FOIA Number: 2018-0756-F

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Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. letter	From: Kristine Gebbie; re: Thanks for Writing (1 page)	10/18/1993	b(6)
002. letter	To: Kristine Gebbie; re: Desperate Mother (4 pages)	10/18/1993	b(6)
003. letter	To: Hillary Rodham Clinton; re: Discrimination in Medical Field (2 pages)	10/25/1993	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 3767

FOLDER TITLE:
October Chron Files 1993 [4]

2018-0756-F
jp4794

RESTRICTION CODES

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

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

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

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

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

10.13.93

Kristine-

Certification is still pending - hopefully, we'll hear something by next week.

Looking forward to working with you! Truly, this is a great honor and an awesome responsibility.

Yours,

Terry Besaw

OCT 19 1993

Human Rights
CAMPAIGN FUND

Kristine Gebbie, RN, MN
National AIDS Policy Coordinator
750 17th Street, Suite 1060
Washington, DC
20500

HUMAN RIGHTS CAMPAIGN FUND
1012 14th Street, NW
6th Floor
Washington, D.C. 20005

Myrin Bentz
David Knapp
Pastors

St. Luke Lutheran Church
6835 S.W. 46th Ave.
Portland, OR 97219

(503) 246-2325

October 13, 1993

Kristine Gebbie
2737 Devonshire Place NW #315
Washington DC 20008

Dear Kristine,

I am enclosing two complimentary tickets to the 50th Anniversary Banquet on October 23, for you and Eric. Everyone here is looking forward to the anniversary weekend and happy you'll be a part of it.

Sincerely,

Carrol Klett
Parish Secretary

THE WHITE HOUSE

WASHINGTON

October 13, 1993

Ms. Kathy Labriola, LVN
1714 9th Street
Berkeley, California 94710

Dear Ms. Labriola:

Thank you for taking the time to write and voice your concerns about the AIDS epidemic. I agree that research is needed to support and expand both service and prevention efforts.

As the National AIDS Policy Coordinator, I will strongly support a response to the epidemic that demonstrates a commitment to HIV research and caring for those who are infected.

I appreciate hearing from you.

Sincerely,

Kristine Gebbie

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

THE WHITE HOUSE

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I appreciate hearing from you.

Sincerely,

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

Prepared by: APO: TFox: 10/13/93:202-690-5560:b:\foxltrs.gbe\labriola.gbe

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

9/19/93 SEP 28 1993

Dear Kristine Gebbie,

I am writing to urge you to put your full support behind the "Barbara McClintock Project" or some similar project that would be the equivalent of a "Manhattan Project" to find a cure for AIDS.

As a nurse caring for AIDS patients for the past 11 years, I have watched hundreds of people die from this horrible disease, + I currently am seeing hundreds more of those young men + women who are sick + dying from this disease. The incredible toll of suffering and death is taking place in every town + city in America, + everywhere families are crying with the pain of losing their loved ones from AIDS. Added to this cost in human suffering is the incredible cost in health care dollars — billions of dollars needed to care for people with AIDS. If even a fraction of this money being spent to care for people with AIDS was available to spend on a "Manhattan Project", we could find a permanent cure for AIDS, rather than treating the symptoms.

Please pledge your support for a major project to find a cure for AIDS. As you know, over a million Americans have HIV + are certain to develop AIDS in the future,

so over a million lives depend on this action. If we could put the best minds to work on the Manhattan Project during World War II to invent the atomic bomb for mass death + destruction, why can't we put the same effort into a cure for AIDS to save lives?

Sincerely,
Kathy Sabriola, LVN
Licensed Vocational Nurse

McClintock Project

letter

Kathy Labriola
1714 9th Street
Berkeley, Ca 94710

Kristine Gebbie, RN
National AIDS Policy Coordinator
The White House
1600 Pennsylvania Ave NW
Washington D.C. 20500

THE WHITE HOUSE

WASHINGTON

October 13, 1993

Ms. Michelle Reillo, R.N., B.S.N.
Life·Force, Inc.
1006 Morton Street, Suite 100
Baltimore, Maryland 21201

Dear Ms. Reillo:

I want to thank you for calling to share information about hyperbaric oxygen therapy for persons infected with HIV. Dr. Fox has informed me of your concerns regarding this supportive therapy.

I have and will continue to encourage research on supportive therapies as well as those that are curative. I encourage you to work with a medical facility or university in your area to further evaluate and/or support the use of hyperbaric oxygen therapy for persons infected with HIV.

As the AIDS Policy Coordinator, I will advocate public health policy that has a sound scientific basis. You can be assured that I will support the use of therapeutic regimens that have been shown to be safe and effective.

Sincerely,

Kristine Gebbie

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

THE WHITE HOUSE

WASHINGTON

October 13, 1993

Ruth M. Harris, Ph.D., R.N., A.N.P.-C
Principal Investigator
University of Maryland
627 West Lombard Street
Baltimore, Maryland 21201-1545

Dear Dr. Harris:

Thank you for your long and detailed letter of September 22 outlining the great success you have had in your Peer Counseling and Leadership Training Program for African American Women in the Drug Using Community.

Based upon your careful work and documented success over the last three years, I am sure that you have a significant and impressive data pool to justify your implementation of the program at the Baltimore City Detention Center and beyond.

Unfortunately, my role as the President's AIDS Policy Coordinator does not allow me to review or endorse proposals submitted to Federal Departments or Agencies for peer review in advance of grants or other forms of funding.

Your history of successfully helping African American women understand the reduction of harm through empowerment will prove a valuable insight as you seek funding for peer teaching and support for these women. I look forward to the results of the next phase of your program.

Thank you for your continued support of this office and the President's program to stop HIV infection and AIDS.

Sincerely,

Kristine Gebbie

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

October 13, 1993

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Principal Investigator
University of Maryland
627 West Lombard Street
Baltimore, Maryland 21201-1545

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Thank you for your continued support of this office and the President's program to stop HIV infection and AIDS.

Sincerely,

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

Prepared by BMerrill:ONAPC:10/7/93:Ruth.Har
Revised by:KGebbie:10/13/93

THE WHITE HOUSE

WASHINGTON

October 7, 1993

Dr. Ruth M. Harris
University of Maryland
622 West Lombard Street
Baltimore, Maryland 21201-1545

Dear Dr. Harris:

Thank you for your long and detailed letter of September 22nd outlining the great success you have had in your Peer Counseling and Leadership Training Program for African American Women in the Drug Using Community.

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Unfortunately, my role as the President's AIDS Policy Coordinator does not allow me to review, endorse ~~or otherwise influence~~ peer reviews in advance of proposals submitted to Federal agencies for grants or other forms of funding. ~~To do so would be viewed as an attempt to interfere with the rigid protections such governmental funding sources have put in place to guarantee objective peer review.~~ is an essential process

However, I am sure that your history of successfully helping African American women understand the reduction of harm through empowerment will prove a valuable insight as you seek funding for peer teaching and support for these women.

I look forward to the results of the next phase of your program.

Thank you for your continued support of this office and the President's program to stop AIDS.

Sincerely, ~~yours,~~

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

School of Nursing

UNIVERSITY OF MARYLAND
AT BALTIMORE

Ben
draft reply
can endorse single
project

September 22, 1993

Ms. Kristine Gebbie, RN
National AIDS Policy Coordinator
750 17th Street, NW
Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

Congratulations on your appointment as the National AIDS Policy Coordinator, and for your dedication to promote research, treatment and prevention programs to combat AIDS. Having worked for several years with inner city women in Baltimore who are at high-risk for contracting HIV/AIDS, I am fully aware of how important a role research, drug prevention and AIDS education can play in our efforts to reduce HIV/AIDS.

I am writing to request your support for an innovative HIV/AIDS prevention research project (see attached) that I and my colleagues are proposing to submit for funding to the National Institute on Drug Abuse.

With four other University of Maryland School of Nursing researchers, I am currently in the third year of a grant funded by the National Institute on Drug Abuse entitled "Strategies for AIDS Prevention: Peer Counseling and Leadership Training (PCLT) Program for African American Women in the Drug Using Community." This program is specifically aimed at educating African American Women in the drug-using community about AIDS so that they will reduce high risk behaviors, and become peer change agents in their communities. The approach aims at empowerment through instillation of inner control and motivation based on increased self-esteem and self-competency involving self, relationships with others, and involvement in the community. The voluntary participants are in treatment in four Baltimore methadone maintenance programs.

Our study has statistically demonstrated that the graduates of our PCLT Program significantly reduced their high-risk AIDS sexual and drug using behaviors (i.e., condom use and IV drugs), increased their self-esteem and AIDS prevention activities in their community and reduced their use of illicit drugs.

In July of 1993, we implemented our PCLT program in the Baltimore City Detention Center (BCDC). This program was enthusiastically endorsed by Commissioner Flanagan. We modified the program to include women of all races because the drug use problem is not a racial issue as much as a socioeconomic issue in Baltimore.

622 West Lombard Street
Baltimore, Maryland 21201-1545
410 706 8195 TELEPHONE
410 706 0345 FAX

Due to the success of our program in the methadone clinics and the BCDC, we are presently preparing a grant proposal (see attached) to begin a four year implementation of our PCLT program at the BCDC. We are planning on employing women who have graduated from our first PCLT Program in the methadone clinics to co-lead the groups and provide support to the participants during their incarceration and after release from prison, which is perhaps the most difficult time for drug users. Aggressive support is essential to help maintain their motivation to stay off of drugs, and this support can be best done by their peers. Peers teaching peers has proven to be successful in numerous studies.

The peer counselors themselves will benefit enormously. They will be given an important employment opportunity that will lead to a sense of pride in themselves while they are contributing to the well being of those in their community. I am currently working with Ms. Patricia Kane with the Mayor's Office of Employment Development to establish a program utilizing their "Customized Work Experience Program". This program would provide the peer counselors the opportunity for employment while still retaining their health care and child care benefits for a transitional period.

We request a letter of support from you for the project to include in our grant proposal to the National Institute on Drug Abuse. Enclosed is a sample letter. Please make any changes you feel appropriate.

Please address it to:
Ruth M. Harris, Ph.D., R.N.
Associate Professor
University of Maryland School of Nursing
Parsons Hall 620
622 West Lombard Street
Baltimore, Md 21201

I have enclosed additional information about our current project and plan for our BCDC project. If you need any more information, please contact me. Thank you for your support to this project.

Sincerely,

Ruth M. Harris

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

Title: STRATEGIES FOR AIDS PREVENTION: USE OF PEER COUNSELING AND LEADERSHIP TRAINING IN REDUCING HIGH RISK DRUG AND SEXUAL BEHAVIORS IN AFRICAN AMERICAN WOMEN IN THE DRUG USER COMMUNITY

Principal Investigator: Ruth M. Harris, Ph.D., R.N., A.N.P.-C
Co-Investigators: Kathryn H. Kavanagh, Ph.D., R.N.
Doris E. Scott, Ph.D.,R.N.
Susan E. Hetherington, Dr.P.H., C.N.M., C.S.P.
Barker Bausell, Ph.D.

Description of Activity/Progress:

The objective of this 3-year community based, experimentally designed research study is to reduce high risk behaviors that lead to the development of AIDS in African American women. Volunteers are recruited from four methadone maintenance clinics in Baltimore City.

Currently, there are 160 low-income African American women participating in this study with 76 completing the entire protocol. Those that are randomly assigned to the treatment group complete a 16-week Peer Counseling and Leadership Training (PCLT) Program where discussion focuses on (1) control and self-esteem as critical issues in development of efficacious selves, (2) sex and sexuality as related to AIDS, (3) the participants self-reported lifestyles with implications for drug use and sexual behavior, and (4) concerns and questions about AIDS.

The goal of the program is empowerment through instillation of a sense of inner control and motivation based on increased self esteem and self competency involving self, relationships with others, and involvement in the community. During the 16 weeks of continuous training and discussion about HIV/AIDS, the women have demonstrated that they have learned the information and have expressed an increased ability to communicate AIDS prevention strategies to members of their group, their families, and to others in their community.

Data Analysis:

On the pretest, all the participants demonstrated high levels of AIDS Knowledge. This knowledge was correlated significantly with their perception of having the AIDS virus ($r=.49$, $p<.05$). There was, however, little evidence of avoidance of high-risk sexual behaviors. Knowing how AIDS is transmitted does not assure change in behavior. Use of condoms to prevent AIDS is not perceived as a realistic option by these women. However, the women who received the Peer Counseling and Leadership Training Program demonstrated significant changes in their behavior when compared to those women who did not receive the training.

Based upon the four month follow-up of the first 119 women, data analysis indicates significant reduction ($p=.044$) of high risk

sexual behaviors and significant increase (p=.004) in self-esteem in the experimental group as compared to the control group. Also, the treatment group has reported engaging in significantly more AIDS prevention activities (i.e., surrounding condom use and the sharing of needles) within the community itself (p=.002) than the control group. Although not a primary purpose in the program, there has been a greater reduction in illicit drug use in the experimental group as compared to the control group. The treatment group has registered a 19% drop in usage (42.2% to 26.2%) as compared to only a 3.6% change (35.7% to 32.1%) for the control group.

Extensive fieldnotes and personal network data reveal content and process patterns of subjects' specific interpersonal relationships. These manifest strong generalized orientations toward external loci of control and of responsibility, as well as dense and stable personal networks. Emphases on links with significant others (e.g., children of all ages) and positive rather than negative behaviors are more effective motivators than foci on risk-free behaviors (i.e., condoms and no street drugs), drug-free networks, or community level strategies. To maximize the considerable strengths of the women's enduring, dense, and strongly influential interpersonal networks, PCLT Program strategies use a collaborative model to promote empowerment through increasing effectiveness of communication, managed relationships, and responsible parenting, as well as health education.

Publications:

Harris, R. M., Kavanagh, K., Scott, D., & Hetherington, S. (1992) Strategies for AIDS Prevention: Leadership Training and Peer Counseling for High Risk African American Women in the Drug User Community Clinical Nursing Research, 1(1), 9-24.

Kavanagh, K. H., Harris, R. M., Hetherington, S. & Scott, D.E. (1992). Collaboration as a strategy for acquired immunodeficiency syndrome prevention. Archives of Psychiatric Nursing, VI(6), 331-339.

Hetherington, S.E., Harris, R.M., Kavanagh, K.H., & Scott, D.E. (1993). AIDS prevention: Reducing high risk drug & sexual behaviors in childbearing women. International Confederation of Midwives 23rd Triennial Congress, Monograph, Vancouver, British Columbia, May 1993.

PROPOSAL

BALTIMORE CITY DETENTION CENTER

Title: AIDS Prevention and Health Promotion For Women in the Prison Community

Principal Investigator: Ruth M. Harris, Ph.D., R.N.

Co-Investigators: Doris Scott, Ph.D., R.N.
Kathryn H. Kavanagh, Ph.D., R.N.
Susan Hetherington, C.N.M., Dr.P.H.
Barker Bausell, Ph.D.
Karen Allen, Ph.D., R.N.

Overall Objective

The overall objective of this four-year research study is health promotion for women in the prison community through reduction of drug use and high risk behaviors that lead to the development of Acquired Immune Deficiency Syndrome (AIDS). Additionally, the study will focus on prevention of other sexually transmitted diseases, TB and drug use. The study will emphasize empowerment techniques within a framework of peer counseling skills that promote culturally acceptable community interventions. Behavioral change requires motivation, conviction that change will be beneficial, and assurance of reasonable chance of accomplishing change. Women in this study will be guided to explore and incorporate into their lifestyles behavioral alternatives that reduce drug use and risk for spread of AIDS in their communities.

The following **specific aims** are addressed:

1) To **promote changes in behaviors (safer sex practices and drug using behaviors)** that are consistent with an individual's existing beliefs and values as measured by reproductive and drug use behaviors questionnaire.
2) To **provide ongoing professional assistance and support to the women** throughout the project.
3) To **educate participants incarcerated in the Baltimore City Detention Center to be role models, peer counselors, and leaders** in their primary networks of friends and relatives.
4) To **assist women in this study to have a positive impact** on their primary networks by teaching them how to educate their family members, friends and others on AIDS and how to reduce its spread.
5) To **stimulate assumption of catalytic roles by the participants** for the purpose of reducing drug use in their community.
6) To **develop self-esteem in the women through empowerment**
7) To **develop a Board of Advisors** to provide consultation, continuity and support to the project and to maintain contact with existing programs in the community.

The following **hypotheses** will be tested:

1. Women incarcerated in the Baltimore City Detention Center (BCDC) who receive Peer Counseling and Leadership Training (PCLT) will demonstrate reduced high-risk behaviors when released, when compared with released women who do not receive PCLT.
2. Women incarcerated in the BCDC who receive PCLT will demonstrate reduced drug use after release, when compared with released women who do not receive PCLT.
3. Women incarcerated in the BCDC who receive PCLT will demonstrate increased self esteem after release, when compared with released women who do not receive PCLT.
4. After release, women that were incarcerated who receive PCLT will demonstrate active and sustained AIDS and drug prevention activities in the community, that are in excess of those demonstrated by women that were incarcerated and released who do not receive PCLT.

The dependent **variables** in this study are:

1. High risk sexual behavior
2. High risk drug-related behavior
3. Self esteem and subscales
4. AIDS prevention activities in the community
5. Drug prevention activities in the community

The independent variable in this study is:

1. Peer Counseling and Leadership Training (PCLT)

Significance or value of research

It is estimated that it will cost $10.4 billion to treat everyone with HIV in the U.S. in 1994 (Hellinger, 1991). The nation's correctional institutions are the destination for large numbers of people at risk for HIV infection, including intravenous drug users (IVDUs), polydrug users, and prostitutes (Sutton et al., 1988). The nation's inmate population doubled in the last decade from a little more than 500,000 in 1980 to more than a million currently. The mushrooming of drug-related arrests in the 1980's is "probably the largest single factor behind the rise in prison populations" (Mauer, 1991). According to the Centers for Disease Control (CDC), over 80% of IVDUs will find themselves incarcerated at some time. On any day, IVDUs make up as much as 30% of the inmate population in a prison system. **Although women account for only 11% of AIDS cases (as of December, 1992; Centers for Disease Control, 1993), they are the fastest growing population to be affected by HIV disease.** Worldwide, the proportion of women infected with HIV rose dramatically from 25% in 1989 to 40% at the beginning of this year (WHO, 1992). This demonstrates that the greatest risk of HIV infection is to women who are partners of IVDUs or who use drugs themselves. However, research on HIV disease in women has been severely limited.

Incarcerated women have been, and continue to be, a forgotten population (Viadro & Earp, 1991). The female prison population is growing rapidly in part because of the mandatory minimum sentencing for drug offenses both at the state and federal levels, and because of emphases in the nation's "war on drugs" on interdiction and incarceration, rather than on prevention and control (Smith, 1990). For reasons yet to be explained, the **HIV seroprevalence observed in women in correctional care is approximately twice that of men** (Vlahov et al., 1991; Sutton et al., 1992), despite the fact that HIV infection is much more common in men (up to 7 times by some estimates) than among women in the general population.

According to the Federal Bureau of Prisons, about 60% of women in federal custody are serving sentences for drug offenses. Substance abuse and AIDS are inextricably linked; overall, 70 % to 80% of women in prison have alcohol and/or drug dependency problems. Most of them have multiple drug problems, and many are IVDUs. Persons using injection drugs accounted for 28% of all adult and adolescent AIDS cases reported between 1981 and 1992. Under the scheme of mandatory sentencing for drug offenses, the percentage of drug offenders in the federal prison system will rise by 1995 from 47% to 70%.

Impact of Drug Use on HIV/AIDS

According to the National Commission on AIDS, HIV transmission through injecting drug poses a threat of rapid infection among drug users. In addition, non-injecting drug use, especially crack cocaine and alcohol, is significantly correlated with risk behavior for transmission, either from exchange of sex for drugs or impairment of behavior decision making (Centers for Disease Control, 1993). Duesberg (1992) proposes that the use of recreational drugs themselves is a cause of the AIDS epidemic. Whether or not experts agree about what roles drug use plays in the spread of AIDS, addressing drug use behavior is necessary for the prevention of AIDS.

