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COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 8300

FOLDER TITLE:
[Miscellaneous Correspondence] [loose] [1]

2018-0756-F
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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]
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b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

185 Quarry Road
Warwick, MA 01378

Tel:(508)249-4696
Fax:(508)249-2134

November 8, 1993

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
200 Independence Ave. S.W. (Rm.729H)
Washington, D.C. 20201

Fax: (202)690-7054

Dear Ms. Gebbie:

Thank you for your latest correspondence of September 3, 1993. Attached is a "letter to the editor" from a news and arts weekly, which I believe would interest you. It deals with an HIV infected man's personal experience, and his awareness of other people who are consciously spreading the deadly virus.

We need a new policy to prevent the indecent spread of such misery and terror, which even effects the newly born. From my perspective, the National AIDS Policy has been stuck in the same ineffective policy of the last ten years. The man who wrote the attached letter understands the controversy of mandatory testing; but it may be the only way to make people responsible for unethical and criminal actions, which spreads the disease to many innocent people.

The debate of mandatory testing, alone, would make an effective AIDS education policy. The American people appreciate ideas rooted in common sense and common decency. Democracy in this day and age requires flexibility to adapt to present circumstances. I urge you to allow us to introduce such ideas, understanding that only our elected representatives, judicial branch and public referendum could successfully enact such a program.

I would be interested in receiving President Clinton's response to this letter and enclosure.

The opportunity to communicate with you is deeply appreciated, and I hope that our Nation's AIDS Policy will be more pronounced and effective.

Sincerely,

Jonathan Haber

Jonathan Haber

Attached: as noted above

ph/geb

TERS

on and on to include roughly 150 women and men who either in word or deed have taken a stand against the egregious violations of national and international law perpetrated by the United States government against the rights of people both within and outside the borders of the United States. The price they have paid is enormous.

I hope that people do take the time to write to President Clinton and others "in power" about Leonard's situation and I urge everyone to seek out a copy of Robert Redford's documentary on Leonard's case, called "Incident at Oglala." It's available at several local video stores.

For anyone interested in contributing to the children of political prisoners, please contact Robert Meerpool. Rosenberg Fund for Children, 1145 Main Street, Suite 408, Springfield, MA 01103 or call 739-9020.

For more information on political prisoners, please write to the Center for Constitutional Rights, 666 Broadway, New York, NY 10012 (212 614-6464).

Christina M. Ryan

AIDS Tests for Marriage Licenses (and more)

Many people with the AIDS virus are still out there shooting drugs and having sex for money. And some who don't practice this type of untraditional morality are just vindictive—they feel they've been dealt a bad hand in life because they have this virus, and they could care less who they murder. These people reject morality and their hearts have hardened into stone.

I know who these people are. I've sat in support groups with them, and after leaving I've seen them working the streets. People who've shot dope with them report, "They never told me they have the virus."

The first month I was diagnosed with this virus I came right out and told friends, and even people I don't know. Ethically, I can't see how if I'm going to be around other people, I can be dishonest with them.

It was in 1980 that 55 men were first diagnosed with the AIDS virus. Now there is a devastation of death. By the year 2000 some 60 million people in the world will be infected with HIV.

I'm saying that we need a stronger moral code in this country with dealing with this disease. Does this mean I'm saying that our civil rights are going to have to be decreased? Yes and no.

Mandatory testing is common sense. The civil rights issue should not even be a question in three instances: One, homosexual bathhouses are still in operation where there still is high-risk sexual behavior. People who go to these bathhouses should be tested for the HIV virus. Two, prostitutes. Some people believe that prostitution is a victimless crime. But it is a crime when prostitutes are not telling their clients that they are HIV positive. Murder is the crime. Three, drug addicts who get high with hypodermic needles.

Education is the first step. We are way beyond that first step—it's time now to confront this disease head on, going after those who knowingly pass it on to another individual. We should also look at mandatory testing of pregnant women; anyone between 15 and 60 who is admitted to a hospital; convicted prostitutes; and all marriage license applicants.

Ernest W. O.

The *Valley Advocate* welcomes letters to the editor from our readers. Please send to: Letters, The Valley Advocate, 87 School Street, Hatfield, MA 01038 and include a telephone number where you can be reached days. Letters for publication must be signed; keep length to 300 words or less.

CITY OF BALTIMORE

KURT L. SCHMOKE, Mayor

OFFICE OF THE MAYOR

250 City Hall
Baltimore, Maryland 21202

January 10, 1994

Bob —
Read carefully &
Draft what advice
we might give
W H / HHS
on this —

Kristine Gebbie, R.N., M.N.
AIDS Coordinator
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20500

Dear Ms. Gebbie:

Attached is a copy of a letter I recently sent to President Clinton regarding a proposal to make Baltimore a pilot site for a new public health approach to the "war on drugs".

Any assistance you can give us in gaining approval for this project would be greatly appreciated.

Sincerely,

Kurt Schmoke
Mayor

Attachment

CITY OF BALTIMORE

KURT L. SCHMOKE, Mayor

OFFICE OF THE MAYOR

250 City Hall
Baltimore, Maryland 21202

November 24, 1993

President William Jefferson Clinton
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Dear President Clinton:

As you are well aware, substance abuse and its attendant consequences, especially AIDS and violent crime, are a major problem in all areas of the country, but particularly in our inner cities. For some time now, I have been calling for a halt to the "war on drugs" that has been waged, unsuccessfully, for years. I think it is imperative that we view substance abuse as a public health problem and treat it as such by reversing the current balance of funding related to illicit drugs from 70% for law enforcement and 30% for treatment/prevention.

