkernagel, Office of AIDS Policy, Senior Policy Analyst
Dorothy Keville, Co-chair, National ADAP Working Group

~~EK -
Annexed covered this,
don't you think? - Bn~~

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MEMORANDUM FOR THE PRESIDENT

*AIDS
Policy*

FROM: Bruce Reed, Assistant to the President for Domestic Policy
Chris Jennings, Deputy Assistant to the President for Health Policy
Sandra Thurman, National AIDS Policy Coordinator

SUBJECT: AIDS Vaccine Initiative - Next Steps

This memorandum will summarize the broad response to the announcement of your commitment to developing an AIDS vaccine, and lay out a strategy to sustain momentum and solidify support for this initiative.

Response to Announcement

There has been broad-based and enthusiastic appreciation for your commitment to developing an AIDS vaccine. The Morgan State speech positively showcased your leadership and willingness to take on a critical research task with vital domestic and international implications. Prior to the announcement, we contacted major constituency groups and several industry leaders to ensure their support for this initiative. Attached are several comments that have been received.

AIDS Groups You have received a great response from the vast majority of national AIDS organizations. The AIDS Action Council, based in Washington and representing 1,400 community-based organizations (CBOs) across the country, and the National Association of People with AIDS have both written strong letters of support. The San Francisco AIDS Foundation, one of the largest CBOs in the country, and the Center for AIDS Prevention Studies, the leader in the prevention arena, continue to provide good comments for the media. The CAEAR Coalition, representing the 49 major cities receiving Ryan White CARE Act funding, are praising this initiative. Additional verbal and written responses are equally positive.

Some community groups and activists are expressing their concern around resource issues: a) will real resources be committed to this effort, and b) will funding or personnel be redirected from current treatment and prevention activities? Unfortunately, the timing of the Morgan State speech coincided with the Administration not requesting additional funds for AIDS drug assistance programs, and not placing AIDS funds in the "protected" category during the Budget discussions.

Consequently, the AIDS community feels that it is getting a mixed message. In their view, the Administration is focusing its efforts and dollars on a new initiative for vaccine development while at the same time de-prioritizing AIDS funding and underfunding treatment.

DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT

Page 2 - The President

Foundations and Industry The Rockefeller Foundation has taken the lead in coordinating an international project known as the International AIDS Vaccine Initiative (IAVI). They strongly support Presidential leadership in this arena, and are anxious to participate in an international effort. UNAIDS, based in the World Health Organization in Geneva, has pledged to work with you to make this effort a success, and are delighted with your leadership. They are writing an op-ed piece to place in the Washington Post or NY Times.

The American Foundation for AIDS Research (AmFAR) in New York has put its support behind the initiative, as has the Albert Sabin Vaccine Foundation. Industry leaders, including those from Merck Pharmaceuticals, have been positive in their comments, but are waiting to see how this dialogue will evolve in the proposed White House meeting.

Next Steps

National Institutes of Health (NIH) Proposal The NIH has put forward more specifics around their proposed role in vaccine development. NIH has begun development of a Vaccine Research Center (VRC) as a joint venture of the National Cancer Institute (NCI) and the National Institute of Allergy and Infectious Diseases (NIAID). The VRC will begin incorporating a core group of NIH scientists with expertise in immunology, virology and vaccine research already on-site at NIH. The primary focus of VRC will be to stimulate multidisciplinary research from basic science through to vaccine design and production.

Initially the VRC will be a "laboratory without walls," while laboratory space is sought in the vicinity of the NIH campus to bring the scientists together. Later, as scientists are recruited from outside the NIH ranks, NIH will consider constructing new space on campus to house the VRC. The funding and support for the VRC will be jointly provided by NCI and NIAID. As you know, funds for AIDS research are allocated according to the plans developed by the Office of AIDS Research (OAR) with the NIH Institutes. The OAR has proposed \$17 million in FY 1998 for the VRC, bringing the overall NIH support to AIDS vaccines to \$150 million. A search committee will be named before the end of May to conduct a nationwide search for a scientist with specific expertise in vaccine development to serve as Director for the new VRC.

Plans to Address Community Concerns To demonstrate that this is a serious proposal, we have set up several meetings to provide information to the community and walk through their concerns. On Wednesday, Sandy Thurman will have a news briefing in her office with Dr. Harold Varmus, Director of the NIH, Dr. Bill Paul of the Office of AIDS Research, and Dr. Tony Fauci of NIAID to provide more details about NIH's plan for a vaccine research center. A follow-up meeting with the community will take place after the news briefing. Sandy has already met with most of the national AIDS organizations individually this week. We are also setting up a meeting next week for the community with OMB to explain FY'97 and FY'98

DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT -- DRAFT

Page 3 - The President

budgetary issues and reaffirm the Administration's full and equal commitment to all of the AIDS programs -- prevention, research and care.

To continue in a consistent and positive direction, we will identify opportunities to reaffirm the breadth of the Administration's commitment to HIV/AIDS. By early June, the expert panel sponsored by HHS and Kaiser Family Foundation to develop model clinical practices for care of adult HIV infection will be ready to publish their recommendations in the Federal Register for public comment. This has been an anxiously awaited document, given the increasing complexity of HIV care with many new drug combinations and laboratory tests to monitor HIV disease. This is a clear demonstration of the Administration's commitment to translating research gains into improved care for all persons living with HIV. A White House roll-out could be orchestrated with both health care providers and community groups.

Many of the leading national AIDS organizations come together in Washington, DC on June 23, 1997 to kick off the HIV Testing Project -- an initiative to encourage people to voluntarily learn their HIV status so they can benefit from effective new treatments. This would be another opportunity to announce the expert panel recommendations to visibly cement your support for the spectrum of AIDS prevention and care issues in addition to active research and vaccine development components.

Sustaining Momentum on Vaccine Initiative The U.S. has proposed that the leaders of the eight major industrialized nations meeting at the Denver Summit in June agree to support a worldwide AIDS vaccine research initiative. The UNAIDS program and the International AIDS Vaccine Initiative (IAVI) are working with us to fashion a proposal acceptable to participating countries. Four countries have already contacted UNAIDS around what specifics could be developed. A few satellite meetings with the scientific and research communities could be put together in Denver to highlight this initiative. We are coordinating with Dan Tarullo of the NEC around the possibility of coordinating an announcement at the Summit.

