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THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. Marvin Rosen
Apartment 2108
253 West 72nd Street
New York, New York 10023

Dear Mr. Rosen:

Thank you for writing. I appreciate your offer to share your experiences with me and my staff. If you have any information you think would be useful to us, please include it in a letter to my office. Best wishes.

Sincerely,

Kristine Gebbie

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

MARVIN ROSEN

253 WEST 72ND STREET, APT. 2108
NEW YORK, NY 10023

(212) 595-3434

March 13, 1994

Director
Office of AIDS Policy
750 17th Street, N.W.
Washington, DC 20050

I am not a doctor nor do I have any expertise in the field of medicine. But I have lived in Latin America (Mexico, Panama, Haiti, Puerto Rico, Dominican Republic) for a number of years and believe that some of the things I observed years ago have a valid pertinence to the spread of AIDS in the Third World, especially among women.

It may also have relevance to the same situation in the United States and other developed countries. If you contact me I will be glad to speak to you.

Sincerely,

Marvin Rosen
253 West 72nd Street, Apt. 2108
New York, NY 10023

cc: Communicable Diseases Control
National AIDS Hotline

Dear Mr. Rosen
Thanks for
your

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. R. C. Adams
435 Encinitas Avenue
San Diego, California 92114-4912

Dear Mr. Adams:

My apology for such a tardy response to your letter. I do appreciate hearing from any concerned citizen.

I will continue to base my recommendations on HIV policy on good science, and to make prevention information available to all, regardless of gender or sexual orientation.

Thank you for writing.

Sincerely,

Kristine Gebbie

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Dear Mr Adams

My apology for such a tardy response to your letter. I do appreciate hearing from any concerned citizen.

I will continue to base my recommendations on HIV policy on good science, and to make prevention information available to all regardless of gender or sexual orientation.

Thank you for writing.

Sincerely

adopt
Stock letter

WHITE HOUSE
11600 Pennsylvania Ave.,
Washington, DC 20500

RECEIVED
JAN 31 1994

January 22, 1994

Attention: Cabinet Member
Kristine Gebbie, AIDS

Dear Ms. Gebbie re: 1-22-94 Union-Tribune, B-6

I read that you will be in charge of AIDS. Also, that those most responsible for AIDS are not about to change their life-styles. "Good boys always wear their rubbers!" What a laugh! Yours is "selling the hard stuff!"

I write because what is underway is not "Locking the barn doors after the horse is stolen," but making me, others, pay for the loss! If those to be afflicted with AIDS are not about to change their life-styles to avoid AIDS, I am not about to change my life-style to pay for their cure. As for FREEDOM & RIGHTS, I am entitled to what pretzels and beer, pleasures, that I can afford! If one is free, all are free! Now, get off my back!

So, I am ignorant and unfeeling? Perhaps! But, that shoe fits their feet equally well as do stupid, self-righteous, and egotistical to name a few. As my peers put to me in my youth, "What makes them god's gift to humanity?"

Frankly, I have opposed the homosexual movement from the beginning and found their arguments to be egotistical, self-righteous, self-serving, misdirecting, excusing their sins by the sins of others, the height of sofistry to name a few. If such is what you want, you've got it with all that goes with it! As yet, it hasn't all ripened! But, it will!

I say that you've got it, "all" and the word for it is "HELL!" We are so awash in hog-wash as to make unbelievable the stupidity, ignorance, and error. For openers, if I cannot believe in a creative God, I am not about to believe in a "creative atom" that comes out of no-where into a vast void, a nothing, to explode and become all that we see in the universe including you. Boy, have I got a bridge for you! "Brooklyn," that is!

Very truly,

R C Adams

R. C. Adams.
435 Encinitas Ave.,
San Diego, CA 92114-4912

For attention, I'm sending copies to others.

THE WHITE HOUSE

WASHINGTON

February 14, 1994

needs rewrite to be responsive to the letter

R. C. Adams
435 Encinitas Avenue
San Diego, California 92114-4912

Dear R. C. Adams:

Thank you for your comments on the Prevention Marketing Initiative sponsored by the Centers for Disease Control and Prevention (CDC). This Administration is committed to stopping the spread of HIV among all sectors of our society and especially among our youth. The age group with the greatest increase of new cases of AIDS is the 18-24 year old group, including both heterosexual and homosexual youths; the majority of these infections occurred during adolescence. Best information indicates that 72 percent of all high school seniors have engaged in sexual activity and 19 percent of those have had 4 or more sexual partners.

Although abstinence is the most effective way of preventing transmission, the campaign is also aimed at those who, because of personal decisions or circumstances, have chosen to be sexually active. The decision to promote safer sexual practices through the use of condoms is supported by research released in 1993 showing that when condoms are used correctly and consistently, they are extremely effective in preventing transmission. The research showed that transmission occurred primarily in those instances where the condoms were used incorrectly or were not used for every sexual act. To obtain more information on this research, please contact the CDC National AIDS Clearinghouse at (800) 458-5231.

The CDC initiative is intended to reinforce young people, regardless of sexual orientation, who have not become sexually active to postpone sexual activity as long as possible. It will encourage young people who engage in sex but have not tried condoms to try them and it will encourage those who use condoms to do so correctly. A national task force will analyze the effectiveness of the various components of the initiative, including the public service announcements.

As a parent, I am particularly concerned that our young people are not receiving the information about changing behaviors that may place them at risk. For those who have chosen to be sexually active, it is our responsibility as adults to provide the means necessary for young men and women to protect their lives. I believe this Prevention Marketing Initiative is a necessary step in our endeavor to end the HIV/AIDS epidemic.

Again, thank you for your input. I hope that you will continue to communicate your concerns with me.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. Raymond Piscopink
21805 Avalon
St. Clair Shores, MI 48080

Dear Mr. Piscopink:

Thank you for your letter about the "AIDS Cure Act" (formerly the "McClintock Project").

I am unable to comment on Representative Jerry Nadler's bill at this time as I have not seen the new version just introduced, but I have discussed the earlier version with Representative Nadler. I have invited Representative Nadler to send me the new bill, and I will comment on the specifics of the bill then if asked.

Over the last several months, I have sought to bring some definition to what many people call the "Manhattan Project" for AIDS. Everyone seems to mean something different when they talk about this, but I believe we cannot shy away from evaluating all the different interpretations in circulation. During the campaign, the President promised a "Manhattan Project for AIDS," and I take this very seriously.

From the administration's viewpoint, I am coming to see that, given the state of the science of HIV and the modern communications technologies available to scientists today, we must begin to regard the entire Federal and private AIDS research enterprise in the United States as a "Manhattan Project" for AIDS research. Then, we have to go about the business of making this huge enterprise work to its maximum potential.

I believe that this is the approach that will bring us effective treatments and vaccines most quickly. The Clinton administration has taken several significant steps on this path, including:

- The revitalized NIH Office of AIDS Research with its centralized planning and budgeting authorities, now under the leadership of Dr. William Paul;
- A 21% increase to the NIH AIDS research budget this year;
- The National Task Force on AIDS Drug Development, which is working now to identify and remove obstacles to the discovery of effective therapies for HIV/AIDS.

We need to turn the **whole** national research effort into a truly efficient, working "Manhattan Project" to find safe and effective treatments and vaccines for HIV/AIDS.

We need to improve what we have by enhancing communication, coordination, and collaboration in the public and private sectors, in the U.S. and abroad, in a way that fosters new ideas and ensures that we do not miss the truly important discoveries.

Guiding research priorities while encouraging innovation is an ongoing process that has to continue and has to be accelerated. We have to constantly evaluate where the research is going and what we may be missing, and we have to carefully consider whether new ideas may help create and maintain an environment more conducive to good, productive science, or unintentionally hurt the cause of AIDS research.

Though to many people the horizon still looks pretty bleak for new effective therapies and vaccines, I am optimistic that all the renewed energy of the last year, and new efforts still to come, will reap some truly great rewards for people with HIV and AIDS.

I will continue to work with members of Congress, all agencies of the administration, the community and private industry to explore new ways to get this job done faster.

Sincerely,

Kristine Gebbie

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Kristine M. Gebbie,

My name is Louise Piscopink and my husband's name is Raymond Piscopink and we live in St. Clair Shores, Mi. We are writing to you today concerning "H.R.3310" which is "THE BARBARA McCLINTOCK PROJECT TO CURE AIDS". We are also urging you to support increased action regarding research, funding and other aids related causes.

"H.R.3310"/McCLINTOCK" is a very real, thought-out,detailed plan to speed new research, new therapies and ultimately arrive at a cure for aids. It was put together by people. Normal, concerned, frustrated people who are sick, tired and fed-up with the current system. "H.R.3310" was recently introduced by Jerrold Nadler (Congressman, New York), phone # (202) 225-5635.

In President Clinton's compaign, he promised a "Manhattan Style" project for aids, yet he does not have a written out plan. As you may already know, the Manhattan Project was an intensive crash program at the presidential level in World War II to develop the atomic bomb. If such skills and resources could be assembled for the purposes of destruction, surely aids, and it"s accompanying devastation, deserves a similar all-out effort. "H.R.3310"/"McClintock" is modeled after a "Manhattan Style Project", and is excitingly realistic and bold.

We are asking you to support "H.R.3310" in any way that you can. Please, we are also asking you, (if it's within your jurisdiction), to co-sponsor "H.R.3310" so that is will grow, stay alive and finally come into law.

A person close to us was diagnosed with aids last spring. We hope you can and will do something to help find a cure for this dreadful disease. Thank you for your time and understanding regarding this issue. Your response is very important to us and we'll be awaiting your reply.

Sincerly,

Louise Piscopink
Louise Piscopink

Raymond Piscopink
Raymond Piscopink
21805 Avalon
St.Clair Shores, Mi. 48080

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. Mark Jones
1222 North Pointsettia Place
West Hollywood, CA 90046

Dear Mr. Jones:

Thank you for your letter about the "AIDS Cure Act" (formerly the "McClintock Project").

I am unable to comment on Representative Jerry Nadler's bill at this time as I have not seen the new version just introduced, but I have discussed the earlier version with Representative Nadler. I have invited Representative Nadler to send me the new bill, and I will comment on the specifics of the bill then if asked.

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Sincerely,

Kristine Gebbie

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Send "Cover ltr" for K[illegible] signature

THE MARK JONES GROUP

Andrew [redacted] Agt.

RECEIVED

MAR 28 1994

19 March 94

Jerry —

RE: your 3/9/94 response to my letter asking you to co-sponsor H.R. 3220.

YOU DIDN'T ANSWER MY QUESTION!

Please do so IMMEDIATELY. Save me your political double talk & answer the the question I asked.

Mark Jones

President

ENCLOSURES

C.C. Kristen Gebbie
Pres. Clinton
V.P. Gore
Feinstein
Boxer
FILE
H. Clinton
Comm. On Aids

P.S. — Did you get a chance to read "How to Act Up" which I presented to you at the L.A. Close breakfast?

PHOTOCOPY PRESERVATION

1680 Vine Street • Suite 100 (213) 462-4994 Hollywood, California 90028

2408 Rayburn House Office Building
Washington, DC 20515-0529
(202) 225-3976

District Office:
8436 West 3d Street
Suite 600
Los Angeles, CA 90048-4183
(213) 651-1040

Congress of the United States
House of Representatives
Washington, DC 20515-0529

HENRY A. WAXMAN
29th District, California

Committees:
Energy and Commerce
Chairman, Subcommittee on Health and the Environment
Government Operations

Philip M. Schiliro
Administrative Assistant

March 9, 1994

Mr. Mark Jones
1222 North Pointsettia Place
West Hollywood, California 90046

Dear Mr. Jones:

Thank you for your recent letter in support of H.R. 3310, the "Barbara McClintock AIDS Cure Act." Although I did not receive your previous letter in support of H.R. 3310, I'm happy to share with you my views on this matter.

Like you, I strongly believe that the federal government must maximize its efforts to combat AIDS, and I will act to ensure that we pursue the most expeditious and thorough research possible. As chairman of the Health and the Environment Subcommittee, I would like to take a moment to bring you up to date on my efforts in this area.

I have held AIDS hearings and sponsored AIDS-related legislation since 1982, and I am committed to doing all I can to stem this tragic epidemic. But I am sometimes frustrated by the cycles of AIDS awareness our country has gone through. We have moved from ignorance to terror to complacency about AIDS. I hope we have now reached the point where our attention will stay focused on this disease.

Despite my frustration, I know we have already made important progress. As you may know, a comprehensive bill I sponsored (The Ryan White CARE Act) was signed into law during the 101st Congress. This legislation establishes a large-scale program of prevention of infection among the uninfected and prevention of disease among those already infected. It also includes federal grants to states and clinics for counseling, testing, diagnostic services such as T-cell counts, and prescription drugs such as aerosol pentamidine and AZT. These services should be widely available to allow all people access to the little bits of progress that have been achieved in AIDS research--<u>early intervention and preventive drugs</u>. We cannot be content that such drugs have been developed; we must also ensure that they are available to those who need them. That's why continued funding for these efforts is essential. You'll be happy to know that the proposed FY 1995 Health and Human Services (HHS) budget includes $672 million in Ryan White funding, almost double that for FY 1993.

The Ryan White Act also provides emergency assistance to those areas that have been hardest hit by the epidemic. There have been 120,000 cases of AIDS in the U.S. in the last eight years, and urban health care systems are stretched to the breaking point. The tragic toll that AIDS is taking in California, New York, Florida, Texas, and other high-incidence states clearly warrants spending to provide emergency assistance for increased health and support services for people with AIDS and HIV infection.

It is also crucial to make early intervention prescription drugs available to low-income HIV-infected people. Although President Clinton recommended allowing states to decide which prescription drugs to pay for under their Medicaid programs, I included a provision in the Medicaid budget reconciliation bill to require states to pay for AZT and other prescription drugs which have no cheaper equivalent. I am also the author of new Medicaid provisions to expand treatment for tuberculosis, an increasingly severe new problem for people living with HIV.

I am also the sponsor of H.R. 4, the National Institutes of Health (NIH) Revitalization Act, which was signed into law on June 10, 1993 and is now Public Law 103-43. This Act authorizes the Office of AIDS Research within NIH to plan and coordinate all AIDS research activities among the numerous NIH institutes and agencies and authorizes the office to distribute directly all AIDS research funds to such entities. The Office of AIDS Research is required to prepare and submit directly to the President an AIDS research budget detailing the funding the office determines is needed to carry out all appropriate AIDS research activities. This budget cannot be altered by the Secretary of Health and Human Services (HHS) or by the NIH Director. The Act also establishes a $100 million emergency discretionary fund for the conduct and support of AIDS research.