However, before the Federal government would undertake such a funding change, I believe it would be a good idea to test the hypothesis that adequately funding treatment and prevention services will, indeed, decrease the prevalence of substance abuse and its consequences, and be cost-effective. Therefore, I would like to propose that Baltimore, along with two other cities, be a pilot site for such funding. In our city, we estimate that we need to increase the number of drug treatment slots from our current 5,300 by approximately 10,000 slots to enable all who desire and need treatment to avail themselves of it. I am enclosing a brief proposal on how these 10,000 slots would be allocated, their cost, and possible barriers to implementation. In addition to adequately funding treatment, further funding is necessary on substance abuse prevention, particularly in our schools.

If such a treatment/prevention expansion were to be funded, a rigorous evaluation of the outcomes of this expansion would need to be done. I would suggest that some of the outcomes to be evaluated would include: a) success in getting substance abusers drug-free or on to methadone maintenance; b) changes in the rates of drug use, particularly among young people; c) change in HIV seropositivity among injection drug users; d) change in costs related to HIV/AIDS care; e) changes in violent crime rates; and f) changes in costs related to arrest, prosecution and

incarceration of drug offenders. Such an evaluation could be conducted under the auspices of the NIH or CDC, or could be run by research institutions. I am sure that one of our outstanding research universities would be quite interested in participating.

Given your Administration's interest in cooperative approaches to major problems, perhaps an inter-agency collaborative arrangement between the Justice Department and the Department of Health and Human Services could be instituted to fund such a program, and waive certain regulations which may be barriers to full implementation of this proposal.

I look forward to hearing from you. Thanks again for the inspiring speech you made at the Convocation of the Church of God in Christ in Memphis.

Sincerely,

Kurt Schmoke
Mayor

KLS:cc

Enclosure

EXPANSION OF BALTIMORE'S SUBSTANCE ABUSE TREATMENT SYSTEM: A CONCEPT PAPER

Background

Baltimore's treatment and recovery system is currently composed of 46 publicly funded treatment providers and 32 privately and federally funded substance abuse treatment programs and hospital-based detoxification units. Across all programs in FY 92, a total of 22,257 clients were treated in Baltimore. Among the publicly-funded program, there are approximately 5300 treatment slots, with 17,000 admissions per year. Roughly half of the available slots are in methadone maintenance programs.

The range of treatment modalities includes outpatient alcohol and drug-free counseling; outpatient methadone maintenance; intermediate care (i.e., 28-day residential treatment); intensive outpatient or day-treatment; halfway houses offering residential living and support for up to one year; outpatient acupuncture detoxification; and assessment and referral services.

Funding for Baltimore's treatment and prevention services comes from a block grant of combined State General Revenue Funds and Federal ADMS Block Grant Funds. Baltimore currently receives approximately $17 million from the State to support public treatment and prevention services. Over $16 million of these dollars are used to support the publicly funded treatment system.

The Need for Treatment Expansion

Prevalence of substance abuse among Baltimore's population is conservatively estimated at 47,800 (based on estimates from the National Household Survey of Drug Abuse). This estimate includes a duplicated count of approximately 35,000 heroin users and approximately 20,000 cocaine users. This estimate excludes persons abusing alcohol; separate estimates indicate that there are at least 70,000 alcohol abusers in Baltimore City; many of whom also use street drugs.

In FY 1992, Baltimore City substance abuse treatment programs provided services to 22,257 clients, of which 14,947 (67.2%) were male and 7,310 were female (32.8%). Approximately 22% were treated by private treatment programs and 78% by publicly funded programs. Given these statistics, it appears that Baltimore is able to provide treatment to fewer than half of those individuals potentially in need of treatment services.

In order to provide treatment on demand to residents in need of addiction services, Baltimore will need approximately 10,000 more treatment slots across all ranges of treatment modalities and serving the general population as well as special needs populations (e.g., the homeless, the dually diagnosed, women and their children). The total cost for these additional slots is approximately $30 million, with another $1 million needed for training and implementation costs, and another $1 million for substance abuse prevention efforts.

A Treatment Expansion Plan

Expansion of Baltimore's treatment system to accommodate 10,000 additional slots will require the establishment of new slots in existing programs, as well as the creation of new programs. There exists some slot expansion capacity on the part of most existing programs, but existing programs could not accommodate as many as 10,000 new slots.

Below is detailed a strategy for the establishment of these new slots in the areas of: (1) methadone maintenance, (2) drug-free programs, and (3) treatment in primary care facilities.

(1) Methadone maintenance

Estimated need: 5,000 slots

Estimated cost: $3,000/slot
Total cost: $15,000,000

Distribution of slots:

- Existing publicly-funded methadone maintenance programs could absorb approximately 1,000 slots (this includes providing additional slots through the Mobile Treatment Van by providing additional vehicles).
- Certain existing community health centers (Total Health Care, Park West, and People's Community Health Center) may have the interest in establishing comprehensive drug treatment programs that include methadone maintenance. It is estimated that 400 methadone slots could be established in these settings.
- The one existing private methadone program (i.e., Glass) could probably absorb 200 more slots through a contract with the City.
- The remaining 3400 slots would have to be established in new treatment programs developed by interested facilities and programs. The ideal way to identify these sites would be through the issuance of a Request for Proposals.