In the next few months, a White House meeting to bring together vaccine development experts, government scientists, community leaders, and representatives of biotech and vaccine manufacturing companies can be put together. This would create an opportunity for you to deliver brief remarks, and for the Vice President to engage biotechnology and pharmaceutical industry partners in AIDS drug and vaccines development efforts.

We are working on a follow-up memo that will provide additional information, including plans relative to the June G8 Summit in Denver.



May 20, 1997

The Honorable Bill Clinton
 President of the United States
 The White House
 1600 Pennsylvania Avenue, N.W.
 Washington, D.C. 20515

Dear Mr. President:

On behalf of the 1,400 community-based organizations AIDS Action Council represents, I would like to take this opportunity to applaud your call this past Sunday, May 18, to make the development of an AIDS vaccine a "new national goal for science." By likening your challenge to find an AIDS vaccine within the next decade to President John F. Kennedy's call to put an American on the moon, you have reminded the country, indeed, the world, that much remains to be done before this terrible epidemic is truly over.

Mr. President, AIDS Action Council recognizes your leadership in the fight against this dread disease. Sixteen years into the AIDS epidemic, the AIDS community is enjoying the new hope that promising AIDS drug therapies represent. Thousands of people living with HIV and AIDS are benefiting from state-of-the-art care, which has contributed to an historic decline in AIDS deaths in the United States. History will record these two advancements, as well as your AIDS vaccine announcement last Sunday, as a part of your legacy on AIDS.

AIDS Action Council urges you to expand that legacy by continuing to make funding for AIDS research, care, prevention, and housing a budgetary priority in fiscal year 1998 and beyond. Research to find more effective treatments, a vaccine, and a cure must continue to be a priority. All Americans living with HIV and AIDS must have access to the health care and the social services they need to stay alive and healthy. Every weapon at our disposal, including needle exchange programs, must be put to good use to curb the further spread of HIV. And no individual living with HIV disease should want for adequate, stable housing. AIDS Action Council is anxious to work with you to ensure that this era of hope - raised to a new level by your call to re-energize our nation's search for an AIDS vaccine - touches the life of every American living with, and affected by, HIV and AIDS.

Best Regards,

A handwritten signature in dark ink that reads "Daniel Zingale". The signature is fluid and cursive.

Daniel Zingale
 Executive Director

cc The Honorable Donna Shalala
 Sandra Thurman, Director, Office of National AIDS Policy

1873

Connecticut Ave NW

Suite 700

Washington DC

20009

Fax 202 986 1345

Tel 202 986 1300

**NAPWA****NATIONAL
ASSOCIATION
OF PEOPLE
WITH AIDS**

May 21, 1997

The President
The White House
Washington, DC 20500

Dear Mr. President:

I am writing on behalf of the National Association of People with AIDS (NAPWA), to commend you on the announcement of a national initiative to develop a protective vaccine against the Human Immunodeficiency Virus (HIV) in the next ten years. NAPWA salutes your commitment to making this a serious national priority.

As the national voice of people living with HIV, NAPWA represents the needs of countless thousands of Americans who face the day-to-day challenges of living with HIV disease. We remain committed to working for a cure for AIDS. We have never strayed from our responsibility, however, to promote and support effective HIV prevention and education. For millions of people at-risk for HIV infection across the globe, the simple knowledge that the greatest nation on earth will lead the effort to develop a preventive vaccine is very powerful.

We applaud your leadership and the leadership of Vice President Gore. In announcing this initiative, NAPWA strongly urges you to renew your commitment to maintaining and expanding HIV/AIDS Housing, Prevention, Research, Medicaid and Medicare and CARE Act services.

Sincerely,

A. Cornelius Baker
Executive Director



UNAIDS
 UNICEF • UNDP • UNFPA
 UNESCO • WHO • WORLD BANK

The Executive Director

Joint United Nations Programme on HIV/AIDS

Reference: ~~xxx~~

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

20 May 1997

Mr President,

Your extraordinary leadership in setting the goal for the development of an AIDS vaccine in the next ten years merits sincere praise. For too long, the research agenda has been turned on its head, with ninety percent of research funds in AIDS going towards cures and only ten percent to vaccines. Important as the new developments in therapy are in reducing the suffering and prolonging lives of people living with HIV/AIDS in the few countries where treatment is possible and affordable, they are doing nothing to halt the relentless march of this disease in Africa, Asia, Latin America and Eastern Europe.

For a vaccine to be brought to the parts of the world where the disease is having its greatest impact, the countries of the industrialized world and the developing world will need to work closely together. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has a Vaccine Advisory Committee, which is chaired by Dr Barry Bloom of the Albert Einstein College of Medicine in New York, and includes representatives from several industrialized and developing countries. UNAIDS and its Committee have as their mission to promote and facilitate the scientific, ethical, legal, and practical involvement of developing countries in vaccine research and testing.

Mr President, we pledge UNAIDS to work with you, Secretary Shalala, the National Institutes of Health and other U.S. institutions in the forefront of this crusade against AIDS. A vaccine which effectively addresses a virus which is devastating the world, must be tested and proven in the most affected countries in accordance with the highest standards of science and ethics.

Again, Mr President, I should like to congratulate you for your bold step forward. By directing the scientific community to leap beyond the tested borders of biology in the 21st century, you do much to ensure your own place in the history of our planet.

Please accept, Mr President, the assurance of my highest consideration.

Peter Piot



May 19, 1997

The Honorable William Jefferson Clinton
President
The White House
Washington, DC 20510

Dear Mr. President:

The Cities Advocating Emergency AIDS Relief (CAEAR) Coalition commends you on the announcement of a ten year federal initiative to develop a vaccine for the Human Immunodeficiency Virus (HIV). We salute your use of the Presidency to keep issues related to the worldwide AIDS pandemic at the forefront.

The CAEAR Coalition represents the federal policy and appropriations interests of the 49 U.S. epicenters of the AIDS epidemic that receive funding through Title I of the Ryan White CARE Act. We are people living with HIV and AIDS, medical providers, support service providers, and health planners who are on the front lines of the U.S. AIDS epidemic. We acknowledge the importance of a targeted initiative for vaccine development and recognize that a vaccine is critical to preventing new infections in youth and adults at risk for infection. We trust that the leadership of the United States in this initiative will have a ripple effect in governments and communities around the world--encouraging them to increase their efforts to end this devastating pandemic.