Finally, I am an original cosponsor of H.R. 1538, the "Comprehensive HIV Prevention Act of 1993." This bill, if enacted, will promote activities for the prevention of additional cases of infection with the AIDS virus. It is a strong first step in beginning the process for community-based and targeted AIDS education. It invests in prevention so that we can save in treatment, and it responds to AIDS as an urgent matter of life and death. You can count on me to do all I can to see that it is enacted into law. In the meanwhile, I will continue to work with the Clinton Administration to make administrative changes to improve AIDS prevention efforts.

Fighting AIDS is a tough, serious business. It's no place for ideological crusades and political stunts (such as the Helms Amendment in the 102nd Congress that would have imposed criminal penalties on health care workers). Please know that I will continue to oppose such efforts.

Thanks again for contacting me. I'm glad to know of your concern for increased funding for AIDS research and prevention, and I hope you will continue to contact me on all issues of concern.

With kind regards, I am

Sincerely,

HENRY A. WAXMAN
Member of Congress

HAW:lkg

Mark Jones
1222 N Pointsettia Pl
W. Hollywood
CA 90046

PM
21 MAR
1994

USA 29
I pledge allegiance...

Ms. Kristin Gebbie
The White House
Wash., DC.
20510

ACTION=LIFE

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. Steve Darmis
1300 Larrabee Street, Apt. 5
West Hollywood, CA 90069

Dear Mr. Darmis:

Thank you for your letter about the "AIDS Cure Act" (formerly the "McClintock Project").

I am unable to comment on Representative Jerry Nadler's bill at this time as I have not seen the new version just introduced, but I have discussed the earlier version with Representative Nadler. I have invited Representative Nadler to send me the new bill, and I will comment on the specifics of the bill then if asked.

Over the last several months, I have sought to bring some definition to what many people call the "Manhattan Project" for AIDS. Everyone seems to mean something different when they talk about this, but I believe we cannot shy away from evaluating all the different interpretations in circulation. During the campaign, the President promised a "Manhattan Project for AIDS," and I take this very seriously.

From the administration's viewpoint, I am coming to see that, given the state of the science of HIV and the modern communications technologies available to scientists today, we must begin to regard the entire Federal and private AIDS research enterprise in the United States as a "Manhattan Project" for AIDS research. Then, we have to go about the business of making this huge enterprise work to its maximum potential.

I believe that this is the approach that will bring us effective treatments and vaccines most quickly. The Clinton administration has taken several significant steps on this path, including:

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We need to turn the **whole** national research effort into a truly efficient, working "Manhattan Project" to find safe and effective treatments and vaccines for HIV/AIDS.

We need to improve what we have by enhancing communication, coordination, and collaboration in the public and private sectors, in the U.S. and abroad, in a way that fosters new ideas and ensures that we do not miss the truly important discoveries.

Guiding research priorities while encouraging innovation is an ongoing process that has to continue and has to be accelerated. We have to constantly evaluate where the research is going and what we may be missing, and we have to carefully consider whether new ideas may help create and maintain an environment more conducive to good, productive science, or unintentionally hurt the cause of AIDS research.

Though to many people the horizon still looks pretty bleak for new effective therapies and vaccines, I am optimistic that all the renewed energy of the last year, and new efforts still to come, will reap some truly great rewards for people with HIV and AIDS.

I will continue to work with members of Congress, all agencies of the administration, the community and private industry to explore new ways to get this job done faster.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

JANUARY 15, 1994

Terry
draft copy

Dear Ms. Gabbie,

MY NAME IS STEVE DARMIS. I LIVE IN WEST HOLLYWOOD, CA. I'M WRITING TO YOU TODAY CONCERNING "H.R.3310" WHICH IS "THE BARBARA McCLINTOCK PROJECT TO CURE AIDS". I'M ALSO URGING YOU TO SUPPORT INCREASED ACTION REGARDING RESEARCH, FUNDING, AND OTHER AIDS RELATED CAUSES.

"H.R.3310"/"McCLINTOCK" IS A VERY REAL, THOUGHT-OUT, DETAILED PLAN TO SPEED NEW RESEARCH, NEW THERAPIES, AND ULTIMATELY ARRIVE AT A CURE FOR AIDS. IT WAS PUT TOGETHER BY PEOPLE. NORMAL, CONCERNED, FRUSTRATED PEOPLE WHO ARE SICK, TIRED, AND FED-UP WITH THE CURRENT SYSTEM. "H.R.3310" WAS RECENTLY INTRODUCED BY JERROLD NADLER (CONGRESSMAN, NEW YORK), PHONE# (202) 225-5635.

IN PRESIDENT CLINTONS CAMPAIGN, HE PROMISED A "MANHATTAN STYLE" PROJECT FOR AIDS, YET HE DOES NOT HAVE A WRITTEN OUT PLAN. AS YOU MAY ALREADY KNOW, THE MANHATTAN PROJECT WAS AN INTENSIVE CRASH PROGRAM AT THE PRESIDENTIAL LEVEL IN WORLD WAR II TO DEVELOP THE ATOMIC BOMB. IF SUCH SKILLS AND RESOURCES COULD BE ASSEMBLED FOR THE PURPOSES OF DESTRUCTION, SURELY AIDS, AND IT'S ACCOMPANYING DEVASTATION, DESERVES A SIMILAR ALL-OUT EFFORT. "H.R.3310"/"McCLINTOCK" IS MODELED AFTER A "MANHATTAN STYLE PROJECT", AND IS EXCITINGLY REALISTIC AND BOLD.

I'M ASKING YOU TO SUPPORT "H.R.3310" IN ANY WAY THAT YOU CAN. PLEASE. I'M ALSO ASKING YOU, (IF IT'S WITHIN YOUR JURISDICTION), TO CO-SPONSOR "H.R.3310" SO THAT IT WILL GROW, STAY ALIVE, AND FINALLY COME INTO LAW.

I'VE ALWAYS BEEN SOMEWHAT POLITCALLY ACTIVE AND CONCERNED ABOUT MAJOR ISSUES EFFECTING PEOPLES LIVES, EVEN IF THE ISSUE DIDN'T DIRECTLY EFFECT ME. I FELT FOR THEM. WELL NOW AIDS IS DIRECTLY EFFECTING ME. MY BEST FRIEND, OTHER HALF, AND CONFIDANT WAS DIAGNOSED WITH AIDS JUNE 18th 1993. OUR LIVES HAVE BEEN BITTERLY CHANGED AND DEVASTATED. THE PAIN, ANXIETY, AND ANGER ARE OVERWHELMING. COPING WITH THE DAY-TO-DAY REALITY IS GUT-WRENCHING AND DRAINING.

FOR US THERE IS NO TIME TO WAIT, PUT-OFF, OR MAKE EXCUSES. OUR LIVES ARE DEPENDING ON THE DECISIONS YOU MAKE. YOUR RESPONSE IF VERY IMPORTANT TO ME AND I'LL BE AWAITING YOUR REPLY. THANK YOU FOR YOUR TIME AND UNDERSTANDING REGARDING THIS ISSUE.

SINCERLY,

Steve Darmis

STEVE DARMIS
1300 LARRABEE STREET, APT. 5
WEST HOLLYWOOD, CA., 90069

THE BARBARA MC CLINTOCK PROJECT TO CURE AIDS

A RATIONALE FOR THE BARBARA McCLINTOCK PROJECT TO CURE AIDS

"Listen to your material." - Barbara McClintock*

Due to years of grassroots pressure from AIDS activists nationwide, President Clinton, in his campaign for the White House, promised to implement a "Manhattan Project for AIDS". The Manhattan Project was a multi-billion-dollar crash program at the Presidential level in World War II to develop an atomic bomb. Based on the premise that such a concept was possible, it proved the premise and produced the product. If such skills and resources could be assembled for the purposes of destruction, surely AIDS, and its accompanying devastation, deserves a similar all-out effort. A project designed to cure AIDS is essential for a sound global future: economically, culturally and - most crucial - ethically.

Many proposals for such a project have been put forward. Unfortunately, none of these plans fundamentally questions the relationship between pharmaceutical companies and the slow pace of AIDS research, or the research establishment's refusal to study diverse theories of pathogenesis. And none provides real power - rather than merely an advisory role - for people with HIV and AIDS of diverse communities in the running of the project.

Any new initiative on federal AIDS research must be based on a comprehensive critique of the current system. After 11 years and several billion dollars of spending, NIH has a track record on AIDS that parrots some of the worst aspects of the National Cancer Institute's (NCI) "War on Cancer". That program (much longer-running and more generously-funded) has resulted in:

1. an "early detection" model with a minimum of available treatments;

2. an emphasis on the development of toxic, debilitating and expensive chemical therapies (individual and combination) of limited efficacy;

3. claims of "survival" when a patient lives two years after diagnosis.

The NCI remains unable to detail a coherent model for the pathogenesis of the disease and has come up with frightfully few effective long-term cancer therapies, yet has systematically neglected (and sometimes attacked) promising experimental treatments not sponsored by large pharmaceutical companies.

Like NCI, the NIH's AIDS programs are becoming self-perpetuating research machines which contribute only marginally at best to uncovering effective treatments, while gobbling billions in tax monies. Among the reasons for this:

---

* In order to reflect the values necessary to end the AIDS crisis, we have chosen to name this project after Nobel laureate Barbara McClintock, a research geneticist who, without advanced technology and bucking the then-prevailing orthodoxy, discovered a revolutionary premise underlying DNA replication. Though her findings were shunned by her colleagues, she continued her work. It was only years later, after the discovery by others of the structure of DNA, that her work was finally acknowledged. Her approach - intense commitment and a focus on divergence rather than the norm - is a model for AIDS research.

1. Corporate domination of research agenda.

Priorities in both basic and clinical research are inordinately influenced by the interests of major pharmaceutical companies. Research directions are thought of in terms of drug outcomes, rather than understanding an illness in a way which could lead to a broad range of effective treatments. Government research priorities become tied to corporate profit interests primarily through direct and indirect conflicts of interests by members of NIH policy-making committees and rank-and-file Principal Investigators (PIs), via either consulting fees or stock ownership.

Other channels of influence are campaign contributions to, or lobbying of, Congresspeople who control the NIH budget. University programs are influenced by the widespread grants and endowments bestowed upon them by drug companies, as well as by personal financial ties of research faculty to those companies.

The result of this entrenched system is a research agenda - both public and private - skewed towards drugs likely to receive FDA approval (or occasionally, for which a Congressional sponsor can be found), a closed-loop process favoring companies rich enough to afford the huge expenses required. Thus, promising treatments are ignored or rejected because:

1. they threaten the markets for already-approved or in-development products of large companies;

2. they are backed by small companies with inadequate funds to navigate the exhaustive FDA approval process; or

3. they are unpatentable (or already on the market for other purposes), making FDA approval uneconomical to the sponsors.

As a result, over 100 treatments (including drugs, vitamins, herbs and no-cost health practices) not backed by large pharmaceutical companies have been reported through medical literature and/or clinical experience to improve the health of people with HIV or AIDS to some degree, yet virtually none has had a large-scale clinical study which could either show its ineffectiveness or move it ahead towards broad recognition and, where relevant, FDA approval.

Furthermore, the corporate focus on profits promotes the development of treatments which are extremely expensive and require indefinite use. When these are the primary treatments investigated by NIH, the mentality created is one of accepting a few more years of life of dubious quality, rather than a striving for a cure. In fact, a therapy from outside the major companies which shows curative promise is viewed as a competitive threat, often provoking moves in academic or government circles to discredit it.

2. Stifled investigation of divergent pathogenesis theories.

Understanding pathogenesis - the origin and development of disease - is the key to finding cures. Through every level of the current AIDS research system, a very narrow band of pathogenesis theories are promoted and well-funded. All posit HIV as the unquestioned necessary and sufficient cause of AIDS, and examine only a few possible biological mechanisms by which the virus could cause immune system damage. Some theories consider viral co-factors (such as cytomegalovirus and various herpes viruses) as "initiators" or "promoters" of HIV's action.

Meanwhile, what remain virtually ignored by mainstream researchers are such alternative theories as auto-immunity (the idea that AIDS results from the immune system turning on itself) or such proposed co-factors as non-viral infections (bacterial, fungal, parasitic or mycoplasmic), side effects of medicinal drugs, nutritional deficiencies, environmental toxins or psychological stress. Shunned completely are those suggesting that HIV may not play a causative role.

Contrary to the claims of mainstream scientists, this set of priorities is not, in most cases, the result of either inadequate credentials by the "dissidents" (many have distinguished backgrounds) or a lack of sound scientific bases for their theories (many have written well-researched papers, although some are unpublished or appear in obscure journals). Rather, the near-exclusive focus on viral causes, particularly new viruses, is a by-product of both pharmaceutical company domination of AIDS research and academic research "trends" of what is deemed the "new frontier" of scientific knowledge (a determination heavily influenced by the former).

Since the 1980s, antiviral drugs - particularly those developed by genetic engineering - have become the medical industry's "hot commodities" (as antibiotics were in the 1950s and 60s) because they involve the highest technology (thus justifying the expensive corporate staff and facilities) and offer high profit margins. In addition, academic and government researchers are pressured by their department heads to seek recognition through publishing and winning grants (both controlled by a "peer review process" in which a small elite sets trends for favored scientific fields).

The result of these factors is stark: scientific work on AIDS, whether basic science or drug development, which could lead to a new antiviral, gains funding and prestige in academic and NIH research circles. In contrast, any theories which significantly differ from those propounded by "leading" (i.e., well-connected) researchers are scorned and funding for investigating them is often rejected. This creates a climate which influences many researchers to steer clear of all but the safest, most conventional approaches. Some with theories outside the mainstream continue to pursue their work with extremely limited funds and no (or only obscure) publishable outlets for their information, guaranteeing a longer than necessary research schedule and the absence of their approaches and findings from the thinking of others in the field.

3. Uncoordinated and competitive research.

The NIH's AIDS research projects are funded through an uncoordinated and competitive system of investigator-initiated research, leaving vital areas unexplored. Within the NIH and in the private sector, many researchers remain compartmentalized within their university, agency or company - or even a department thereof - and do not communicate, much less collaborate, with colleagues working on identical problems. This is especially true in terms of cross-disciplinary contact (e.g., virologists rarely speak to immunologists or nutritionists). An inordinate emphasis in both public and private agencies on secrecy and glory-seeking discourages researchers from challenging this isolation. Further, the location of AIDS research in 21 separate NIH institutes and centers has prevented a concerted, comprehensive and multidisciplinary approach to understanding and thus treating this disease.

The newly enhanced powers of the NIH office of AIDS Research will help somewhat in reducing the most obvious inefficiencies and in highlighting, through the construction of a "strategic plan", some areas of neglected research. But the absence of a single unified research project (rather than separate programs coordinated by one office) and the lack of a multidisciplinary approach will prevent that strategic plan from being complete or from being implemented quickly.

Furthermore, while coordination and multidisciplinary teamwork (rather than competition and isolated research efforts) would do much to advance our knowledge, these are not the only problems with the current organization of the research effort. The NCI is more coordinated bureaucratically and financially than the AIDS programs, yet it has not fared any better in its cancer research.