Nemoto, Brown, Foster and Chu (1990) noted in their review of the literature, that most HIV transmission studies among IVDUs were targeted at needle sharing and other drug use related behaviors. Fisher and Fisher (1992) comprehensively and critically reviewed the AIDS risk-reduction literature and concluded that most intervention studies address drug use from the perspective of needle exchange programs. The purpose is to reduce use of contaminated needles and reduce the number of times a person injects.

To have greater impact on HIV transmission high-risk behaviors among injecting drug users, other methods may be needed, such as cessation of risk behavior itself (drug use) (Neaigus et al., 1990). Booth, Watters, & Chitwood (1993) found that "crack smokers", both injecting drug users and non-injecting drug users, exhibited more HIV transmission high-risk behaviors. The "crack smokers" reported: 1) more sex partners with more acts of unprotected sex; 2)more likelihood of exchanging sex for drugs and/or money; and 3) using drugs more often before or during sex. Additionally, they reported that the addition of crack use did not reduce injecting behavior, and may have increased the user's overall risk behavior. For example, there is an association between crack smoking and incidence of sexually transmitted diseases, which increases the crack smoker's risk of contracting HIV/AIDS. The findings from this study demonstrate the need to do more than needle exchange to reduce HIV/AIDS in the drug using community. Frischer et al. (1993) found that drug use treatment engendered safer practices with regard to both sexual activity and drugs.

The focus of AIDS interventions is not drug treatment, however many of the activities of drug treatment focus on disease prevention and health promotion. Included in a comprehensive drug treatment program (Wells & Jackson, 1992) is the provision of information (by educating) and counseling to alter lifestyles for stopping drug use. Healthy People 2000 states that health promotion strategies are those related to individual lifestyles. They are personal choices made in a social context that can have a powerful influence over one's health prospects (US Dept Health and Human Services, 1991). However, few AIDS risk reductions intervention studies emphasis drug use education and counselling for altering lifestyles changes leading to decreased drug use.

Prevention Efforts

HIV risk reduction prevention efforts have been absent in many prisons and jails. Because inmates fear stigmatization or loss of privileges if determined to be HIV positive, many avoid testing and counseling. In this way, opportunities are missed to educate high risk groups concerning the further spread of AIDS, as well as other important preventable diseases.

The IVDUs population is one of the hardest to reach with AIDS educational programs. Additionally, there is evidence that women addicts have adequate AIDS knowledge, and that they are changing their needle sharing activities, but not high-risk sexual behaviors.

In addition to understanding addictive behavior, understanding sexuality and gender role socialization is essential to implementation of effective AIDS prevention program. An understanding of behaviors that spread AIDS and other STDs is essential for design of effective educational programs and intervention strategies.

Women's Health

Whether through mandate or persuasion, the corrections system has a major public health opportunity to influence incarcerated women. Women in prison need intensive education on safer sex and perinatal transmission of HIV. Men need this information too but for women there needs to be an opportunity to discuss gender roles and explore strategies for gaining greater control over sexual decision-making. Female inmates also need to learn about the potential for female-female sexual transmission, especially in those cases where drug using women may already be infected.

The number of health care issues affecting women is far greater than the number encountered by men, and many are linked to GYN and pregnancy. Women appear to have more interest in maintaining their health than men; it does not affect their higher incidence of HIV infection and AIDS. Their index of suspicion regarding HIV seropositivity is often lower, and as a result they may be diagnosed later. As female census in jails and prisons increases, so does the demand for services they require in a male oriented environment.

AIDS Educators

There seems to be some problem in finding credible AIDS educators. Inmates tend to be suspicious of administration and staff. Education efforts that involve outside authorities whom inmates have read or heard about, would feel comfortable with or would not feel pressured by, would be more acceptable to inmates. In our current study, we found this to be true with the women in the methadone clinics. There was no pressure in our groups sessions to reduce their drug use. The focus was specifically on AIDS and issues that would foster empowerment to change their high risk behaviors.

Description of the Research Proposal

This will be an experimentally designed study in which high-risk sexual behavior, and self-esteem of incarcerated women (both

known drug users and non-drug users) will be measured before and after treatment (pretest/posttest). The questionnaires will include: Demographic Questionnaire; Rosenberg's ten-item Guttman scale to measure general social psychological attitudes toward self; Gurin et al.; a research developed Sexual and Drug Behaviors Questionnaire; an Individual and Community HIV/AIDS Activity Checklist; an AIDS Knowledge questionnaire; an Attitudinal Scale and the Marlowe-Crowne Social Desirability questionnaire to measure need for approval of others.

Interested women volunteers from the Baltimore City Detention Center (BCDC) will be asked to participate. It is projected that the study will take from 3 to 4 years and the projected number of participants will be from 200 to 300. They will be randomly assigned to two groups - treatment and control. The treatment group will be trained in peer counseling and leadership skills with the expected outcome that they will change their high-risk sexual behavior that puts them at risk for contracting AIDS, and have an impact on their community, family members and/or friends. The other group will be given the pretests and posttests at the same time as the treatment group, and will continue in their regular schedule at the detention center. The women that will be asked to volunteer will be individuals that will be incarcerated long enough to complete the training program, and agree to follow up sessions after release. They do not have to be HIV positive to be part of this study. The women will be paid $10 for each set of questionnaires they complete. This will include a pretest and a posttest while still in prison, and three follow-up sessions where they will complete the posttests at the University of Maryland at Baltimore.

A training model (see attached) has been developed based on information learned in the two pilot studies and our current NIDA funded study; a peer counseling program (Tindall and Gray 1985); and Pedersen's (1988) training program for development of cross-cultural sensitivity, knowledge, and skills. Components of the training model as adapted to this study's population include: self esteem building, community networking, community outreach and peer counseling, and personal empowerment with the intent of assisting women to personalize their own risk in order to facilitate change.

The groups will be co-lead by one of the co-investigators and a graduate (peer leader) from our current NIDA funded grant entitled "Strategies for AIDS Prevention: Peer Counseling and Leadership Training (PCLT) for High-Risk African-American Women in the Drug User Community." This study is being conducted for African American women in four methadone maintenance clinics in Baltimore City. Approximately 5 to 6 women will be employed to be co-leaders or peer leaders. They will be selected on the basis of their enthusiasm and participation in the program and their stability in the methadone program. The women will be part of the City of Baltimore's Customized Work Experience Program which will allow them to receive payment for their employment while still retaining their welfare benefits (child care and health care) for a transitional period of time.

After the implementation of the PCLT Program in the BCDC, the peer co-leaders (co-leader of PCLT groups) will provide support and

reinforce HIV/AIDS education to the participants in the treatment group during the rest of their incarceration and after release from prison, which is perhaps the most difficult time for drug users. The peer co-leaders, themselves, will meet weekly with the co-investigators to receive encouragement, get help with any problems they are encountering, provide reinforcement for their reduction in high-risk sexual and drug using behaviors, and be provided with the latest AIDS information.

A counseling center will be developed at the University of Maryland School of Nursing to provide space for the peer co-leaders to see the participants of the PCLT program on a weekly basis after their release from the BCDC. The participants will be followed for one year and will be paid for their participation.

Participants will be asked to volunteer by letter from Evelyn Wood, the Director of Special Inmate Projects at the BCDC. All volunteers will give informed consent to participate. No participant's name will be written down or recorded at any time, except on the consent form. A total of 300 volunteers will be solicited to be in the study. A total of 100 to 150 volunteers will be given peer counseling and leadership training (PCLT) by trained leaders. The other 100 to 150 volunteers will be part of the control group. Volunteer participants will be randomly assigned to either the treatment or the control group. The treatment group will be trained in peer counseling and leadership skills with the expected outcomes of: (1) change in high-risk sexual and drug-related behaviors, and (2) positive impact on their communities, family members, and/or friends and associates. This intervention will involve an eight session training program (2 hours a day, for a total of 16 hours). In addition to attending these sessions, they will complete a series of questionnaires during five scheduled interviews. There will be one at the beginning of the research study, one at the end of the training program, and three during follow up sessions, one within a month after release from the Baltimore City Detention Center and one at six months and one a year following release. Both treatment and control will complete all pretest and posttest questionnaires. Members of the control group will be given the pretests and posttests at the same time as the treatment group but will not receive the intervention program. All participants will receive $10 for completion of the pretest and posttest questionnaires while they are still incarcerated. This will be placed in their commissary fund. For each of the follow up sessions, all participants will be offered $25 to complete the questionnaires and $5 for cab fare to the University of Maryland at Baltimore. The treatment group will receive additional monies for their follow up sessions with the peer counselors and co-investigators.

Funding

We currently have a three-year funded grant from the National Institute on Drug Abuse (NIDA) for $650,000 to implement a program to reduce HIV/AIDS high risk behaviors in African American women in the drug using community. We are in our third year of the study and have plans to submit our Baltimore City Detention Center grant proposal in January, 1993 for funding starting July 1, 1994. We have talked with several individuals at the National Institute on Drug Abuse, including Dr. Peter Hartsock, deputy director of clinical medicine. They were quite enthusiastic about the project. They feel that very few researchers are interested in doing research with incarcerated individuals - particularly women inmates, and that this an extremely important area, but neglected area for research on AIDS and drug use. We believe the potential for funding would be high.

Potential Benefits

Certainly a program such as this would bring credit to the administrators and staff of the Baltimore City Detention Center, as well as Baltimore City and the State of Maryland. It would demonstrate a desire to implement an AIDS prevention program that would benefit the women incarcerated in the BCDC. Considering the tremendous risk of HIV/AIDS to this population, a program that would potentially reduce the numbers of HIV/AIDS infected individuals will be a tremendous benefit. The service this study will provide to the Baltimore community will be invaluable.

Additionally, for our current study, we have published two articles and have two more ready to be submitted to journals. The proposed study would result in several articles highlighting the research being done in the Baltimore City Detention Center.

TRAINING PROGRAM

The Peer Counseling and Leadership Training (PCLT) is based on a peer counseling program developed by Tindall and Gray (1985), and theoretical research, training and expertise of the principal investigator and co-investigators. Components of the training model adapted to this study's population include: community networking, community outreach and peer counseling, personalization of risk to facilitate control, and self-esteem building.

The purpose of the 8 session training program is promotion of change of high risk sexual and drug use behaviors of women who are at risk for developing AIDS. PCLT will (1) increase their knowledge of AIDS, its transmission, and risk-reducing practices and (2) promote the use of condoms and, if using IV drugs, stop sharing needles or clean tools appropriately. Additionally, through peer interaction, participants will have a positive impact on family, friends and community members through increased ability to communicate knowledge and attitudes about safer sex and drug practices that reduce AIDS risk. Within the context of culturally appropriate, group-based social process and reference group norms (Fisher, 1982), the training emphasis is on enhancing self esteem and confidence in capabilities as effective community change agents. This, in addition to AIDS education, is reinforced in each training session. With positive feed back during training, leader-trainees will experience rewards for health-promoting alternative behaviors. To enable the women to move from specific knowledge about their abilities and accomplishments to global evaluations of their self worth (Pelham & Swann, 1989), the training program focuses on: (1) convincing persons with negative self views to accept themselves for what they are to increase their self esteem (i.e., to acknowledge what is changeable and what is not e.g., "I can complete my GED; I cannot live my youth over again," "I can stand and dress to appear taller, I cannot actually grow taller", and (2) assist those with predominantly negative self views, recognize strengths and increase feelings of self worth and positive self views to enhance self esteem even more. There is evidence that females generally score lower than men in self efficacy in this society, and demonstrate more learned helplessness (Gecas, 1982). Sexual assertion training (Kelly et al., 1989) focuses on: 1) initiation of discussion about commitment to low risk behavior prior to sexual relations with any potential partner, 2) refusing pressure to engage in high risk behaviors, and 3) declining propositions that might be high risk. Women need a powerful way to communicate and negotiate sexual activity with men, and peer counseling is one way to do this (Fullilove et al, 1990). They also need to believe that they have some choices in life, and they have value and worth despite negative stigmatization of drug use and addiction. According to Nurius (1986), it is important to give individuals a sense of what is possible, "I am..." versus "I could be..." They need to understand the range of alternative perspectives or choices available to them.

To change attitudes requires a model of psychological health and a model of procedures that establishes conditions for change (Johnson & Matross, 1975). Change is brought about by adding

forces for change, reducing forces preventing change and redirecting forces to support change. This involves the ability to understand and effectively manage overt relationships with other people and attitudes of trusting, confidence in one's abilities, purpose and direction in life and an integrated and coherent self identity (Johnson & Matross, 1975). According to Bandura's model (1977a & 1977b), change is fostered by imitation, copying, identification and modelling (observational learning).

Objectives

The objectives of the peer counseling program (Peer Counseling and Leadership Training [PCLT]) are to:

1) Learn from participants their thoughts and ideas as to how they can become effective members of the community, with specific emphasis on reduction of risk for AIDS among members of the community
2) Explore the relationship between HIV/AIDS and drug use.
3) Examine personal social support networks for their, meaning, extent, composition, significance, potential for risk-taking behaviors, and implications for AIDS-related phenomena
4) Promote responsible health improvement and health maintenance practices within a context that is acceptable to the participants
5) Examine gender and sexual relationships within the contexts of urban poverty, drug using culture and African American culture, as they relate to risk for AIDS
6) Promote assertive and responsible sexual behavior
7) Measure levels of AIDS knowledge and associated high risk behaviors
8) Measure impact of the participants on the community.

Each of the eight, two-hour training sessions focuses on a specific area of peer and leadership training in addition to discussion about the transmission of AIDS, which includes behaviors that allow risk for developing AIDS (i.e., failure to use condoms, sharing of needles, and drug use).

9) Provide a safe forum for discussion

Session topics

Session 1 - Introduction to group and objectives, values clarification, establishment of peer orientation of group and of working relationships across ethnic and socioeconomic differences. Go over AIDS questionnaire answer sheet, and begin discussion on HIV/AIDS.

Session 2 - AIDS: transmission, prevention (e.g., condom usage, safer needle use, reduced needle sharing, educating others about safer sex), and discussion of attitudes and biases. Stress that HIV is transmitted through direct, NOT indirect contact with bodily fluids. Exploration of the possibility of HIV entering by crossing intact mucous membranes. Discussion of signs and symptoms of AIDS, opportunistic diseases including TB. Additionally, exploration of ways to promote healthy

behavior in themselves and others.

Session 3 - Exploration of personal social support resources and liabilities. Examination of strengths and weaknesses of networks, and of implications if involved individuals became HIV+ and/or developed AIDS (i.e., who would and could turn to whom for what types of help). Based on information presented and discussed about AIDS, introduce potential strategies for supporting those with HIV or AIDS, and for preventing further transmission.

Session 4 - Discussion of AIDS regarding sex and sexuality to increase knowledge about reproductive anatomy and physiology, and contraceptive methods with particular emphasis on condom use (symbols of love and caring, not destruct and disrespect) in prevention of AIDS and other sexually transmitted diseases. Demonstration of condom use. Exploration of each type of oral sex separately, and why anal sex is a high risk. Discussion of knowledge, attitudes, and behaviors related to contraceptive methods. Explore how babies are infected with HIV, and the father's role.

Session 5 - Discussion of empowerment as associated with male/female roles, communication, conflict, and power and control in relationships. Emphasis is on interrelationships among self esteem, empowerment, and reducing risk for AIDS.

Session 6 - Expression of aspects of male/female conflict and communication through role plays of AIDS-related scenarios. Discussion of women's dependence on men and alternative sources of self-esteem and social status.

Session 7 - Cooperative playwriting activities to reinforce AIDS-related knowledge, intervention strategies, and personal capabilities. Development of plays to be presented in following session.

Session 8 - Presentation of plays and termination of group. Discussion of development of future programs from perspectives of participants.

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THE WHITE HOUSE

WASHINGTON

October 13, 1993

The Honorable Héctor Luis Acevedo
City Hall
San Juan, Puerto Rico 00901

Dear Mayor Acevedo:

Thank you for taking the time to meet with Dr. Lawrence and me while you were visiting Washington last month. I apologize for having to step out of our meeting. However, your views and suggestions have been relayed to me by Dr. Lawrence.

I appreciate your kind offers of assistance. Addressing Hispanic populations in a meaningful manner is of great concern and will occupy a central place as my staff works on plans and initiatives. Having concerned officials, such as yourself, available to call on for help is essential for the progress of my work.

I am pleased that the first year of the Puerto Rico-New York "Air Bridge" project has been funded by the Health Resources and Services Administration. It is a model for cooperation between cities. I will be following the project with great interest. Both youself and Mayor Dinkins are to be applauded for your innovation.

Once again, many thanks for taking time out of your busy schedule to visit with me.

Sincerely,

Kristine Gebbie

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

cc: Mr. Ortiz-Daliot

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Sincerely,

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

cc: Mr. Ortiz-Daliot

Prepared by:ALawrence:ONAPC:10/09/93

The Jefferson®
GROUP

September 22, 1993

Ms. Kristine M. Gebbie
Coordinator
Office of National AIDS Policy
Executive Office of the President
The White House
Washington, DC 20500

Dear Ms. Gebbie:

As agreed, we hereby confirm Mayor Héctor Luis Acevedo's invitation as Chair of the AIDS Task Force of the U.S. Conference of Mayors (USCM), to attend the Task Force meeting in January 27th, 1994, during the USCM Annual Winter Meeting.

Ms. Enid Morales, of my office, will call your assistant Regina to follow up on this matter with specific time and place, but we would appreciate if you can reserve this date for the meeting.

The Mayor was very pleased to meet you and make your acquaintance as well as Dr. Arthur J. Lawrence, with whom he had a very interesting exchange.

In the near future, we will send you a copy of the Ruben Blades videotape used in the AIDS awareness campaign in San Juan. We also want to take this opportunity to reteirate the Mayor's interest in assisting your office with the development of any visual material for a culturally sensitive campaign for Hispanic communities in the U.S., as well as in Puerto Rico. Also, the Mayor wanted me to convey to you his availability to assist you in seeking Congressional action through either legislation or appropriations, to increase the emphasis on prevention and education, the primary tools in the fight against AIDS.

Thanking you for your attention to these matters, I remain,

Cordially,

José A. Ortiz Daliot

JAOD/edm
cc: Dr. Arthur J. Lawrence, Ph.D.

The Jefferson Group, Inc. The Colorado Building
1341 G Street, N.W., Suite 1100, Washington, D.C. 20005 (202) 638-3535 Fax (202) 638-3536

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GROUP

SEP 27 1993

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JAT (Return — Calendar)

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Cordially,

CITY HALL

00901

José A. Ortiz Daliot

JAOD/edm
cc: Dr. Arthur J. Lawrence, Ph.D.

The Jefferson Group, Inc. The Colorado Building
1341 G Street, N.W., Suite 1100, Washington, D.C. 20005 (202) 638-3535 Fax (202) 638-3536

HÉCTOR LUIS ACEVEDO

Mayor of San Juan, Puerto Rico

Héctor Luis Acevedo was elected Mayor of San Juan, Puerto Rico in 1988. Mayor Acevedo graduated from the University of Puerto Rico School of Law in 1972, and has participated in the Education Program for Lawyers offered by Harvard Law School.

Mayor Acevedo has served in a number of posts in his public service career. He began in 1969, as a professor at the University of Puerto Rico, and has also been a professor at the Inter-American University and the Catholic University of Puerto Rico. In 1973, he was appointed Legal Advisor to the Washington Office for Puerto Rico. From 1973 to 1975, he served as Assistant to the Secretary of Justice. In 1975, he accepted an appointment as Assistant to the Governor. From 1976 to 1984, he served as a Commissioner on the Puerto Rico Electoral Commission. From 1985 to 1988, he served as Secretary of State of Puerto Rico.

Mayor Acevedo was elected President of the Inter-American Foundation of Cities in September, 1990, during the organization's meeting held in Buenos Aires, Argentina. Mayor Acevedo is also President of the Pan-American AIDS Foundation and Chair of the AIDS Task Force of the U.S. Conference of Mayors.