Barriers/deterrents:

- Possible deterrents to new facilities opening methadone treatment programs include:
  - Limited opportunity to clear a profit (of special concern to private programs or practitioners)
  - The amount of time and effort required in handling the billing and collection procedures.
  - Zoning and community opposition to the establishment of the program in the neighborhood.
  - Identification of and obtaining a suitable facility.
  - Meeting and maintaining State and Federal regulations, reporting requirements and certification.
  - Perceived and/or real difficulties with treating persons addicted to drugs, including the behavioral, legal, social and medical challenges they present.

(2) Drug-free Programs

Estimated need: 3,000 slots

Estimated cost: $3,000/slot (Note: Although drug-free counseling slots are traditionally less expensive than methadone maintenance, they also show less success. To improve their success rate, add-on services such as intensive case management should be provided, thereby driving up the slot cost.)
Total cost: $9,000,000

Distribution of slots:

- Existing publicly-funded and private programs could absorb some slots; the remaining slots would have to be established in new treatment programs identified through the issuance of a Request for Proposals.
- Would need to create new programs to meet special needs (e.g., transitional housing/treatment for pregnant women)
- Would need at least 200 more residential treatment slots (of which existing programs could probably absorb 100) for the general population
- Would need at least 300 residential treatment slots for special needs populations (e.g., dually-diagnosed, homeless)
- Would need approximately 100 short-term non-hospital detoxification slots.

Barriers/deterrents:

- Deterrents to new facilities opening drug-free outpatient or residential treatment programs include are similar to those listed above for methadone maintenance programs.

(3) Treatment in Primary Care

Estimated need: 2,000 slots

Estimated cost: $3,000/slot (it may be less)
Total cost: $6,000,000

Considerations:

- Primary care providers traditionally have not also been providers of substance abuse treatment within their own clinics or office practices. A few examples of primary care providers entering the arena of substance abuse treatment do exist in Baltimore. For example, a primary care physician at Maryland General Hospital has gotten a license to dispense methadone within the detox program at the hospital (not within his private practice). There are also private practitioners (e.g., Dr. Patricia Newton) who serve substance abusing patients in their practices and offer acupuncture or detox, but they are not advertised as addiction treatment services (generally, their services are listed under mental health or general

counseling). The State does not certify these practices and no data is collected about their services.

- For primary care providers to begin offering treatment services, many steps must first occur:
  - Establishment of training programs so that providers and their staff become educated in the treatment of addictions.
  - Education of providers regarding the steps necessary to take to become a certified treatment program. If State dollars are used for these providers to offer treatment services, the providers must become certified treatment programs, following all State requirements for certification (including having adequate staff with appropriate addictions backgrounds). Even if State dollars are not used, these providers will still need to meet certification requirements to advertise themselves as offering addiction services.
  - The BCHD should consider hiring consultant physicians (as is the case in Amsterdam) who provide consulting services to physicians treating addicted patients. These physicians can provide technical assistance and help determine if a patient's needs are so severe that the patient would be better served in a publicly-funded treatment program.

Barriers/deterrents:

- There is little incentive for private providers to enter the treatment field. Profit margins are low (if at all existent) unless services are provided to private pay or third-party insured patients.
- The State certification requirements will prove onerous for private practitioners or private clinics.

THE WHITE HOUSE

WASHINGTON

February 4, 1994

The Honorable Kurt L. Schmoke, Mayor
City of Baltimore
Office of the Mayor
250 City Hall
Baltimore, Maryland 21202

Dear Mayor Schmoke,

Thank you for your letter of January 10 requesting my assistance in gaining approval for Baltimore to be treated as a "pilot site" for special assistance in developing a new public health initiative to help deal with the drug problem. I am delighted that Lee Brown and the Office of National Drug Control Policy have seen fit to develop a specialized initiative for both Baltimore and Washington, D.C. as a part of their new efforts. I understand that Baltimore will be eligible for its share of more than 300 Million dollars which are being added to the Alcohol, Drug, and Mental Health Block Grants as well.

I also believe that a good portion of your proposal should also be helped by the passage of the President's Health Security Act. Under that plan many of your citizens will be eligible for treatment services who are not currently eligible. The new resources which you can identify may well be most cost effectively used to pick up all or a portion of the co-payments which will be required. Either way this plan should allow the enfranchisement of many who would have been unable to get treatment services and should substantially expand the treatment resources available.

The problems our Nation faces with drugs, violence, and AIDS/HIV are finally being recognized as the public health problems that they are and their relationships to each other are also finally being acknowledged. I am delighted that you are moving your city's efforts in that direction as well.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

The Honorable Kurt L. Schmoke, Mayor
City of Baltimore
Office of the Mayor
250 City Hall
Baltimore, Maryland 21202

John / Terry - do you see any mileage in a letter to the Post or other followup? Don's points are fairly consistent w/ my observations -

RECEIVED JAN 24 1994

---ONE PAGE FAX---
TO: Kristine Gebbie (202)632-1096 Fax
FROM: Don Burke / (301)295-6422 Fax
DATE: 23 January 1994
SUBJ: Washington Post article today

Kristine,

I was dismayed to read the article by John Schwartz today entitled "Pentagon Drops Plan to Test an AIDS Vaccine: Health officials had opposed single-drug trial." My parochial objections:

(1) The facts are wrong: From my perspective the true agency positions are completely reversed in this article. The Army has expressly opposed doing this trial since it was first proposed in August 1992. The gp160 trial never would have gone forward had not the NIH and FDA voted for doing the trial in November 1992. The "spin" in this article suggests that the DHHS (NIH and FDA) has convinced the DoD to reverse its position. In fact, exactly the opposite happened: finally the NIH and FDA reversed their position after initially declining the opportunity to veto the trial 15 months ago.