As consumers and providers of CARE services for people living with HIV, we ask that you continue to use the Presidency as a bully pulpit to keep the issues of people living with HIV in the hearts and minds of the American people. CARE programs will continue to need significant increases in support from the federal government as more people live longer with HIV disease. Medical care, housing, substance use treatment, mental health treatment, transportation, nutrition, and of course new antiretroviral drug therapies continue to be critical to the quality of life and survival of people living with HIV. Your ongoing support for increased funding for CARE programs is paramount to our success in filling these needs.

Thank you for your leadership and the leadership of Vice President Gore. We encourage you to continue to clearly articulate your commitment to ending this epidemic while caring for those living with HIV. The CAEAR Coalition looks forward to working with you to realize the goal of this laudable initiative.

The CAEAR Coalition
1413 K Street N.W., Suite 700
Washington, D.C. 20005

202 789 3565
202 789 4277 fax

Executive Committee

Ernest Hopkins, *Chair*
Suzi Rodriguez, *Vice Chair*
Robert Ryblecki, *Treasurer*
Jacqueline Muthar, *Southern*
Marc Halpern, *Southwestern*
Rex Sandborg, *Midwestern*
A. Gene Copella, *Northwestern*
Matthew McClain, *Mid-Atlantic*
Paul DiDonato, *At-Large*
Shawn Griffin, *At-Large*
Kathy Corra, *At-Large*
Luanna Clark, *At-Large*

**Administrator of
Federal Affairs**

H. Alexander Robinson

**Governmental Relations
Representative**

The Sheridan Group



1413 K Street, NW, Suite 700
Washington, D.C. 20005
(202) 789-3565 Fax (202) 789-4277

FACSIMILE COVER SHEET

TO: Debra Von Zinkernagel
FAX#: 202.690.7560
FROM: H. Alexander Robinson
TELEPHONE#: (202) 789-3565
DATE: May 23, 1997

2 Pages (including this cover).

Note:

This was a sign-on letter. Let me know if you need the signature pages and I will try to get those to you.

World Health Organization Activity In June 1994, the WHO hosted a meeting of researchers and public health practitioners from the U.S., Europe, and countries in Africa, Asia and the Caribbean which have a high incidence of HIV disease. The purpose of the meeting was to examine the results of the NIH ACTG 076 trial in terms of their applicability internationally. The following recommendations were issued from this meeting:

- 1) Encourage the use of AZT as outlined by the NIH ACTG 076 study in industrialized countries; and
- 2) Immediate exploration of alternative regimens that could be used to achieve prevention of perinatal HIV prevention in the developing world.

WHO participants established parameters for the conduct of research studies in developing countries. The studies supported by the U.S. and France were consistent with these parameters.

Concerns of Some U.S. Public Interest Groups Dr. Sidney Wolfe of the Public Citizen Health Research Group wrote a long critique of U.S. involvement and support for these international perinatal HIV prevention studies in a letter to Secretary Shalala. The letter was broadly distributed to the media. Key concerns raised were:

- o Some research designs include a placebo arm when AZT has proven benefit. Such a research design would never be allowed in the U.S.
- o The studies violate major international ethical guidelines, specifically: the World Medical Association's 1975 Declaration of Helsinki; four of the Nuremberg codes for human experimentation; and the International Ethical Guidelines for Biomedical Research Involving Human Subjects designed to address ethical issues in developing countries
- o There is no guarantee that women and infants in host countries will benefit from the research knowledge gained
- o The lack of appropriate care in host countries does not justify study designs with placebo arms that have no benefit. The standard of care in many countries does not include access to prenatal care, medications, hospital births or intravenous infusions
- o Comparison of these studies to the Tuskegee syphilis study; criticism that IRBs should ensure that risks to subjects are minimized and subjects are not unnecessarily exposed to risk; this is colonialism at its worst

Senator Carol Moseley-Braun (D-IL) has also voiced her concern regarding study designs with a placebo arm when there is a known effective treatment for HIV prevention. She is alarmed that such studies are supported with U.S. funds, and thinks it is inappropriate to continue such funding in face of the apology being offered to the Tuskegee survivors this Friday.

Department of Health and Human Services The Department of Health and Human Services has conducted a review of the U.S.-funded studies in question and continues to support both the study designs and public health importance of completing them. They are ongoing as of this date. HHS testified to this effect before the House Government Reform and Oversight Committee last week. There was very little discussion of the issue among Representatives present.

In brief, the HHS position maintains:

- o The studies address a pressing need in the global control of the spread of HIV, defining interventions that will result in reductions in maternal-infant transmission which can be safely and routinely implemented in the developing world;
- o The studies are based on the assumption that the NIH ACTG 076 regimen is not a feasible therapeutic intervention in developing countries due to lack of medical infrastructure and cost constraints; the research design examines options for treatment which are viable and affordable within the medical care delivery systems of the study countries
- o All ongoing studies are in full compliance with U.S. and in-country regulations and laws, have gone through extensive in-country and U.S. ethical review processes and an international ethical review, and all studies have strong in-country support; an independent Data and Safety Monitoring Board continues to provide oversight of research findings at regular intervals
- o Broadly accepted ethical principles for international research recognize a role for the local standard of care when testing the effectiveness of a new intervention. In the case of developing host countries, the local standard is minimal to no health care access. Studying new research options of AZT administration at specific times during pregnancy offers a new benefit to individuals who would not otherwise have had it, while defining research knowledge that may allow many individuals to benefit if shorter courses of AZT prove effective for HIV prevention. The placebo arm is equivalent to the local standard of care.

Attached are Q&As and talking points which support the HHS position on this issues.

THE WHITE HOUSE

WASHINGTON

QUESTIONS AND ANSWERS

Q. Did you know about the NIH supported clinical trials using AZT and placebos in HIV infected pregnant women in developing countries?

A. I am aware that NIH is funding some research into how to improve prevention of mother to infant transmission of HIV in some developing countries. I understand that AZT is the drug that is being used in these studies.

I have asked the Secretary of Health and Human Services to provide me with a report on these NIH studies. I also asked for an evaluation of how these studies will help the women and infants involved and how the studies are helping to curb maternal transmission of HIV in these countries.