Mayor Acevedo is a Major in the United States Army Reserve.

BRIEFING MATERIAL

9/17/93

Time: 8:30 - 9:00

With: Hector Louis Acevedo
Mayor of San Juan, Puerto Rico.

Art —
draft follow up
letter
please

· DRAFT INSIDE

out PYL

THE CITY OF NEW YORK OFFICE OF THE MAYOR DAVID N. DINKINS

TEL.: (212) 788-2958 571-93

For Immediate Release:
Wednesday, October 6, 1993

MAYOR DINKINS AND SAN JUAN MAYOR ACEVEDO ANNOUNCE PUERTO RICO-NEW YORK CITY "AIR BRIDGE" TO ASSIST HIV/AIDS PATIENTS

Mayor David N. Dinkins and San Juan Mayor Hector Luis Acevedo today announced that $590,000 of City, state and federal funds have been secured to fund the first year of the Puerto Rico-New York City "Air Bridge" to provide care and services for patients with AIDS or who are HIV ill and travel between New York City and the cities of San Juan and Ponce, Puerto Rico.

The "Air Bridge" is one of several programs established in May of 1992 under the Sister City agreement between the City of San Juan and the City of New York. The project is also part of the Mayor's program, "Creating a Healthy New York: A Plan to Promote the Health of All New Yorkers."

Under the "Air Bridge" program, 200 clients will be able to receive treatment and counseling in New York at the William F. Ryan Community Health Center and the Hispanic AIDS Forum, and in Puerto Rico by the San Juan AIDS Institute.

The program will be funded by a $200,000 Federal grant from the United States Department of Health and Human Services, $300,000 from the New York City Department of Health, and $90,000 from the New York State Department of Health's AIDS Institute.

Mayor Dinkins said, "While we continue to respond

(more)

aggressively to the impact of AIDS in New York City, we also recognize the linkage between the epidemic here and the epidemic in Puerto Rico. Puerto Rico has the third highest rate of AIDS cases in the United States, after Washington, D.C. and New York State. AIDS has become the leading cause of death of individuals between 20 and 32 years of age in Puerto Rico. Here in New York City, AIDS is the leading cause of death among Latinos between the ages of 25 and 44.

"As a natural outgrowth of the bonds among the nearly one million Puerto Ricans here and their families in the island, an extensive migration of HIV positive individuals developed -- and so did the idea for the "Air Bridge."

"With the funding now in place, we will move immediately to begin this critical effort to provide quality, integrated care for the HIV-positive individuals who travel between New York and Puerto Rico."

Mayor Acevedo said, "This is a historic step in the fight against AIDS. Due to the easiness of air transportation and social mobility, the expansion of this epidemic represents our times. Our response to the AIDS epidemic reflects our humanity. It is indeed a historic achievement in our crusade against this fatal disease."

The Office of the Regional Administrator of the United States Public Health Service estimates that more than 500 AIDS/HIV infected individuals travel from Puerto Rico to New York

City to seek medical treatment and that many who are in the advanced stages of the disease return to their families in Puerto Rico.

The Puerto Rico-New York City "Air Bridge" program has been designed to reduce the number of AIDS/HIV patients who are forced to use emergency rooms in either Puerto Rico or New York City where doctors have no access to their medical records. Under the program, a case manager will be assigned at the location where the patient is living. In addition, healthcare professionals will be able to transmit medical records and other information regarding medication, stage of illness, other medical history, reason for travel, addresses and contact names by a specialized scrambled computer system to assure the patient's confidentiality.

The "Air Bridge" program, which will be in full operation after a development period of six month, also will focus on AIDS/HIV patients with TB or hemophilia to assure that they receive ongoing treatment and appropriate care. The program also will extend services to obtain Medicaid, food stamps and public assistance to eligible patients.

# # #

am/10-6-93

Puerto Rico.

Today I am pleased to announce the we have secured $590,000 from federal, state and City funds to serve some 200 clients under the Puerto Rico-New York "Air Bridge" network.

Our distinguished Senator Daniel P. Moynihan has informed us that we will receive $200,000 in Federal funding from the United States Department of Health and Human Services, in addition to the $90,000 we will receive from the New York State Department of Health's AIDS institute, and $300,000 my HIV Health and Human Services Planning Council of New York has committed from our Department of Health budget.

While we continue to respond aggressively to the impact of AIDS in New York City, we also recognize the linkage between the epidemic here and the epidemic in Puerto Rico. Puerto Rico has the third highest rate of AIDS cases in the United States, after Washington, D.C. and New York State. AIDS has become the leading cause of death of individuals between 20 and 32 years of age in Puerto Rico. Here in New York City, AIDS is the leading cause of death among Latinos between the ages of 25 and 44.

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With the funding now in place, we will move immediately to begin this critical effort to provide quality, integrated care

for the HIV-positive individuals who travel between New York and Puerto Rico.

During its first year, the project will serve 200 clients who will be linked to a medical care provider and a social services provider in the William F. Ryan Community Health Center and the Hispanic AIDS Forum in New York City, and by the San Juan AIDS Institute in Puerto Rico. These individuals will have access to primary care, clinical trails, and drug treatment programs, and will receive assistance to access Medicaid and other benefits as needed.

Mayor Acevedo and I share a deep concern and commitment to the individuals afflicted by this disease. As Chairman of the U.S. Conference of Mayor's sub-committee on AIDS, Mayor Acevedo has provided national leadership to the fight against AIDS. As the Mayor of a city hard hit by the HIV/AIDS epidemic, Mayor Acevedo knows first-hand the impact of AIDS on individuals and families.

# # #

am/10-06-93

THE WHITE HOUSE

WASHINGTON

October 14, 1993

Mr. Alex MacDonald
55 Mason Street, No. 607
San Francisco, California 94102

Dear Mr. McDonald:

On August 31, Congresswoman Nancy Pelosi, forwarded to me your letter of August 19 to her, which enclosed a copy of another letter you sent to me on the same date. Your letter is frank and to the point. Let me respond in a similar manner.

Health care reform is going to happen in America. It will, with some adjustment, give care to PWAs where care has been lacking. The President is paying particular attention to the reform package as the final adjustments are made to the proposal. He believes it is essential that the support and care of HIV infected individuals be continued as we implement health security for all. I believe that you too support a health care reform program that will guarantee health care to every American, including those who are HIV positive and which cannot be taken away despite a loss of health, of employment, or of funding sources.

The government is attempting to move toward a simplified, universal reporting system under the plan that will codify health status. It is possible that the plan will require the kinds of data collection that many will find suspiciously "big-brother" in nature. That is the nature of government.

The design of the program and of the reporting requirements are subject to the input of countless individuals, groups, and communities. What do you propose HIV sensitive people do to assure that: a) they get the same basic coverage as other Americans; and, b) that they do not suffer new or old forms of discrimination?

This question is not easily answered. Will all Americans except HIV positive people subscribe to the program, but HIV positive people will ghettoize themselves into some kind of category outside the Government's protection? I doubt seriously that you would wish that kind of "special solution."

Rather, can systems be put in place that "self-contain," that is that compartmentalize information of a sensitive nature within the proposed health care plan and do not allow easy access to those who do not have a "need to know" status of the health program consumer? I believe that they can. But designing them will not be easy. Many of us are struggling with the outlines of such a system.

While the plan must be reviewed to assure that it is not abused, I do not believe that the plan should give rise to a system which will violate the confidentiality of HIV positive persons; therefore, I disagree with your appraisal that I have a sanguine attitude towards the maintenance of records of People with AIDS (PWAs); I believe I have a practical and beneficial one.

Your suggestions are solicited and will be examined along with the many others who have given this question their serious attention. Please forward them to my office. I will see that they do not go unnoticed.

Thank you for supporting the President's program to stop HIV infection and AIDS.

Sincerely,

Kristine Gebbie

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

THE WHITE HOUSE

WASHINGTON

October 14, 1993

Mr. Alex MacDonald
55 Mason Street, No. 607
San Francisco, California 94102

Dear Mr. McDonald:

On August 31, Congresswoman Nancy Pelosi, forwarded to me your letter of August 19 and a copy of the letter you sent to me. Your letter is frank and to the point. Let me respond in a similar manner.

Health care reform is going to happen in America. It will, with some adjustment, give care to PWAs where care has been lacking. The President is paying particular attention to the reform package as the final adjustments are made to the proposal. He believes it is essential that the support and care of HIV infected individuals be continued as we implement health security for all. I believe that you too support a health care reform program that will guarantee health care to every American, including those who are HIV positive and which cannot be taken away despite a loss of health, of employment, or of funding sources.

The government is attempting to move toward a simplified, universal reporting system under the plan that will codify health status. It is possible that the plan will require the kinds of data collection that many will find suspiciously "big-brother" in nature. That is the nature of government.

The design of the program and of the reporting requirements are subject to the input of countless individuals, groups, and communities. What do you propose HIV sensitive people do to assure that: a) they get the same basic coverage as other Americans; and, b) that they do not suffer new or old forms of discrimination?

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

This question is not easily answered. Will all Americans except HIV positive people subscribe to the program, but HIV positive people will ghettoize themselves into some kind of category outside the Government's protection? I doubt seriously that you would wish that kind of "special solution."

Rather, can systems be put in place that "self-contain," that is that compartmentalize information of a sensitive nature within the proposed health care plan and do not allow easy access to those who do not have a "need to know" status of the health program consumer? I believe that they can. But designing them will not be easy. Many of us are struggling with the outlines of such a system.

While the plan must be reviewed to assure that it is not abused, I do not believe that the plan should give rise to a system which will violate the confidentiality of HIV positive persons; therefore, I disagree with your appraisal that I have a sanguine attitude towards the maintenance of records of People with AIDS (PWAs); I believe I have a practical and beneficial one.

Your suggestions are solicited and will be examined along with the many others who have given this question their serious attention. Please forward them to my office. I will see that they do not go unnoticed.

Thank you for supporting the President's program to stop HIV infection and AIDS.

Sincerely,

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

Prepared by:BMerrill:ONAPC:10/7/93

NANCY PELOSI
8TH DISTRICT, CALIFORNIA

240 CANNON BUILDING
WASHINGTON, DC 20515-0508
(202) 225-4965

DISTRICT OFFICE
FEDERAL BUILDING
450 GOLDEN GATE AVENUE
SAN FRANCISCO, CA 94102-3460
(415) 556-4862

Congress of the United States
House of Representatives
Washington, DC 20515-0508

COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEES:
LABOR-HEALTH AND
HUMAN SERVICES-EDUCATION
FOREIGN OPERATIONS, EXPORT FINANCING
AND RELATED PROGRAMS
DISTRICT OF COLUMBIA

COMMITTEE ON STANDARDS OF
OFFICIAL CONDUCT

CONGRESSIONAL WORKING GROUP
ON CHINA, CHAIR

September 11, 1993

Bev - how's your time? Do you want to take a crack at a draft reply?

Alex McDonald
55 Mason Street, #607
San Francisco, California 94102

Dear Alex:

At your request, I have forwarded your letter to Kristine Gebbie to her at the White House.

For your information the address is as follows:

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

(202) 632-1090

If I can be of further assistance, please let me know.

Sincerely,

Nancy

NANCY PELOSI
Member of Congress

NP:sm

Alex MacDonald, #607
55 Mason Street
San Francisco
California
94102

August 31, 1993

Congresswoman Nancy Pelosi
240 Canon Building
Washington, D. C., 20515

Dear Congresswoman Pelosi,

I wrote the enclosed letter to Christine Gebby during the first week of July. Because I cannot find an address for her, it has been cocooning, with only slight up-dates, inside my computer ever since.

I thought of calling the White House, but, luckily, before wasting any money on the call, I read a newspaper story to the effect that another caller had to call an Undersecretary in Health and Human Services in order get the same information. The story unfortunately did not carry her address.

As I don't personally know any Undersecretaries to whom I might appeal, it occurred to me that your office might be willing to forward the letter for me.

Thanks.

Sincerely yours,

Alex MacDonald

Alex MacDonald, #607
55 Mason Street
San Francisco
California
94102

August 19, 1993

Dear Coordinator Gebbie,

A recent news story quotes you as asking that we that we give you a chance. That sounds to us like bureaucratic soft-soap. The President has given you the only chance you're going to get. It's up to you to hold him to his word. It's possible that circumstances will permit us to help you in that regard.

You ask that we share with you our expectations, concerns, and suspicions. Your sanguine attitude towards the maintenance of records of People with Aids concerns me.

You say that lists of PWA's can be kept confidential. If you were gay, and of a certain age, you would know that medical confidentiality is a sham. Violations, though easy to recognize, are hard to prove. Violators are even more difficult to identify. Prosecution and conviction are rarely possible. Penalties, whatever the rules and the laws say, virtually never happen. Further, trust would in fact extend from the care givers to their support workers and from these to the systems and institutions in which they work. Promises of confidentiality therefore amount to little more

appeals for trust in those who have already shown, by promising what they know they cannot deliver, that they are undeserving of precisely the trust they demand.

We have every reason to fear that lists would be misused and fall into the hands of groups willing and even eager to misuse them. We remain the only minority in American society whose very right to life can be explicitly and publicly challenged from the pulpit. Collectively, and in spite of the record of the public health establishment in defending the civil rights of gay men and of people with AIDS, the medical professions, like all others, reflect the prevailing prejudices and bigotry of society as a whole. Worse, eminent physicians have been among our most brutal oppressors, and not so long ago. For us, anonymity is still the only reliable guarantee of medical confidentiality.

In one of the most disturbing remarks attributed to you, you suggest that local option might be an appropriate way of deciding about whether to keep lists of PWAs and people who are HIV positive. The suggestion made me think of Ryan White and of the Florida family whose home was firebombed when the town learned that the children had AIDS. Do you really intend to give a local option

to those localities?

In the same statement, you betrayed your expectations with regard to the prospects for finding a cure for AIDS. You suggest that it may take as long as fifteen years before AIDS becomes a reportable condition in some communities. Do you really wonder why you begin your new job without the confidence of the community you have been appointed to serve?

Other issues concern us, too, such as money for research. No amount of bureaucratic efficiency will substitute for the hard science that will find a cure for AIDS. The costs of research are as great in hard times as in good. Invocations of budgetary constraints to excuse inadequate funding for research can be heard only as appeals that we die out of sight, out of mind, and offstage.

But more about that later: It's a subject that will not go away.

Sincerely yours,

Ken MacDonald

THE WHITE HOUSE

WASHINGTON

October 14, 1993

Mr. William W. Waybourn
Executive Director
The Victory Fund
1012 14th Street, NW, 7th Floor
Washington, D.C. 20005

Dear Mr. ~~Waybourn~~ William:

Thank you for your kind invitation to participate in the Victory Fund's breakfast on November 2. As an openly gay man, I am aware of the great work that the Gay and Lesbian Victory Fund does on behalf of the gay and lesbian community. Unfortunately, I will be attending the National Skills Building Conference the week of November 2, and will not be back in Washington until November 8.

I hope to be able to meet with you in the near future to discuss ways in which we can collaborate on other activities. I also wanted to express my gratitude to you and the Victory Fund for your support in the past. I am looking forward to working with organizations such as yours in the development of policies that will serve those at risk for HIV infection. If you have any questions, or would like to set up a time to meet, please feel free to contact me at (202) 690-5560.

Sincerely,

Carlos Vélez, JD
Director, HIV/AIDS Prevention

THE WHITE HOUSE

WASHINGTON

October 14, 1993

Mr. William W. Waybourn
Executive Director
The Victory Fund
1012 14th Street, NW, 7th Floor
Washington, D.C. 20005

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Sincerely,

Carlos Velez, JD
Director, HIV/AIDS Prevention

Prepared by: APO: CVelez: 202-690-5560: 10/14/93: b:\velez.lts\wayburn

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

GAY AND LESBIAN VICTORY FUND

1012 14th Street, NW
7th Floor
Washington, DC 20005
202.842.8679 (Voice)
202.289.3863 (Fax)

The Hon. Carlos Velez
Director of the AIDS Prevention Cluster
White House Office of AIDS Policy
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

The official title of my position is:

Director of ~~the~~ HIV/AIDS Prevention ~~Cluster~~

Office of National AIDS Policy

____ I plan to attend the November 2, National Press Club Breakfast.

X I will not attend the November 2, National Press Club Breakfast, but please include my name in the ad.

The best mailing address and telephone numbers for me are:

Address: 750 17th STREET, NW #1060
Washington, DC 20503
20503

Home Phone: (202) 544-5830

Office Phone: (202) 690-5560

VICTORY FUND
1012 14th Street, NW, 7th Floor
Washington, DC 20005

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The White House
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Washington, DC 20500

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GAY AND LESBIAN VICTORY FUND

William Waybourn
Executive Director

1012 14th Street, NW
7th Floor
Washington, DC 20005
202.842.8679 (Voice)
202.289.3863 (Fax)

October 8, 1993

The Hon. Carlos Velez
Director of the AIDS Prevention Cluster
White House Office of AIDS Policy
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Carlos,

The Gay and Lesbian Victory Fund is hosting a breakfast reception at the National Press Club on Tuesday, November 2, 1993 at 8:00 AM to honor you and the other openly gay and lesbian appointees of the Clinton Administration. This breakfast will also be an opportunity for the press to meet all of you and learn of your positive impact on the administration.

Prior to the breakfast we will acknowledge your appointment in a format similar to the enclosed ad which appeared in our newsletter, *Victory*. In order to assure that we have all of the correct information on file, please complete the enclosed form and return it to us in the envelope provided by Monday, October 18th. If you have any questions please feel free to contact Charles Cox at 202-842-8679.

Again, congratulations from all of us.

Sincerely,

William W. Waybourn
Executive Director

P.S. We also plan to honor Andrew Barrer for his work as a volunteer and project director of Coalition '93.

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VICTORY
The Newsletter of the Gay and Lesbian Victory Fund

VICTORY FUND SUPPORTS RECORD NUMBER OF CANDIDATES

"You gotta play to win" is as apt a truism for politics as it is for any other competitive forum. And thanks in large part to the expanding impact of the Victory Fund political network, openly gay candidates are competing for and winning elective office in unprecedented numbers.


Derek Belt

The Victory Fund has recommended 16 candidates to our donor network in 1993 — compared to 12 in the 1992 election cycle, and 2 in 1991, when the Victory Fund made its debut.

The steady increase is proof that the Victory Fund is succeeding at both of its bottom-line goals: maximizing the number of openly-gay and lesbian officials who hold elective office, and maximizing the number who seek it.


Michael Nelson

"We can't accomplish the first goal without accomplishing the second," said William Waybourn, Victory Fund executive director. "The commitment of our members to gay and lesbian political empowerment is helping to encourage more and more of our community to consider running."

On Tuesday, November 2nd, six recommended candidates will be on the ballot across the country. They are:


Christine Kehoe

Derek Belt for Attleboro (MA) City Council; **Christine Kehoe** for San Diego City Council; **Michael Nelson** for Carrboro (NC) City Council; **Tom Roberts** for Santa Barbara City Council; **Marilyn Shafer** for Manhattan (NY) Civil Court Judge; and **Wallace Swan** for Minneapolis Board of Estimate and Taxation.


Marilyn Shafer

Three other recommended candidates are on the ballot in 1994, **Larry Bagneris** for New Orleans City Council, **Ken Wolf** for Fort Lauderdale City Commissioner, and **Victoria Sigler** for Dade County (FL) Court Judge.

The Victory Fund has helped elect three new openly gay and lesbian office-holders this year, including **Jackie Goldberg** to the Los Angeles City Council; **Craig McDaniel** to the Dallas City Council; and **Shelley Gaylord** to the Wisconsin


Tom Roberts

(continued on Page 2)

VICTORY
The newsletter of the
Gay and Lesbian Victory Fund
1012 14th Street, Suite 707
Washington, D.C. 20005
Volume 3, Fall 1993

THE WHITE HOUSE

WASHINGTON

October 15, 1993

Mr. Russ Brady
1407 S Street, N.W.
Washington, DC 20009

Dear Mr. Brady:

The Office of the National AIDS Policy Coordinator is holding meetings to determine the chief concerns of PWA and CBO organizations regarding the proposed health care reform (HCR) package.