4. Closed circuit of researchers focused on empire-building rather than creative investigations.

An "old-boy-network" of researchers, most working for either large pharmaceutical companies, major universities or private research institutions, gets the lions-share of the funds. Due to the structure of academic institutions and the requirements for career advancement, many academically-based researchers (regardless of their good intentions) submit proposals aimed more at enhancing their institution's prestige, facilities or budgets than at creatively probing for solutions to this urgent crisis.

One outcome of this system is the waste produced by university research departments receiving multiple grants, each including indirect (overhead) costs. Some grants provide greater overhead than substantive research funds. Another outcome is that a single researcher can be the Principal Investigator (PI) on numerous grants (17 in the case of one prominent AIDS researcher). Regardless of a PI's individual skill or reputation, one person cannot possibly attend to the research content of these projects in any concerted or creative way. This is a factory model of research, reaping large amounts of overhead for one institution and pushing out more of the same product rather than taking new paths.

Other problems with current AIDS research priorities include:

- a focus on the similarities or "norms" among people with HIV or AIDS, rather than the differences, resulting in the systematic neglect of populations whose pathogenesis and manifestations of the disease may be significantly different (such as women, people of color from diverse national/cultural backgrounds, injection drug users, and people with inadequate medical care and/or nutrition).

- the relative neglect of the need for developing treatments towards the end of the disease spectrum (people viewed as "near death") and the beginning (people recently infected and asymptomatic).

- the lack of meaningful power by people with HIV or AIDS from diverse communities in determining the federal research agenda.

For all these reasons, it is imperative that Congress immediately enact an intensive AIDS research initiative to cast a broad net which will unravel the pathogenesis and lead to the cures for this disease. The same government that could find the resources to set up a unified command and transport, feed and shelter 400,000 troops to wage a war in the Persian Gulf can certainly quickly create a powerful, well-funded project to pursue a life-giving struggle to end the suffering and deaths from AIDS.

Endorsements for the McClintock Project

as of April 25, 1993

Thayer Quoos, of AIDS PROJECT NEW HAVEN, CT

Jeff Kost, of AIDS ROCHESTER, Rochester, NY

Beth Bomze, HIGH SCHOOL HIV/AIDS RESOURCE CENTER

Johnny Fambro, of CENTRAL CITY AIDS NETWORK, Macon GA

and THE RAINBOW CENTER, Macon, GA

Anne Milano-Tedeschi, COMMUNITY HEALTH PROJECT, NYC

Joey Tajonera, of the

CONFERENCE ON JUSTICE AND PEACE, Brooklyn, NY

Cliff Scott, of the DOWNTOWN ART COMPANY, NYC

Latia Docty, of the EAST ORANGE V.A. MEDICAL CENTER, NJ

Maryanne Guiney, of FAXTON HOSPITAL, Utica, NY

David Acosta, THE GALAEI PROJECT, Philadelphia, PA,

Sharon Lerner and Nancy McKenzie, of the

HEALTH POLICY ADVISORY CENTER, NY

Eileen Durkin, of the HOWARD BROWN HEALTH CENTER, Chicago IL

Alex Conchola, of the K.C. FREE HEALTH CLINIC, Kansas City, MO

Morris Kight, Commissioner on Human Relations, Los Angeles, CA

Kevin Langely, R.N., of San Francisco General Hospital, CA

Nicolas Carballeira, LATINO HEALTH INSTITUTE, Boston MA

Tim Sherman, of LET ME BE ME, Glens Falls, NY

Michael Carr, of MIDDLE GEORGIA PEOPLE WITH AIDS, Macon GA

Supervisor Carol Midgen, San Francisco Board of Supervisors

Ivy Duneier of MOTHERS' VOICES, NYC

Kathleen Brackel,

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, Atlanta, GA

Diane Welsh, of the

NATIONAL ORGANIZATION FOR WOMEN - NYC Chapter

Robert Darrow, of the THE PHILADELPHIA CENTER, Shreveport, LA

Randall Gorbette, PHOENIX SHANTI GROUP, THE Phoenix, AZ

Mabrey Russell Whigham III,

of the PHYSICIANS ASSOCIATION FOR AIDS CARE, Chicago

Gwen Martinez, of PROMESA, INC., Bronx, NY

REPUBLICANS FOR INDIVIDUAL FREEDOMS, Atlanta, GA

Ulle Koiv, of the ST. MARKS WOMEN's HEALTH COLLECTIVE, NYC

Quincy Kirks, of the UPPER ROOM AIDS MINISTRY, NYC

Sylvia Racca, of VERMONT CARES, Burlington, VT

Yvonne Chambers, of the

WOMEN AND AIDS RESOURCE NETWORK, Brooklyn, NY

Mari Nobles-da Silva,

WOMEN IN CRISIS/ PROJECT RETURN FOUNDATION, NYC

Shannon Cain, WOMEN'S HEALTH EDUCATION PROJECT, NYC

ACT UP / Denver

ACT UP / Ithaca

ACT UP / Kansas City

ACT UP / Los Angeles

ACT UP / New York

ACT UP/ New Haven

ACT UP / New Orleans

ACT UP / Seattle

ACT UP / Shereveport

The Barbara McClintock Project to Cure AIDS / 212-631-4251

❑ **Yes, I endorse the McClintock Project.**

Name

❑ For my Organization. ❑ List Organization for identification only.

Address

City, State Zip

The McClintock Working Group
ACT UP/New York
135 W. 29th Street, 10th Floor
New York, NY 10001

ACT UP

❑ **Hay otro panfleto disponible en español.**

❑ **I've enclosed a check to support ACT UP's work.**

DEMAND FOR THE BARBARA McCLINTOCK PROJECT TO CURE AIDS

The present U.S. AIDS research effort is incapable of bringing the AIDS crisis to an end. Therefore, the federal government must take extraordinary steps to remove all barriers to the development of cures. President Clinton has called for a "Manhattan Project for AIDS." ACT UP demands that Congress enact legislation to implement such an all-out effort as follows:

I. A declaration of the dire urgency of the international AIDS pandemic and the need for immediate, rapid, focused steps towards curing AIDS.

II. The establishment of the Barbara McClintock Project to Cure AIDS, jurisdictionally separate from the National Institutes of Health (NIH) and reporting to but not directed by the President through the "Special Assistant on AIDS". The Project shall have the following mandates:

1. The Project's goal will be to find a cure for AIDS, with cure being defined to include "any and all approaches which will ensure a well-functioning immune system and a normal life span with a reasonable quality of life." To that end, it will have two missions: [see page 9 for details]

a. to pursue any and all basic science investigations, based on diverse theories and schools of thought which elucidate the pathogenesis of AIDS,

b. to identify, based on this work, all promising curatives and to oversee their timely and adequate testing through the extraordinary powers detailed in section 4 below.

2. In order for the Project to achieve its goals, its work must be carried out in the most efficient and cooperative manner possible, free of private interests and bureaucratic red tape. To this end,

a. The Project shall establish one central location for its work. All primary research staff will work at that location; contributing researchers located around the world will interact via video teleconferencing, an international computer network, and regularly scheduled face-to-face meetings. [see page 9]

b. The NIH's existing AIDS research programs will be maintained. All NIH basic science research supplementary to that done by the Project will be performed cooperatively with the Project.

c. All primary research staff and administrators shall be financially compensated only by the Project and may not have conflicts of interests with private organizations (including but not limited to universities, pharmaceutical companies, private research organizations, etc). [see page 12]

d. The Project shall be funded by public - not private - monies. Appropriations for the Project shall not be diverted from other health care or human service programs.

e. The Project will be governed by, not merely advised by, a council composed of scientists and clinicians representing divergent approaches, and people with AIDS and HIV, and their advocates, from all affected communities. This council will set policy and oversee research priorities, ethical standards, conflict of interest rules and hiring of researchers, consistent with 3a below. [page 13]

f. The project shall, in addition to basic research investigations, operate an on-site clinic to conduct small scale research trials with human participants in such trials are crucial for testing hypotheses related to its basic research.

3. To ensure that the most open and productive research paths are pursued, and to produce a cure accessible to and usable by all affected people:

a. Equal consideration shall be given to conventional and other medical approaches and scientific theories, and researchers representing divergent approaches shall be on the primary research staff as well as be contributing researchers. **[see page 15]**

b. The Project's study of AIDS pathogenesis and manifestations must focus on all populations of people with AIDS and HIV. Equal consideration shall be given to the differences between these populations as to their similarities or "norms." This includes women, gay men, lesbians, people of color (of various affected national-cultural groups), injection drug users, hemophiliacs and people with inadequate medical care and/or nutrition. **[see page 17]**

c. Basic science investigations and therapeutic results will be geared to people at every point on the spectrum of AIDS and HIV - form the sickest to the healthiest. Saving people considered "near death" must be considered as important as early intervention.

d. Information generated by the Project shall be made freely available to researchers, health care providers, people with AIDS and HIV and their advocates as soon as it is available, without being inhibited by professional publication practices.

e. Curatives ultimately released due primarily to project research shall not result in financial gain to any private organization, and shall be made available to all affected people regardless of ability to pay. **[see page 18]**

4. In order to accomplish its goals, the Project shall have extraordinary powers to:

a. direct the utilization of any and all existing U.S. government funded research entities and their facilities to clinically test promising cures developed on the basis of its research and to direct the manner in which such research shall proceed, including staffing, participants, location and timing. Such research will be funded by the McClintock Project. **[see page 19]**

b. exercise the right of eminent domain to: **[see page 20]**

- **obtain from public and private organizations - with just compensation - samples of all potential curatives and all data regarding their development (including safety and efficacy data) as well as other information, materials or products deemed crucial to the Project.**

- **implement clinical testing for potential curatives owned by private companies, whether under development or not, unless said companies adhere to an approved time frame and are forthcoming with their data as such work proceeds.**

- **use existing pharmaceutical company facilities (with just compensation) for the production of promising curatives to be utilized in McClintock research and, if effective, to produce such curatives in sufficient amounts to be disseminated to all people needing them.**

5. A seed budget must be allocated immediately to be used for project planning (including creating facilities, selection of staff, funding, structure and schedules), so that the Project can begin functioning as soon as possible.

THE BARBARA McCLINTOCK PROJECT TO CURE AIDS

A Detailed Explanation

1. The Project's goal will be to find a cure for AIDS, with cure being defined to include "any and all approaches which will ensure a well-functioning immune system and a normal life span with a reasonable quality of life."

The McClintock Project's search for a cure will reject the current cancer model: early detection, followed by toxic treatments, with "survival" defined as two more years of life. It is this very model that is being pursued in AIDS research now, and the first three approved treatments for HIV - AZT, ddI and ddC - are actually old chemotherapy medications abandoned after they proved too toxic for cancer patients or were ineffective.

McClintock will investigate all theories regarding the pathogenesis of AIDS, and investigate all potential curatives, regardless of their potential money-making ability.

2a. The Project shall establish one central location for its work. All primary research staff will work at that location; contributing researchers located around the world will interact via video teleconferencing, an international computer network, and regularly scheduled face-to-face meetings.

"The mainspring of progress in science is the free interplay of creative minds that had to be brought together and allowed to talk to each other. Only through their unrestricted exchange could they make speedy headway [during the Manhattan Project]...*We needed a central laboratory devoted wholly to this purpose, where people could talk freely with each other, where theoretical ideas and experimental findings could affect each other, where the waste and frustration and error of the many compartmentalized experimental studies could be eliminated; where we could begin to come to grips with [the diverse] problems that had so far received no consideration.*" [Stoff, M.B., A Documentary Introduction to the Atomic Age]

Three issues need to be addressed concerning the creation of a central facility for McClintock:

1. Is it necessary?

Current AIDS research efforts, particularly basic science and pathogenesis research, are not only fragmented and compartmentalized, but also are conducted by researchers from a variety of disciplines. A good part of this research is not funded by the government or is done by researchers not considered part of the "AIDS network." While these investigators may not be aware of each others' efforts, their theoretical and experimental findings could profoundly affect one another.

The reporting and discussion of the basic science of AIDS research is currently conducted at meetings around the world throughout the year, including the International AIDS Conference, Gallo Conference, Keystone Conference, AIDS Clinical Trials Group Meetings, Biological Response Modifiers Meetings and the Antimicrobial Agents in Chemistry Conference, to name only a few. Researchers in one field, eg. molecular biology, usually do not attend conferences in other fields, i.e., virology; researchers from related fields whose work may be relevant often do not even attend conferences focused on AIDS.

Basic science research has minimal coordination even within one institution in the U.S., let alone within the country or across the world. Since the complexity of AIDS requires that a diverse group of scientists, including immunologists, virologists, molecular biologists, biochemists, nutritionists, herbologists, etc., interact on a regular basis, a central location is essential to facilitate the cross-fertilization of ideas. The inclusion of sophisticated global telecommunications equipment will allow affiliated researchers from around the world to be contacted quickly for the dissemination and sharing of information and ideas.

2. *Will researchers be willing to relocate to be part of the Project?*

Currently many scientists do exactly this -- sometimes for better pay, more opportunity, or to be part of more interesting research projects. It is not unusual for scientists to seek out visiting professorships, post-doctoral fellowships and the like, which can require several years of commitment. One year sabbaticals are common, with scientists moving their families to other parts of the country or to another part of the world. For many scientists, the opportunity to focus their work in a concerted effort and to dialogue with other creative minds, using the best equipment and facilities available, would be extremely enticing.

In the past, scientists have even been willing to relocate under trying circumstances. During the Manhattan Project, for example, entire families were moved to a central location which, for security reasons, was physically remote (a precaution not needed for the McClintock Project, which would be located in an area with a high incidence of AIDS). Living conditions were strictly regulated: people were put under surveillance, their travel restricted, and so on. Similarly, during the Apollo project, "When the Space Task Group in Hampton, Virginia was required to move to Houston, Texas, here was a reaction: 'I was so upset about going to Texas. I wouldn't even let them send me the free subscriptions to their goddanged newspaper. It was my intention never to go to Houston.'...[In the end]...Houston it was, and off they went, 700 engineers and their families. Almost everyone in the Space Task Group did ." [Murray, C. and Cox, C.B., Apollo, The Race to the Moon].

Robert Oppenheimer had similar experiences when recruiting for the Manhattan Project. Travelling across the country, he relied on researchers' "sense of interest, the urgency and feasibility of the Los Alamos mission. It aroused great misgivings because of the very severe restrictions...But there was another side to it. Almost everyone realized that this was a great undertaking. Almost everyone knew it was an unparalleled opportunity to bring to bear the basic knowledge and art of science for the benefit of his country. Almost everyone knew that this job, if it were achieved, would be part of history. The sense of excitement, of devotion...in the end prevailed." [Stoff]. Surely this would also apply to the task of finding a cure for AIDS.