Q. Some of the women in these studies are not receiving AZT, they are getting a placebo. How does this compare with the U.S. position that all HIV infected pregnant women and their infants should be offered AZT?

A. That question will be addressed in Secretary Shalala's report. Just let me say that in many developing countries no HIV treatment at all is available for pregnant women or their infants. It is totally different situation than what we have in this country where AZT is readily available.

Q. Some critics are saying that the NIH funded AZT studies in developing countries are not different from what happened in the Tuskegee study where treatment was withheld from some of the participants. How do you answer that?

A. Well, I will need to see the report from HHS before I can fully address that. But I must emphasize that in the Tuskegee study, treatment that was widely available in this country was deliberately withheld from some of the participants. In the AZT studies overseas, the only AZT treatment available is the treatment provided to participants in the study.

Q. Some critics are saying that there is an issue of violation of international ethical codes in the AZT studies. Is this true?

A. I will know more about the studies and the specific concerns surrounding it when I review Secretary Shalala's report. Until then, I can't say anything further on this. I can assure you that we will not support any studies where such violations occur.

TALKING POINTS

- * OUR GOAL IN SUPPORTING THESE STUDIES IS TO FIND EFFECTIVE WAYS TO PREVENT MOTHER-TO-CHILD TRANSMISSION OF HIV THAT CAN BE USED IN DEVELOPING COUNTRIES. THAT MEANS FINDING A REGIMEN THAT IS EFFECTIVE FOR THE SPECIFIC POPULATION AND AFFORDABLE IN THAT COUNTRY.
- * THE FULL AZT-076 REGIMEN, WHICH IS THE STANDARD OF CARE IN THE UNITED STATES, IS NOT FEASIBLE FOR THESE COUNTRIES. IT IS EXPENSIVE AND REQUIRES SOPHISTICATED MEDICAL MONITORING.
- * WE HAVE WORKED WITH THE WORLD HEALTH ORGANIZATION, UNAIDS AND THE HOST GOVERNMENTS TO DESIGN THESE TRIALS. THEY ARE FULLY SUPPORTED BY THE INTERNATIONAL BODIES AND BY THE HOST GOVERNMENTS.
- * THESE TRIALS HAVE BEEN REVIEWED FROM AN ETHICAL STANDPOINT BY THE CDC AND NIH INSTITUTIONAL REVIEW BOARDS, AND BY REVIEW BOARDS IN THE HOST COUNTRIES. WE AGREE THAT THESE ARE DIFFICULT AND COMPLEX ISSUES, BUT THAT IS EXACTLY WHY WE WENT TO SOME LENGTHS TO ACHIEVE MEDICAL AND ETHICAL CONSENSUS ON THE RESEARCH NOT ONLY WITHIN HHS, BUT WITH INTERNATIONAL ORGANIZATIONS AND THE HOST COUNTRIES THEMSELVES.
- * WE ARE DEDICATED TO FINDING AN EFFECTIVE THERAPEUTIC INTERVENTION THAT CAN REALISTICALLY BE ADMINISTERED IN THE HOST COUNTRIES AND IS AFFORDABLE.

THE WHITE HOUSE
WASHINGTON

May 6, 1997

MEMORANDUM FOR THE PRESIDENT

FROM: Bruce Reed, Assistant to the President for Domestic Policy
Dr. Eric Goosby, Acting Director, Office of National AIDS Policy

SUBJECT: Follow up to the April meeting of the Presidential HIV/AIDS Advisory Council

We are pleased to transmit to you the most recent recommendations of the Presidential Advisory Council on HIV and AIDS following its meeting of April 5 - 8.

A copy of the Council's recommendations is attached. These recommendations, in summary, ask for the following:

- Opposition of the HIV Prevention Act of 1997;
- Work to eliminate all regulations and requirements for mandated reviews by citizen review panels of the content of HIV prevention materials;
- Continued leadership and highest priority by our government on development of a successful HIV/AIDS vaccine within a decade;
- Encourage scientific research on the potential benefits and/or risks of medical marijuana and pending results of such research, the government refrain from any efforts to prosecute doctors, who in good faith, discuss the use of medical marijuana or recommend it for their patients;
- Continued advocacy for prison issues relating to compassionate release, discharge planning, standards of care, protective barriers, and substance use; and
- Continued leadership by the Administration on providing the science in a report to Congress on the efficacy of syringe exchange programs to reduce the transmission of HIV and the certification of such syringe exchange programs as effective in reducing the incidence of new HIV infections while not increasing substance abuse.

The Council also sent a letter to you regarding the elimination of discrimination against those infected with HIV by certain Federal agencies (copy attached).

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendation on Coburn Bill

The President should forcefully oppose the HIV Prevention Act of 1997. Many provisions of this bill, including enforced mandates, interference with State and local control over health care policies, and the potential for institutional discrimination against people living with HIV/AIDS, will undermine rather than enhance our nations HIV prevention strategy.

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendation on Content

The Secretary of Health and Human Services should eliminate all regulations and requirements for mandated reviews by citizen review panels of the content of HIV prevention materials. HIV prevention materials produced or distributed with federal funding should be free of restrictions on content, subject only to review for scientific accuracy and cultural appropriateness for the targeted population. Grantees should be given great flexibility in utilizing the least burdensome methods of conducting these reviews.

Final

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendations: HIV Vaccine Development

Development of a successful HIV/AIDS vaccine is clearly feasible and should be considered of the highest priority by our government. In order to succeed, we suggest the following recommendations:

1. The President must declare an urgent goal of developing a vaccine to prevent HIV/AIDS within a decade in order to mobilize public opinion, political will, and international collaboration, and to assign high priority to this effort within each of the governmental agencies involved in HIV/AIDS vaccine research and development. As the HIV/AIDS epidemic has no borders, and a successful vaccine will require international collaboration, the President should work with the leaders of other nations in a global effort to achieve an HIV/AIDS vaccine for all the world.
2. A significant and sustained increase in funds must be made available for HIV/AIDS vaccine research and development. These funds must be derived from NEW sources from both government and industry, and must not be taken from existing programs aimed at prevention, research, care, services, and/or treatment for persons with HIV/AIDS. Innovative use of such funds is essential, as seed money to initiate new and creative hypotheses in vaccine research; to support product development; to expand the proportion of successfully funded grant applications; and to bring additional entities into the HIV/AIDS vaccine field.
3. Development of an effective HIV/AIDS vaccine will require expertise in many areas, including basic science, applied research, public health policy, and legal, ethical, industrial, and international issues. Dr. David Baltimore has recently been chosen to provide advice and leadership for the NIH HIV/AIDS vaccine effort, and the Council is highly supportive of this appointment. Additionally:
 - Participation by non-governmental sectors and organizations is also essential to achieve the goal of expedited vaccine research, product development and use. The Vice President should convene a public-private HIV/AIDS vaccine consultative forum, composed of senior representatives to encourage communication between sectors, to address gaps in the field, and to speed progress towards the President's goal. Participation on this HIV/AIDS vaccine forum should include representation from: US Government agencies, industry, the international community, academia, the World Bank and other funding agencies, the insurance industry, ethicists, and communities most affected by the epidemic.
 - To achieve the goal of a more comprehensive vaccine development effort within the government, ALL relevant agencies within the US Government—including NIH, CDC, DOD, DVA, FDA, USAID and relevant offices within these agencies, especially those relating to minority and women's health—must be substantively involved in the vaccine effort. The agencies must regularly communicate with one another and share information.

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendations on Medical Marijuana

Background

On November 5, 1996, voters in California and Arizona approved the use of marijuana for medical purposes. In 1994, Ohio approved the use of medical marijuana, though its legislature is currently considering reversing that stand. Virginia and Louisiana have decriminalized possession of marijuana in certain medical cases. Today, 26 states and the District of Columbia have existing laws and resolutions establishing therapeutic research programs, allowing doctors to prescribe marijuana or asking the federal government to lift the ban on its medical use. In 10 states, similar laws have either been repealed or have expired.

Proponents of the use of medical marijuana cite anecdotal evidence of beneficial effects from its use, while opponents claim no convincing scientific evidence of such benefits and cite potential dangers. Research on the potential health benefits and/or risks associated with medical marijuana use is clearly needed.

Resolution

The President should direct appropriate agencies to take all steps necessary to encourage scientific research, including clinical trials, to gauge the potential benefits and/or risks of medical marijuana use (including smoked marijuana) on chronic pain, nausea, glaucoma and other conditions due to illnesses such as AIDS, cancer and other chronic diseases.

Further, the President should direct that, pending the results of such research, the government refrain from any efforts to prosecute doctors who, in good faith, discuss the use of medical marijuana or recommend it for their patients.

Final

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendations: Prison Issues Subcommittee

1. **Compassionate Release**

The President should direct the Justice Department and the Director of the Federal Bureau of Prisons to revise administrative and judicial standards of compassionate release for use in all Federal and Federally-funded prisons. Prisons will do this in accordance with American Bar Association (ABA) Standards. Furthermore, equivalent compassionate release programs should be required in state and local prisons as a condition of these institutions receiving federal funds. The Federal Bureau of Prisons also should be directed to maintain statistical and evaluative records concerning the compassionate release policy and file an annual report to the President, Secretary of Health and Human Services and the Office of National AIDS Policy.

2. **Discharge Planning**

The President should direct the Secretary of Health and Human Services to develop standards of care to ensure that, prior to release, ex-offenders with HIV/AIDS are provided timely, thorough, and appropriate case management/discharge planning. These standards should address behavioral and social service needs; continuity of care; and appropriate linkages to local community services, medical services, social service benefits, appropriate case management, and housing assistance programs to ensure against homelessness.

3. **Standards of Care.**

The President shall direct the Federal Bureau of Prisons to incorporate the upcoming Report from the HHS Panel on Clinical Practices for the Treatment of HIV Infections in all correctional medical facilities. It should be required that care providers be adequately trained to implement these standards and all appropriate therapeutic options associated with the management of HIV disease be available.

4. **Protective Barriers.**

The President shall direct the Attorney General to direct the Federal Bureau of Prisons to ensure that condoms and dental dams are made readily available for all prisoners within correctional facilities to prevent transmission of HIV/AIDS.

5. **Substance Use.**

The President shall direct the Attorney General to direct the Federal Bureau of Prisons to investigate and report within 90 days on the feasibility of and various options for providing comprehensive substance abuse treatment for incarcerated individuals with a dual diagnosis of chemical dependency and HIV disease.

SIXTH PRESIDENTIAL ADVISORY COUNCIL ON AIDS

April 5-8, 1997

Recommendations on Needle Exchange

The PACHA commends the Secretary of Health and Human Services and the Department of Health and Human Services on the Report to Congress on Appropriation for the Department of Labor, Health and Human Services Agencies: Needle Exchange Programs in America: Review of Published Studies and Ongoing Research which acknowledges the efficacy of syringe exchange programs to reduce the transmission of HIV.

WHEREAS, this report to the Congress confirms that syringe exchange programs reduce the rate of new HIV infections among injection drug users, and further confirms that such programs constitute a sound public health practice as part of an overall effort to reduce the incidence of new HIV infection; and

WHEREAS, the Secretary's report found no evidence which established that syringe exchange programs increase drug use; and

WHEREAS, a panel of nongovernmental public health experts convened by the National Institutes of Health found no scientific or medical evidence that syringe exchange programs increase drug use; and

WHEREAS, the President has set a goal of reducing the number of new infections each year until there are none; and

WHEREAS, the President has established a drug policy seeking to reduce the prevalence and incidence of drug abuse through prevention, counseling and treatment;

WHEREAS, syringe exchange programs and appropriate and effective substance abuse treatment and counseling efforts provide a unique opportunity to reduce the incidence of substance abuse and the number of injection drug users;

THEREFORE, we strongly recommend that the President ensure that the Secretary of Health and Human Services take all necessary steps to promptly certify syringe exchange programs as effective in reducing the incidence of new HIV infections while not increasing substance abuse; thus, the use of federal funds for syringe exchange and substance abuse counseling and treatment programs must be permitted in those communities that determine such programs to be appropriate.

Final

PRESIDENTIAL

May 6, 1997

ADVISORY

COUNCIL ON

The Honorable William Jefferson Clinton

HIV/AIDS

The White House

Washington, D.C. 20500

Dear Mr. President:

On February 7, 1997, the Office of National AIDS Policy Director Patsy Fleming met with representatives of this Council and representatives of several Federal agencies to discuss elimination of discrimination against those infected with HIV. I am writing to you to express our deep concern about the lack of progress by those Federal agencies toward elimination of discriminatory policies. You will remember that almost three years ago you asked this Council to meet with you to discuss issues of major concern regarding HIV/AIDS. One of the most critical issues raised was the previously established policy of several Federal agencies (i.e., the U.S. Foreign Services, the Peace Corps, the Job Corps, the U.S. State Department, and the Military) requiring mandatory HIV testing, and exclusion of those found to be HIV positive.