The first focus group was held in Washington D.C. on October 5. Enclosed for your use are: (a) a list of attendees at the first meeting; (b) a summary document highlighting the areas of concern of the group; and, (c) a back-up detailed document of the questions raised. Please take some time and review the documents. If you have new suggestions and comments, please fax them to me at (202) 690-6584 as soon as possible. The plan is undergoing revisions daily. We will be meeting regularly with the HCR Task Force and wish to protect the communities' interests in the plan.

The group has suggested a strategy group to be formed and housed somewhere such as the AIDS Action Council or National Minority AIDS Council. We have also committed to obtaining the next draft of the proposal and distributing it so that we can comment on changes.

Our next meeting will be October 20, 21, or 22. As soon as we have a consensus on that date, we will let you know. If you have any questions, please give me a call at (202) 690-6248.

Sincerely yours,

Ben Merrill, J.D.
Special Assistant
Office of the National AIDS
Policy Coordinator

Enclosures

THE WHITE HOUSE

WASHINGTON

NATIONAL AIDS POLICY COORDINATORS OFFICE

Focus Group
HIV/AIDS AND HEALTH CARE REFORM
CONCERNS OF THE COMMUNITIES

Attendance
October 5, 1993

Name	Office	Address	Telephone/Fax	Modem
Ben Merrill	ONAPC	750 17th ST, NW DC 20503	(202)690-6248 FAX 690-6584	y
Vesta Jones	ONAPC	750 th ST, NW DC 20503	202-690-6248 FAX 690-6854	y
Alice Litwinowicz	ONAPC	750 17th ST, NW DC 20503	202-690-5560 FAX 690-7560	y
Bob Moran	ONAPC	750 17th ST, NW DC 20503	202-690-5560 FAX 690-7560	y
Carlos Velez	ONAPC	750 17th ST, NW DC 20503	202-690-5560 FAX 690-7560	y
George Walter	ONAPC	750 17th ST, NW 20503	202-690-6248 FAX 690-6584	
Carlos Vega	COSSMHO	1501 16th ST, NW 20036	(202)387-5000 FAX 797-4353	y
Helen Fox	NMAC	300 I ST, NE Suite 400 20002	544-1076 FAX 544-0378	y
Jack Jackson,jr		300 I ST, NE Suite 400 20002	544-1076 FAX 544-0378	y

NAME	OFFICE	ADDRESS	TELEPHONE/FAX	MODEM
Pat Hawkins	Whitman Walker	1407 S ST, NW DC 20009	(202)797-3500 FAX 797-3504	
Hank Carde	PWA	732 11th ST, SE 20003	(202)547-7971 voice/fax/modem	y
Bill Bailey	AMY Assn.	750 1st St, NE 20002	(202)336-6066 FAX 336-6063	y
Scott Sanders	AMFAR	1828 L ST, NW Suite 802 DC, 20036	(202)331-8600 FAX 331-8606	y
Jane Silver	AMFAR	1828 L ST, NW #802 DC 20036	(202)331-8600 FAX 331-8606	y
Ruth Finklestein	GMHC	129 W. 20th ST, New York, NY 10011	(212)337-1230 FAX 777-8130	y
Christine Lubinski	AIDS Action Council	1875 Connecticut Ave NW Suite 700 DC, 20009	(202)986-1300 X46	
Joan McCarley Terrific Inc. "Grandma's House"		1222 T ST, NW DC, 20009	(202)462-8526 FAX 234-2705	n
Cornelius Baker	NAPWA	800 E. Capital ST, Apt. 3 20003	(202)898-0414 FAX 898-0435	
Christina Lewis	NAPWA	1413 K ST, NW 8th fl DC, 20005	(202)898-0914 FAX 898-0435	bbs
Toni Young	NWAP	P.O. Box 53141 Washington, DC 20009	(301)587-0504	n

Name	Office	Address	Phone/FAX	Modem
Mike Isbell Lambda Legal Defense Fund		666 Broadway New york, NY 10012	(212)995-8585 FAX 995-2306	y
Irma Maldonado National Hispanic Education & Communications Projects (HDI Projects)		1000 16th ST, NW Suite 401 20036	(202)452-8750 FAX 452-0086	n
Valerie Sines		2114 So. Kenmore ST, Arlington, VA 22204	(703)892-8762	
Elena Alvarado National Hispanic Educations & Communications Projects (HDI Projects)		1000 16th ST,NW Suite 401 20036	(202)452-8750 FAX 452-0086	n
Regina Aragon SF AIDS Foundation		1170 Market ST 5th Floor SF CA 94102	415-864-5855 X3099	n
Martin Hiraga NGLTF		1734 14th st NW DC 20009	202-332-6483 FAX 332-0207	y
Rocco Claps	Dem Natl, Committee	430 South Capital 20003	202-863-8056 FAX 863-8140	
Margaret Fine		4617 Schenley RD. APT. 2F Baltimore, MD. 21210	410-235-4296	n

To: Ben Merrill, JD
Special Assistant to the Coordinator

From: Carlos Velez, JD
Director, HIV/AIDS Prevention

Date: October 5, 1993

Re: Issue Summary

The following are the five most critical issues on the Health Care Reform Initiative discussed at this morning's meeting:

1. Access

Participants indicated that the plan is not clear on the mechanics of how to join alliances, how the alliances would determine what benefits to offer, how much premiums would be and how much would be paid in out-of-pocket expenses. Individuals with very limited income will need special attention, especially those who may need the same range of services that they can obtain under the current system at little-or-no cost. The participants were concerned also about geographic (territories) and non-financial (discrimination) limitations imposed by the plan, and wanted to know what controls would be placed on the states to ensure equal access.

2. Benefits

Questions were raised on the range of services which will be available. Many are not covered by the plan or are limited. Critical among these: medications and treatments (especially off-label use); psychosocial support, substance abuse and mental health services for persons living with HIV; ob/gyn; and, non-primary care services (e.g., transportation, food banks,etc.). The participants suggested that many of these services, which are currently being provided by community based organizations (CBOs), may be provided by them under the new plan, and the plan must allow for reimbursement for services even when the providers are not certified.

3. Confidentiality

The plan will provide for integration of medical information. The participants wanted to stress that confidentiality should be paramount, even where there is intent to aggregate information for surveillance and epidemiological purposes.

4. Transition

The participants communicated their desire for an extensive transition plan that would allow for current categorical programs to continue to serve the needs of individuals and communities. Participants also indicated that many of these categorical

programs may need to continue after HCR is instituted, but that the plan will have to coordinate current categorical programs with the services being provided by the alliances.

5. Non-financial Barriers

Participants indicated that HCR addresses the financial barriers to care, but that the plan makes no specific provision to eliminate discrimination based on race, ethnic background, sexual orientation, age or gender. The plan must allow for service providers to learn about cultural competency and for individuals to learn how to access the system better. The system must also indicate what redress individuals will have in situations where they do not obtain the necessary services.

To: Ben Merrill, JD
Special Assistant to the Coordinator

From: Carlos Velez, JD
Director of HIV/AIDS Prevention

Date: October 5, 1993

Re: Health Care Reform Summary of issues discussed with HIV/AIDS Community Representatives

The following is the summary of issues from the meeting held this morning:

1. Access

The plan is not clear on the mechanics of how to join alliances, how the alliances would determine what benefits to offer, how much premiums would be and how much would be paid in out-of-pocket expenses. Individuals with very limited income will need special attention, especially those who may need the same range of services that they can obtain under the current system at little-or-no cost. The participants were concerned also about geographic (territories) and non-financial (discrimination) limitations imposed by the plan, and wanted to know what controls would be placed on the states to ensure equal access.

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To: Ben Merrill, JD
Special Assistant to the Coordinator

From: Carlos Vélez, JD
Director, HIV/AIDS Prevention

Date: October 6, 1993

Re: Health Care Reform and HIV Issues Meeting

ACCESS

1. "Managed care" as currently defined raises questions as to available legal recourse if benefits not provided. There must also be a way of stopping the states from opting out of delivering certain types of services to specific communities.

2. There is needed guidance on the definition of "disability" for coverage and subsidies. Definition must be expanded to include classes not currently covered.

3. Steps must be taken to eliminate discrimination as a barrier to care, especially for gays/lesbians and minorities. The plan must also provide for cultural competency training for service providers. How will the plan ensure that service providers are actually providing the necessary services.

4. Examine the ability to pay thresholds, as they may exclude people from coverage based on their inability to make out-of-pocket payments.

5. Although plan provides for limits on out-of-pocket expenses, this may affect people that enter alliances that do not provide the necessary services. They may have to resort to seeking other types of coverage outside their alliance.

6. What will be the structure for the delivery of services in the territories?

7. How will individuals access "second choice" alliances or plans if their first choice is full?

8. How will members of non-traditional families be able to access healthcare?

9. The plan must provide training on how to use increased access, especially for populations that have traditionally used emergency care. Persons must not be pigeonholed into specific alliances.

10. Will individuals be able to retain their benefits even when

they are capable of working again?

11. Current projections estimate a cap on funding for Medicaid, while the service delivery population will continue to increase. Cap must be examined.

12. Limits on benefits persons with need for intensive care will eliminate services for children born with HIV who may later recover. Limitations must be flexible.

13. Small business concerns about payment also applies to community-based organizations providing services to people living with HIV. May be burdensome.

14. How will the plan affect undocumented individuals that may need care and not be covered? Migrants face increased access issues due to their mobility.

15. Alliances will have to access the most expensive options in order to provide the necessary services. As with the current system, service delivery issues are geared towards the ability to pay the highest premium. Some alliances will not seek to provide a full range of services.

16. Full plan evaluation will be the means of determining whether the plan actually provides services.

PRESCRIPTION DRUGS

1. The language is silent on "non-label use" of certain prescription drugs (i.e., drugs may be prescribed for opportunistic infections that are not their intended use, or in the case of AIDS drugs, away from the FDA approved limited use). Will these drugs be covered?

2. Some current insurance plans exclude newly-approved drugs. Will new drugs be automatically covered?

3. The plan needs to be more explicit on co-payments for prescription drugs.

CONFIDENTIALITY

1. In high incidence states, confidentiality for PWAs is currently well ensured. Will new confidentiality guidelines reduce the current protections?

2. Medical information is intended to be tied to PHS surveillance? Can this be done through two separate systems to keep confidential information out of PHS?

SERVICES

1. Plan allows for skilled nursing care, but must also allow

for "buddies" type care and other services provided for individuals without license or certification. As this is more cost effective, the plans must look for ways of reimbursing for these.

2. Substance abuse and mental health benefits are totally inadequate. Should be expanded to support the long term psychosocial needs of HIV+ individuals to improve on their own access to services. The 30 visits in 60 days limit is not sufficient for most people with substance abuse issues.

3. Substance abuse and mental health is currently provided by community-based organizations (mental health centers). These services should not be cut to provide limited services through the plan. In some communities, these are a cornerstone of the health care system.

4. Current service delivery models provide more services than what is being contemplated. Will there be a fall back position on additional services (e.g., transportation, referrals, food banks)?

5. Need clarification on services specific for women. Although mention is made of ob/gyn, more is needed on pap smears, etc.

COORDINATION WITH OTHER PROGRAMS

1. What will happen to programs currently funded to provide services (e.g. Ryan White, HOPWA)? Will there be a mechanism for coordinating these?

2. Will categorical funding for substance abuse services be eliminated to pay for HCR?

3. The plan must provide for transition. Current programs at the community level must be preserved.

4. There needs to be more clarity on the meaning of behavioral research and explanations on medical research.

5. The Indian Health Service is the primary health care provider for the Native American/Alaska Native population. Will steps be taken to improve services through IHS.

PREVENTION

1. Counseling and testing must be included in prevention. There is also need to provide outreach to hard to reach populations.

To: Ben Merrill
Special Assistant to the Coordinator

From: Carlos Vélez, JD
Director, HIV/AIDS Prevention

Date: October 7, 1993

Re: Issue Summary - Health Care Reform Meeting with Persons living with HIV/AIDS

Participants at the meeting indicated that they had not received sufficient information to make an informed decision on whether they supported the proposed plan. The attendess stressed the need to disseminate information on the mechanics of the plan to persons living with HIV/AIDS.

1. Access

The participants expressed concern about the need to formulate a system that would provide the wide range of quality services and care that persons living with HIV/AIDS require. In particular, concern was raised on the ability to retain current primary care practitioners that have been serving their needs. For women, the issue also includes obtaining services of practitioners that understand their particular needs. The participants also communicated their eagerness to contribute to pay for the cost of their services, so long as it would not endanger the range of benefits that they could receive. Similarly, the stress on paperwork reduction was very appealing.

2. Benefits

The participants questioned the availability of various services, and in particular requested clarity on who would make the decisions on what services would be covered by the individual alliances and plans. The participants also expressed concern about the plan requiring copayments that have not been defined. Issues related to experimental medications were paramount, with clarification being provided that the plan would allow for the use of medication in approved trials. Concerns were also raised on the inadequacy of the proposal to limit mental health services to 60 days per year.

3. Confidentiality

The participants wanted clarity on the use of the health insurance card, especially on what information it would contain and how confidentiality would be ensured.

4. Transition

The participants wanted to reiterate that they are concerned that they should not lose the benefits they currently have available,

especially those provided under the Ryan White CARE Act.

5. Non-financial barriers

Concerns were raised about the need to avoid discrimination under the new plan. Provisions should be made to provide compassionate care for persons living with HIV and single persons with no care givers.

To: Ben Merrill, JD
Special Assistant to the Coordinator

From: Alice Litwinowicz
Planning and Information Group

Date: October 7, 1993

Re: HCR Issues Meeting - Issues Presented by persons living with HIV/AIDS

The following are the issues raised at this morning's meeting:

PROCESS ISSUE

The participants expressed an overall concern that there has not been enough information provided on the plan to make informed decisions or even articulate questions about the plan for persons with HIV/AIDS. More detailed information on "how the plan" works needs to be communicated.

The President needs to say more about how AIDS will be covered under the plan. In his message to the nation, he said mentioned AIDS only once. It is very important that he speak out on AIDS.

ACCESS

1. Will you be able to work, while receiving disability payments, on the plan? If you cannot work, disability payments are too low to live on. Want assurances that chronically ill persons will not be penalized for working and trying to pay back the system.

2. What if the doctors currently providing treatment are not in the plan? Medical specialty care is needed for the complex problems of PWAs.

3. "One-stop-shopping" would be great; however, it is unlikely that all of the specialists needed will be in one plan, how will referral work?

4. Women with HIV are very concerned that physicians with knowledge of the special medical problems of women and HIV/AIDS are even more scarce and will not be available through the plan.

5. Will the government choose the doctor one uses in the plan?

6. Does the cutback in paperwork mentioned in the plan also cut through the paperwork required to qualify for disability and other benefits. Also, if one moves will the same services be available without a lot of paperwork and forms.

7. What happens with disability waiting periods and coverage

under the plan?

BENEFITS

1. Persons on disabilty need financial assitance for the purchase of food. Food stamps do not adequately cover the high cost of nutritious food that PWAs need.

2. Is there language in the plan that specifically addresses life-threatening illness?

3. Are alternative therapy, homeopathy and acupuncture services covered under the plan?

4. Burial assistance - PWAs do not want to burden others with worry over burial and many choose cremation because of concerns about cost. How will the plan address this issue?

5. A limit of 60 days per year for mental health services under the plan is unrealistic for the severe depression and related problems PWAs experience. Need mental health support to cope with the "roller coaster" of problems when first diagnosed, dealing with loss of job, income and trying to pay for prescription drugs. This can lead to related substance abuse problems. Alternatively, if substance abuse was already a problem 60 days does not provide adequate time for treatment.

6. Non-approved drugs and drug importation policy addressed under the plan?

7. Who will determine what care is covered under the plan - what is justified and what isn't? Who establishes the standard of care?

8. How will copayments work under the plan for prescription drugs.

9. If a person is diagnosed with dementia or Alzheimer's disease will the 60 day mental health limit apply?

10. Transportation and other support services are critical to women with HIV and all single persons with no caregivers. Services need to be provided with compassion.

CONFIDENTIALITY

1. How will the insurance card work under the plan? Will there be a unique identifier and how will records be maintained.

TRANSITION

1. An overall concern, is that PWAs, especially long term survivors, do not lose the services that they are currently

receiving. How is transition going to work and what assurances that current coverage/services will not be lost during the transition.

2. How will the services provided under the plan affect the Ryan White CARE Act services currently provided? What will happen to the community-based organizations under the plan?

NON-FINANCIAL BARRIERS

1. Support services are critical to persons living with HIV and single persons with no caregivers. Services need to be provided with compassion.

2. Assurances are needed that the alliances are familiar with HIV and not "hostile" to persons with HIV.

THE WHITE HOUSE

WASHINGTON

October 15, 1993

Mr. William D. Barcheck
6917 Spur Road
Springfield, Virginia 22153

Dear Mr. Barcheck:

Thank you for taking time to share your views. Clearly you and I see the stamp differently.

This new AIDS Awareness stamp is designed not to honor any individual, but to stimulate all Americans to become fully informed about HIV and AIDS. I am taking this opportunity to ask the National AIDS Information Clearinghouse to send you some current materials.

I hope they will be informative.

Sincerely,

Kristine Gebbie

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

cc: National AIDS Information Clearinghouse

6917 Spur Road
Springfield, Va. 22153

September 2, 1993

Kristine Gebbie

Subject: AIDS Stamp Honoring Fags and Drug Addicts

I don't really believe this country needs a stamp to honor drug addicts and homosexuals. Those who use the human body's blood lines to inject drugs and HIV as well as those who use their penis to inject HIV into someone's anus as well as those who use the body's sewer as a plaything should not be honored but rather be condemned for their perverted actions.

The tremendous social, financial, and health burden placed on society by the actions of these perverts must not be treated as a responsibility of all but let the blame be placed on those who caused and continue to perpetuate this plague, regardless of what Liz and the Hollywood crowd believe. Tell your friends Bill and Hillary that the majority of the people do not agree with issuing this homosexual honoring stamp.

William D. Barcheck

THE WHITE HOUSE

WASHINGTON

October 15, 1993

Ms. M. Cristina López
Assistant Vice President for
Institutional Affairs
National Council of La Raza
810 First Street, NE, #300
Washington, D.C. 20002

Dear Ms. López: Cristina

I would like to thank you for kind invitation to attend "Herencia y Orgullo," the NCLR gala for Hispanic/Latino appointees of the Clinton Administration. I was honored to be among so many individuals who share the same concern and passion for our communities. I am fully aware of the wonderful work that NCLR does on behalf on the Hispanic/Latino community, and am proud to have been invited.

As Director of HIV/AIDS Prevention at the Office of National AIDS Policy, I also know of the work you do in the fight against HIV/AIDS. I hope to be able to meet with you in the near future to discuss ways in which we can collaborate to stop the spread of HIV/AIDS.

I am looking forward to working with organizations such as yours in the development of policies that will serve those at risk for HIV infection. I have enclosed the information on the meetings we have held on Health Care Reform. The next meeting will be held on the week of October 18th. I will be in touch with you, in order to ensure that we have obtained your feedback on all of these issues. If you have any questions, or would like to set up a time to meet, please feel free to contact me at (202) 690-5560.