(2) No effort was made to get the facts straight: no DoD officials are quoted, or apparently were contacted by Mr. Schwartz for comment. I was not contacted, nor as far as I know was anyone in DoD Public Affairs.

(3) The article seems to intentionally provoke conflict between agencies. This is the sixth straight Washington Post article on the gp160 issue in which the following phrase is reprinted verbatim: "The Defense Department, with its huge network of medical facilities, has long played a major role in AIDS drug research ... But choosing which drugs to test traditionally has been the role of NIH." This view is incorrect. Decisions about which drugs and vaccines to test within the DoD have always been, and always will be, the exclusive prerogative of the DoD. It is not clear why the Washington Post perseverates on this erroneous notion.

Taking a step back from these admittedly parochial (but nonetheless legitimate) objections, it seems to me that the real tragedy here is that the Post failed to pick up on the story that the agencies acted in cooperation on this issue. I would gladly have accepted these few distortions of reality had the article reflected what I believed to be truly happening - that all government parties had finally agreed on a best course of action to serve the public interest. Any ideas as to why the Post didn't present the story this way? And how can we get a better resolution next time?

Don

THE WHITE HOUSE
WASHINGTON

Don —
your points are well-
taken, but I don't know
that there's much to be done
about it — we're doing
some inquiries —
Maybe I/we goofed in not
putting out an announcement
of our own — a lesson
for the next time —

RCutler

MEMORIAL HOSPITAL
of Rhode Island
DEPARTMENT OF MEDICINE

BROWN UNIVERSITY
School of Medicine

December 10, 1993

Mr. Steven Lee
c/o Ms. Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, NW/Suite 1060
Washington, DC 20503

Dear Mr. Lee,

I just spoke with Mr. Terry Beswick about several areas of mutual interest with regard to AIDS research. He also indicated to me that Ms. Kristine Gebbie and you are in receipt of a letter that I sent on behalf of the Brown University AIDS Program (dated November 18, 1993), in which I invited her to visit Brown University and to give a major policy address related to AIDS on a topic of her choosing. Terry, who I know and his previous incarnation from community-based clinical AIDS research, indicated to me that the next step for me would be to contact you directly and indicate the possible format and topics that might be appropriate to the Rhode Island setting.

As you are aware, the University is a small free-standing, private university which prides itself on its liberal educational traditions. The Medical School is fairly new and has a great emphasis on primary care. The Brown-affiliated teaching hospitals are located off campus and provide primary and specialty care for more than 90% of the people living in Rhode Island with HIV infection. To give you and Ms. Gebbie a better idea of the demographics of the epidemic in Rhode Island, I have enclosed two recent publications that are relevant. The article in the Brown Alumni Monthly underscores the fact that we have made a major commitment to studying the natural history of HIV in women early on in the epidemic. Thus, we have developed a wide array of programs that are specific for HIV-infected women. Brown is currently one of the four Centers for Disease Control-funded sites in which the HIV Epidemiology Research (HER) Study is being conducted which fully enrolled will be the first large-scale national study of the epidemic in women. The second publication is a special issue of Rhode Island Medicine which deals with many aspects of the epidemic in Rhode Island. Because Rhode Island has such a small minority population because of a large number of intravenous drug users, some of the demographics of the epidemic in Rhode Island are distinctive, i.e. increased numbers of women infected, increased heterosexual transmission, and increased prevalence among Caucasians.

Division of Infectious Diseases
Pawtucket, Rhode Island 02860 401-729-2000

I would not be as presumptuous as to tell you or Ms. Gebbie what you should come here to talk about. However, Brown program strengths have been in some of the issues I have mentioned above (i.e. studies of HIV in women, as well as NIH-funded studies of the heterosexual spread of HIV. In addition, we have been one of the American Foundation for AIDS Research funded Community-Based Clinical Trial sites and thus have made a major commitment to low tech community-based clinical research. Thus, the Brown campus could be a very appropriate setting for discussing the changing demography of the epidemic, or the need for the federal government, community-based clinical researchers, and industry to forge novel partnerships. We are really flexible with regard to the date of Dr. Gebbie's visit. Thus, we would be more eager to work directly with you or one of your staff people to find a time that would work in both the academic and clinical calendars here and with regard to her work schedule.

In terms of the specific format of her visit, we are also open to discussion. We often have invited distinguished speakers from different parts of the country. They fly in early in the morning or early afternoon and give their talk in the late afternoon. We often try to schedule either a luncheon or dinner in honor of the speaker and try to find opportunities for the speaker to meet with interested colleagues. Thus, we would be happy to arrange for meetings of Dr. Gebbie with specific Brown faculty if you indicate to us area that you think would interest her the most. We have researchers working in areas of epidemiology and community health, virology, clinical medicine, immunology, etc.

We also work very closely with several important community groups that have distinctive programs that might make for interesting visits for Kris Gebbie. For example, there is a home for families and children, the FACTS House (Family and Children Treatment Services), that offers a comprehensive family based continuum of care for people living with HIV and their families. We also have a definitive program for HIV outreach in the community as well as a program for HIV screening and education in our correctional facilities. We have a very active Center for Alcohol and Addiction Studies that looks at some of the AIDS-related risk behaviors, and we work very closely with the local community-based AIDS service organization, Rhode Island Project AIDS. We would be happy to arrange for meetings for Ms. Gebbie and be happy to be in contact with the local media.