At that time, you expressed your concern about and disapproval of such policies and instructed your staff to investigate those policies and report back to you. We are dismayed that the February 7, 1997 meeting clearly confirmed that policies requiring mandatory testing and exclusion from entry of all applicants found to be HIV positive continue in these agencies. The policies of these Federal agencies represent a disturbing aberration from the general application of HIV/AIDS employment practices by the vast majority of federal agencies.

We are also concerned that those already employed by such agencies who later test positive face discrimination in assignments, promotions, and career advancement opportunities. Particularly in light of the promise offered by new treatment options, these policies serve to deprive qualified HIV-positive individuals equal employment opportunity and to deprive the federal government of the contributions those individuals could be making as dedicating public servants.

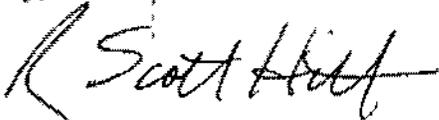
The Honorable William Jefferson Clinton
May 6, 1997
Page two

The Council has little optimism that without your intervention these discriminatory policies might be changed. We would therefore urge, Mr. President, that you renew your instructions for review and reconsideration of such policies. It is only through such action that your commitment "to fight AIDS related discrimination at every turn" contained in your National AIDS Strategy can be realized.

Your Council stands ready to assist in any way you deem appropriate.

Thank you for your consideration and concern.

Sincerely,

A handwritten signature in black ink that reads "R. Scott Hitt". The signature is written in a cursive style with a large, stylized initial "R".

R. Scott Hitt, MD
Chair, on behalf of the members of
the Presidential Advisory Council
on HIV and AIDS

Presidential Advisory Council on HIV and AIDS

Stephen N. Abel, D.D.S.
Mr. Terje Anderson
Ms. Judith Billings
Mr. Nicholas Bollman
Mr. Tonio Burgos
Jerry Cade, M.D.
Rabbi Joseph Edelheit
Mr. Robert Fogel
Ms. Debra Fraser-Howze
Ms. Kathleen Gerus
Ms. Phyllis Greenberger
Mr. Bob Hattoy
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Mr. Richard W. Stafford
Ms. Denise Stokes
Ms. Sandra Thurman
Bruce Weniger, M.D.

THE WHITE HOUSE

WASHINGTON

May 6, 1997

MEMORANDUM FOR BRUCE REED

FROM: Dr Eric Goosby, Acting Director, Office of National AIDS Policy

RE: Presidential Advisory Council on HIV and AIDS

Attached is the Letter to the President from the Council for your transmittal. Please forward.

cc: Elena Kagan

PRESIDENTIAL

May 6, 1997

ADVISORY

COUNCIL ON

The Honorable William Jefferson Clinton

HIV/AIDS

The White House
Washington, D.C. 20500

Dear Mr. President:

On February 7, 1997, the Office of National AIDS Policy Director Patsy Fleming met with representatives of this Council and representatives of several Federal agencies to discuss elimination of discrimination against those infected with HIV. I am writing to you to express our deep concern about the lack of progress by those Federal agencies toward elimination of discriminatory policies. You will remember that almost three years ago you asked this Council to meet with you to discuss issues of major concern regarding HIV/AIDS. One of the most critical issues raised was the previously established policy of several Federal agencies (i.e., the U.S. Foreign Services, the Peace Corps, the Job Corps, the U.S. State Department, and the Military) requiring mandatory HIV testing, and exclusion of those found to be HIV positive.

At that time, you expressed your concern about and disapproval of such policies and instructed your staff to investigate those policies and report back to you. We are dismayed that the February 7, 1997 meeting clearly confirmed that policies requiring mandatory testing and exclusion from entry of all applicants found to be HIV positive continue in these agencies. The policies of these Federal agencies represent a disturbing aberration from the general application of HIV/AIDS employment practices by the vast majority of federal agencies.

We are also concerned that those already employed by such agencies who later test positive face discrimination in assignments, promotions, and career advancement opportunities. Particularly in light of the promise offered by new treatment options, these policies serve to deprive qualified HIV-positive individuals equal employment opportunity and to deprive the federal government of the contributions those individuals could be making as dedicating public servants.

The Honorable William Jefferson Clinton

May 6, 1997

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The Council has little optimism that without your intervention these discriminatory policies might be changed. We would therefore urge, Mr. President, that you renew your instructions for review and reconsideration of such policies. It is only through such action that your commitment "to fight AIDS related discrimination at every turn" contained in your National AIDS Strategy can be realized.

Your Council stands ready to assist in any way you deem appropriate.

Thank you for your consideration and concern.

Sincerely,

A handwritten signature in cursive script that reads "R. Scott Hitt". The signature is written in black ink and is positioned above the typed name and title.

R. Scott Hitt, MD

Chair, on behalf of the members of
the Presidential Advisory Council
on HIV and AIDS

Presidential Advisory Council on HIV and AIDS

Stephen N. Abel, D.D.S.
Mr. Terje Anderson
Ms. Judith Billings
Mr. Nicholas Bollman
Mr. Tonio Burgos
Jerry Cade, M.D.
Rabbi Joseph Edelheit
Mr. Robert Fogel
Ms. Debra Fraser-Howze
Ms. Kathleen Gerus
Ms. Phyllis Greenberger
Mr. Bob Hattoy
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R. Scott Hitt, M.D., Chair
Michael Isbell, J.D.
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Mr. H. Alexander Robinson
Ms. Debbie Runions
Mr. Benjamin Schatz
Mr. Richard W. Stafford
Ms. Denise Stokes
Ms. Sandra Thurman
Bruce Weniger, M.D.