Sincerely,

Carlos Vélez, JD
Director, HIV/AIDS Prevention

cc: Mr. Raúl Yzaguirre
President
National Council of La Raza

THE WHITE HOUSE

WASHINGTON

October 15, 1993

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Assistant Vice President for
Institutional Affairs
National Council of La Raza
810 First Street, NE, #300
Washington, D.C. 20002

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Sincerely,

Carlos Vélez, JD
Director, HIV/AIDS Prevention

cc: Mr. Raúl Yzaguirre
President
National Council of La Raza

FILE COPY

Prepared by: Carlos Vélez 202 690-5560. 10/15/93: b:\velez.its\lopez

SURNAME	DATE	SURNAME	DATE	SURNAME	DATE	SURNAME	DATE

Office of the National AIDS Policy Coordinator

Executive Office of the President
750 17th Street, N.W. Suite 1060
Washington, D.C. 20500

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

Deliver To: Carlos Velez

Sent From:

___ Kristine Gebbie, RN, MN, National AIDS Policy Coordinator
_X_ for Sandy Bart
___
___

Number of Pages: 5 + Cover Fax Number:_____ Date:_____

Message:

Attached came in for you at the Humphrey Bldg.

NCLR
NATIONAL COUNCIL OF LA RAZA

Raúl Yzaguirre, President

National Office
810 First Street, N.E., Suite 300
Washington, DC 20002-4205
Phone: (202) 289-1380
Fax: (202) 289-8173

FAX COVER MEMO

DATE: 10/8/93

TIME: 5:10 p.m

COST CENTER #: CCH

TO: NAME Carlos Velez

COMPANY

CITY FAX # (202) 690-7560

FROM: NAME Cristina Lopez

FAX # (202) 289-8173

PHONE # (202) 289-1380

OF PAGES IN TRANSMISSION, INCLUDING COVER 5 pages

MESSAGE:

October 12, 1993

The Secretary of the Smithsonian Institution
The Director of the National Air and Space Museum
and the
President of the
National Council of La Raza

cordially invite you to

Herencia y Orgullo:
A Salute to Hispanic Appointees

Honoring

Hispanic Appointees in the Clinton Administration

Tuesday, October 12, 1993
7:30 pm - 10:30 pm
National Air and Space Museum
Independence Avenue at Sixth Street, Southwest
Washington, D.C.

Reception 7:30 pm

Program 8:30 pm

Black Tie
RSVP with the enclosed card
or call Dina Flores
(202) 289-1380 by October 5

Invitation admits two
Non-transferable
Present at Fourth Street
garage for parking

Herencia y Orgullo:
A Salute to Hispanic Appointees

Hosted by

PepsiCo, Inc.
United Parcel Service
US West

Contributors

J.C. Penney Company, Inc.

Herencia y Orgullo: A Salute to Hispanic Appointees

R.S.V.P.

Name/Title _____

Organization _____

Address _____

City/State/Zip _____

Telephone _____

____ Please reserve one ticket

____ Please reserve another ticket for my guest:

_____

Guest's Name

Please respond by Tuesday, October 5, 1993

!R!SPSZ 6; STM 0; SBM 0; SLM 0; SRM 0; EXIT;

COPY FOR YOUR INFORMATION

October 15, 1993

MEMORANDUM FOR KRISTINE GEBBIE

FROM JOHN PAUL GURROLA
OFFICE OF THE NATIONAL AIDS POLICY COORDINATOR

SUBJECT AIDS' 101 LETTER

We received a letter from Robert D. Cole the producer of AIDS' 101, a weekly broadcast tv program. I followed up the letter with a phone call and spoke with Mr. Cole to inquire what he wanted of us.

Mr. Cole said he just wanted to inform us of his program, since it is the only of its kind and also wanted to solicit funding. He said he did not have time to wait for a grant and wondered if we had any funds available.

Can you suggest any re-course for him fund wise?

His number is (407) 439-8077.

I have attached a copy of his letter for your review.

Buck — reply & refer him to Funders?

Handled by phone 10/28/93 [illegible]

File (c correspondence?)

Producer
Robert D. Cole

Associate Producer
Donna Robinson

Robert D. Cole
12375 Bimini Avenue
Palm Beach Gardens, FL 33410

October 4, 1993

Ms. Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street, NW/Room 1060
Washington, DC 20503

Dear Ms. Gebbie:

I am writing to you about the only weekly, broadcast television program devoted strictly to AIDS education and awareness -- ***AIDS 101***.

Did you know that ***AIDS 101*** is the only program of its kind in America? And that it is produced in **Florida**?

Did you know that a **Floridian** is the creator and producer of ***AIDS 101***?

Did you know how hard hit **Florida** is by HIV and AIDS -- with over 31,000 reported cases?

AIDS 101 is the first weekly, comprehensive 30-minute broadcast television program devoted strictly to fighting the AIDS pandemic. It is a disease that is expected to infect between 30 and 40 million people worldwide by the year 2000 -- and a disease that has already killed over 200,000 Americans.

AIDS 101 premiered on WXEL TV 42 (Palm Beach County's Public Broadcasting System affiliate) in May of this year. Unfortunately, the much needed financial support has not been forthcoming, and now ***AIDS 101*** will be forced off the air at the end of this month. Presently, ***AIDS 101*** needs $23,000 to stay on the air through May of 1994.

None of the producers of ***AIDS 101***, myself included, draw any salaries whatsoever for their work on the program, and neither do the host, makeup, hair or wardrobe people. Aside from the studio crew and the cost of production, ***AIDS 101*** is strictly a volunteer effort. Considering that the only line of defense we have against AIDS is education and awareness, it will be a tragedy to lose a resource that is helping educate South Florida in a humanistic fashion about HIV and AIDS.

AIDS is not about risk groups...it is about risk behaviors. And ***AIDS 101*** has been successful in presenting the realities of HIV and AIDS...one being that ignorance kills.

It is my hope that you can help find funding sources for ***AIDS 101***. We have explored the possibilities of grants, but the time frames involved will see ***AIDS 101*** off the air long before any grant funds could be realized.

If $23,000 is the only thing standing between the ground-breaking efforts of a group of people dedicated to stopping the spread of AIDS, I hope as a concerned citizen and political leader you will be able to help save ***AIDS 101***.

If anyone wishes to contribute to ***AIDS 101,*** they may make their checks payable to **AIDS 101/WXEL TV 42** and mail to Robert Cole, P.O. Box 33124, Palm Beach Gardens, Florida 33420-3124.

Should you have any questions, I may be reached directly at (407) 439-8077.

Sincerely,

Robert D. Cole

Robert D. Cole

enclosures

The Palm Beach Post

SATURDAY, MAY 29, 1993

WXEL produces AIDS TV series

■ **WXEL series premiere: AIDS 101:** 6-6:30 p.m., Sunday, WXEL-Channel 42.

By MICHAEL LASALANDRA
Palm Beach Post Staff Writer

A first-in-the-nation weekly series on AIDS is being launched Sunday by WXEL-Channel 42, the public television station serving Palm Beach County and the Treasure Coast.

AIDS 101 will air Sundays from 6-6:30 p.m. and will be repeated the following Saturday at 2:30 p.m.; 52 shows are planned.

Produced locally, the show will tackle a different AIDS-related subject each week, interviewing experts and others, primarily in Palm Beach County, who have been touched by the AIDS epidemic.

Sunday's episode will feature interviews with parents who have lost children to AIDS. Upcoming programs will focus on West Palm Beach Mayor Nancy Graham's crusade to clean up prostitution, interviews with people with AIDS and HIV, AIDS education in the schools, and whether the blood supply is safe.

Producer Robert Cole said the program is educational in nature and aimed at raising awareness. "It is needed and necessary," he said. "A lot of people still have their heads in the sand."

Cole, director of college relations and marketing at Palm Beach Community College, said the documentary series is being produced on a "shoestring" budget of just $26,000 per year. The show is underwritten by private donors, including the Palm Beach Blood Bank and the Red Cross. All participants volunteered their

Please see 'AIDS 101'/4D

Weekly AIDS show a first in nation

'AIDS 101'
From 1D

time, Cole said.

Shelley Vana, a Palm Beach County high school teacher and a WXEL on-air volunteer, will host the shows. On some, she will stay in the studio and interview guests or host panel discussions. On others, she will go to places such as Connor's Nursery, a home for babies with AIDS.

Cole said he hopes the show can be distributed nationally to other public television stations and is trying to get some nationally known figures to appear, including Liz Taylor and Magic Johnson. Dr. Mervyn Silverman, president of the American Foundation for AIDS Research, has already accepted an invitation.

Coming up with something new each week for 52 weeks may be something of a stretch, since not much has changed in the epidemic's 12-year history. There still are primarily just two ways to get AIDS. There is still no cure. And there is still no vaccine.

But Cole said he isn't necessarily concerned with doing anything new. "We don't have to say anything new," he said. "We just have to say it over and over again."

To his credit, however, Cole said the series will not shy away from controversy. "We are not going to sugarcoat anything," he said.

The fourth episode, on AIDS education, comes down hard on the Palm Beach County School Board for failing to approve an AIDS-education curriculum, for example.

And Cole vowed the show will not simply serve as a mouthpiece for the government and medical establishment's official position on AIDS, but will examine cutting edge issues, such as the effectiveness of accepted AIDS treatments and whether HIV in fact even causes AIDS.

"We're going to give voice to everything," he said. "And people can draw their own conclusions."

If so, *AIDS 101* could become a required course.

PEOPLE TO WATCH

Robert Cole

Directly to the point and without embarrassment questions and answers about HIV and AIDS are being talked about on TV. *AIDS 101* is a 30-minute talk show that airs twice a week on WXEL-Channel 42.

Produced by Robert Cole, the show's creator and AIDS awareness advocate, *AIDS 101* looks at the problem through the eyes of people who live it.

From mothers who have lost sons or daughters to AIDS to FDA regulations on medication to adolescents with AIDS and safe sex being taught in schools.

"People don't want to admit that AIDS can happen to anybody," said Cole, 33, a publicist and adjunct professor at Palm Beach Community College. "I don't know how many more people need to die before people realize how widespread the disease is becoming," he said.

Personal: Divorced.

Birthplace: West Palm Beach, Fla.

Car: 1988 Camaro.

The best thing about Palm Beach Gardens The beautiful beaches.

The worst thing about Palm Beach Gardens The traffic.

My greatest asset: My compassion.

My biggest weakness: Not being able to say no.

My biggest accomplishment: Getting *AIDS 101* on the air.

My personal hero: Joe Montana. He's cool.

The best part about being the producer of *AIDS 101*: We're able to reach so many people and educate them about AIDS.

The worst part about being the producer of *AIDS 101*: Not enough people are listening.

Favorite midnight snack: Anything chocolate.

Last good book I read: *Gone With the Wind.*

Last good movie I saw: *What's Love Got To Do With It.*

My most embarrassing moment: I asked an old friend I hadn't seen in a while about an old girlfriend in front of his fiance, but I didn't realize that the old girlfriend was out of the picture three years ago.

Robert Cole is the creator and producer of *AIDS 101*, a 30-minute talk show on WXEL-Channel 42. "I don't know how many more people need to die before people realize how widespread the disease is becoming," he said.

If I couldn't be the producer of *AIDS 101*, I'd: Keep volunteering for the cause of AIDS.

My personal philosophy: Don't sit around waiting for someone else to do it, do it yourself.

Any other words of wisdom: People need to realize that aids can infect anyone. Protect yourself and protect the people you love. Don't turn your back on anyone living with HIV or AIDS.

SABRINA A. CARTER

THE WHITE HOUSE

WASHINGTON

October 18, 1993

Mr. Richard H. Roffman
Attorney and Counselor-at-Law
697 West End Avenue
New York, New York 10025

Dear Mr. Roffman:

Thank you for writing. I would be interested in more complete information on the AIDS health project being developed by Miss Carol Lynn, the Matchmaker. I am unable to comment on it at all from the material you sent. Please direct the information to Carlos Velez, J.D., of my staff. He can also be reached at (202) 690-5560.

Thank you for your interest.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

October 18, 1993

Ms. Ellen Toplin
President
Toplin & Associates, Inc.
715 Twining Road, Suite 216
Dresher, Pennsylvania 19025

Dear Ms. Toplin:

This is a belated thank you for sharing "How Many?" with me. As National AIDS Policy Coordinator I am devoted to the development and implementation of policies that will stop the spread of HIV and provide care for those already infected. I am also devoted to finding a cure for AIDS as soon as possible. As you may know, the Office of National AIDS Policy was created out of the President's commitment to take some positive steps to end the HIV/AIDS epidemic.

It is through the encouragement and input from individuals like Ms. Margie Adam and yourself that we will be able to fight to end this epidemic. In our labor, we need the inspiration of those who can communicate the feelings that come with the great loss we all incur when one more person is lost to AIDS. I applaud Ms. Adam's efforts to communicate such a powerful message.

Sincerely,

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

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Sincerely,

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

Prepared by: APO: CVelez: 202-690-5560: 10/18/93: b:\velez.lts\toplin

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

TOPLIN
& ASSOCIATES INC.

July 9, 1993

Kristine Gebbie
National AIDS Policy Coordinator
Room 738 G HHH Building
200 Independence Ave., SW
Washington, DC 20201

Dear Ms. Gebbie:

Enclosed is a newly released recording, on which singer/songwriter Margie Adam, one of the stars of the women's music movement recorded a song about AIDS. When Adam performed *How Many?*, the fourth cut on the tape (it is already wound to this point), during her recent spring tour, the audience response was consistently a "resounding" silence. The song is that moving, that evocative.

In light of your new appointment, I thought you might appreciate hearing the song.

Just to let you know some more about Margie, she is well-known to gay, lesbian, feminist and progressive communities, nationwide. Acclaimed for her work since the mid-seventies, and credited as one of the three pioneers in the women's music movement, Adam's recording "We Shall Go Forth," performed with 10,000 women at a national women's conference, was placed in the archives of the Political History Division of the Smithsonian. Many of her songs have also been recorded by others, including "Best Friend (The Unicorn Song)," recorded by Peter, Paul & Mary.

I hope you take a moment to listen to *How Many?* and find it to be as moving as others have.

Sincerely yours,

Ellen Toplin
President

enc.
cc: Margie Adam

Marketing • Public Relations • Advertising

715 Twining Road Suite 216 Dresher, PA 19025 215-886-4644 FAX 215-886-4648

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. letter	From: Kristine Gebbie; re: Thanks for Writing (1 page)	10/18/1993	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 3767

FOLDER TITLE:
October Chron Files 1993 [4]

2018-0756-F
jp4794

RESTRICTION CODES

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

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

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

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

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

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. letter	To: Kristine Gebbie; re: Desperate Mother (4 pages)	10/18/1993	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 3767

FOLDER TITLE:
October Chron Files 1993 [4]

2018-0756-F
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THE WHITE HOUSE

WASHINGTON

October 18, 1993

Mr. Hezekiah Nickelson
2450 North 16th Street
Philadelphia, Pennsylvania 19132

Dear Mr. Nickelson:

Thank you for sharing your thoughts on HIV/AIDS Prevention and homosexuality with me. As National AIDS Policy Coordinator, I am devoted to the development and implementation of policies that will stop the spread of HIV. I am encouraged by the interest of individuals on the complex issues of HIV/AIDS prevention.

Your comments address the need to contain the spread of the virus. You indicated, however, that this should be done by isolating persons living with HIV. HIV/AIDS is not like other diseases for which quarantine and isolation have been the traditional methods of containment. HIV is transmitted by very specific behaviors, not by casual contact.

Effective education campaigns have proven effective in changing those behaviors in persons that have participated in programs in all parts of this country. Under those circumstances, it would be more advisable to improve the nature of the prevention messages that we are delivering to populations at risk rather than trying to limit the civil liberties of those infected.

I have been entrusted by the President with the task of protecting the lives of <u>all</u> Americans, regardles of race, creed, gender, age or sexual orientation. Our Constitution grants the right to life to all those fortunate enough to be born under our flag. In order to safeguard their safety, it is imperative that we do not confuse the message and that we understand that we are all equal under the American flag and are entitled to its protection.

I would like to thank you again for your input.

Sincerely,

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

OCT 25 1993

CDN REGION II

CLINICAL • DIRECTORS • NETWORK

October 18, 1993

Michael Swiller, BA, MS, DC
Chiropractic Physician
120 Whitney Street
Hartford, CT 06105

Dear Dr. Swiller:

Thank you for your letter dated September 20, 1993 and for sharing your article entitled "AIDS Treatment: 1) After Exposure but Before Seroconversion; 2)In the HIV-1 Patient without AIDS; 3) In the HIV-1 patient with AIDS: A Role for Nutritional Therapy" with me.

As mentioned in our recent telephone conversation, I will try to identify an epidemiologic consultant either at the University of Connecticut or at Yale who may be interested in working with you on your project.

Also, I want to take this opportunity to invite you to consider enrolling in the CDN course entitled "Epidemiology, Biostatistics and Clinical Informatics for Clinical Leaders" for next year. We currently have an acupuncturist, a homeopath and an osteopaths but no chiropractor. If you wish, we can add your name to our waiting list for next year's course. Enclosed is a description of the program and its fees.

We will keep in touch. Once again, thank you for your interest in CDN and in our research projects.

Very truly yours,

Jonathan N. Tobin, PhD
Executive Director

JNT:jp
enc.
cc: K. M. Gebbie, RN, MN, National AIDS Policy Coordinator, The White House
J. Jermano, Special Asst., Medical Branch, NIH
M.I. Johnson, PhD, NIH
(JNT:jp/Corresp. Disk/letters.jnt/letters.new/10.18.93)

8 West 19th Street • 8th Floor • New York, New York 10011 • Tel: (212) 255-3841 • Fax: (212) 255-5227

OCT 25 1993

DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service

Memorandum

Date OCT 18 1993

From Director, Division of Data Policy, OHPE
and Reports Clearance Officer, PHS

Subject Executive Order 12862 (Setting Customer Service Standards) and OMB Memorandum M-93-14 (Facilitating Customer Surveys)

To Agency Reports Clearance Officers
OASH Office Directors

Executive Order 12862 (Attachment A) directs all executive departments and agencies that provide significant services directly to the public to identify their customers, to survey customers to determine the kind and quality of services they want and their level of satisfaction with existing services, and to take appropriate steps to establish and meet customer service standards. A report on customer surveys is due to the President by March 8, 1994.

In support of this effort, the Office of Management and Budget (OMB) has issued a memorandum (Attachment B) that describes its initiatives to facilitate the development, review and operation of customer surveys. You will note that a resource manual is to be released this month by OMB. There is also a commitment for two-week review of specific customer survey clearance requests and a discussion of the use of generic clearances.

We are forwarding these documents to you so that you will be aware of them, and we are attempting to obtain more information about this initiative from OMB. We will keep you informed.

Please feel free to call Nancy Pearce of this office on (202) 690-7100 if you have any questions.

James Scanlon

2 Attachments

Attachment A

Presidential Documents

Executive Order 12862 of September 11, 1993

Setting Customer Service Standards

Putting people first means ensuring that the Federal Government provides the highest quality service possible to the American people. Public officials must embark upon a revolution within the Federal Government to change the way it does business. This will require continual reform of the executive branch's management practices and operations to provide service to the public that matches or exceeds the best service available in the private sector.

NOW, THEREFORE, to establish and implement customer service standards to guide the operations of the executive branch, and by the authority vested in me as President by the Constitution and the laws of the United States, it is hereby ordered:

Section 1. *Customer Service Standards.* In order to carry out the principles of the National Performance Review, the Federal Government must be customer-driven. The standard of quality for services provided to the public shall be: Customer service equal to the best in business. For the purposes of this order, "customer" shall mean an individual or entity who is directly served by a department or agency. "Best in business" shall mean the highest quality of service delivered to customers by private organizations providing a comparable or analogous service.

All executive departments and agencies (hereinafter referred to collectively as "agency" or "agencies") that provide significant services directly to the public shall provide those services in a manner that seeks to meet the customer service standard established herein and shall take the following actions:

(a) identify the customers who are, or should be, served by the agency;

(b) survey customers to determine the kind and quality of services they want and their level of satisfaction with existing services;

(c) post service standards and measure results against them;

(d) benchmark customer service performance against the best in business;

(e) survey front-line employees on barriers to, and ideas for, matching the best in business;

(f) provide customers with choices in both the sources of service and the means of delivery;

(g) make information, services, and complaint systems easily accessible; and

(h) provide means to address customer complaints.