Terry Beswick indicated that there are very few travel funds available for Ms. Gebbie. We have very little in the way of additional funding in the Brown University AIDS Program as most of our grants are educational. But in lieu of paying Ms. Gebbie an honorarium, we could certainly reimburse her for the coach fare flight to and from Washington, DC to Providence. Once in Providence, we would be delighted to have her as our guest for a meal and be responsible for all of her transportation and other arrangements. Please get in touch with me at your earliest convenience if you think it is feasible for us

to arrange for a day visit of Ms. Gebbie to Brown and the affiliated teaching hospitals and other associated AIDS-related activities in our community. Once we have established contact, I can be in touch with our colleagues in the State Department of Health and other related agencies in order to maximize her exposure during this visit. Thank you once again for your consideration.

Best wishes,

Kenneth Mayer

Kenneth H. Mayer, M.D.
Chief, Infectious Disease Division
Memorial Hospital of Rhode Island

Professor of Medicine and Community Health
Brown University School of Medicine

Director, Brown University AIDS Program

KHM/nkp
Enclosure
cc: M Freeland

Women AND AIDS

One in eight new AIDS patients in the United States is a woman, but until recently their special symptoms and needs were ignored by the health-care establishment. A team of Brown medical researchers is beginning to make a difference

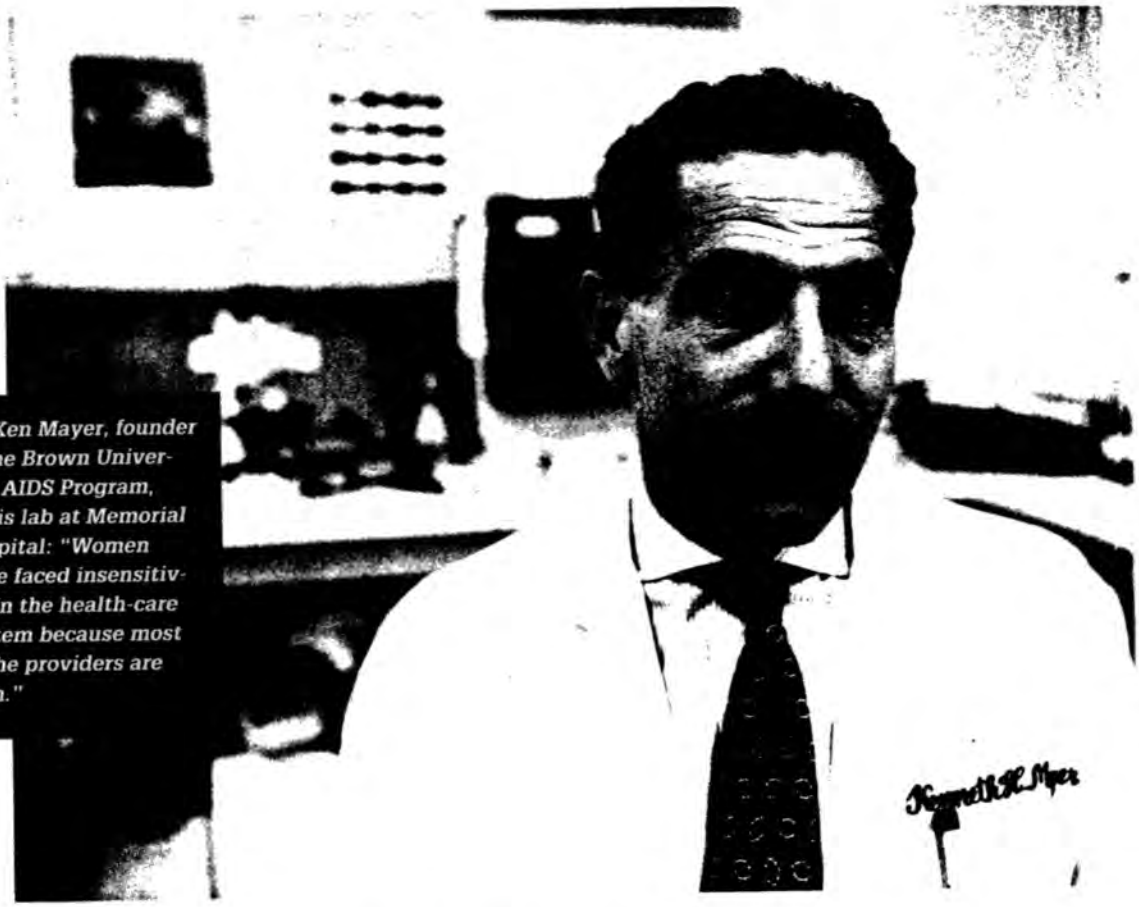
By Jennifer Sutton

In 1986 Donna Keegan got herself clean. She left behind an addiction to alcohol that began in her teens and a twelve-year drug binge that rocked her twenties. Her thirties, and the rest of her life, she hoped, would be happier.

Now thirty-eight, Keegan has found peace and confidence. She has grown into a close relationship with her fifteen-year-old daughter, and two years ago she fell in love and married for the first time. Tall and robust with rosy cheeks, fashionably cropped blonde hair, and a strong, self-assured manner, she looks the picture of health. She talks fast, her blue eyes flashing as she tells an abridged version of her life story.

One of the recent chapters in that story is about Keegan's fight for decent health care in the face of a terrifying illness. After detox, after pulling her life together, after going back to school and finding a new job, Keegan developed a nagging yeast infection that wouldn't go away. Anti-fungal medication

helped temporarily, but as soon as Keegan used up one of her many prescriptions, the infection returned. Over the next few years, other symptoms became chronic, including sinus infections, thrush (an oral yeast infection most often seen in newborns), skin rashes, neuropathy (a nerve disorder in the hands and feet), and sore joints. In late 1988, Keegan's pap smear showed cervical dysplasia, which developed into full-blown cancer in five months and required a hysterectomy.