3. Is such a facility feasible in terms of the time and money it would take to create?

Existing AIDS research facilities most likely could not physically support the McClintock Project. More importantly, these facilities do not have the needed equipment for research and communications, and have no priority for obtaining it. While it will take time and effort to build the laboratories, office space and communications facilities needed, this can occur in parallel with the planning and recruiting for the project.

Quick construction is possible: "In mid-November 1942, Los Alamos was little more than a large ramshackle main house and a group of log cabins set among the poplars just below the timberline. By July 1945...more than 4,000 people -- mostly scientists, engineers and their families were living there." The Pentagon, intended as a "temporary structure" was built in only 16 months. It has an outside circumference of one mile, the world's largest telephone system, and a staff of 32,000. It follows that physically creating a central facility for McClintock is feasible within a short amount of time.

Research spending for AIDS in the past decade has been roughly $3 billion. Compared to this, the Apollo Project cost $94 billion in 8 years, the Osprey (a vertical take-off aircraft) optimistically budgeted at $22 billion, will more likely cost 3 to 4 times more, and the "Star Wars" program currently costs $4 billion a year. A fraction of these funds could find a cure for AIDS.

The McClintock Project would require adequate funding and the same top purchasing priority that the Manhattan and Apollo projects enjoyed; that is, the Project would receive the first specialized machines out of manufacturing lines, and would be the first to get the raw and semi-worked materials it needs. This type of priority can only work for a "project" with an intended goal, a project which will terminate after the goal is achieved. It cannot be employed indefinitely by any "institute".

In truth, it is neither feasibility nor cost that is the issue. If the U.S. government could find the funds for the Manhattan and Apollo projects, and for the war in the Persian Gulf, to "serve the national interest", it can do the same to find a cure for AIDS, which is most certainly in the national interest. All that is missing is the will and the vision to make it happen.

2c. All primary research staff and administrators shall be financially compensated only by the Project and may not have conflicts of interests with private organizations (including but not limited to universities, pharmaceutical companies, private research organizations, etc).

> "The pharmaceutical industry is criticized for spending money on promotion. What is promotion? It involves sending young scientists and clinicians to national meetings to present research, giving textbooks to residents and medical students...[funding] scholarship endowments for clinical investigators, [and] subsidy of clinical journal publication...*Most importantly, it involves paying for the vast majority of basic and clinical research in U.S. medical centers*. This results in the training of graduate students, post doctoral fellows, clinicians...*and the creation of a forum for the pharmaceutical industry to carry out its clinical studies*." - Richard Blackwell, M.D., Univ. of Alabama

Perhaps no other provision of the McClintock proposal raises as many eyebrows as the strict conflict of interest regulations. Yet it is this concept that is at the core of McClintock; without it, the Project would be doomed to failure, as was the "War on Cancer" in the 1970's.

Conflicts of interest in biomedical research have always existed on some level. Government-funded researchers are often consultants, employees or even heads of companies developing major pharmaceutical products, or are large shareholders. Yet, they do not disclose their financial interest when submitting papers for publication or when presenting their findings at professional conferences. These papers often demonstrate the superiority of their product or technique over competitors.

But this is only part of the problem. After attending training sessions given by a pharmaceutical company, researchers appear at research symposia, also often supported by that same company, to present the latest information about an illness and the company's treatment. A well-respected researcher can earn $2,000 for a 45-minute presentation, and be booked many times a year across the country. Several major researchers earn up to $100,000 per year for such work. Some researchers have become identified as proponents for a particular drug, while receiving fees from the drug's manufacturer.

Another example includes the large number of clinical newsletters, AIDS and otherwise, published by not-for-profit medical foundations, yet funded by major pharmaceuticals. The editors of these publications, often prestigious university-based researchers, can earn $2,000 per issue. Clinicians can earn $1,500 for a published article.

There are no requirements that researchers disclose these relationships, and it is questionable if such disclosure would be sufficient to guarantee objective research. We propose that, as in other areas of government, it is essential that there be no conflicts of interest, to avoid the continuation of a basic science research agenda for AIDS that superimposes the desire for future pharmaceutical profitability on the decision making process for research priorities.

Therefore, strict conflict of interest regulations will be applied to the primary research staff,

administrators and members of the Policy Council of the McClintock Project. All primary research staff and administrators will be required to suspend their relationship with any private organizations for the duration of their association with the McClintock Project. Policy Council members will be required to suspend their relationship with for-profit organizations which represent a conflict of interest.

These requirements will include full-time, part-time or consultant positions with a private organization or other government agencies, and the suspension would include employment, consulting or board membership fees, and stock or business ownership.

Although this standard is significantly more stringent than that currently applied by the NIH, it is similar to the code of ethics imposed by the Clinton administration on its political appointees. The rationale is identical: governmental decisions on vital matters of public needs cannot be even slightly influenced by the possibility of personal financial gain. For too long, the domination of the NIH peer review and advisory committee process by scientists with direct financial ties to drug companies has skewed decisions on which theories and treatments to study, and led to the extreme narrowing of promising research directions.

Some have expressed concern that such strict conflict of interest regulations will discourage leading AIDS researchers from joining the McClintock Project. But the primary focus of the Project will be to bring together many of the scientists who, despite excellent credentials and/or important investigative work, have been excluded from most existing private organizations funding AIDS research, due either to the unpopularity of their theories or the lack of interest in their academic disciplines. And for more "mainstream" researchers who would have to suspend their financial interests, the excitement of being part of a cutting-edge project that hold the possibility of major breakthroughs - combined with the time-limited goal of the project and competitive salaries - should be more than adequate to lure those who are genuinely devoted to finding a cure, rather than a career.

2e. The Project will be governed by, not merely advised by, a council composed of scientists and clinicians representing divergent approaches, and people with AIDS and HIV, and their advocates, from all affected communities. This council will set policy and oversee research priorities, ethical standards, conflict of interest rules and hiring of researchers, consistent with 3a below.

1. The Policy Council

For overall policy-making and accountability, the Project will be governed by a Policy Council composed of scientists representing divergent approaches, clinicians with both research and community-based experience and people with AIDS and HIV and their advocates. The following structural guidelines are suggested:

Such a council should have at least twenty-one (21) members in order to adequately represent diverse communities, opinions and disciplines. Whatever the final number of Council members,

people with AIDS and HIV from diverse communities will be in the majority to insure that Project staff are ultimately accountable to people directly affected by the course and outcome of the research. Council members will step down and be replaced by new members on a regular basis.

The Council will set policy for and oversee research priorities. It will develop guidelines for and oversee the hiring of primary research staff, ensuring both high quality (scientific credentials and experience) and a diversity of disciplines and perspectives. While certain staff will have pursued specific AIDS theories, this cannot be a necessary prerequisite for hiring; indeed, it will be important to have some primary research staff members who approach the subject freshly. The Council will have the power to create new research positions when necessary and to remove scientists from their positions after due process and appropriate review of their work.

The Council will be charged with evaluating the work of the Project, as well as the pace of the research, to insure that it matches the urgency of the epidemic. Initially, and throughout the life of the Project, the Council, in cooperation with the primary research staff, will solicit and evaluate all new theories developed outside the Project. It will direct the Project scientists to evaluate and respond to deserving proposals and to devise new research plans where desirable.

The Policy Council will adopt strict, detailed codes governing medical ethics and conflicts of interest (according to 2c) and will monitor compliance with these codes. Project scientists will report directly to the Council about the progress of their work in a manner to be determined by the Council. The Council will report directly to the President about the progress of the Project.

Council meetings, including those at which all decisions are made, will always be public and will be held at least quarterly, with time allotted for public comment. In addition, the Council will hold an annual public hearing on its priorities and progress. A complete report of the Project's goals and accomplishments will be updated by the Council, submitted to the President and released to the public at least once quarterly. The Council will evaluate its structure and process at least once per year and make changes which allow it to function more effectively.

2. The Coordinating Committee

In addition to an overall Policy Council, there must be day-to-day leadership in the Project. It cannot be governed by research bureaucrats or a single person who might create an entrenched research agenda. Therefore, the community of scientists selected for the Project will elect three of their members to serve as the Coordinating Committee for the Project, and determine whether these positions should be permanent or rotating. It is here that the McClintock Project must differ from the structures and process of military projects such as the Manhattan and Apollo projects. The development of an AIDS cure requires an open and cooperative research environment with scientists from different disciplines and perspectives interacting in a creative and free manner yet focused on a set of shared goals.

The Coordinating Committee will be responsible for facilitating communication among the different scientists working on the Project, for evaluating the progress of its work, and for convening the entire staff on some regular schedule (or when necessary) to evaluate the progress

of the Project as a whole, re-evaluate its direction, and to consider newly developed theories emanating from both within and outside the Project.

The Coordinating Committee will be also be responsible for keeping the Policy Council informed of the progress of the Project's work, at times and in a manner to be determined by the Policy Council. The coordinating Committee will also make decisions regarding the hiring of research associates, technical staff, purchases of equipment and other day-to-day needs.

The first task of the Coordinating Committee will be to facilitate an intensive preliminary review, lasting no more than three months, of all existing pathogenesis hypotheses, as well as other relevant information about AIDS pathogenesis. At the end of this review, the primary research staff will collectively develop plans for evaluating and testing each of the viable hypotheses, including timelines for evaluating the progress of this work.

3a. Equal consideration shall be given to conventional and other medical approaches and scientific theories, and researchers representing divergent approaches shall be on the primary research staff as well as be contributing researchers.

The key to the McClintock Project's success will be its ability to provide a venue for scientists with diverse - even conflicting - approaches and theories about AIDS pathogenesis to fully pursue their hypotheses. It is particularly important that approaches and theories previously under- or unfunded by large institutions be given a chance to be tested. These approaches include unconventional theories within both conventional and "alternative" medical disciplines (which not only have entire systems of medical interventions, but also complex theoretical paradigms explaining the pathogenesis of disease). This applies to both the basic science work and the uncovering of potential cures.

Pathogenesis refers to the actual course of a disease. We still have precious little knowledge of what happens to the bodies of people with AIDS, apart from the eventual loss of CD4 cells. McClintock will aggressively pursue research into all areas of AIDS pathogenesis. The two broad categories of theories to be researched by the Project include:

1. Understudied virological/immunological theories about how immune system damage occurs.

The NIH has focused almost exclusively on one model of pathogenesis: the destruction of CD4 cells due to viral replication. Study of the virus' effect on macrophages, Langerhans and dendritic cells, CNS and GI involvement, etc. is sorely lacking. In truth, we do not have a clear understanding of HIV's effect on any body system, much less the immune system.

Many researchers have, however, presented information on the pathogenesis of AIDS, including theories of *autoimmunity* (the body's tendency to attack its own tissue after

seroconversion, whether of not HIV is directly involved), *apoptosis* (programmed cell death that seems to occur more extensively in people with HIV), the presence of a *superantigen*, *chronic inflammation* of mucosal tissues (including the gut, rectum, vagina, nasal passages, mouth and throat), the role of *cytotoxic T-lymphocytes* in suppression of HIV, *cytokine disregulation* (people with HIV have elevated levels of IFN-α, IL-6, TNF, and IL-10, to name a few), and effects of HIV on the *endocrine system* (particularly with regard to cortisol and testosterone levels).

All these hypotheses must be studied in depth, in order to determine their role in damaging the immune system. Such research is not now pursued by the NIH unless it appears likely it will lead to a marketable drug.

2. Theories about co-factors which may precede, activate or even substitute for HIV in the process of immune system damage leading to AIDS.

Up until now, the sparse research on co-factors has clustered around a very few viruses (CMV, EBV, HHV-6), and has not even been adequate to establish or disprove these theories. Still to be adequately explored are the role of several micro-organisms for which strong presumptive evidence has been developed: other viruses (hepatitis-B, African Swine Fever virus); mycoplasmas; bacteria (those causing syphilis and gonorrhea); yeast (Candida); and parasites (malaria, amoebiasis, giardia). Investigations must also be done of the possible immuno-suppressive role (suggested in numerous non-AIDS studies) of many medications for the above conditions, several of which are common in the medical histories of people with AIDS and HIV.

Likewise, further work must be done on the potential role of recreational drugs (including alcohol) in progression. A huge area with substantial - but usually small-scale and uncoordinated - evidence for co-factorial role are micro-nutrient deficiencies. Given the widespread use of nutritional interventions by people with AIDS and HIV, nutritional research must be included in the Project. Current evidence also suggests a possible role for several chemical and heavy-metal toxins (including cigarette smoke) which must be explored. Finally, a vast body of knowledge grouped under psychoneuroimmunology - some of it now specifically based on people with AIDS and HIV - demonstrates connections between psychological stress, lack of social support, and immune compromise, and must also be studied.

Equally important as exploring each individual theory will be the integration of these into proposed interactive models. This multi-disciplinary, integrative approach, so rare in AIDS research, may hold the key to devising the most effective curatives. Here, too, diversity in approach should be the guideline in hiring staff and setting priorities. Examination should be given to the full spectrum of pathogenesis theories, from those maintaining that HIV is the sole and sufficient cause to those considering HIV a primary cause together with co-factors to those believing that HIV does not necessarily play a causative role.

Diversity of perspective should also be applied to methodology. Theories should be developed and tested through both laboratory experiments and epidemiological research, including careful

examination of existing medical records of people with HIV and AIDS. Another key method involves epidemiological and blood studies of long-term survivors from diverse populations to attempt to isolate the factors that have sustained them. Overall, so-called "subjective" evidence - i.e., asking people with AIDS and HIV and their care providers what factors they think may be playing a role, and how the factors may have interacted - should be collected to supplement, and possibly help to synthesize, the more "quantifiable" data.

International cooperation must also be maximized, meaning both the open-minded consideration of hypotheses and results obtained in other countries, and the implementation of an aggressive effort to recruit the best and brightest researchers from other countries. This could include agreements by another country to reassign particular researchers to the Project for an indefinite commitment. But since speed is of the essence, the Project's progress would not await the conclusion of such international agreements.

3b. The Project's study of AIDS pathogenesis and manifestations must focus on all populations of people with AIDS and HIV. Equal consideration shall be given to the differences between these populations as to their similarities or "norms." This includes women, gay men, lesbians, people of color (of various affected national-cultural groups), injection drug users, hemophiliacs and people with inadequate medical care and/or nutrition.

The inclusion of a diverse range of people in AIDS research, and a focus on the differences among them, is basic to sound scientific research. It is not just a vague call for inclusion nor an attempt to deal with what some have called "social issues." In fact, almost all research on AIDS thus far has focused on white men, most of them gay. Conclusions drawn from this research are generalized to all people with AIDS.

This cannot continue if we are to unravel the complexity of AIDS pathogenesis and develop a cure that will be usable by all affected people. Despite the dearth of scientific research on diverse groups of people with AIDS, the little we do know points to significant differences in not only the manifestations of AIDS, but also in immunological markers and routes of transmission.