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

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FACSIMILE COVER SHEET

TO: Bruce Reed

FAX NUMBER: 456-2878

FROM: Eric Goosby

DATE: April 24, 1997

PAGES INCLUDING COVER SHEET: 3

Comments: FYI

April 24, 1997

The Honorable William Jefferson Clinton
The White House
Washington, DC 20500

VIA FACSIMILE

Dear Mr. President:

I am writing on behalf of AIDS Action Council, the national voice for 1400 community-based AIDS service organizations and the people living with HIV/AIDS whom they serve. I write to express our strong opposition to significant cuts in the Medicaid program and in domestic discretionary spending as components of a balanced budget agreement.

Your Administration has made a strong and ongoing commitment to adequate funding for AIDS-specific discretionary programs in the budget requests you have submitted to Congress each fiscal year. It is clear that budget negotiations now underway between Administration officials and Congressional leaders will chart the course for domestic discretionary spending from fiscal year 1998 through fiscal year 2002. Significant reductions in domestic discretionary spending will have a chilling effect on the ability of the nation to mount an aggressive and comprehensive response to the AIDS epidemic, at a time when breakthroughs in research and treatment offer new hope to those already infected and tens of thousands of other Americans at high risk for contracting the HIV virus. The prioritization of AIDS by your Administration must translate into active negotiations with Congressional leaders to ensure that overall domestic discretionary spending is sufficient over the life of the budget agreement to ensure adequate funding for AIDS and other vital programs.

Over 53 percent of adults and 90 percent of children with AIDS depend upon the Medicaid program for their health care. As recently as this month, your Administration again acknowledged the importance of the Medicaid program to poor people living with HIV/AIDS by announcing your intention to develop a Medicaid expansion demonstration program to respond to the current Medicaid eligibility limitation which prevents many low-income individuals living with HIV disease from accessing the Medicaid program until they are totally disabled by AIDS. This initiative could expand access to life-prolonging health care for many HIV-infected individuals, and we are profoundly grateful to Vice-President Gore and other high-ranking Administration officials for their commitment to this expansion.

The proposed HIV Medicaid expansion program would not affect the eligibility or benefits of those individuals who now qualify as "medically needy" or of currently categorically eligible individuals living with HIV/AIDS. The Administration's proposed federal per capita cap on Medicaid spending could effectively restrict



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April 24, 1997

eligibility and benefits for individuals with HIV/AIDS who already qualify and receive services under the Medicaid program. We are especially concerned about the response of states which shoulder the majority of the AIDS cases in the nation. With significant numbers of people with AIDS exceeding the per capita cap because of the high costs associated with HIV care, these states are likely to experience a significant cost shift in financing Medicaid-related AIDS services. We have grave concerns that states will react to this new financial burden by eliminating or limiting optional eligibility categories like the "medically needy" program or optional benefits like prescription drug services. Ironically, just as the Administration proposes a pilot program to address gaps in Medicaid eligibility for low-income people living with HIV disease, its Medicaid budget proposal threatens eligibility and critical prescription drug benefits for individuals and families already participating in the program.

While this Medicaid eligibility expansion is vital, it is inconsistent and incompatible with the Administration's proposed reductions in and restructuring of the Medicaid program. Not only would current HIV-infected Medicaid beneficiaries be harmed, but it is extremely unlikely that any state would agree to participate in the Medicaid expansion program in the context of a restructured Medicaid program with a cap on federal spending per beneficiary.

We are not convinced that slashing Medicaid funding is necessary to balance the federal budget or that achieving modest savings in Medicaid requires a complete restructuring of the Medicaid program. We are quite sure, however, that a per capita cap on federal Medicaid spending will threaten the health care that tens of thousands of people with HIV/AIDS now receive, and will undermine the success of the Administration's proposed Medicaid HIV expansion initiative which holds the promise for enhancing the health and productivity of many individuals who are poor enough, but not yet disabled enough to qualify for Medicaid.

A balanced budget through the year 2002 with deep reductions in Medicaid and in domestic discretionary spending, especially in the out years, means losing ground in fighting the AIDS epidemic. The budgetary impact of AIDS will be far greater in the years ahead, and countless lives will be needlessly lost. I urge you to reject cuts in the Medicaid program and in domestic discretionary spending in budget negotiations with Congressional leaders.

Sincerely,



Daniel Zingale
Executive Director

February 3, 1997

Mr. Bruce Reed
Domestic Policy Advisor
The White House
Washington, DC 20500

Dear Mr. Reed:

I am writing to you in lieu of Carol Rasco who was serving in the Domestic Policy Advisor post when my son and I were invited guests of President Clinton on World AIDS Day in 1994. President Clinton and Mrs. Rasco were very helpful at that time in clearing up a situation involving my son, Jay, a hemophiliac who contracted HIV through the use of contaminated blood products. Jay's medical insurance had lapsed and he was being covered under COBRA benefits that were in jeopardy of ending unless he could be classified as disabled by the Social Security Administration, which would extend his benefits an additional 11 months. Enclosed is a letter to Jay from President Clinton which noted how the situation was resolved.

At this time, I am writing about another situation which has occurred that I was hoping someone in the Executive Branch could resolve. Jay is presently covered by Medicaid, as are several hundred other hemophiliacs who are part of a 6,000-member class action law suit against several pharmaceutical companies who sold contaminated factorate (blood product used by hemophiliacs in the treatment of their disease). After years of legal wrangling, the drug companies finally agreed to a \$600,00 million settlement which would provide each bonafide claimant with a \$100,000 payment. However, the settlement has been held up by the fact that the payment could affect the eligibility of claimants who are Medicaid recipients. Simply stated, their eligibility could be negated, meaning that the settlement would be a moot point since the claimants would have to pay several thousand dollars in medical fees that are now covered by Medicaid.

Mr. Reed, I don't know how knowledgeable you are about the situation during the early eighties when blood companies stalled for several years, despite warnings and indisputable evidence from the CDC, in testing donors so that blood product consumers could be guaranteed that what they were infusing into their bodies was uncontaminated. Their negligence is the reason that 89 percent of all hemophiliacs born before testing commenced in 1984 are HIV positive. Thousands of hemophiliacs have since died, and thousands more have severely damaged immune systems. One of those hemophiliacs is my son.

Now after years of litigation, my son and some 6,000 other hemophiliacs are supposed to receive \$100,000 from these companies, poor compensation for what they have had to endure, not to mention their prospects for the future. But it is something.