Sec. 2. *Report on Customer Service Surveys.* By March 8, 1994, each agency subject to this order shall report on its customer surveys to the President. As information about customer satisfaction becomes available, each agency shall use that information in judging the performance of agency management and in making resource allocations.

Sec. 3. *Customer Service Plans.* By September 8, 1994, each agency subject to this order shall publish a customer service plan that can be readily understood by its customers. The plan shall include customer service standards and describe future plans for customer surveys. It also shall identify the private and public sector standards that the agency used to benchmark its performance against the best in business. In connection with the plan, each agency is encouraged to provide training resources for programs needed by employees who directly serve customers and by managers making use of customer survey information to promote the principles and objectives contained herein.

Sec. 4. *Independent Agencies.* Independent agencies are requested to adhere to this order.

Sec. 5. *Judicial Review.* This order is for the internal management of the executive branch and does not create any right or benefit, substantive or procedural, enforceable by a party against the United States, its agencies or instrumentalities, its officers or employees, or any other person.

William J. Clinton

THE WHITE HOUSE,
September 11, 1993.

[FR Doc. 93-22648
Filed 9-13-93; 11:39 am]
Billing code 3195-01-P

Editorial note: For the President's remarks on signing this Executive order, see issue no. 37 of the *Weekly Compilation of Presidential Documents.*

Attachment B

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

THE DIRECTOR

September 29, 1993

M-93-14

MEMORANDUM FOR HEADS OF DEPARTMENTS AND AGENCIES

FROM: LEON E. PANETTA
DIRECTOR

SUBJECT: Facilitating Customer Surveys

In recent years there has been increasing interest in management strategies that incorporate accurate measurement of "client satisfaction." This Administration is committed to making the management of Federal programs responsive to the needs of the public. Pursuant to Executive Order No. 12862, "Setting Customer Service Standards" (September 11, 1993), customer surveys will become an important tool for meeting this goal.

In order to make customer surveys more responsive tools for agency management, the Office of Management and Budget (OMB), which has authority under the Paperwork Reduction Act to approve such surveys, is undertaking three initiatives to facilitate their development, review, and operation. These include:

1) preparing and disseminating a resource manual to advance sound professional practice in the design and execution of customer surveys and to promote further development of agency capabilities;

2) employing "generic" clearances to expedite approval of certain voluntary customer surveys; and

3) soliciting the assistance of the recently established Joint Program in Survey Methodology to design mechanisms that will foster improved Federal capabilities for opinion research with a particular focus on sound, efficient methods for customer surveys.

Resource Manual: Recommended Practices and Technical Guidance

OMB plans to publish a resource manual that will include recommended practices drawn from the best methods and procedures observed in the private sector and in Federal statistical agencies. This manual is being developed by the Statistical Policy Office of OMB with the assistance of the principal Federal statistical agencies, and will include a directory of statistical design, development, and research services available from those agencies. The manual is intended to promote efficient planning and to permit more experienced agencies to develop their own review capabilities. The manual also will enable agencies to identify areas where training of on-board personnel is needed to improve the quality of in-house statistical work, to properly develop and oversee contracts for acquiring high-quality statistical services, or to develop capabilities for technical review.

The basic manual will be released in October 1993. It will be supplemented from time to time to reflect current experience and new resources. These supplements will include information on new training and research resources as well as brief case studies summarizing the methods used in successful programs to measure client satisfaction.

Generic Clearances

OMB will expand its use of generic clearances, which involve advance approval of a well-defined class of low-burden data collections that are documented at the time they are actually used. First, OMB plans to review and approve generic clearances that permit agencies to expand their capabilities for routine qualitative research tasks (e.g., focus groups to explore the validity of proposed survey methodologies) and to make efficient use of existing agency experience in developing and using such methods. Such generic clearances have in the past included an agreed-upon limitation on methods and usage, a burden cap, a periodic reporting requirement to update the OMB Docket, and a commitment by OMB to review any specific application within two weeks.

Second, on occasion OMB has approved generic clearances for certain classes of quantitative surveys. One such clearance included a catalog of tested and pre-approved questions from which individual surveys could be quickly assembled in "kit" form. Since the parent generic clearance is reviewed by OMB, this model effectively uses agency expertise in designing or managing surveys, but does not require independent technical review within the agency. OMB will be receptive to additional requests for such clearances.

Third, in view of the need for increased measurement of public satisfaction, OMB will also review and approve generic clearances for voluntary customer surveys (both questionnaires and focus groups) that assess agency performance. As set forth in the NPR report, "voluntary" means truly voluntary, i.e., the request for information has to be perceived as voluntary by recipients in order that the burden of supplying the information be a matter of absolute personal choice. For this reason, this category does not include any questionnaires for which the information is required in order to maintain or obtain eligibility for a program or benefit; nor would it include surveys by regulators of regulated entities. Because some designs for customer satisfaction or opinion surveys lack statistical validity, care should be taken to ensure that results of such surveys reflect the target population, are unbiased, and have response rates adequate to support quantitative inferences. OMB staff will assist agencies in addressing these issues.

Training

OMB is working with the Joint Program in Survey Methodology (JPSM) to provide training and tools needed to develop high quality surveys of client satisfaction. The JPSM is a graduate education and research unit conceived by the Statistical Policy Office of OMB as a means to provide interdisciplinary training needed to improve Federal statistical programs. In December 1992, the National Science Foundation competitively awarded funds to establish such a program to a consortium of two universities and a private survey firm.

The base curriculum of the JPSM, which already covers many disciplines required for designing customer surveys, will be enhanced to address additional methods useful in developing sound efficient surveys of Federal customers. These offerings will permit agencies to improve their capabilities in this important new area. Classes will train agency staff to perform in-house work and to develop the technical expertise required to manage contracts for needed statistical services. Such skills will be an essential component of agency plans to develop the in-house capabilities for technical review.

THE WHITE HOUSE

WASHINGTON

October 18, 1993

COPY

Roscoe M. Moore, Jr., DVM
Associate Director for Development Support
and African Affairs
Office of International and Refugee Health
OASH
Room 18-75
5600 Fishers Lane
Rockville, Maryland 20857

Dear Dr. Moore:

The purpose of this letter is to request your assistance in locating financial support to attend the VIIIth International Conference on AIDS in Africa in Marrakech, Morocco, on December 12 to 16.

Due to budgetary constraints, my office does not have the necessary funds to support this trip. I do believe, however, that it is important that I attend. It is critical, at this early stage, to make the necessary international and regional contacts with my colleagues in order to advance both the global and African AIDS agendas, of which the United States plays a major role.

If the program has not been finalized, I would be delighted to participate formally in the meeting. If you believe this is appropriate, I can suggest several topics that would be pertinent to the theme of the conference, "Time to Act."

Thank you for your consideration of my request. Please contact Nancy Hazleton of my staff for further information and coordination. Ms. Hazleton can be reached on (202)690-5560.

Sincerely,

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

cc: Dr. Helene Gayle, USAID
Mr. William Lyerly, USAID

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003. letter	To: Hillary Rodham Clinton; re: Discrimination in Medical Field (2 pages)	10/25/1993	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 3767

FOLDER TITLE:
October Chron Files 1993 [4]

2018-0756-F
jp4794

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

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

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

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

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

THE WHITE HOUSE

WASHINGTON

October 18, 1993

Mr. Benjamin F. Mobley
5926 Fauntleroy Way, S.W. #1
Seattle, Washington 98136

Dear Mr. Mobley:

This is a belated thank you for sharing your thoughts on HIV/AIDS Prevention and "Sex...It's Not Worth Your Life" with me. As National AIDS Policy Coordinator, I am devoted to the development and implementation of policies that will stop the spread of HIV. I am encouraged by the interest of individuals like yourself on the complex issues of HIV/AIDS prevention.

As you correctly point out in your letter, HIV/AIDS prevention is very controversial. What may be appropriate for one group may be less appropriate for others. However, I honestly believe that in order to stop the transmission of the virus, we must address the issues from a public health standpoint. Although your proposed campaign appears to deliver a message of abstinence, after twelve years of the HIV/AIDS epidemic, we have come to realize that this message is not well received by those who choose to be sexually active.

My primary aim is to promote programs and educational campaigns that are flexible enough to address the needs of those who choose to abstain as well as those who choose to be sexually active. In order to do this effectively, it is my belief that the messages must speak the language of those we are trying to reach. If the language of abstinence will prevent some from hearing the more important message of HIV/AIDS prevention, then it may not be the correct message to concentrate on.

I would like to thank you again for your input.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

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5926 Fauntleroy Way, S.W. #1
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I would like to thank you again for your input.

Sincerely,

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

FILE COPY

Prepared by: APAC\Mobley 10/14/93 B:\wles.lts\mobley

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

In addition to the slogan and all that I have stated above, I have also written a song that I think would be very appropriate for this campaign. It is also entitled "It's Not Worth Your Life!" I have enclosed with this letter a copy of this song on the tape. If you will, please listen to it, and by all means let me know what you think. Please note: the tape contains two versions of the same song. The first version is directed toward our young people. It is asking the question, "How to get the message to our young?" The second version is universal and it is asking, "How to get the message to everyone?" The reason for the two versions is obvious. I believe that this song delivers a very powerful and straightforward message—one that anyone could understand. And I might add here that I am, and will forever be, eternally grateful to be associated with it.

In concluding, I must say that the phrase "Sex . . . It's Not Worth Your Life" is the key to this campaign. However, like its predecessor, "Just Say No," the words alone are not the real educators. They are simply a tool . . . a means of opening the door to promote questions, conversation and, subsequently, education. To use this tool, I need your help, your expertise and, most of all, your input. You see, this is not my campaign . . . it is our campaign. It was given to me that I might share it with you and everyone else.

It is clear that the time is out for pointing fingers and blaming this or that group for our dilemma. It is time now for compassion, understanding and working with one another, because truly as the song says, "We're All In This Together!" May God bless!!! Please call me at (206) 937-3718.

Sincerely,

Benjamin F. Mobley

Benjamin F. Mobley

Enclosures

BENJAMIN MOBLEY
5926 Fauntleroy Way S.W., #1, Seattle, Washington 98136 (206) 937-3718

August 24, 1993

Ms. Kristine Gebbie
Executive Office of the President
Washington, D.C. 20500

Dear Ms. Gebbie:

Let me first say congratulations on your recent nomination as AIDS Czar, and may God be with you in all that you do.

I am writing you because I, too, am deeply concerned about this disease, and I also want to share something with you.

Like most people, I believe that our best weapon against AIDS is education. However, I do realize that all over the world, and indeed here in America, when you speak of education, it often causes more confusion, fear and anxiety. The question here is: How do we go about educating people of all ages, race, creed and color without offending or hurting anyone? Personally speaking, because of the many personal and moral issues involved, I don't believe that any one person or group has all the answers to this question. Therefore, I believe that we must continue with the programs that we presently have in place and improve on them in any and every way that we can. And this is why I am writing you . . . I am trying to suggest something else that we can do.

If you recall, in the 70s and 80s, we had an all-out national campaign against drugs. Our slogan was "Just Say No." Through this program, we began teaching young and old alike the negative consequences of taking drugs. Everywhere you looked—billboards, buses, T-shirts, bumpers, magazines, T.V., etc.—we saw those words. What I am saying is why not use this same kind of nationwide approach to reach people about AIDS. For this campaign, our slogan could be: Sex . . . It's Not Worth Your Life!!!

To me, this slogan or statement is not offensive, but I am sure that there are those who would disagree. What it is, however, is what I believe we need most right now in terms of discussing this crisis . . . and that is a sense of honesty, openness and being direct and to the point.

THE WHITE HOUSE

WASHINGTON

October 18, 1993

Thomas J. Wojtalak
Box 379, RTGA
Truro, Massachusetts 02666

Dear Mr. Wojtalak:

I am delighted to know that my visit to Provincetown was helpful to you. Thank you for sending the article on the saga of hydrazine sulfate. I will take the time to read it and will also share it with my staff.

The Food and Drug Administration and the scientific community work together to assure that all drugs that are approved for therapeutic purposes are both safe and effective. As the National AIDS Policy Coordinator, I will strongly advocate public health policy that has a sound scientific basis. You can be assured that I will support the use of any treatment that has been shown to be safe and effective in finding a cure for this disease.

Your interest in HIV/AIDS is very much appreciated.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

October 18, 1993

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Box 379, RTGA
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Your interest in HIV/AIDS is very much appreciated.

Sincerely,

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

Prepared by:APO: JMessore: 202-690-5560: 10/12/93: b:wojtalak

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

SEP 29 1993

Box 379 RT 6A
TRURO MA 02666
508 349 6247

9/21/93

Dear Ms. Gebbie;

First, I would like to thank you for coming to Provincetown to hear us. It really makes a difference and gives us all new hope.

As you told us, you wanted any ideas & information we could share that might help with your work. I've enclosed an article which I hope you will have time read. It contains many unanswered important questions. You may already know some of this material. again thanks.

Sincerely

Thomas J Wojtalak

HOPE HEARTBREAK & HORROR

THE SCANDALOUS INSIDE STORY OF THE TRASHING OF A DRUG THAT COULD SAVE THE LIVES OF MILLIONS OF PEOPLE

If you or someone you love should come down with cancer or AIDS, you will probably be denied the one drug that may offer the best possibility of an effective treatment with the least side effects. It's called hydrazine sulfate. It's cheap, simple to make, and easy to take. It works for roughly half of all the patients who have received it, and it's being deliberately suppressed by some of the most influential doctors in the U.S. cancer establishment. As a result, a million Americans alone are being denied lifesaving benefits each year. What you are about to read is the story of a scandal that has already caused untold human suffering.

This article and supporting research documentation are being presented to appropriate committees in Congress where a full, public investigation is being considered. Careful reporting over the past ten years by *Penthouse*, by ABC's *20/20*, and by this reporter on Independent Network (TV) News has informed mil-

Dr. Joseph Gold (left), the developer of hydrazine sulfate, realized that if he could find the key to give cachexia's lock on cancer patients, and to process food, many of them would gain [illegible] to death.

TEXT BY JEFF KAMEN • ILLUSTRATIONS BY KENT BARTON

lions of Americans about hydrazine sulfate's lifesaving powers and has pressured the federal government into ordering a much-needed national clinical trial.

But now one-third of that massive test is over, and the net effect is to continue the almost-20-year suppression of this extraordinary drug, which stops the starvation that kills most cancer patients, shrinks some tumors, and, research suggests, may even be a long-sought "magic bullet" against a broad range of cancers. Considering the spread of AIDS and the high probability that cancer will touch you or someone you love, the unending attack on hydrazine sulfate may become very personal in your own life.

By now you are probably asking yourself questions like: How can this be true? When it comes to fighting deadly diseases, aren't we all on the same side? Who would want to stop a good drug from getting to those who are suffering? If it is true that reputable scientists in the United States and in Russia have successfully used hydrazine sulfate, why isn't it available? Where is this drug if someone you care about needs it tomorrow?

We'll answer that last one first: Hydrazine sulfate is meticulously blocked from even your doctor's hands by federal regulations, and strangled by tests that make the drug look like a worthless fake. The drug's developer, Joseph Gold, M.D., director of the nonprofit Syracuse Cancer Research Institute, in Syracuse, New York, is appalled and alarmed because of what it means for cancer victims, as well as for his own efforts. Since he left the U.S. space program, Dr. Gold has devoted his life to unraveling the mysteries of cancer cachexia and its treatment with hydrazine sulfate. As the developer of this drug, he really knows how it works and what gets in the way of its curative qualities.

For over a decade, Dr. Gold has been warning that if you drink or take sleeping pills or tranquilizers, you might as well not bother taking this drug, because it simply doesn't do its thing when alcohol or any of the rest are in your blood.

Simple, right? Well, naturally, Dr. Gold told the National Cancer Institute to keep those incompatible chemicals out of the nationwide clinical trials of hydrazine sulfate, the first of which was finally concluded last year. Don't worry, they told Dr. Gold, we know what we're doing, and hydrazine sulfate will receive a fair test.

Right. The National Cancer Institute participated in compromising this first test by allowing alcohol, sleeping pills, and tranquilizers to be taken by dying lung-cancer patients who were being given hydrazine sulfate in conjunction with chemotherapy. That cynical act denied the 270 desperate patients who were in the group of even a fighting chance at less pain and longer life. The undermining of the first test also guarantees that the overall judgment on hydrazine sulfate will be tainted, even if the last two test groups demonstrate positive results.

The trouble with this story is that the "bad guys" all wear white coats. Having done pioneering work against cancer in some cases, on the surface they seem to be fulfilling their responsibilities as guardians of the public health. Perhaps this drug and its developer stuck so deeply in their personal and institutional craws that the high priests of cancer found every possible excuse to trash hydrazine sulfate, a drug not invented by any of them or the corporations and research centers that are members of their old-boy network.

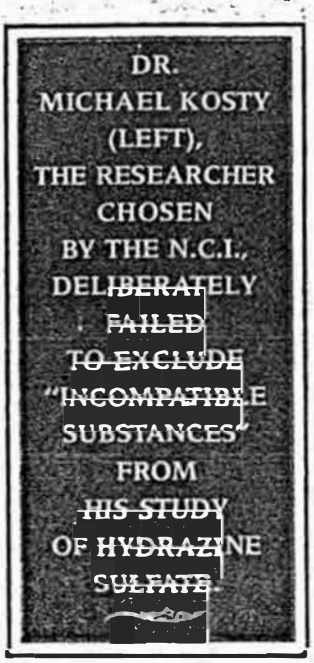
Raging egos, self-righteous turf-protection (including thousands of jobs that might be threatened if the drug got a truly fair test), and a subtle but very effective signal to researchers whose work supports hydrazine sulfate—researchers who have been forced to abandon more than a decade of carefully controlled clinical trials, their work neatly consigned to obscurity—are the apparent reasons why millions of cancer patients in our own country and around the world are presently being denied the benefits of hydrazine sulfate.

In a ballroom of the Omni Shoreham Hotel in Washington, D.C., some of the nation's top AIDS researchers gathered on November 3, 1992, to develop improved strategies for helping the growing number of straight and gay Americans who are being picked off by the only lethal sexually transmitted disease of our time. During a break from the heavy work, Albert Wu, M.D., a young assistant professor of medicine at the renowned Johns Hopkins Hospital in Baltimore, walked from the AIDS conference into the nearest ballroom to check out the much less depressing scene.

It was the election-night headquarters of the Democratic National Committee. As balloons and a huge victory map were being prepared for later use, Wu watched TV monitors as early returns signaled Bill Clinton's elec-

toral-vote landslide. A reporter noticed Wu's AIDS Clinical Conference badge and asked him if he did any work with cachexia, the starvation that seizes many AIDS patients, sending them to an early and painful death. "Yes," said the physician, "I work on cachexia. Why do you ask?" The reporter asked the doctor if he'd ever heard of hydrazine sulfate, the only substance that has demonstrated its ability to arrest and then reverse the terrible wasting away of body and spirit that is cachexia.

Wu said he did not know anything about hydrazine sulfate, and wanted to know lots more after the reporter told him that the drug blocks cachexia in cancer patients. "Why don't I know about this?" asked the AIDS specialist. Why indeed! One reason is the long-standing and continuing hostile climate in which the medical establishment has enveloped the drug, which has resulted in a virtual purging of the medical literature of any reference to hydrazine sulfate's documented curative powers and to its even greater potential.



One of the results of continuing high-level intimidation is its clear signal to the pharmaceutical industry. The principal method for bringing a new drug to the public—the one most often taken—is research and development by drug companies. But those manufacturers rely on the goodwill of the cancer establishment, and, in fact, are integral parts of it, ultimately employing many senior officials of the National Cancer Institute who—in some cases—dip in and out of the private and public sectors. In fact, the high priests in white coats created such a negative environment for hydrazine sulfate that pharmaceutical houses were discouraged from marketing it. So all doors appear to have been closed to this drug, which could be extending the lives of millions of dying people all around the world right now.

CANCER CONFLICTS OF INTEREST?