For example, while it is generally believed that there is a direct relationship between CD4-cell depletion and the occurrence and severity of infections, differences in that relationship have been found for different groups of people. People with hemophilia, as a result of years of infusions of other people's proteins in their clotting factor, have lower T-cell counts in comparison to other people. Yet, they are less likely to get opportunistic infections at these low levels compared to non-hemophiliacs with HIV.

Healthy children have higher CD4 counts than adults, yet infected children deteriorate more rapidly than adults; 20% die within the first year after birth. And, we know virtually nothing about normal CD4 counts in women or about CD4-Cell depletion and severity of illness in women. We do know that compared to HIV negative women, HIV positive women with invasive cervical cancer have lower CD4 counts and are more likely to die. Yet, their CD4

counts average around 340, while 200 CD4 cells is considered the marker of severe immunosuppression.

With regard to infections, cervical cancer is one manifestation of AIDS in women which of course does not appear in men, bacterial pneumonia is more common in former and present injection drug users, and proportionately more women than men get MAI.

Finally, even the possibility of HIV transmission appears to be related to overall health at the time of exposure - a European study found that, with good prenatal care, the rate of perinatal transmission was only 15-20% without pharmaceutical interventions, compared to the findings of 30-50% in the U.S.

Routes of transmission can also affect the course of disease. A recent report showed that white babies with AIDS suffer more and earlier oral symptoms than black infants; researchers suspect the difference may be linked to whether the mother was infected through vaginal intercourse or injection drug use. Most importantly, differences in route of transmission may be crucial in finding a cure usable by all people. Most vaccines currently being tested are designed to confer systemic immunity, that is, immunity through the blood stream. Yet HIV is found in the mucosa and systemic vaccines do not confer mucosal immunity. This may be especially significant for women infected vaginally since HIV has likely entered the body through the mucosa.

Each of these differences, and the many more which undoubtedly exist but remain unresearched, indicates that the inclusion of diverse populations and a focus on their differences is the only way to understand the complexity of AIDS.

3e. Curatives ultimately released due primarily to project research shall not result in financial gain to any private organization, and shall be made available to all affected people regardless of ability to pay.

> "Industry representatives say they are in the business of making medicine and making money, and that it is for society to decide, through its government, what social needs should be met. If society wants drugs for rare diseases or vaccines for public health programs or medicines for Third World countries, then it is for society to find a way to pay for this work. People should not expect a private industry to do it for them, they say." (Drake, Donald C. and Uhlman, Marian. "'Me-too' drugs boost profits", The Tampa Tribune, Feb. 93)

The key phrase here is, "due primarily to the Project's research." That is, any curatives developed by the Project, resulting exclusively from its own work or work begun by a private company and completed predominately by the Project, should not create opportunities for private gain. The same logic applies to the use of existing pharmaceutical facilities for production of promising curatives. Since just compensation will be provided, it is reasonable that the affected company should not reap gains from Project-supported research.

Conversely, this provision will in no way prevent private companies from continuing to see profits from compounds developed on their own, even if McClintock assisted in identifying their usefulness, as long as the company developed them independently and quickly, requiring no use of eminent domain (as described in 4c).

The principle of no private gain from public financing means that Project-developed curatives will not be licensed to for-profit companies. This stands in stark contrast to current NIH practice. Government funded research has led to FDA approval of many drugs, including AZT, ddI, ddC, ganciclovir, foscarnet and others licensed to private companies, resulting in substantial profits and exorbitant prices, thus seriously limiting access to those who need the drugs.

Making curatives available to all affected people, regardless of ability to pay, is predicated on the simple idea that it is immoral to allow people to die because they can not afford to pay for something which would save their lives. This is in line with President Clinton's stated intention to make vaccines available free to all children who have not been vaccinated (some 40%). But adopting this principle implies nothing about how it is accomplished. That is left for later determination by Congress, when it becomes relevant.

Keeping financial gain out of McClintock and guaranteeing that a cure be available to all affected people regardless of ability to pay will not slow basic scientific research nor will it prevent drug companies from making profits. It will however, ensure that the basic research necessary to find a cure will be done under circumstances in which saving lives, rather than producing unnecessary and ineffective products, is the primary motivation. Finally, lack of ability to pay for a cure will not be a death sentence for someone with AIDS.

---

4. In order to accomplish its goals, the Project shall have extraordinary powers to:

> **a. direct the utilization of any and all existing U.S. government funded research entities and their facilities to clinically test promising cures developed on the basis of its research and to direct the manner in which such research shall proceed, including staffing, participants, location and timing. Such research will be funded by the McClintock Project.**

To avoid duplicating the NIH's efforts in establishing a nationwide program for the testing of new compounds, the McClintock Project will direct the use of the AIDS Clinical Trials Group (ACTG) and other clinical trials programs for large-scale testing of compounds identified or developed by the Project. The Project will design its own protocols and work with these existing clinical trials programs to develop research designs and methods appropriate to the Project's goals, assuring that data gathered by the NIH would accurately reflect the use of these compounds in the "real world", i.e. all populations and stages of illness. The Project will provide funding for these clinical trials of its own compounds. The McClintock Project's goal is to work cooperatively with these existing programs, albeit free from the numerous roadblocks described earlier. However, in areas of conflict, the Project will have the power to implement its goals.

4b. The Project shall have extraordinary powers to exercise the right of eminent domain to:

- **obtain from public and private organizations - with just compensation - samples of all potential curatives and all data regarding their development (including safety and efficacy data) as well as other information, materials or products deemed crucial to the Project.**

- **implement clinical testing for potential curatives owned by private companies, whether under development or not, unless said companies adhere to an approved time frame and are forthcoming with their data as such work proceeds.**

- **use existing pharmaceutical company facilities (with just compensation) for the production of promising curatives to be utilized in McClintock research and, if effective, to produce such curatives in sufficient amounts to be disseminated to all people needing them.**

Research into potential curatives and treatments for AIDS has been hampered on numerous occasions by the economics of drug development. While the conflicts of interest inherent at the NIH may result in faster development of treatments sponsored by major pharmaceutical companies, the self-concern of these same companies can stall or even prevent a drug's development. Examples include Abbott's HIVIG, (the trial of which was delayed by a year while the company sold the drug to avoid liability problems) and Hoffman LaRoche's tat inhibitor, the development of which was stopped for a year while Roche sought a buyer for the compound.

The McClintock Project must be able to research all potential curatives, unencumbered by the secrecy produced by marketplace competitiveness. Therefore, the Project will forge a new alliance with the pharmaceutical industry; an alliance unlike that which currently exists at the NIH. Rather than allowing it staff to profit from consulting agreements with drug companies, the McClintock Project will objectively examine patented compounds currently owned by the various pharmaceuticals, and gauge the company's development plan. In order to assess the current state of the numerous drugs being developed or sitting "on the shelf", the Project will require access to samples of these drugs, as well as data, published or not, relating to them. Such data will be kept in strict confidence within the Project, although researchers associated with the Project will have access to such information as deemed necessary.

If a drug company is found to be impeding or halting the development of a promising compound, the Project will first attempt to work with the company to develop the needed timetable for research and trials. A company lacking the resources to develop a compound will have the option of selling the compound to the Project for a just compensation, or allowing portions of its development to be undertaken by the Project, thereby reducing the company's later profits from the marketing of the drug.

If, however, a company refuses to cooperate with the Project by not releasing needed data, or by withholding samples of requested compounds, the McClintock Project will be empowered by

Congress to use powers of eminent domain to procure samples and data. Ultimately, the Project will have the power to obtain the patents of such compounds if, after reasonable attempts at cooperation, it finds that a company will not develop a promising compound in an accelerated fashion. After notification by the Project that this power will be used, a company will have thirty (30) days in which to develop, for the Project's approval, a plan for accelerated development of the compound to avoid losing its patent.

Eminent domain

Eminent domain is defined as "the power of the nation or a sovereign state to take private property for a public use without the owner's consent, conditioned upon the payment of just compensation". This power, while generally used to obtain land and buildings, also extends to "intangible and corporeal rights, such as contracts...franchises...and patent rights." The U.S. government has used this power to obtain various patents in peacetime as well as wartime. (For example, a number of Buckminster Fuller's patents for geodesic domes were taken by the Department of Defense in peacetime. Mr. Fuller initially resisted and then realized that his patents would be developed more swiftly with government assistance.) The urgency which will be the hallmark of the McClintock Project warrants the use of these powers in this health crisis.

With regards to patents, "Most of the case law dealing with the provision addresses the issue of compensation. A patent holder's claim under the section is treated as an 'eminent domain taking of a patent license.' Drawing on precedents...courts have repeatedly stated that the appropriate measure of damages is to be based on what the owner has lost and not on what the taker has gained." [Mary Griffin, "AIDS Drugs & the Pharmaceutical Industry: A Need For Reform", American Journal of Law & Medicine]

Idealistically, such powers would not need to be invoked. During the Manhattan Project, certain companies "divulged the processes covered by [their] patents to the United States, and...they were widely used." The research frenzy which drove the search for an atomic bomb led private companies to surrender their patents voluntarily to the government. Unfortunately, this same urgency has been sorely lacking in the AIDS research effort.

In another example of swift action, Congress passed the Atomic Energy Act of 1946, which, in "revoking all existing patents useful exclusively in production of fissionable materials and prohibiting issuance of new patents insofar as they were useful for such purposes, government exercises constitutional powers of eminent domain and must render just compensation." Here not only existing patents, but all possible future patents regarding atomic energy were commandeered by the federal government.

Will the threat of eminent domain deter needed private research?

Since the late 19th century, the pharmaceutical industry has threatened that any government interference will result in an end to drug development and prevent the saving of lives. This argument caused the Federal Pure Food and Drug Act of 1906 to lead to negotiations with pharmaceutical companies, and accusations of collusion between the industry and the federal

agencies set up to oversee it. The pharmaceutical industry also opposed the Food, Drug, and Cosmetic Act of 1938, claiming that "requiring proof of safety would greatly slow, even cripple," research efforts. Yet, the following two decades were a heyday for the industry, producing dozens of new drugs that reaped profits in the millions.

The pharmaceutical industry (the most profitable legal business in America) claims its high profits are appropriate because of the high risk research and development work involved. Yet, a review of historical and recent data shows that these profits, contrary to its claims, are not based on investments in basic science, but on producing unnecessary variations on already existing products, on taking the least risk possible (by using research funded largely by the government or by small companies), and by manipulating pricing so that government attempts at price controls do not make a dent in their profits.

In truth, the goal of the pharmaceutical industry, and the reward system for its scientists, is not to find useful drugs; it is to find profitable drugs. Pharmaceuticals spend more than $10.9 billion per year on research and development ($1 billion more than the entire NIH budget). But more than half of that is spent on "me-too" drugs (versions of drugs already on the market). 53% of the drugs approved in the U.S. from 1981-1991 were "me-too" drugs. Only 16% represented significant improvements over drugs already on the market, and these were not necessarily for diseases for which new treatments were desperately needed.

Actually, commercially motivated drug companies seldom do the kind of basic research the McClintock Project will focus on and which could produce a cure for AIDS. The Nobel Prize in Medicine, given for significant discoveries in basic science, has been awarded to seventy-four scientists funded by the government, compared to only three who have worked for drug companies. The existence of McClintock will not threaten industry profits, since their profits are not based largely on basic scientific research.

To refuse to take the bold steps needed to find a cure for AIDS rapidly because of industry-fed fears, is a smokescreen. It is clear that when the U.S. had the will to remove roadblocks to research and development, as in the Manhattan and Apollo projects, it did so swiftly and broadly. No less commitment from both government and industry is acceptable in the search for a cure for AIDS.

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Ms. Hazel M. Roehrig
2607 South 500 East
Salt Lake City, Utah 84106

Dear Ms. Roehrig:

Thank you for your letter about the "AIDS Cure Act" (formerly the "McClintock Project").

I am unable to comment on Representative Jerry Nadler's bill at this time as I have not seen the new version just introduced, but I have discussed the earlier version with Representative Nadler. I have invited Representative Nadler to send me the new bill, and I will comment on the specifics of the bill then if asked.

Over the last several months, I have sought to bring some definition to what many people call the "Manhattan Project" for AIDS. Everyone seems to mean something different when they talk about this, but I believe we cannot shy away from evaluating all the different interpretations in circulation. During the campaign, the President promised a "Manhattan Project for AIDS," and I take this very seriously.

From the administration's viewpoint, I am coming to see that, given the state of the science of HIV and the modern communications technologies available to scientists today, we must begin to regard the entire Federal and private AIDS research enterprise in the United States as a "Manhattan Project" for AIDS research. Then, we have to go about the business of making this huge enterprise work to its maximum potential.

I believe that this is the approach that will bring us effective treatments and vaccines most quickly. The Clinton administration has taken several significant steps on this path, including:

- The revitalized NIH Office of AIDS Research with its centralized planning and budgeting authorities, now under the leadership of Dr. William Paul;
- A 21% increase to the NIH AIDS research budget this year;
- The National Task Force on AIDS Drug Development, which is working now to identify and remove obstacles to the discovery of effective therapies for HIV/AIDS.

We need to turn the **whole** national research effort into a truly efficient, working "Manhattan Project" to find safe and effective treatments and vaccines for HIV/AIDS.

We need to improve what we have by enhancing communication, coordination, and collaboration in the public and private sectors, in the U.S. and abroad, in a way that fosters new ideas and ensures that we do not miss the truly important discoveries.

Guiding research priorities while encouraging innovation is an ongoing process that has to continue and has to be accelerated. We have to constantly evaluate where the research is going and what we may be missing, and we have to carefully consider whether new ideas may help create and maintain an environment more conducive to good, productive science, or unintentionally hurt the cause of AIDS research.

Though to many people the horizon still looks pretty bleak for new effective therapies and vaccines, I am optimistic that all the renewed energy of the last year, and new efforts still to come, will reap some truly great rewards for people with HIV and AIDS.

I will continue to work with members of Congress, all agencies of the administration, the community and private industry to explore new ways to get this job done faster.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

May 4, 1994

Paul —
draft reply

Hazel M. Roehrig
2609 South 500 East
Salt Lake City, Utah 84106

Kristine M. Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th St., NW, Suite 1060
Washington, D.C. 20530

Dear Ms. Gebbie;

I'm another concerned citizen writing to express my urgent desire that some action be immediately taken upon the AIDS epidemic. A cousin of mine is now in the last stages of this horrible disease, and a friend of mine is also suffering from AIDS.

I implore you to support "H.R. 3310," the Barbara McClintock Project to help cure AIDS. We need increased funding for research into this; because for so many it's actually a matter of life and death.

Your response is very important to me and I eagerly await your reply.