Dr. Ken Mayer, founder of the Brown University AIDS Program, in his lab at Memorial Hospital: "Women have faced insensitivity in the health-care system because most of the providers are men."

Despite Keegan's known history of drug use and unprotected sex, the doctors at her health maintenance organization never suggested she get tested for Human Immunodeficiency Virus (HIV), the disease that causes Acquired Immune Deficiency Syndrome (AIDS). They did test her for lupus several times, with negative results, and they treated her yeast infections – again and again and again – without pursuing a cause. When Keegan asked the obvious question – why do I keep getting sick? – they responded with assurances that there was nothing seriously wrong.

"I was in the doctor's office all the time, but they didn't have a clue that what I was going through were possible red flags for HIV," Keegan says. "They treated me like I was a nosy person. Every time I asked a question that maybe they didn't know the answer to, a wall would go up. It got so I hated to see the doctor, because every time I went in there, I ended up feeling worse than before, like I was a bad patient."

Finally, Keegan diagnosed herself. In the fall of 1990 she went to an anonymous HIV testing site in Boston, and the results came back in a big, red stamp on a piece of paper: positive. Because she took so many risks during her drinking and drug-taking years, Keegan is unsure when and how the virus entered her body. It could have been dirty needles or unprotected sex; it could have been the blood transfusions doctors ordered during several operations she had before the medical industry began monitoring blood supplies in the mid-1980s.

However Keegan got HIV, she believes it lived in her body undetected for at least four years. Unfortunately, her experience is typical of women who contract HIV. The virus affects women differently than it does men, manifesting itself most often in gynecological disorders. Although Keegan's was a textbook case – chronic yeast infections, thrush, cervical cancer – the textbook is just now being written. Research on women and AIDS is relatively scarce, compared to that on gay and intravenous-drug-using men, and so are doctors who can spot early symptoms in women. It wasn't until last January that the Centers for Disease Control and Prevention (CDC) included invasive cervical cancer on the U.S. government's official list of illnesses that define AIDS.

Once diagnosed, Keegan might have expected her treatment to improve. But when she requested a mental health referral at the HMO, her doctor asked why she thought she needed counseling. When she decided to switch doctors, she says her new physician warned her that he "didn't want to be known as the HIV doctor."

Worried by the HMO's insensitivity, a priest and social worker who led Keegan's HIV support group in southeastern Massachusetts put her in touch with Dr. Charles Carpenter, a professor of medicine at Brown. "I was terrified," Keegan remembers. "This was my third doctor, and if it didn't work this time, I was really going to feel like a bad patient."

It was December of 1991 when Keegan met Carpenter. "I tried to explain how I felt and what had happened," she says. "He just listened and listened and listened."

In most parts of the country, women don't find out they're HIV-positive until late in the course of the disease," Carpenter says, sitting in his office at Providence's Miriam Hospital, where he is physician-in-chief. "By that time, it's often too late to help them very much."

Carpenter is a tall man, well over six feet, all sharp angles in a white lab coat. His voice softens the picture: quiet and low, with a trace of a southern accent. A well-known expert on cholera before HIV began appearing in the early 1980s, Carpenter came to Brown in 1986 from Case Western Reserve and, before that, Johns Hopkins. He now divides his time

between seeing patients at Miriam's AIDS clinic; traveling around the country – often to Washington, D.C., where he is chairman of the National Institutes of Health's (NIH) AIDS Program Advisory Committee; and overseeing research projects on HIV for the Brown University AIDS Program (BRUNAP), of which he is an associate director.

BRUNAP is the creation of Dr. Kenneth Mayer, associate professor of medicine. Chief of infectious diseases at Memorial Hospital in Pawtucket and a board member of the American Foundation for AIDS Research, Mayer launched his medical career in Boston just as HIV began infecting gay men. He came to Brown in 1983, and in 1988 he established the AIDS program to connect medical-school faculty who were working with HIV and AIDS on campus and at the eight hospitals affiliated with Brown. That interdisciplinary approach has allowed the program to combine the expertise of researchers, psychiatrists, gynecologists, pediatricians, internists, and others. "AIDS is a perfect paradigm for how Brown works best," Mayer says. "It pulls people together. The whole is stronger than the sum of the parts."

BRUNAP is one of a handful of research groups across the country that are focusing on women with HIV and AIDS. Of the joint projects conducted under the BRUNAP umbrella, the largest, currently, is the HIV Epidemiology Research Study (HERS), an examination of the natural course of HIV and AIDS in several hundred women in Rhode Island and southeastern Massachusetts. Funded by the CDC and NIH at Brown and three other research sites, the study is the first of its kind to concentrate exclusively on women.

For Donna Keegan, such research is long overdue. During the epidemic's first few years in the United States, one woman got AIDS for every twenty men who fell ill. Now the national ratio is one woman for every seven men, and in poor urban areas such as the South Bronx, in parts of the rural South, and among teenagers, the male-female ratio is closer to fifty-fifty. In Rhode Island, according to state Department of Health documents, one woman for every nine men got AIDS before 1987; in 1992, the ratio was one woman for every three men.

Many of these women contract HIV through drug use, but more and more, they are being infected by male sex partners – husbands, boyfriends, johns – who use or once used injection drugs. The statistics are frightening: until 1988, heterosexual transmission accounted for 22 percent of the female HIV cases in Rhode Island and southeastern Massachusetts that were monitored by Brown doctors; since 1991, it has accounted for 75 percent. Mayer predicts that the majority of all new local HIV cases in the next year will result from sex between men and women. It's impossible to know exactly how many women in the region have HIV, but Carpenter estimates that Brown doctors treat nine of every ten. Most of them are poor.