My son's health continues to deteriorate. But now it appears because of more legal and governmental entanglements, it is possible that he will not live long enough to receive this

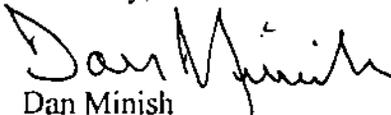
settlement and what little happiness it could bring. He had hopes of buying a car, some nice clothes, and even contributing some of the settlement to AIDS research. Not a week goes by that he does not ask me about the settlement.

Mr. Reed, I am attaching a recent letter from lead counsel for the claimants which summarizes where we currently stand. Surely, Mr. Reed, the government can do something, something much more expeditious than legislative changes, that would make it possible for these deserving claimants receive their money and be able to enjoy it while they still have the health to do so. Frankly, it just doesn't seem fair. The federal government, namely the FDA, should have stepped in long ago and forced the drug companies to test blood from donors when one of their fellow agencies, the CDC, was crying out for it. By the time they did, it was too late for thousands.

Legislation, namely the proposed Ricky Ray Relief Fund, which would require the federal government to pay each HIV infected hemophiliac \$250,000, is now in congressional committee. God only knows if it will ever get to the floor of the Senate and Congress. But in this situation in which a financial settlement has been reached, surely to God the government can step in and make this situation right.

Four years ago, Carol Rasco and President Clinton stepped in and made a difference in a situation when representatives of the Social Security Administration said my son could not be classified as disabled, making him eligible to receive extended COBRA benefits. Hopefully, you in your position and President Clinton can make a difference for my son and thousands of others like him. Any help you could offer would be greatly appreciated.

Sincerely,

A handwritten signature in cursive script that reads "Dan Minish". The signature is written in dark ink and is positioned above the printed name.

Dan Minish

316 Briarwood Drive
Carrollton, Georgia 30117
770-834-4375 (H)
770-830-1904 (O)

THE WHITE HOUSE

WASHINGTON

December 12, 1994

Mr. Jay Minish
316 Briarwood
Carrollton, Georgia 30117

Dear Jay:

I want to thank you for meeting with me in Washington on World AIDS Day. I was delighted to meet you and to hear how well you are coping with HIV.

I was glad to hear that the difficulties your father was having with your insurance coverage have been resolved. As a result of your visit, the Social Security Administration will be issuing new guidance to all its regional offices to assure that no person with HIV encounters the same difficulties you did. Thank you for helping to make the federal government more responsive to the needs of all people with HIV.

Please know that you will be in my thoughts.

Sincerely,

Bill Clinton

THE WHITE HOUSE

WASHINGTON

January 11, 1996

Mr. Dan Minish
File Solutions
340 Tom Reeve Drive
Carrollton, Georgia 30117

Dear Dan:

Carol Rasco recently shared a copy of your letter with me. I am glad to learn that Jay has obtained continued health coverage and the disability designation.

I appreciate knowing your concerns about the Medicaid program. Medicaid has helped to ensure health care for millions of Americans since its creation thirty years ago. Today, half of all Americans who are living with AIDS depend on this important program for their care. We are currently in the midst of a profound debate in Washington over the long-term prospects of Medicaid. As you know, Republicans in Congress have proposed cuts that are simply unacceptable -- cuts that would hurt beneficiaries, their families, and their health care providers in order to help finance a tax cut for the wealthy.

While we need to balance the budget and strengthen Medicaid to ensure a strong future for our citizens, we must do so without gutting essential programs and hurting people who, like your son, need our help. Our nation has always recognized the obligation to care for others in need, an obligation that my Administration has pledged to honor. Even as we work to promote fiscal responsibility, I will continue to fight to ensure that our nation does not turn its back on the health and well-being of its most vulnerable citizens.

Hillary and I are keeping Jay and your family in our thoughts and prayers.

Sincerely,

Bill Clinton

DAVID S. SHRAGER
EDWARD B. McDAID
WILLIAM A. LOFTUS
JOANNA HAMIL FLEM
WAYNE R. SPIVEY
*MICHAEL S. BLOOM
*ROBERT L. SACHS, JR.
*DANIEL S. WEINSTOCK

**also member New Jersey Bar*



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January 29, 1997

Mr. Dan Minish
316 Briarwood Drive
Carrollton, GA 30117

RE: James Dan Minish, Jr.

Dear Mr. Minish:

Thank you for your letter of January 15. Your views are entirely understandable. Your frustrations are no less than our own.

For the past several months there have been ongoing efforts, most with positive results, to resolve those elements of the settlement which are necessary for its successful implementation. Thus, we have been able to come up with a form of special needs trust which should largely protect those who have eligibility issues in terms of the continued or future receipt of public collateral benefits (e. g., Medicaid/SSI). With respect to liens that have or could be asserted for public sector benefits previously paid, significant progress has been made with representatives of the Executive Branch to reach an agreement in principle to resolve such claims. With respect to potential private insurer subrogation claims, an agreement has been reached which should resolve just about all such claims. That's the good news. The problem is that the final conclusion of these issues (so that there is a high level of assurance that just about everyone who is potentially eligible to share in the settlement in fact will do so without finding out that the \$100,000 they are supposed to get is less than that amount), could still take several more months to accomplish. The only action which would more definitively resolve these issues would be an act of congress and that too, by the most optimistic estimate, could not occur before June.

Accordingly, I have already demanded in writing and during a recent phone conference call with defense counsel repeated that it was critical if the settlement process was to

January 30, 1997

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hold together for them to put the money up in escrow so that people would understand that the money is there, earning interest, and that those who are entitled to recover \$100,000 who do not have subrogation and lien issues should be entitled to get their money here and now. People continue to die every day. The fractionators claim that they can't, at least at this stage, undertake the risk that people who have subrogation and lien issues which cannot fully be solved would, as a legal matter, be entitled to opt out and therefore subject themselves to an additional number of law suits. Again, their position has been they don't wish to accept this risk of unknown dimension.

We are working at this subject every day. I can't control the fractionators' money. I believe that the risk they bear is an insignificant one, a risk which they should have understood from day one. We continue to do everything we can. These issues should have been considered when those who came up with the idea of the settlement first put it on the table. We were not "at that table." We inherited a proposal negotiated by others.

Frankly, I have serious misgivings as to whether we can keep this settlement together if things stretch out for several more months. Class counsel continue to consider various alternatives so that we can get this situation resolved at a much earlier date.

Sincerely,



David S. Shrager

DSS/tah

Dictated, but not read.