Respectfully,

Hazel M. Roehrig

Hazel Roehrig
2607 South 500 East
Salt Lake City, Utah
84106

SALT LAKE CITY UT 87
PM
04 MAY
1994

MAY 10 1994

Kristine M. Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th St., NW, Suite 1060
Washington, DC 20530

MAY 11 1994

THE WHITE HOUSE

WASHINGTON

June 6, 1994

Mr. Christopher Craig
123 Sachez Street, No. 12
San Francisco, CA 94114

Dear Mr. Craig:

Thank you for your letter about the "AIDS Cure Act" (formerly the "McClintock Project").

I am unable to comment on Representative Jerry Nadler's bill at this time as I have not seen the new version just introduced, but I have discussed the earlier version with Representative Nadler. I have invited Representative Nadler to send me the new bill, and I will comment on the specifics of the bill then if asked.

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From the administration's viewpoint, I am coming to see that, given the state of the science of HIV and the modern communications technologies available to scientists today, we must begin to regard the entire Federal and private AIDS research enterprise in the United States as a "Manhattan Project" for AIDS research. Then, we have to go about the business of making this huge enterprise work to its maximum potential.

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We need to turn the **whole** national research effort into a truly efficient, working "Manhattan Project" to find safe and effective treatments and vaccines for HIV/AIDS.

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Though to many people the horizon still looks pretty bleak for new effective therapies and vaccines, I am optimistic that all the renewed energy of the last year, and new efforts still to come, will reap some truly great rewards for people with HIV and AIDS.

I will continue to work with members of Congress, all agencies of the administration, the community and private industry to explore new ways to get this job done faster.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Dee = "Cure" letter

Bobby Griffin

Kristine Gebbie
Director, Office of AIDS Policy
750 17th Street, NW
Washington, DC 20050

Dear Ms. Gebbie

Please support the "McClintock Project to Cure AIDS" H.R. 3310. I have already informed my local, state and national representitives about the importance of passing this bill. Where are you Kristine? I watch C-SPAN everyday looking for you and you're never on. We need someone who can take the bull by the horns and do everything possible to stop this devestating plague, and this means getting on the tube and causing a storm. I'm sure your job is no picnic, everyone dumping their AIDS frustrations on you, but it's hard to defend the job you have been doing when the only time I've seen or heard from you is on "AIDS-day". I would love to see you on T.V. every week, with new info on new treatments, drugs, research that looks promising etc..

Also, please talk to President Clinton about advising Janet Reno to authorize the immediate release of all documents from the CIA regarding "germ warfare/biological warfare","viral and gene research",etc.. and give this information to the National Institute of Health so they can investigate the data and hopefully gain more insight into how AIDS is made and how it can be destroyed. The CIA has been doing research in this field since it's inception in the early 1950's. We need this data!!

I would love to hear back from you on this, also, if you have a regular newsletter please put me on the mailing list. Thank you.

Christopher Craig
123 Sanchez Street, No.12
San Francisco, CA 94114

THE WHITE HOUSE

WASHINGTON

June 6, 1994

David Satcher, M.D., Ph.D.
Director
Centers for Disease Control
and Prevention
Atlanta, Georgia 30333

Dear Dr. Satcher:

Thank you for the invitation to speak at the Second Annual National School Health Leadership Conference on Wednesday, June 8, 1994 in Atlanta, Georgia. Unfortunately, my schedule does not permit me to participate. If I can assist in some other way, for instance with a video address, please let me know.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

4/15

Called Beth Patterson to let her know that 6/8 is being held — she offered some other times, but late in the week. Those dates, also do not work. Her print deadline is 5/14.

— REGRETS

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

5/14

APR 1 1994

work with them
on alternatives—
I'd certainly like
to accept for
Right now the days are held for
the AMA.

RECEIVED
APR 11 1994

Ms. Kristine Gebbie, R.N.M.N.
AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W., Suite 1060
Washington, D.C. 20503

Dear Ms. Gebbie:

I invite you to address the participants of the Second Annual National School Health Leadership Conference on Wednesday afternoon, June 8, 1994, in Atlanta, Georgia.

The conference will be held June 6-8 at the Nikko Hotel. It is sponsored by the Centers for Disease Control and Prevention (CDC). The theme of this year's conference is "Working Together: Partnerships to Improve Comprehensive School Health Programs." More than 500 professionals from State and local departments of education, health, and social service; universities; national nongovernmental organizations; Federal agencies; voluntary organizations; and philanthropic organizations are expected to attend. A draft agenda is enclosed.

This conference affords an opportunity to demonstrate a leadership role in HIV prevention and youth. Your addressing the conference participants would send a clear message to the Nation's education leaders that you place a high priority on HIV prevention education programs.

If your schedule permits you to attend, please have your office contact Ms. Beth Patterson, telephone (404) 488-5324, for arrangements. I look forward to your participation.

(404) 639-3291

Sincerely,

David Satcher, M.D., Ph.D.
Director

Enclosure

DRAFT

Second Annual National School Health Leadership Conference
June 6-8, 1993

"Working Together: Partnerships to Improve
Comprehensive School health Programs"

Co-Sponsored by

U.S. Department of Health and Human Services
U.S. Department of Education
U.S. Department of Agriculture

Monday, June 6, 1994

2:30 - 5:30	Opening Session for Second Annual National School Health Conference
2:30 - 2:50	Welcome-- David Satcher, MD, Director, Centers for Disease Control and Prevention (CDC)
2:50 - 4:20	Town Meeting with Phil Lee, MD, Assistant Secretary for Health; Tom Payzant, DoE Assistant Secretary for Elementary and Secondary Education; and Ellen Haas, DoA Under Secretary for Nutrition Programs.
4:20 - 4:30	Pursuing a Common Vision: Collaborative Planning During the Second Annual Conference -- Lloyd Kolbe
4:30 - 5:30	Breakout Sessions: Assessing Progress in Achieving Recommendations from the First Annual National School Health Conference
6:00 - 7:30	Reception/Exhibits

Tuesday, June 7, 1994

8:30 - 5:00	National Conference - Participative Sessions/Workgroups
8:30 - 8:40	Collaborative Planning to Improve School Health Programs: Recommendations from the First Annual Conference
8:40 - 9:30	Working Together: A Vision for Improving School Health Programs for Our Nation-- Joycelyn Elders, MD, Surgeon General (invited)

DRAFT

DRAFT AGENDA: Conference on Preventing HIV Infection Among School-aged Youth

Wednesday, June 8, 1994

1:00 - 5:00	Opening Session for the Conference on Preventing HIV Infection among School-aged Youth
1:00 - 1:15	Welcome
1:15 - 1:40	The Nature of the HIV/AIDS Epidemic among Youth
1:40 - 2:10	National Direction for Preventing and Addressing HIV Infection among Youth-- Kris Gebbie, National AIDS Policy Coordinator (invited)
2:10 - 2:35	Recommendations from the CDC National AIDS Advisory Panel, CDC National AIDS Advisory Committee
2:35 - 3:00	BREAK
3:00 - 3:25	CDC's First Response to the Recommendations-- Lloyd Kolbe
3:25 - 4:05	Community Planning: How Will It Address Youth?
4:05 - 4:30	NAIEP, Media, and the Prevention Marketing Initiative
4:30 - 5:00	Developing a More Integrated National Effort to Prevent HIV Infection among Youth

Thursday, June 9, 1994

8:00 - 9:15	Four Concurrent Sessions
9:30 - 10:45	Four Concurrent Sessions
11:00 - 12:15	Four Concurrent Sessions
12:15 - 1:30	Lunch On Your Own
1:30 - 5:00	Meeting for State Departments of Education
1:30 - 5:00	Meeting for Youth in High Risk (YHRS) Projects
1:30 - 5:00	Meeting for DASH-funded University Projects
1:30 - 5:00	Meeting for Local Education Agencies
1:30 - 5:00	Meeting for DASH-funded National Organizations

DRAFT

Tuesday, June 7, 1994, continued

9:30 - 12:00	Participative breakout sessions: Developing Action Plans to Address the Recommendations from the First Annual National School Health Conference [this time slot will include a break period]
12:00 - 1:30	LUNCH/Roundtables/Exhibits
1:30 - 3:00	Participative breakout sessions: Discussion of proposed action plans across agencies
3:00 - 3:30	Break
3:30 - 5:00	Participative breakout sessions: Return to original breakout groups (by agency type) to refine action plans.
5:00 - 7:00	DINNER (On Your Own)
7:00 - 8:30	Project Exchange Roundtables

Wednesday, June 8, 1994

9:00 - 11:30	Closing Session for Second Annual National School Health Leadership Conference
9:00 - 9:15	Introduction
9:15 - 10:30	Reports from the participative sessions
10:30 - 11:30	Closing keynote speaker

DRAFT

Friday, June 10, 1994

9:00 - 12:00 Closing Session for the Conference on Preventing HIV Infection among School-aged Youth

Closing Keynote

DASH Business Meeting

Open Mike

Awards

DRAFT

THE WHITE HOUSE

WASHINGTON

June 7, 1994

Mr. Eddie Hugh Bethune, Jr.
President
TechniCare
Post Office Box 145
523 West Poplar Street
Griffin, Georgia 30224

Dear Mr. Bethune:

Thank you for writing to inquire about HIV/AIDS health organizations in your area. The delivery of home health services is indeed an important and cost-effective component of comprehensive health care for people living with HIV/AIDS.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides Federal funding for HIV/AIDS health care and support services, including home-based care. To explore the availability of CARE Act funds for home medical treatment in your area, please contact:

Kathy Bush, Director
Ryan White Projects
Division of Communicable Disease
2 Peachtree Street, N.E.
6th Floor Tower
Atlanta, Georgia 30303
(404) 657-2607

I hope this will be helpful.

Sincerely,

Kristine Gebbie

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

TECHNICARE
MEDICAL EQUIPMENT SPECIALISTS

Tim -
reply directly -
refer to Atlanta
HIV group

May 23, 1994

ONAPC
Executive Office of the President
750 17th Street N.W. Ste. 1060
Washington, DC 20503

Dear Sir/Madam,

TechniCare, Inc. is a home medical equipment supplier that is joint-ventured with a home IV Infusion company. Within recent years we have noticed an expanding need for home medical treatment for AIDS related illness, but do not see many of these cases being bound over for home treatment. Home treatment is not only more cost-effective, but it allows the individual to remain at home in a familiar and comfortable setting. I am looking for any information regarding groups in my area that I could contact to provide them with details regarding home IV Infusion therapy. I am located near the Atlanta, Georgia area.

It is my opinion that most people receiving infusion therapy for AIDS would prefer treatment in their home by someone who has a sincere interest in their health and plan of treatment. If there are any AIDS health organizations that your office is aware of I would greatly appreciate the information.

Sincerely,

Eddie Hugh Bethune, Jr.
President

P.O. Box 145 • 523 West Poplar Street • Griffin, Georgia 30224 • 404-227-9313 • Fax 404-412-0014

JUN - 7 1994

THE WHITE HOUSE

Kathleen —

Sorry I missed you - I never got to the exhibit area. It was good to get your card, and I do look forward to a chance to visit a bit. If you ever get to DC, please stop by - The phone # is 202-632-1090.

Kathleen O'Connor
President
O'Connor Communications
1516 2nd Avenue, Suite 300
Seattle, WA 98101

JUN - 7 1994

THE WHITE HOUSE

Dear Helen —

I'm a bit slow with this "thank you" - it was so great to see you (and Mary & Tina) in Helena - and many thanks for the ride to the airport. I got all my connections & arrived in New York safely! I hope it's not quite so long before we meet again ~~Kathie~~

Ms. Helen Dawson
1805 Joslyn
Apt. 103
Helena, Montana 59601

JUN - 7 1994

THE WHITE HOUSE

Bill -

Thanks for the calendar - it's very helpful.

No - I'm not quite as slum- my committee & I are having trouble pinning down a date for my defense.

Hillary

Washington State
WSSDA School Directors' Association
221 College St. N.E. • Olympia, WA 98506-5313
Telephone: (206) 493-9231
FAX: (206) 493-9247

Bill

The enclosed is:

☐ **For your information**

☒ **To answer your request**

Karen Russell

KAS—
HERE'S THE INFO
YOU REQUESTED
RE: STATE & NAT'L
SCHOOL BOARDS.
SORRY I DON'T
GET IT TO YOU
SOONER -- HOPE IT'S
HELPFUL.

Bill Willard

P.S. ARE YOU A
MICHIGAN ALUM YET?
(Go Wash State!
— DOH, Olympia)

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Gerald Whitburn
Secretary
State of Wisconsin Department
of Health and Social Services
Post Office Box 7850
Madison, Wisconsin 53707-7850

Dear Mr. Whitburn:

Thank you for the invitation to be the keynote speaker for the first Wisconsin Teen Peer Education Conference in Madison on Wednesday, June 22 or Thursday, June 30, 1994. Unfortunately, my schedule does not permit me to participate on either date. I understand that there is a possibility that you will hold the conference on a different date altogether. Please advise me if you do change the conference date. I would be interested in attending if it is at all possible. If you need suggestions for other speakers, or if I can assist in some other way, for instance with a video address, please let me know.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

State of Wisconsin
Department of Health and Social Services

FACSIMILE COVER MESSAGE
(608)266-7882 (Fax #)

TO: Ms. Retina Holmes LOCATION: _____

FAX NUMBER: 202/632-1096 TELEPHONE NUMBER: _____

FROM: OFFICE OF THE SECRETARY: Gerald Whitburn
Name

OFFICE OF LEGAL COUNSEL: _____
Name

DIVISION: _____
Name

TELEPHONE NUMBER: _____

NUMBER OF PAGES INCLUDING COVER SHEET: 2

IF THERE IS A PROBLEM WITH THIS TRANSMISSION, PLEASE CONTACT:

Kathy Hebert AT 266-9622
Name Telephone Number

MESSAGE:

Tommy G. Thompson
Governor

Gerald Whitburn
Secretary

Mailing Address
1 West Wilson Street
Post Office Box 7850
Madison, WI 53707-7850
Telephone (608) 266-9622

State of Wisconsin
Department of Health and Social Services

April 5, 1994

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
Office of National AIDS Policy
750 17th Street, NW
Washington, D.C. 20050

Dear Ms. Gebbie:

I'm writing to follow-up my previous correspondence and also the contacts that your staff have had with my office concerning the possibility of your participating in an event here in Wisconsin. We would like to have you keynote the first Wisconsin Teen Peer Education Conference in Madison in June. We are prepared to schedule the event on either Wednesday, June 22, or Thursday, June 30.

We would like to have you make a 30 to 40 minute keynote presentation beginning at approximately 9:00 a.m. followed by a brief question and answer period. In addition to addressing the conferees, we would want to encourage you to hear the presentations of several of our Teen Peer Aids Prevention Programs from across the State of Wisconsin.

Currently, Wisconsin has 13 teen peer programs operating out of our AIDS service organizations and minority community based organizations. This conference will provide an opportunity for the teens and adults to demonstrate their projects, dialogue with each other, plan and generally underscore the value of youth involved in AIDS prevention.