Now, as to why the big guns in cancer officialdom would oppose any simple, easy-to-administer, effective, inexpensive, and safe therapy for cancer, here's the short list:

- The two-billion-dollar-a-year budget for the National Cancer Institute and its programs could be radically cut; other National Institutes of Health budgets could suffer similar effects.
- Big regional cancer centers like Memorial Sloan-Kettering in New York, M. D. Anderson in Houston, Dana-Farber in Boston, and the Mayo Clinic in Rochester, Minnesota, as well as the monies they receive, would shrink drastically. Thousands of careers could be jeopardized.
- There would be much less need—except for prevention programs—for the American Cancer Society, the Leukemia Society, the American Institute for Cancer Research, or any other national cancer fund-raising society.
- The cancer-related pharmaceutical industry's income would be severely impaired. Such drugmaking giants as Bristol-Myers Squibb would probably suffer significant contraction of income.
- The need for cancer specialists would vanish. Oncologists would become as extinct as syphilologists, whose ineffective treatments for syphilis bled their hapless patients of millions until the advent of the "magic bullet" penicillin.
- Hospital income would be significantly diminished. Hospitals with high cancer-related income could be forced to close.
- Thousands of smaller companies that constitute a cancer cottage industry would vanish.
- Thousands of physicians and researchers in America alone would lose their jobs or have to be retrained.

Those are the main reasons why hydrazine sulfate—or any other potentially broad-based, easy-to-administer treatment against cancer—would draw such terrible fire from those now dining at the trough of cancer cash. Since we are not talking about a violation of law, it probably does not matter if the opponents of hydrazine sulfate have consciously considered the above consequences and acted upon those considerations. Whatever their motivations, their actions, including the apparent sabotaging of federally funded clinical trials of the drug, deny the public access to it.

SETTING THE STAGE FOR CONFLICT

Hydrazine sulfate's most recent modern use was as a military rocket fuel. The developer of its use as a drug was himself a military officer—a U.S. Air Force medical-research physician assigned to help win the space race against the Soviet Union during some of the most frightening days of the Cold War. Joe Gold, M.D., was one of a handful of elite young doctors who devised selection procedures for the first seven Mercury Astronauts from a group of 31 candidates, and helped make the critical judgments as to which U.S. test pilots were sufficiently

prepared to become America's first spacemen.

The world had been stunned and alarmed when the U.S.S.R. orbited the sputnik and then flew Major Yuri Gagarin into orbit. President Dwight D. Eisenhower—and later John F. Kennedy—promised that the United States would follow the Russians into space and surpass them. It was up to the rocket riders of the Mercury program to accomplish that mission; it was up to the Mercury doctors to make sure that the astronauts were fit to withstand their body-pounding thunderous rides free of the earth's gravity, and then the fiery reentry of their space capsules into the earth's atmosphere.

So the medical team had to be both brilliant and bold, identifying their goals and charging unswervingly at them, tolerating no interference as they screened and tested the pilots who would dare the cold darkness of space and return. Gold was one of the doctors who certified that a Korean War Marine Corps combat veteran named John Glenn was ready for the challenge.

To match the needs of the Project, Gold and his physician colleagues, like their spacemen patients, became dedicated, tough, and uncompromising—impatient with fools, incompetents, or self-serving careerists whose philosophy was: Stick with the old ways and you won't get into trouble. In short, Gold was the kind of doctor who would not tolerate anyone standing in the way of the welfare of his patient.

Of course, that is exactly the kind of doctor you'd want on your team if you were sick. But it turns out that a hard-charging, nothing-is-more-important-than-the-patient approach is precisely the wrong personality to have if you want to survive in the world of the cancer establishment's research bureaucracy. It is a largely hidden world, but sadly similar to the rest of governmental bureaucracy—self-perpetuating and self-protecting. Survival within it demands that you become meticulous about not offending those whose goodwill can make or break your access to funding. If you are an insider, you have some latitude, but God help you if you are an outsider, no matter how good your credentials, your work, or your ideas. Outsiders are inherently regarded with suspicion, distrust—and anathema.

Into this spun-glass universe of ever-so-diplomatic medical men came young Joe Gold, fresh out of the Air Force. He was filled with the fervor of the Mercury Program (having received a Presidential Citation from Eisenhower for his work), but his intensity was now directed at finding the answer to a single scientific question that haunted him: Is there some chemical way to block the abnormal process in the body that causes the tumor-triggered starvation called cachexia?

Gold realized that if he could find the key to pick cachexia's lock on cancer patients' ability to process food, many of them would, quite literally, stop starving to death. At the very least, he thought, that would restore considerable quality of life and keep them alive longer, so other treatments might have time to cure their cancers and save them. As the idealistic doctor was developing his concepts and, ultimately, hydrazine sulfate, he had only a theoretical idea that this drug would also be found to stop tumor growth. "That," says a still enthusiastic Gold, "is the expected side effect of stopping cachexia."

IF AN INEXPENSIVE THERAPY FOR CANCER WAS MARKETED, HOSPITAL INCOME WOULD BE SIGNIFICANTLY DIMINISHED AND THERE WOULD BE LESS NEED FOR NATIONAL CANCER FUND-RAISING SOCIETIES.

In the 1970s Gold published early results of his animal studies, and the prestigious Memorial Sloan-Kettering Cancer Hospital on Manhattan's wealthy East Side summoned him to make a presentation to their top scientists. Gold took another trustee of the Syracuse Cancer Research Institute with him and made a formal presentation. As a result, Sloan-Kettering indicated that it would like to proceed with human studies.

The Sloan-Kettering enthusiasm was unanimous, except from one quarter—the old-guard chemotherapists, who made clear their undisguised antipathy. Gold was nevertheless delighted, and in conjunction with members of the Sloan-Kettering executive staff, wrote a protocol for administering the drug, to which all parties firmly agreed and were committed. What followed were two collisions—of style and substance—that forever poisoned the way Gold and hydrazine sulfate were treated by the reigning medicrats of the U.S. cancer establishment.

EARLY CONFRONTATIONS

Dr. Gold is invited by telephone to a Memorial Sloan-Kettering Hospital news conference, which will announce a plan for a joint study of hydrazine sulfate with the Syracuse Cancer Research Institute. Gold advises them that he must first consult with his own board of directors. His board advises Gold to inform Sloan-Kettering that it would welcome a news conference, but that it should take place in Syracuse. The news conference nev-

er happens. (Years later Gold has a chance encounter with a former senior medical-liaison officer of the hospital, who still remembers the incident. "You cost us 16 million dollars back then," the ex–Sloan-Kettering official says. "We were going to showcase you and your work, invite a lot of wealthy donators who could have made substantial contributions to our general efforts. We may have even shared some of these funds with your institute.")

Gold visits Memorial Sloan-Kettering to check on the patients receiving his experimental new drug and cannot believe what he sees. Instead of following the jointly agreed-on protocol of 60 milligrams of hydrazine sulfate per single dose, the hospital is engaged in underdosing and overdosing. In some cases patients are being given only one, two, three, four, or five milligrams a day. Others who have been started on the correct dose and are beginning to show anti-cachexia improvements are abruptly switched to 90 to 100 milligrams per single dose, wiping out their good responses. Gold is appalled and complains to the Sloan-Kettering physicians that they are not obeying the study protocols. They tell him that "[they] know how to test cancer drugs. [They] know exactly what they are doing," Gold recollects.

A NOTHING-IS-MORE-IMPORTANT-THAN-THE-PATIENT APPROACH LIKE DR. GOLD'S IS PRECISELY THE WRONG PERSONALITY TO HAVE IF YOU WANT TO SURVIVE IN THE CANCER ESTABLISHMENT.

Naturally, the results of the Sloan-Kettering study—the first by a major cancer hospital—are dismal. By their measure, hydrazine sulfate was "inactive," the kiss of death for a new drug. The results of the flawed study were published in a major cancer journal, and both Gold and hydrazine sulfate were permanently "marked." Almost 20 years later, that study is the one that most middle-aged physicians recall first, if they have any knowledge of hydrazine sulfate.

TIMING IS EVERYTHING

That test at Sloan-Kettering came at a curious time in the history of the U.S. fight against cancer. Only a few years earlier, a brilliant researcher named Vincent DeVita, M.D., announced to the world that he had developed a combination drug therapy called MOPP, which killed the tumors of Hodgkin's disease in 80 percent of all cases. The oncological community underwent a revolution. Dr. DeVita's work on Hodgkin's gave birth to the boom in tumor-killing, or cytotoxic, chemotherapy. Doctors now had high hopes that chemicals could be developed that would vanquish all cancers.

DeVita became the director of the federal National Cancer Institute—in effect the nation's cancer czar—and through him billions of taxpayer dollars were ultimately spread among research centers from coast to coast. Unfortunately, 23 years after DeVita's meritorious work on Hodgkin's, senior cancer researchers like Professor Jerome Block, M.D., of the University of California at Los Angeles (U.C.L.A.) Medical Center, have come to the conclusion that in most cancers, cytotoxic chemotherapy has failed to seriously improve patient survival, and that the quality of patients' lives has often been made additionally miserable by devastating side effects.

Gold and hydrazine sulfate were going in exactly the opposite direction from cytotoxic chemotherapy. Virtually no important side effects of hydrazine sulfate were produced, and when doctors followed the established protocol, 50 percent of all patients receiving the drug lived longer, higher-quality lives. Gold did not mean to be—but had become—a heretic, an iconoclast, a defiler of the one true faith of cytotoxic chemotherapy. His refusal to capitulate, his continuing publishing of research results, and the drug's clear potential attracted two diverse supporters to him and hydrazine sulfate: a high cancer official in the United States, and one of Russia's most respected senior research physicians. On separate tracks, Dr. Frank J. Rauscher, Jr., a former director of the National Cancer Institute and senior vice-president for research at the American Cancer Society, and Michael L. Gershanovich, M.D., chief of the Departments of Therapy and Clinical Chemotherapy of the famed Petrov Research Institute of Oncology of the Soviet Ministry of Health in Leningrad (now St. Petersburg), moved to further test the drug.

The Russians moved first. They tested hydrazine sulfate against cancer cachexia in dozens of "factually terminal" patients suffering from a broad range of tumors. No matter which specific cancer was the trigger of the starvation, in about 50 percent of all cases, the patients' symptoms improved or disappeared, their cancers stopped growing or regressed, and some patients even went on to long-term survival. In the United States, the Petrov Institute's report by Dr. Gershanovich was read with keen interest.

Rowan Chlebowski, M.D., Ph.D., an insightful and ambi-

tious research physician at the Harbor-U.C.L.A. Medical Center, brought the Gershanovich report to the attention of his boss, Professor Jerome Block, who said he "wanted to check out this Russian thing." Block had been a senior official of the National Cancer Institute when its director was Frank Rauscher, the avuncular and gentle scientist who was a predecessor of DeVita's as the nation's top cancer doctor. Rauscher was now running the research arm of the American Cancer Society. Block sent Rauscher Chlebowski's proposal to do a carefully controlled study to see if the Russian results could be authenticated. If they could, that would mean the American medical establishment would have to fully test hydrazine sulfate's potential as the first anti-cachexia drug.

A peer-review committee of the American Cancer Society gave Chlebowski's proposal high marks and voted to fund it. Then an A.C.S. advisory panel—composed of mostly outside, "old-boy" scientists—reversed this decision. Rauscher disregarded the advisory panel's recommendations and used A.C.S. discretionary money to fund Chlebowski's study. Following the established protocol of drug administration—and making sure that patients did not also take sleeping pills, tranquilizers, or alcohol (known incompatible agents that ruin the drug's effectiveness)—Chlebowski gave hydrazine sulfate to terminally ill lung-cancer patients whose bodies were wasting away because of cachexia.

DR. ROWAN CHLEBOWSKI (RIGHT) SAID THAT AT LEAST "HALF A MILLION AMERICANS EACH YEAR SUFFERING FROM CANCER CACHEXIA COULD BE HELPED" IF THE DRUG WERE WIDELY AVAILABLE.

It would be the first of four successful, double-blind, placebo-controlled trials of the drug at U.C.L.A.'s Harbor Medical Center. With each set of results, Chlebowski published in top medical journals, creating renewed interest in the drug and, apparently, incurring the wrath of the "high priests" who had trashed it from the beginning.

In 1983, following Chlebowski's presentation of a paper on the effectiveness of hydrazine sulfate at the prestigious annual scientific meetings of the American Society of Clinical Oncology, Gold encountered DeVita, who, Gold remembers, "poked me in the chest with a finger and said, 'I'm going to take off my gloves on hydrazine sulfate!'" (At press time DeVita had not responded to repeated calls to comment on this article.)

So it came as a shock but no surprise that in the next edition of DeVita's influential textbook on cancer, hydrazine sulfate was lumped with other treatments in the chapter entitled "Unproven Methods of Cancer Treatment." And that was well after the U.C.L.A. and Soviet teams had reported their successes at medical conventions and in widely read oncology journals.

Some of the more independent-minded physicians who read the journal reports obtained hydrazine sulfate for their patients through the Food and Drug Administration and reported to Dr. Gold that many stopped starving and were once again able to eat, and that some returned to fully functional lives.

A VERY PERSONAL MATTER

In Sarasota, Florida, in the summer of 1987, 64-year-old Erna Kamen was sent home to die in "three to nine days"—after surgery, radiation, and chemotherapy had failed to prevent her from being eaten alive by metastatic lung cancer. Cachexia was consuming her. But her oncologist had read the journal reports and prescribed and obtained hydrazine sulfate as a last resort.

The patient, who was this reporter's mother, managed to swallow the first 60-milligram capsule and collapse back into her bed, her eyes growing vacant. Only hours later she rebounded, saying she was hungry and eager for some good conversation. Two days before I had flown to Sarasota from Washington, D.C., to help take her home from the hospital, to tell her that I loved her, and, really, to say farewell. Her sudden return to life was especially shocking to me, because the National Cancer Institute's public-information service had told me by phone (800-4-CANCER) the day before that hydrazine sulfate had no value. The National Cancer Institute was giving that line to doctors, patients, and families until I broadcast a series of five television news stories on the more than 100 stations that carried Independent Network News.

In those reports my mother spoke about the impact of the drug on her own life. Dr. Chlebowski said that at least "half a million Americans each year suffering from cancer cachexia could be helped" if hydrazine sulfate were widely available. Dr. Rauscher called for nationwide testing of the drug, and Robert Wittes, M.D., a senior official at the National Cancer Institute, said hydrazine sulfate wasn't given a high priority because it "doesn't kill tumors." Of course, almost nothing the N.C.I. spends money on *does* kill tumors for any great length of time. It was the same old song: If it isn't cytotoxic chemotherapy, it just can't be good. After my

interview with Wittes, he walked me to the elevator and asked how I'd gotten interested in hydrazine sulfate. As the elevator doors opened, I told him that the drug had kept my mother alive. The high priest of cancer looked at me as though he'd been punched in the gut. I stepped into the elevator and was gone.

Weeks later I received a phone call from Dr. Henry Masur of the National Institutes of Health, the parent institution of the N.C.I. Dr. Masur was the chair of the experimental-AIDS-drug screening committee. After an interview with him on another subject the previous week, I had asked what he knew about hydrazine sulfate. "Nothing. What is it?" He had sounded very interested when I told him the drug works against cachexia—a major killer of AIDS patients as well as cancer victims—and had said he would look into it. But his present phone call wasn't about AIDS. Masur said simply, "The Cancer Information Line has stopped saying hydrazine sulfate doesn't work. Instead, they're referring callers to the results of the U.C.L.A. study." Naturally, I felt terrific. My mother was recovering, and my journalism had helped to clear the name of hydrazine sulfate; thousands of viewers were calling our news desk to find out how to get hydrazine sulfate for their dying mothers and fathers.

My mother had four mostly good months thanks to the drug. If she had continued on it, she might still be with us. Because of her strengthened condition (she had gained back 23 pounds of real weight), however, a decision was made—against Dr. Gold's advice—to take her off hydrazine sulfate to try a new cytotoxic treatment. As Dr. Gold had warned, she was dead five days after the commencement of the new treatment. That was January 1988. But the good news about hydrazine sulfate had gotten out. She had wanted that very much. Dr. Gold was hopeful that, at long last, the National Cancer Institute would order a large-scale trial of the drug, using patients from coast to coast.

But a few months later, N.C.I. Director DeVita was trashing the drug once again—at least, so he thought. He told Sandy Rovner of *The Washington Post*, "You have to distinguish between good ideas and bad ideas and ho-hum ideas. And hydrazine, I think, is a ho-hum idea." DeVita went on to characterize hydrazine sulfate as a therapy that merely resulted in "plumper people." Yet it is well-known in the medical community that weight gain has been a therapeutic goal for many years and that fully two-thirds of all cancer deaths are traceable to cancer cachexia.

LEFT JAB, RIGHT CROSS

Chlebowski's team at U.C.L.A. submitted a grant application to the N.C.I. for a more advanced test of hydrazine sulfate, a multiinstitutional confirmation trial that would have moved the drug further down the road to acceptance and sharply increased the likelihood that, finally, a pharmaceutical house would pick up the rest of the drug's development costs and proceed to marketing. In the world of federal grants, an application is rated on a number system. In this case, a perfect score is "1." The bigger the number, the worse your work is regarded. Chlebowski is not only an extremely bright researcher but is internationally recognized in his field of intermediary metabolism and cancer chemotherapy. (He was one of 13 scientists selected by the U.S. government to help establish a cancer treatment and teaching center in Taipei, Taiwan, in 1990.) So he was surprised, to say the least, when the N.C.I.'s peer-review panel rejected his application and resoundingly insulted him with a very high number. Always careful in his public utterances, Chlebowski says now that "a lack of enthusiasm for the drug . . . and an overall [hostile] climate surrounding it" were responsible for stopping his decade of hydrazine-sulfate research dead in its tracks.

The January 1990 issue of the *Journal of Clinical Oncology* arrived in the offices of the nation's cancer doctors bearing what Dr. Gold calls "a bizarre medical paradox." The lead, peer-reviewed article by Chlebowski and a team of seven other physicians and scientists reported that in their final test of the drug—a prospectively randomized, placebo-controlled, double-blind study—hydrazine sulfate increased the survival of end-stage lung-cancer patients. That's a very significant finding, and signals physicians that they should give greater heed to the possible use of this drug for cancer patients in general. But as the readers of this journal turned the pages, they ran smack into an editorial slamming Chlebowski's rationale, methodology, and conclusions. Entitled "Hazards of Small Clinical Trials" and written by Dr. Steven Piantadosi of the Johns Hopkins Oncology Center in Baltimore, the editorial rips the reliability of "small" groups of patients as indicators of a drug's

performance in wide use. The trouble is, the only drug he gives specific mention to is—you guessed it—hydrazine sulfate. What is curious, to say the least, is that Chlebowski's final study drew on 65 patients, an appreciable number for this kind of study. Moreover, in this same journal issue, 12 out of a total of 22 studies reported—or 54.5 percent—employed far *less* patients than the Chlebowski study, some as few as 15 patients. Nevertheless, there was not a word of criticism of these studies or of any conclusions they had reached.

For Dr. Gold, the Piantadosi editorial "gives an unmistakable signal that any study of hydrazine sulfate bearing positive data will be singled out for special attention." He characterizes this work as a "'hired-gun' editorial whose effect is not only to demolish legitimately obtained positive results with hydrazine sulfate, but to deter further independent clinical study of this drug."

So the left jab and the right cross landed hard. First Chlebowski's multi-institutional grant application was given an exceedingly poor grade; then his final report to the medical community on hydrazine sulfate was attacked by Piantadosi, who, besides being a senior researcher, also sits on the oncology advisory panel of the F.D.A., which makes recommendations to the F.D.A. on which cancer drugs should and should not be approved.