Because Rhode Island's population is overwhelmingly white, Brown doctors treat a smaller proportion of minority women than do most urban clinics and hospitals, where three-quarters of the patients are minorities, mainly African-American and Latina. But minorities in southeastern New England still contract the virus at a disproportionately high rate: they make up one-tenth of the population, but one-third of the HIV cases.

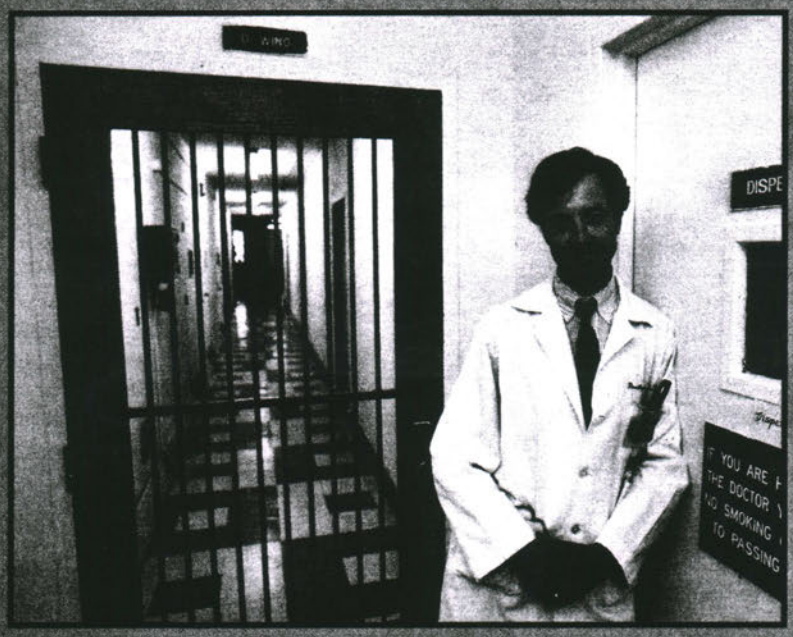
Women need not be promiscuous to contract HIV. Those treated by Carpenter who got the virus through heterosexual sex "range from university professors and business executives to women on welfare," he says. "They simply had, at some time in the past, a relationship with a man who was HIV-infected." Among women participating in the HERS study who contracted the virus heterosexually, the median number of sexual partners in the past decade was two.

With such seemingly tame sexual histories, women infected with the virus often don't know they've been at risk, so they see no reason to seek testing. Some may be aware of a partner's risky habits, but fears of HIV and how it will affect their families keep them from getting tested. Or, like Donna Keegan, they rely on doctors who know so little about the virus in women that they fail to diagnose it early on.

Pelvic Inflammatory Disease and recurring vaginal infections are possible symptoms of HIV, and BRUNAP gynecologist Susan Cu-Uvin of Miriam Hospital has found that women with HIV are three times more likely to have abnormal pap smears – which can indicate the early stages of cervical cancer – than women who do not carry the virus. But when AIDS and HIV were first defined by the Centers for Disease Control, very few women had developed the disease, so official symptoms were based on the male immune system. Until the CDC updated its definition in January, a gay man with one Kaposi's sarcoma lesion on his body would be recorded as having AIDS, while a woman such as Donna Keegan, with cervical cancer and years of other gynecological illnesses, would not.

"Men don't have vaginas," states epidemiologist Sally Zierler, associate professor of medical science. "All the questions that have been asked about women's experience with HIV have been in terms of men's experience. But that assumes there's nothing outside of men's experience, which is simply not true." Zierler, an associate director of the Brown AIDS program, isn't just talking about medical symptoms. There's a world of social pressures that make women especially vulnerable to the virus and its aftermath that rarely, if ever, occur with men.

In most cultures, men are allowed more sexual freedoms than women: if a teenaged boy has sex with several partners, he is considered macho; if a teenaged girl does the same, she is likely to be branded a slut. Females are expected to be "good," to hide their sexuality, but even if a woman stays monogamous, she may not be safe from HIV. Women are three times more likely to contract the virus through heterosexual contact than men, but they must depend on condoms – and their partners' willingness to wear them – to prevent transmission. When men dominate heterosexual relationships, women may fear violence or abandonment if they even suggest protecting themselves from HIV. This is especially true among women who have been abused. "To say to a woman, 'Here, use a condom,' is at the very least meaningless, and in many cases, it's dangerous.



Dr. Timothy Flanigan, assistant professor of medicine, pays weekly visits to the women's prison in Cranston, Rhode Island, where 12 percent of the inmates have HIV or AIDS.

AIDS at the ACI: Specialized care for the high-risk prison population

It's a steamy July day in the middle of a heat wave, and most prisoners and guards at the Adult Correctional Institutions (ACI), Rhode Island's only prison, are moving in slow motion to keep from sweating. The grounds bake in the thick, sultry air, and on top of the gates, coils of barbed wire glint sharply in the sun.

Dr. Timothy Flanigan, assistant professor of medicine, seems immune to the heat. He strides across the grounds at a rapid clip, talking nonstop, his white doctor's coat flapping around him. "It's wild, isn't it?" he asks later. "The first time I came here, I thought it was the Gulag Archipelago."