Will this work for you?

Best regards.

Sincerely,

Gerald Whitburn
Secretary

State of Wisconsin
Department of Health and Social Services
1 W. Wilson Street P.O. Box 7850 Madison, Wisconsin 53707-7850 608-266-9622

Gerald Whitburn
Secretary

5-5

Ms Holmes —

Thanks.

I will get to
you ASA.

J. Whitburn

EXS-232 (Rev. 1/93))

JUN - 8 1994

THE WHITE HOUSE

Dear friends –

It was such a pleasure to spend a little time at the Ark of Refuge... It is a wonderful ministry for women in need of support and growth. My very best wishes to all staff and residents.

Hillary Rodham Clinton

Rev. Yvette Flunder
Executive Director
Residential Treatment for African
American Women
304 Goldmine Drive
San Francisco, CA 94102-6033

JUN - 8 1994

THE WHITE HOUSE

Dear Mayor Jordan —

It was a pleasure to meet with you during my trip to San Francisco in late May. I remain impressed with the ways that the public & private institutions in your city have responded to the HIV epidemic. My best wishes in your continuing efforts.

Kristine Iscilio

Mayor Jordan
City Hall
400 Van Ness Avenue - 2nd Floor
Room 200
San Francisco, CA 94102-4603

JUN - 8 1994

THE WHITE HOUSE

Dear Lance —

Thank you for the update on issues of concern to the S.F. AIDS Foundation, and its clients. You and your staff provide an impressive advocacy — in addition to the service — I always learn. Thank you too, for accommodating the ACT-UP participants with good grace. I look forward to continued communication as we work on Ryan White & other issues —

Mr. Lance Henderson
San Francisco AIDS Foundation
25 Van Ness Avenue
Suite 600
San Francisco, CA 94102-6033

JUN - 8 1994

THE WHITE HOUSE

Dear Randy -

Many thanks for the visit and lunch and conversation and information at the Brothers Network while I was in San Francisco in May. The breadth of your outreach is impressive, and I look forward to hearing more in the months to come. Please give my best to all staff & volunteers - Christine

Mr. Randy Miller
Executive Director
Brothers Network -- Health Services
for Men of Color
944 Market Street, Suite 210
San Francisco, CA 94102-4010

SCHEDULE FOR

KRISTINE M. GEBBIE
NATIONAL AIDS POLICY COORDINATOR
May 26, 1994

MAY 25, 1994

10:10p Arrive San Francisco

RON - Hyatt Regency Hotel

May 26, 1994

7:00a - 9:15a Office time/breakfast - Hotel

9:15a **Depart for Mayor's Office (see attached bio)**
400 Van Ness Avenue - 2nd Floor
Room 200 POC: Meridth Halperin 415/554-6131 94102-4603

9:30a Meeting with Mayor Frank Jordan

10:00a **Depart for Un Puente para Ninos (Bridge for Kids)**
Kelly Smith, Executive Director 415/522-0100
43 Franklin Street, Suite 303 (at Page Street) 94102-6019

10:15a Tour Un Puente para Ninos

11:00a **Depart for National Task Force on AIDS Prevention**
Brothers Network -- Health Services for Men of Color
Randy Miller, Executive Director 415/403-3800
944 Market Street suite 210 94102-4010

11:15a Tour and lunch at National Task Force

12:40p **Depart for Arc of Refuge -- Residential Treatment for African American Women -- Reverend Yvette Flunder, Executive Director**
304 Goldmine Drive 415/431-8811 94124-2526

12:45p Tour Arc of Refuge

1:30p **Depart for San Francisco AIDS Foundation**
Lance Henderson, Executive Director 415/487-3036
25 Van Ness Avenue, Suite 600

94102-6033

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Gail Gray
OPI
1300 11th Avenue
Helena, Montana 59620

Dear Ms. Gray:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Tom Freeman
Post Office Box 511
Saint Ignatius, Montana 59865

Dear Mr. Freeman:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Judy Peterson
AIDS Program
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Ms. Peterson:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Rick Chiotti
OPI
1300 11th Avenue
Helena, Montana 59620

Dear Mr. Chiotti:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Jim Murphy
AIDS Program
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Mr. Murphy:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Bruce Desonia
Program Manager
AIDS/STD Program
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Mr. Desonia:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Judith Gedrose
Bureau Chief
Preventive Health Services
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Ms. Gedrose:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Ashley Kennedy
Missoula AIDS Council
554 West Broadway
Missoula, Montana 59802

Dear Ms. Kennedy:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Gwen Ganjeau
Southern Montana AIDS Coalition
Post Office Box 1276
Bozeman, Montana 59771

Dear Ms. Ganjeau:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Cindy Ballew
Southern Montana AIDS Coalition
1403 South Third
Butte, Montana 59715

Dear Ms. Ballew:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Cheryl Lowe
Flathead AIDS Council
723 5th Avenue East
Kalispell, Montana 59901

Dear Ms. Lowe:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Sue Bonin
Flathead AIDS Council
723 5th Avenue East
Kalispell, Montana 59901

Dear Ms. Bonin:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Aylett Wright
Missoula AIDS Council
2321 Gerald
Missoula, Montana 59801

Dear Ms. Wright:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Sue Swan
Northern Montana College
Student Health Center
Post Office Box 7751
Havre, Montana 59501

Dear Ms. Swan:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Corky Smith
P-FLAG
38 Sloway West
Saint Regis, Montana 59866

Dear Ms. Smith:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Carl Donovan
127 20th Street
Black Eagle, Montana 59414

Dear Mr. Donovan:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Julie O'Connor
Lewis and Clark AIDS Project
Post Office Box 832
Helena, Montana 59624

Dear Ms. O'Connor:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Jewell Dalgarno
Wheatland County AIDS Task Force
Post Office Box 219
Harlowton, Montana 59036

Dear Ms. Dalgarno:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. James Livingston
Samaritans of Montana
Post Office Box 1903
Great Falls, Montana 59405

Dear Mr. Livingston:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Ken Fremont-Smith
Missoula City-County Health Department
301 West Adler
Missoula, Montana 59802

Dear Mr. Fremont-Smith:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Greg Patent
Missoula AIDS Council
5445 Skyway Drive
Missoula, Montana 59801

Dear Mr. Patent:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Kevin Roberts
Valley County Health Department
Box 1
501 Court Square
Glasgow, Montana 59230

Dear Mr. Roberts:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Harriet Pearson
Southern Montana AIDS Coalition
Post Office Box 969
Ennis, Montana 59729

Dear Ms. Pearson:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. David Gay
Southern Montana AIDS Coalition
108 Sourdough Ridge Road
Bozeman, Montana 59715

Dear Mr. Gay:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Shelly Videon
Bridger Clinic, Inc.
Suite 2001
300 North Willson
Bozeman, Montana 59715

Dear Ms. Videon:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Laura Mentch
Bridger Clinic, Inc.
Suite 2001
300 North Willson
Bozeman, Montana 59715

Dear Ms. Mentch:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Karma Alfredson
Apartment 3
1205 Broadway
Helena, Montana 59620

Dear Ms. Alfredson:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Frank Gary
Butte AIDS Support Services
Post Office Box 382
Butte, Montana 59703

Dear Mr. Gary:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Kathy Hayes
Missoula AIDS Council
554 West Broadway
Missoula, Montana 59802

Dear Ms. Hayes:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. John Sims
Lewis and Clark AIDS Project
Post Office Box 832
Helena, Montana 59624

Dear Mr. Sims:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

JUN - 8 1994

THE WHITE HOUSE

Dear Dian —

It was a pleasure to meet you on my recent visit to San Francisco General. As I have been before, I'm impressed with the caring and the professional support provided. I look forward to seeing you again —

Best wishes - Hillary

Dian Jones, RN
San Francisco General Hospital
Bldg. 80, AIDS Ward 5A
San Francisco, CA 94110

JUN - 8 1994

THE WHITE HOUSE

Dear JB -

Thanks for showing me around the AIDS clinic - I know it was late in the day, and I appreciated the time. San Francisco, & St Generals, have been leaders in this epidemic - your caring, your professionalism, your pride shows. All best wishes -

Hillary

JB Molaghan, RN, NP
Head Nurse, AIDS Clinic
Bldg. 80, AIDS Clinic
San Francisco, CA 94110

JUN - 8 1994

THE WHITE HOUSE

Dear Ron -

just a quick word of thanks for the very informative visit to the telephone "warm line" - it is an excellent resource. Also appreciated your tour guide and transportation assistance!

Did your Neural health association presentation go well? I hope so.

All best wishes — Kristine

Ron Goldschmidt, MD
Professor of Clinical Family
and Community Medicine
San Francisco General Hospital
Bldg. 80, Ward 83
San Francisco, CA 94110

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Dale Taliaferro
Administrator
Health Services Division
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Mr. Taliaferro:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. John Sims
Lewis and Clark AIDS Project
Post Office Box 832
Helena, Montana 59624

Dear Mr. Sims:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Claudia Montagne
Montana Department of Health
and Environmental Sciences
AIDS Program
1400 Broadway
Helena, Montana 59620

Dear Ms. Montagne:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. David Herrera
FDH and Associates
Post Office Box 1253
Billings, Montana 59103

Dear Mr. Herrera:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Camille Spitzer
Dawson County Health Department
207 West Bell
Glendive, Montana 59330

Dear Ms. Spitzer:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Ms. Joyce Galster
Butte AIDS Support Services
Post Office Box 382
Butte, Montana 59703

Dear Ms. Galster:

It was a pleasure to meet you, even if briefly, over lunch during the recent HIV/AIDS conference in Helena. Montana is lucky to have a committed network of community members such as you. I wish you every success in your endeavors and look forward to hearing about your work.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 8, 1994

Mr. Bob Robinson
Director
Montana Department of Health
and Environmental Sciences
1400 Broadway
Helena, Montana 59620

Dear Mr. Robinson:

Thank you for meeting with me during my recent stay in Helena. I came away impressed by the challenges you face, but even more impressed by your commitment to having a responsive network for services and prevention. My best wishes to you.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

JUN - 9 1994

Dear Bill —

- Thank you for your kind letter — we will keep working & we will beat this disease! I too have great hopes for Drs Fauci & Varmus - & will work with them. All the best — Hillary

Billi Goldberg

FAX COVER SHEET

Sat May 28 1994 10:34 am

To: Ms. Kristine Gebbie
Fax #: 1-202-690-7560

Fax #: 1-415-826-4928
Voice #: 1-415-826-3597

Fax: 1 page and a cover page.

AIDS: Ignorance = Death
Knowledge = Life

2261 Market Street #436 San Francisco, CA, USA 94114
Phone: (415) 826-3597 Fax: (415) 826-4928

May 28, 1994

Kristine Gebbie
National AIDS Policy Coordinator
Washington, D.C.

Dear Ms. Gebbie,

I am personally quite upset about the attacks on you from the so-called AIDS activists from NAPWA, ACTUP, etc. My feelings have been expressed to some individuals involved in the actions.

Responsibility for many of the problems in the AIDS pandemic are related to activists representing organizations that have personal agendas while taking money from pharmaceutical companies. They do not truly represent individuals who are infected with the AIDS virus but only their silly and futile attempts for publicity and status. They are known as "wannabes" in the underground, and are held in contempt by those of us that are personally helping people stay alive on the streets.

The primary responsibility for the sad state of affairs in AIDS should be placed at the feet of the scientists who have focused their efforts on killing the virus with bad drugs and even worse vaccines. Bernard Fields, in the 5/12/94 *Nature*, expressed these concerns albeit in a very conservative way so as not to alienate others in the closed scientific community.

Those scientists that realized that AIDS is an immunological disease were silenced by the scientific powers that controlled research for their personal benefit. AIDS activists that screamed for more drugs only sanctioned the power-grabbing efforts of the so-called big names in AIDS research.

I have great hope that the efforts of Harold Varmus and William Paul will result in positive gains in basic science. It is my understanding that they do not "suffer fools gladly." That is good, because their is a surfeit of fools in AIDS research.

All of us involved in trying to save lives must be prepared to be attacked by those who agenda is personal rather than altruistic. Please do not let these negativists interfere in what you are trying to do.

It is my understanding from Sister Mary Elizabeth and others that your are a kind and compassionate woman. Please continue the fight to the best of your ability, which, I understand, is considerable. You are not alone, even though it may seem so at times.

Sincerely,

Billi Goldberg
AIDS and DNCB Treatment Activist

JUN 10 1994

THE WHITE HOUSE

Dear Faye —

Springer sent me your new book — yet another contribution to nursing!

Thank you once again for all you do —

Hillary

Faye G. Abdellah, Ed.D., Sc.D., RN, FAAN
Acting Dean
Graduate School of Nursing
Uniformed Services University of the
Health Sciences
4301 Jones Bridge Road
Bethesda, MD 20814-4799

THE WHITE HOUSE

WASHINGTON

June 13, 1994

Dear Ann Landers:

I would like to thank you for your powerful words on the need to talk frankly to young people about the need to protect themselves from HIV and other sexually transmitted diseases. As you may know, the President appointed me National AIDS Policy Coordinator to spearhead the nation's efforts to end the AIDS epidemic. The President and I are committed to preventing the spread of HIV, to providing adequate care to those already infected and to finding a cure as soon as possible. It is important for each and every American to join us in our work and to take on a personal commitment to do something against this epidemic. Until there is a cure, prevention is our best tool in ending this epidemic.

In a recent response you mentioned that we must get the word out that the people most at risk are homosexuals and drug abusers. This is not the message that I wish to convey because it is quickly becoming untrue. Forty percent of new cases being reported are women, most of who are infected through heterosexual sex. Additionally, reported cases are double in rural areas as opposed to urban areas. We need to get the message out to all of America that anyone who shares injecting equipment or engages in sexual activity outside of a lifetime, mutually monogamous relationship is at risk.

We need everyone's help in defeating this disease. We need to make sure that we get every person and every group talking about this disease, thereby educating our communities about this epidemic. We need to talk about compassion for those living with HIV and AIDS from the pulpit at our churches and synagogues. We need community groups like the American Legion and local women's groups to reach out to those in need with true support. We need parents to go to school board and city council meetings to demand prevention programs in the community and in our children's schools. And finally, we need to encourage our children not only to gain a firm understanding of this disease, but to do something about it, like becoming a peer educator.

There is so much we can do and so much we need to do: Everyone can and should become a part of the fight against HIV infection. If we don't, AIDS will continue to destroy the lives of our loved ones. If your readers want more information, they can call the Centers for Disease Control National AIDS Hotline at 800/342-AIDS (En Espanol 800/344-SIDA; TDD 800/243-7889) or write me here at the White House.

Again, thank you Ann.