Chlebowski was stunned by the editorial. As a result, after ten years of studies and coming to the conclusion that hydrazine sulfate could have helped millions over that period, he dropped out of hydrazine-sulfate research. Shortly thereafter, he received an invitation to join the executive board of the prestigious American Society of Clinical Oncology, the publisher of the *Journal of Clinical Oncology* in which he and the drug were pilloried. Chlebowski is enjoying his newly found prestige, but he is still smarting from Piantadosi's lash. Almost three years later, he is still wearing the scars.

Over breakfast at the Sheraton New Orleans, where the ASCO executive board was meeting this past Halloween, Chlebowski labeled Piantadosi's effort "not a helpful editorial, [but one] which could have been written about 20 other papers published in *J.C.O.* [the previous] year. . . . I can tell you that I was shocked by the tone of the editorial. . . . He said my work had not advanced the development of hydrazine sulfate. That is not correct." Understand that for a career organization man like Rowan Chlebowski, those are incendiary words, uttered only because he cannot fully contain his rage at the attack that rained down on him because of his successful studies of hydrazine sulfate.

Like Dr. Gold, Chlebowski said he feared the editorial would scare off potential partners in research that he had still wanted to do on hydrazine sulfate: "It might make other people lots more cautious than I was going to be, and that would make it hard to package the right group of people together to be able to make [an] application strong enough so that it would be more compelling [to win grant approval]."

Chlebowski's final involvement with hydrazine sulfate might well have been his most explosive—an approved (and funded) grant to study the effects of the drug on AIDS patients, who, like so many cancer victims, often succumb because their bodies have lost the ability to process food in any form. If hydrazine sulfate could be shown to stop and reverse cachexia in AIDS patients, they might have the chance to fight on. But no sooner had Chlebowski received his grant to do the work, he says, than he discovered that F.D.A. regulations would tie him up in red tape for months just to get his hands on a reliable supply of the easily manufactured chemical. It was the last straw. He dropped the project.

> WHEN AN N.C.I. OFFICIAL ASKED HOW I'D GOTTEN INTERESTED IN HYDRAZINE SULFATE, I TOLD HIM IT HAD KEPT MY MOTHER ALIVE. HE LOOKED AT ME AS THOUGH HE'D BEEN PUNCHED IN THE GUT.

Burned and disappointed but still needing to continue with his career, Chlebowski moved on to other, much less controversial, less politically loaded, work. For his boss, Dr. Jerry Block, dropping hydrazine-sulfate research was deeply disappointing, since his early decision to buck the politically correct crowd—including N.C.I. Director DeVita—had paid off in what he still regards as good, solid research, which he thought would have included the AIDS study. Block said he had high hopes that hydrazine sulfate would be effective against AIDS cachexia.

During an interview in the Los Angeles suburb of Redondo Beach this past November, Block said that no other drug has ever been subjected to the "gauntlet of scientific criticism" that hydrazine sulfate has been forced to run. A former senior official of the NCI, Block called for the convening of an "international conference" on hydrazine sulfate. "Cachexia isn't a trivial problem. It isn't only cancer, it isn't only AIDS. Cachexia touches our lives in many ways. It is a part of advanced aging as well."

Block was mid-bite on a warm raisin scone at the Redondo Beach Inn and in a genial mood. But when he was told that the first portion of the nationwide testing of hydrazine sulfate paid for by the N.C.I. had deliberately included the incompatibles, his generally warm and smiling face hardened into a mask. Like Chlebowski, he said he too would have excluded the incompatibles. Block clearly believes that hydrazine sulfate and its developer have been the subjects of continuing harassment by the medical establishment.

"Look at how long they've been working on immunotherapy," he says. "There's never been a randomized clinical trial [he laughs], a randomized, controlled clinical trial that shows immunotherapy is good. Yet they're still funding that. They've been investing in that for decades. Possibly Joe [Gold] made a political mistake by not calling hydrazine sulfate 'immunotherapy.'"

In 1985 Dr. Maxwell Gordon was senior vice-president of the Science and Technology Group of Bristol-Myers. After deciding that hydrazine sulfate was going to save a lot of lives, he sent a letter to Dr. Gold to signify the pharmaceutical house's "intention to conclude an exclusive worldwide license agreement with you on hydrazine sulfate" (for which Gold holds the patent). Gordon's letter signaled three important coming events: a comprehensive testing of the drug against all forms of cancer, the marketing of the drug throughout the world, and an enormous intellectual, emotional, and monetary payoff to Gold after 17 years of hard, lonely work during which his pioneering efforts had been greeted with scorn and abuse.

IF REPUTABLE SCIENTISTS IN THE UNITED STATES AND IN RUSSIA HAVE SUCCESSFULLY USED HYDRAZINE SULFATE, WHY ISN'T IT AVAILABLE? AREN'T WE ALL ON THE SAME SIDE?

But none of those good things was to be. To learn why, we interviewed Dr. Gordon this past November at Lenti-Chemico Pharmaceutical Laboratory, Inc., in Teaneck, New Jersey, where he is the chairman of the board and the C.E.O. of the U.S. subsidiary of Japan's Ajinomoto Co., Inc. Gordon remembers what happened to the hydrazine-sulfate deal as if it were yesterday, not almost eight years ago. He said his bosses at Bristol suddenly reversed themselves and declared, "Forget it, the deal's off." Gordon said the deal-killer had been "Stephen K. Carter, an N.C.I. alumnus and part of the establishment. [Carter] put himself on the line and said, 'If you do this [take on hydrazine sulfate] I'm quitting.'" Gordon left Bristol; Carter—who denied through a spokesman that he had threatened to quit to kill the deal—stayed on and is now director of the company's Worldwide Clinical Development.

Gordon remains a detached but enthusiastic supporter of Gold's work and of hydrazine sulfate. But "without a positive, multi-institution, clinical trial of the drug," he says, there is little probability that any drugmaker will pick up hydrazine sulfate.

When Gordon learned three years ago that exactly such a trial was about to begin—paid for by taxpayer dollars—he contacted the doctor in charge and urged him to make sure that the test excluded from patients' diets all alcohol, sleeping pills, and tranquilizers. Those substances had been shown in the past to ruin hydrazine sulfate's effectiveness. Gordon has a clear recollection of his conversation with Dr. Michael Kosty, the researcher selected by the N.C.I. to direct the first of three trials at the Scripps Clinic, a cancer center in San Diego.

"I emphasized the importance of those exclusions," Gordon says, "so I'm at a loss why they didn't do it." Gordon also says that Kosty had plenty of time to make sure the test was fair and honest. "He [Kosty] was writing the protocol" when Gordon called. (Gordon sent him a letter dated September 19, 1989, emphasizing in writing the importance of the exclusions.) How did Kosty respond to Gordon's guidance? "He said, 'You're right,' and that he would follow my advice," Gordon says.

Kosty, responding to *Penthouse*'s follow-up, contends, "This is incorrect. We talked with many individuals prior to finalizing the study and made no commitments to include/exclude specific medications."

Not only did Kosty deliberately fail to exclude the incompatible substances from the study (because of this failure, Rauscher terms the results of this study "suspicious"), but he said in an interview with me at his home in San Diego that "we just think that that's a nonissue." Sure. Like mixing gravel in with the gasoline that you put in your Porsche. Not surprisingly, the Kosty study, with its protocol of incompatibles, was reported as negative. Kosty further said that the Russian work—a 740-patient, 15-year study—had been "shoddy," and stated that his own study of hydrazine sulfate proved that the study conducted by Chlebowski and his team at U.C.L.A. was "meaningless."

Kosty even went beyond the portfolio of his assignment. In his report on hydrazine sulfate presented at last spring's ASCO meeting, Kosty stated, "We discourage the general use of hydrazine sulfate in cancer." The word *general* in that context means "all types" of cancer. But Kosty didn't test all types of cancer—his study was restricted to non-small-cell lung cancer. The fact is, his statement is unsupportable. Moreover, since Kosty's assignment was strictly to study hydrazine sulfate in combination with chemotherapy, he could not state what the effects of hydrazine sulfate itself were against non-small-cell lung cancer—no hydrazine sulfate–alone "arm" was tested. And since Kosty failed to exclude the known incompatibles of hydrazine sulfate, no statement can even be drawn as to the effect of hydrazine sulfate in combination with chemotherapy. In effect, the Kosty study demonstrates nothing. No scientifically valid conclusions whatsoever can be drawn. The entire study, which cost the N.C.I. up to a million dollars, can be seen as a total waste of the taxpayers' funds.

A curious counterpoint to Kosty's negative report to ASCO was his statement that was reported in *Oncology Times*, a monthly newspaper for cancer doctors and researchers. On April 24–26, 1991, Kosty and his group from the Cancer and Leukemia Group B, charged with overseeing the N.C.I.-Kosty study, met to consider the preliminary results of this study.

On April 29, 1991—three days after the evaluation of these preliminary results was completed—Naomi Pfeiffer, a science writer for *Oncology Times*, reported that she was told by Kosty in a telephone interview that the results indicated that those patients who received hydrazine sulfate had "far superior" survival than patients in studies where hydrazine sulfate was not used, and, further, that side effects were "negligible." This story was published in the newspaper's June 1991 issue. In her telephone interview with Dr. Kosty, Pfeiffer asked, "Are the definitive data likely to be different?" Kosty replied, "No, they [the data] can only get better."

In November of last year, Kosty insisted that Pfeiffer had misquoted him: "I never said it. I said that as a group, since we hadn't broken the codes on the patients in the study yet [on the double-blind], all the patients were doing better in terms of how long they were living, in terms of other Phase III studies. Both the people receiving placebo and the people receiving hydrazine. I said nothing about one group or the other because I was blinded to the results until the study was virtually completed." If that is so, then why did he and his group meet to discuss and then report on preliminary results in April 1991? Kosty is new to the business of high-profile research. Pfeiffer is an old hand with 30 years' experience. She told me, "I did not misquote him. I remember what he said. For some reason, he's trying to make me out a liar."

Dr. Gold quickly realized that there was no way that he could alter the outcome of the Scripps Cancer Center–based study, given the inclusion of its negative bias factor of incompatibles. The two other N.C.I.-sponsored Phase III studies of the drug—against lung cancer and colorectal cancer—were soon to begin at the Mayo Clinic in Rochester, Minnesota, under the supervision of Dr. Charles Loprinzi. In response to appeals from Dr. Gold, Loprinzi said in a letter dated June 15, 1990, "I have made modifications to both of our hydrazine [sulfate] studies to exclude the use of any alcohol and tranquilizers."

When I asked Kosty how he felt about Loprinzi's changing the Mayo protocols to exclude the incompatibles, Kosty said, "They didn't change it. They had excluded it from the very beginning." Who told him that? "Chuck Loprinzi. . . . He sent me a copy of the protocol before it was opened, and it had those things excluded." Did he ask him why he had done it? "No. I guess they decided not to make that an issue. Obviously, by excluding, you remove that as a potential criticism."(!)

But Dr. Gold contends that the doctors at the noted Mayo Clinic appear to have engaged in an unorthodox practice in the design of their hydrazine-sulfate study, which could also compromise the results. A careful reading of Loprinzi's June 15, 1990, letter to Gold shows that Loprinzi started his patients first on chemotherapy, waited for nausea to clear, and then started hydrazine sulfate. "We have written into the protocol," he wrote, "that these pills should not be started for several days until after the first emesis [vomiting] from the first cycle of chemotherapy [has] cleared."

To this Gold responds, "In effect, this means that his team has administered what is called 'prior therapy,' prejudicing the study against hydrazine sulfate in violation of his own protocol. Section 3.18 of the official Mayo protocol No. 89-24-51 reads, 'Patients [admitted to the study group would have to be] previously untreated

with chemotherapy for this cancer or other cancers.' Loprinzi thus tips the scales against hydrazine sulfate, since nausea from the first course of chemotherapy can take from a few days to up to a week to clear. He should have started hydrazine sulfate and chemotherapy concurrently. Or, if he wanted to tip the scales in a protocol-justified manner, hydrazine sulfate *before* chemotherapy."

When questioned by *Penthouse*, Dr. Loprinzi replied, "No, we did not bias the outcome. I can't buy that. We wanted to give hydrazine sulfate the best possible shot."

We can only hope that the physicians at Mayo live up to their reputations as good and wise healers and do not succumb to pressures to smear hydrazine sulfate.

Some of you reading this right now have just lost a friend, loved one, or colleague to cancer. Hydrazine sulfate might have spared them, alleviated their pain and suffering, even given them back their normal life. Yet only a minority of doctors—and even fewer ordinary citizens—have even heard of the drug.

AUTHOR JEFF KAMEN (LEFT) HAS A PROFOUND INTEREST IN EXPOSING THE TRUTH ABOUT HYDRAZINE SULFATE AND THE CONCERTED EFFORTS TO SUPPRESS THIS POTENTIALLY LIFESAVING DRUG.

And what about the AIDS patients? Like cancer victims, many of them die not of the disease itself, but of the terrible wasting away the disease mechanism creates. Can hydrazine sulfate reverse the cachexia metabolism of AIDS as it does the cachexia of cancer? Preliminary metabolic studies say yes. But clinically, the question remains unanswered. And that is because the U.C.L.A. team has relinquished its AIDS grant, caught in the vise of a 16-year concerted effort to destroy the drug.

Why should an N.C.I. director threaten to "take off [his] gloves on hydrazine sulfate" after the presentation of a positive clinical study of the drug at an important cancer conference by a team of experienced and objective cancer investigators? Why should the U.C.L.A. team give up ten years of escalatingly successful controlled clinical trials of hydrazine sulfate at the zenith of its success? Throw away its AIDS grant? Why should a prestigious mainstream cancer journal print an editorial whose only apparent functions are to selectively attack its lead article and serve notice to the cancer community that positive results on hydrazine sulfate will be singled out for "special attention"? Why should an N.C.I. study group want to retain substances in its protocol that are known to be incompatible with hydrazine sulfate—that could only result in harm to the patients taking the drug (and help guarantee a negative outcome of the clinical trial)—when to exclude those substances would do no harm to the study? Why should a high official of the N.C.I. derisively label hydrazine sulfate a drug that results only in "plumper people" when weight loss is a major factor in cancer death? Why should the principal investigator of an N.C.I. study of hydrazine sulfate recant his original statement of favorable preliminary results? Why should all independent clinical research of this extraordinary drug cease? The consequences of this destructiveness are enormous, not only denying a fighting chance to both the drug and the patients caught in compromised studies, but presenting alarming ramifications for the cancer community at large. In Dr. Gold's words:

"Each year 500,000 Americans die from cancer, and there are over a million new cases annually in this country alone. The U.C.L.A. data indicate that over half of these afflicted patients would be helped by hydrazine sulfate, some achieving significant extensions in survival. The Soviet data, consistent with the U.C.L.A. results, indicate that of every million late-stage cancer patients, 500,000 would receive significant symptomatic improvement, 400,000 would show a halt or regression in tumor growth, and some would go on to long-term survival. If, indeed, any one of the N.C.I. studies has been rigged, or if official intimidation and coercion against further independent clinical studies of hydrazine sulfate are at work, as may well be the case, the result will be increased suffering to these hundreds of thousands of human beings and their families. That the N.C.I. should be part of an effort to snuff out hydrazine sulfate constitutes what is truly one of the most shameful, scandalous medical undertakings in this country's history, depriving vast numbers of people of their health, happiness, and lives."

Tax-deductible contributions to further Dr. Gold's research can be sent to Syracuse Cancer Research Institute, 600 East Genesee St., Syracuse, NY 13202.

Editor's note: Omni *is reprinting this article from the April 1993 issue of* Penthouse *to update our readers on the latest battle in the war on cancer and the challenges facing researchers.* Omni *first addressed hydrazine sulfate in the February/March 1993 article "Unconventional Cancer Treatments."*

THIS ARTICLE WAS ORIGINALLY PUBLISHED IN THE APRIL 1993 *PENTHOUSE*. HERE ARE THE LATEST DEVELOPMENTS.

After the April issue of *Penthouse* was safely off the newsstands, National Cancer Institute officials responded in a letter to the *Washington Post*—not about the truly challenging issues raised in my story, but about the full-page ad for the article which appeared in the *Post* and the *New York Times*. The fact that the NCI letter was published at all is testament to the political power of the Cancer Establishment, since the *Washington Post* has a policy against printing letters about ads. The NCI condemned the *Penthouse* ad—which was an accurate reflection of the article—charging that the ad gave cancer patients false hope.

In my reply published four days later, I wrote that the National Cancer Institute's letter was a cover-up tactic to deflect public anger over the NCI's undermining of federally funded testing of hydrazine sulfate, an easy-to-take, easy-to-make drug which stops cancer-induced starvation in more than half the patients who take it and retards tumor growth in 40 percent. I also noted that this drug's therapeutic effects occur only when doctors adhere to the established protocol, which excludes all alcohol, barbiturates, and tranquilizers from patients' diets, since those substances wipe out the beneficial effects of hydrazine sulfate. To the astonishment of independent experts, NCI deliberately allowed incompatible agents to be taken by patients in its three nationwide tests of the drug. The NCI's letter to the *Washington Post* omitted that critical fact. In its letter, NCI labeled the ad for my story "a disservice to cancer patients and the public." But it is the NCI who has done the "disservice," by sabotaging the testing of hydrazine sulfate.

WE HOPE THIS INVESTIGATION COMES TO THE ATTENTION OF HILLARY RODHAM CLINTON'S TASK FORCE AND TO THAT OF SECRETARY DONNA SHALALA. HUNDREDS OF THOUSANDS OF LIVES ARE AT STAKE.

So it came as no surprise when the results of the recent multiinstitutional clinical trials of hydrazine sulfate were reported as negative. But there were two bizarre and revealing twists: First, the abstract announcing the most recent of the test findings, published in *Proceedings of the American Society of Clinical Oncology 1993*, says the drug, in combination with chemotherapy, had no survival benefit in patients with advanced lung cancer. Yet the data of this same abstract reveal a greater first-year death rate in the placebo patients, contradicting the conclusions of the study. Second, the stated purpose of these trials was to test the UCLA findings on early stage patients, but apparently only late-stage patients were tested, rendering this study totally superfluous and yielding no new results.

In preparation for this update, the data from the massive clinical trial undertaken by the Russians and published two years ago were reviewed with surprising effect: Since much of the emphasis on hydrazine sulfate was focused on cancers of the lung and colon, I initially missed data which suggest that the drug shows promise against cancers that strike women, including cancer of the breast, ovaries, cervix, endometrium, and vulva. It's one thing for a reporter to overlook data, but for the NCI to miss the significance of these Russian findings is simply inexcusable. The NCI failed to follow up on these studies of the drug's effectiveness in cancers of women, and thousands of American women may have suffered needlessly because of that failure.

If Hillary Rodham Clinton's task force missed the article in *Penthouse*, this *Omni* update is giving her staff and the Department of Health and Human Services another opportunity. We hope this investigation comes to Mrs. Clinton's attention and to that of Secretary Shalala. Congressional investigators who have examined the documentation for my article have already decided to move forward with their own probe. Soon, NCI officials may have to testify under oath about their actions and lack thereof.

The very first thing that needs to be done is ordering new, unbiased clinical trials of hydrazine sulfate by respected scientists who are not part of the old-boy network which trashed and sabotaged this drug for almost 20 years. This is one piece of health-care reform that requires no new taxes—just the will to get it done. Hundreds of thousands of lives are at stake in the United States alone over the next year.

Author's note: Jeff Kamen is at work on a book and documentary film about hydrazine sulfate. He asks anyone who has had firsthand experience with the drug to write him at Box 15600, Washington, DC 20003.

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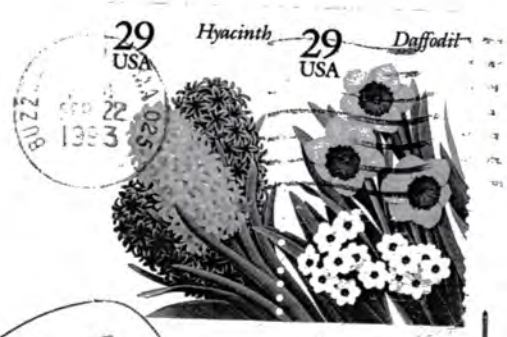

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