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

THE WHITE HOUSE

WASHINGTON

June 13, 1994

MEMORANDUM FOR PATRICK BRIGGS

FROM JOHN PAUL GURROLA
OFFICE OF THE NATIONAL AIDS POLICY COORDINATOR

SUBJECT Request for Presidential greetings

Could you please send graduation greetings to the following:

Gina Gurrola
4475 Gardenbrook
Chico, CA 95926

Deanna Gurrola
1391 Feather Street
Thousand Oaks, CA 91360

Could you send new baby greetings to the following:

Sylvia Zywiciel
729 Sylvan Street
Anaheim, CA 92804

Gustavo Vargas
2313 171st Street
Torrance, CA 90504

Could you send retirement greetings to the following:

Kenneth G. Blake, Assistant Superintendent
Hawthorne School District
4301 West 129th
Hawthorne, CA 90250

Could you send birthday greetings to the following:

Nancy Battaglia
1323 Park Western Drive #11
San Pedro, CA 90731

Thanks Patrick!!! Give me a call sometime.

THE WHITE HOUSE

WASHINGTON

June 13, 1994

Ms. Barbara A. Smith
Executive Director
Camp Fire Boys and Girls
Mahoning Valley Camp Fire Council
79 North Broad Street
Canfield, Ohio 44406

Dear Ms. Smith:

Thank you for writing concerning funding for the Teens In Action project on AIDS and teen violence. I am happy to be able to refer you to some organizations in your area that might be interested in underwriting such a project. At the very least, they will be able to point you in the right direction regarding available funding in your area. The organizations in your area that I suggest contacting are as follows:

- The local chapter of the American Red Cross located in Youngstown. The number is 216-744-0161.
- The Multi-County AIDS Network in Akron at 216-434-6226.
- The Northeast Ohio Task Force on AIDS also in Akron at 216-762-2437.
- Neighborhood Counseling Services in Cleveland at 216-781-9222.
- Stopping AIDS Is My Mission also in Cleveland at 216-881-7266.

For the names of additional HIV/AIDS organizations in your area or for further information, I suggest calling the CDC's National AIDS Information Hotline at 800-342-AIDS or the Ohio AIDS Hotline at 800-332-2437. Both information services can provide you with a comprehensive list of HIV/AIDS organizations near you (I understand that there are at least seventy-one within the 216 area code) and other helpful information related to funding for projects such as yours.

Additionally, you may wish to contact Robert J. Campbell, Ph.D., AIDS Director of the Ohio Department of Health. As AIDS Director he is familiar with the available grant money in the state and can help focus your search. His number in Columbus is 614-466-0295.

I hope this information is helpful to you. Please let me know if I can be of further assistance. I wish you and the Teens In Action group every success.

Sincerely,

Tanya L. Dean

Tanya L. Dean
Assistant to the Senior Policy Adviser
Office of National AIDS Policy

AB —
Comments? Changes?
Also, should it be in my name since she wrote to me or yours?
— TD

June 13, 1994

Ms. Barbara A. Smith
Executive Director
Camp Fire Boys and Girls
Mahoning Valley Camp Fire Council
79 North Broad Street
Canfield, Ohio 44406

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Sincerely,

Tanya L. Dean
Assistant to the Senior Policy Adviser
Office of National AIDS Policy

MAY 27 1994

Camp Fire Boys and Girls

Mahoning Valley Camp Fire Council

79 N. BROAD STREET • CANFIELD, OHIO 44406 • PHONE (216) 533-4121

BARBARA A. SMITH
Executive Director

LIZ WRONA
President

May 6, 1994

Office of the National AIDS
Policy Coordinator
750 17th Street, N.W.
Washington, DC 20530

Dear Ms. Tanya Dean:

Our Teens In Action group of 20+ teens traditionally put on seminars and speaking engagements regarding teen issues. The issues they are working on for the next two years is AIDS and teen violence. We are a non profit youth service agency.

Because of the AIDS issue and topics that surround it (such as sexual responsibility, drug and alcohol abuse...) I believe there should be a legitimate way for the seminar costs to be underwritten.

Please point me in the direction for available grant funding. I do realize ultimate financial assistance would depend on a written grant proposal being accepted.

Sincerely,

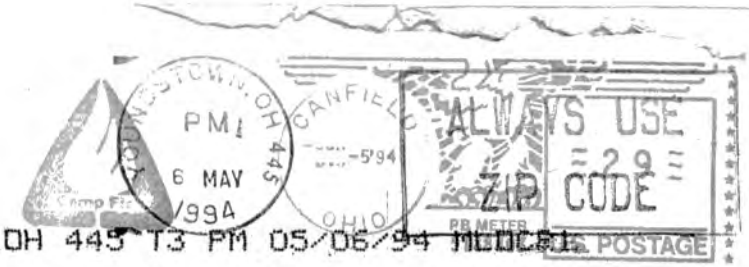
Barbara A Smith

Barbara A. Smith
Executive Director

BAS/dw

Am. Red Cross
AIDS. Dir.
Ohio
AIDS Service
Organizations
in their area
Send phone #s
clearinghouse too

Mahoning Valley Camp Fire Council
79 N. Broad Street
Canfield, Ohio 44406



YOUNGSTOWN, OH 445 T3 PM 05/06/94

MAY 9

MAY 9

Office of the National AIDS
Policy Coordinator
750 17th Street, N.W.
Washington, DC [redacted]

THE WHITE HOUSE

WASHINGTON

June 13, 1994

NOTE TO RANDY WYKOFF, M.D., M.P.H.

FROM: Terry Beswick
Paul Tran, Ph.D.
Office of National AIDS Policy

Subject: Drug Discovery Subcommittee Meeting
National Task Force on AIDS Drug Development

As mentioned on the recent conference call of the Drug Discovery Subcommittee, we wanted to informally note some additional potential resources, focusing in particular on those outside of HHS, that we believe may be of use to the Task Force. Some of these may be appropriate for the agenda of the June or July meetings. Please pass these along to the Co-chairs of the Subcommittees for their information. Your office or the Task Force members may contact either of us at 202-690-5560 for more information or follow-up on any of these items.

1. Industry Surveys

Over the last several months we have had a few informal conversations with trade groups, including the Pharmaceutical Research and Manufacturer's Association (PhRMA) AIDS Task Force, the Biotechnology Industry Organization (BIO) and the Inter-Company Collaboration (ICC) for AIDS Drug Development. Each of these associations are potential resources for conducting the survey of industry discussed on the last call.

Both PhRMA and BIO in particular have expressed a willingness to collaborate on surveying their membership on AIDS drug development issues and programs. PhRMA surveys their membership annually for their compilation, "AIDS Medicines; Drugs and Vaccines in Development", and they have expressed a willingness to include a questionnaire from the Task Force with their survey, which goes out late this summer.

We have recently discussed the survey idea with John D. Siegfried, M.D., Associate Vice President of Medical Affairs at PhRMA. (Many of BIO's relevant members would be included in the PhRMA membership, though BIO is also willing to include a questionnaire in their regular mailing to their membership). Dr. Tran is interested in assisting with developing the questionnaire or serving as a liaison with PhRMA if that would be helpful.

2. Federal Research Compendium

As you know, ONAP has been conducting a survey of all federal departments' and agencies' activities in HIV/AIDS research, and is in the process of evaluating the first round of responses now (we will be coordinating with the Office of AIDS Research and the HHS Coordinating Group on the HHS portion of this).

The goal of the project is to associate all federally funded research with the NIH Plan for HIV-related Research so that, when completed, the Compendium might be useful for establishing mechanisms for cross-governmental coordination as appropriate. The Task Force will be provided a copy of the Compendium when completed so that they might be aware of all federal research resources and programs with potential relevance to HIV/AIDS drug development. You may contact Terry Beswick for more information on the Federal Compendium of HIV/AIDS Research.

3. Patent Database

We have been working with the U.S. Patent and Trademark Office (PTO) to develop a comprehensive database of HIV- or AIDS-related patents, both at PTO and on the Internet information highway. The PTO Biotechnology Group is currently classifying these patents. There may be interest on one of the Task Force Subcommittees in this project. Dr. Tran can work with PTO to prepare a written or verbal description of the status of the project for the Task Force if there is interest.

4. Patent Issues

We have also spoken several times with the PTO about possible problems with the agency's processing of patent applications, an issue also raised on the last conference call of the Discovery Subcommittee. Mr. Charles E. Van Horn, Deputy Assistant Commissioner for Patent Policy and Projects, would be an excellent resource for the Task Force to include in further discussions on this subject. He can be reached at 703-305-9054. (Dr. Tran has already provided your office with detailed information on this project).

5. NIST Advanced Technology Program

We would like to recommend that the Task Force invite the National Institute of Standards and Technology (NIST) of the Technology Administration, Department of Commerce, to give a brief presentation to the Task Force or a Subcommittee about the Advanced Technology Program (ATP).

President Clinton has significantly increased support for this program, which previously has funded research projects strictly on an investigator-initiated basis. The ATP has recently established an interesting model for funding research. Principally designed to "promote the economic growth and competitiveness of U.S. industry by accelerating the development and commercialization of promising, high-risk technologies with

substantial potential," ATP's new "focused program" competitions are being established in specific areas of research and development based on well-defined technical and business goals. We believe a discussion of their research funding and cooperative agreement model could be of interest to the Task Force.

The ATP focused programs provide funding directly to private companies on a competitive basis. Each program is funded at the rate of $20 to $50 million annually. For example, ATP recently announced a five-year, $145 million program to develop DNA diagnostic tools. The program was created at the urging of the NIH Human Genome Project as well as a number of individual biotechnology firms. We are interested in stimulating further awareness and interest in the ATP among the HIV/AIDS biomedical research industry. If there is sufficient interest from private industry, the ATP might consider creating a drug discovery or other program with potential clinical applications in HIV/AIDS, which could be developed in collaboration with other federal research programs.

To arrange a presentation on this program, or distribution of written materials, please contact Terry Beswick or Dr. Stanley Abramowitz, Program Manager of the NIST Advanced Technology Program at 301-975-2587. (E-mail address: stan@micf.nist.gov).

6. "The Madison Project"

This series of recommendations was developed by participants in the "Future Directions in AIDS Research" workshops convened by Project Inform, the University of Wisconsin at Madison Medical Center, and the Harvard AIDS Institute. As you know, many Task Force members participated in this process which has resulted in a group of recommendations which are being finalized now. It may be helpful to the Task Force to consider some of these recommendations which relate to each of the Subcommittee's subject areas.

We believe it is important to acknowledge and respect the time and effort many individuals devoted to the development of these recommendations for improving HIV/AIDS drug development mechanisms. To arrange distribution and presentation of the final reports to the Task Force, please call Dr. Richard Marlink at the Harvard AIDS Institute at 617-495-0478.

cc: Kristine Gebbie, R.N., M.N.
Philip R. Lee, M.D.
Patsy Fleming

JUN 14 1994

THE WHITE HOUSE

Dear Paul –

Thanks for the copy of Out in the Mountains. I hope things are going well – I certainly had a great day in Vermont – learned a lot & have used that information in subsequent works –

Please stay in touch

Cordially

Dear ms. Gebbie,

Thanks for taking time to talk with me on your visit to vermont.

Enjoy OITM.

Paul Gebbie

Where is KG reply? reply to what?

Clinton Presidential Records
Digital Records Marker

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

This marker identifies the place of a publication.

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

Out in the Mountains

VERMONT'S NEWSPAPER FOR LESBIANS, GAY MEN, AND BISEXUALS

Volume IX, Number 3 May, 1994

VT CARES Hosts AIDS Czar

John Olson

National AIDS Policy Coordinator, Kristine Gebbie (President Clinton's choice as AIDS Czar) was the featured guest for a full day of meetings recently with Vermont CARES and other members of the AIDS community. Ms. Gebbie was the guest speaker for the Vermont CARES Annual Dinner, held in Burlington on March 18, which was attended by over 300 supporters, volunteers and people with HIV/AIDS.

The Annual Dinner included honoring three volunteers, recognition of CARES staff (including honoring five years of service by Marita Hartnett) comments by Governor Howard Dean, Senator James Jeffords, CARES Board Chair David Curtis, and Executive Director Kate Hill. Students from Harwood Union High School performed a dramatic educational piece. Ms. Gebbie concluded the evening with her remarks urging cooperation among community groups and service providers and the local, state, and federal government. ▼

AIDS Czar Kristine Gebbie Visits VT

Paul Olsen

National AIDS Policy Coordinator Kristine M. Gebbie visited Vermont on March 18, 1994. Gebbie's visit included breakfast with representatives of AIDS Service Organizations and the Vermont Department of Health, a visit to the University Health Center's Comprehensive Care Clinic, meetings with members of the Vermont Legislature, Governor Howard Dean, and people with AIDS, and a speech at the Vermont Committee for AIDS Resources, Education & Services (CARES) annual dinner. Formerly Secretary of the Washington State Department of Health, an Administrator with the Oregon Health Division, and a member of the first National Commission on AIDS, Gebbie was appointed "AIDS Czar" by President Clinton on June 25, 1993. Since beginning her tenure in Washington DC, Gebbie has been traveling throughout the country focussing on AIDS prevention, research, and education programs. What follows are excerpts from Gebbie's exclusive interview with *Out in the Mountains.*

OITM: How do the needs of people with AIDS in Vermont differ from those who live in inner cities and how do you balance the conflicting needs of urban and rural areas?

Gebbie: The basic needs are the same - people with this virus need good competent medical care, they need it early, and they need a chance to make their own decisions about treatment, lifestyle and all those things to try to live a healthy life despite the virus. They need access to support and comfort and resources, they need opportunities to keep being productive as long as possible - all of those things are common everywhere in the country. The challenge in rural areas is that the general community level of denial of the disease is higher so it's a lot harder to say "I've got it" or to find somebody that will admit that. It's also harder to find a support group of people like me-whatever I am like. The third thing is the complication of how do you get care? When higher tech care or good consultations are needed there is a

Continued on page 10

THE PROGRESSION OF PROGRESSIVES: The G/L/B community after a big win in Burlington

Fred Kuhr

On Town Meeting Day, March 1, 1994, residents of Burlington spoke their minds at the polls and elected three Progressive Coalition members to the City Council bringing their total to five, more than any other party. The new 14-seat council will include five Progressives, four Democrats, two Republicans, and three Independents, all of whom are expected to vote frequently with the Progressives. This ultimately could give the Progressive Coalition a voting majority, a major stride for a political party that many thought had lost most of its influence since losing the mayorship last year to Republican Peter Brownell.

According to Progressive Donna Bailey, the openly lesbian former-City Councilor, gays and lesbians play an important role in the Progressive Coalition. Although she credits the results of this past election as a "report card on Brownell", gays and lesbians helped "get the message out (asking) 'Hey is this guy doing the job you want done?'" She said that residents want the city-run programs to which they have grown accustomed "without being taxed to death." To Bailey, these issues are just as important to gays and lesbians as are issues that more directly impact the gay and lesbian community because "every issue is a gay and lesbian issue."

Continued on page 8