Flanigan, director of immunology at Miriam Hospital, heads a small team of doctors, nurses, and social workers who provide specialized health care to ACI inmates with HIV and AIDS. The program, a cooperative effort by the Brown University AIDS program and the state Departments of Health and Corrections, is one of the few examples in the country – if not the only one – of academic hospital personnel going into public prisons to treat patients with the virus, according to Flanigan.

"Prisons, traditionally, are unfriendly to academic environments," he says. The cooperative arrangement works in Rhode Island, he explains, "because we're a small state and people know each other. It's easier to build a trust between the institutions and cut through all the individual agendas."

Dr. Charles Carpenter of Brown University and Miriam Hospital began treating HIV-positive inmates at the prison in 1986, but the program wasn't officially established until 1989, when the state passed a law that requires HIV testing for all convicted criminals entering the ACI. Flanigan took over when he came to Brown in 1991. By that time, the medical team had treated one-quarter of the state's AIDS cases.

As Brown's AIDS program has begun paying more attention to women with the virus, so have Flanigan and his colleagues. And with good reason. In 1990, 40 percent of the women who tested positive for HIV in Rhode Island were tested at the ACI. One-third of the women who pass through Miriam Hospital's AIDS clinic have been in the prison at least once. And about 12 percent of the female inmates have HIV or AIDS, compared with 4 percent of the men. Flanigan says the women test positive for HIV at a higher rate than men because almost all of them are arrested on drug-related charges.

All inmates, women and men, receive counseling with social workers after the HIV test. If they test positive for the virus, they see Flanigan or another attending physician regularly. A few months before they're released from prison, they sit down with a nurse for "discharge planning" – a discussion of where they'll live, what social services they need, and where they'll receive follow-up medical care. "For a lot of these people, it's the first time they've ever gotten comprehensive care," says Flanigan.

Many released inmates end up back in prison, but more than half "succeed," Flanigan says, which means they keep in touch with his staff and continue to seek medical care at an AIDS clinic. Women tend to follow up with their medical care at a higher rate than men, mainly because "they're more likely to have children," Flanigan says. "They want to stay healthy so they can take care of the kids. The kids mean everything to them." – *J.S.*

There's no appreciation of what a test that's going to be for her," Zierler says. "It all comes down to an issue of power. For her to say, 'I want you to use a condom,' suggests that she's taking control of a dynamic that she's not supposed to. It's putting a restriction on her man and making a statement about his behavior. If that's interpreted as judgmental, then she's breaking the rules."

The consensus among researchers at Brown and across the country is that women need another option besides condoms. At the international AIDS conference in Berlin this summer, the World Health Organization announced that finding an effective female-controlled method of curbing HIV was at the top of its priority list. One research possibility is a cream or gel that a woman could insert in her vagina to kill the virus – "an invisible shield," Mayer calls it. It would protect against sexually transmitted diseases much as spermicides protect against pregnancy. The only drawback is that the more potent the virucide, the more likely it is to damage vaginal tissues and scare off liability-minded drug companies. "It's a dilemma . . . but I still see reasons to be optimistic," Mayer says.

Another option – recently approved by the U.S. Food and Drug Administration – is the vaginal pouch, better known as the female condom. The plastic pouch looks like a large condom at first glance, rolled up in a small circle, but it unfolds to about seven inches in length and two inches in diameter. A woman inserts it in her vagina like a diaphragm and pulls out the open end so it is visible outside her vagina, where it must be held during intercourse.

"Right now the response to this is, 'You've got to be kidding,'" Zierler laments. "But imagine what people thought when the condom first came out, and how bizarre that must have been." The pouch has not yet gone on the market, but at a projected cost of $2.50 apiece for a one-time use, it's too expensive for the women who need it most. Still, Zierler says, it's a start. "It's the first, and only, female-controlled technology that can prevent sexually transmitted diseases. Women who are heterosexually active better get as used to this as possible because it could save their lives."

Epidemiologist Sally Zierler heightens the awareness of medical students in her public health classes: "Women with HIV come from different cultures, different classes, different experiences. You can't stereotype them."

Unfortunately, however, some women believe their own lives are not worth saving. Many who contract HIV have lived with verbal, physical, or sexual abuse; unstable relationships; drugs and alcohol; and sometimes prostitution. "Their self-esteem is zero," says Dr. Robert Boland, an assistant professor of psychiatry who counsels HIV and AIDS patients at Miriam Hospital. "Life has been crappy for them all along, and HIV is just one more thing that's happened, one more thing to deal with."

In a study published in 1991, Zierler found that women who were sexually abused as children were more likely to put themselves at risk for HIV through unprotected sex and drugs than women who were never abused. They "remove" themselves from their bodies to handle the abuse, Zierler says, and it becomes painful for them to come home, to learn that their bodies need care and attention. Women in abusive situations are also socialized to think that every mistake is their fault – including the virus. Boland explains. "With gay men, you've generally got feelings like 'Why me? What did I do to deserve this?' They get angry. Women, on the other hand, often feel all too well that they deserve this. They've been taught that they're bad people who deserve to die."

But women have children, and children need taking care of. More than 90 percent of the female patients seen by Brown doctors have dependent children, most of whom do not have the virus themselves. These maternal ties create a huge difference in how men and women deal with HIV. "Women's lives revolve around the schedules of their children, and men's lives do not," explains Theresa Fiore, a nurse at Miriam Hospital who helps run the AIDS clinic. "If a mother can't find anyone to watch her kids, or she can't afford [a babysitter], then she's not going to get to a clinic or a support group."

"It's the biggest factor limiting health care for HIV-positive women in this country," Carpenter agrees. "The care

for the children takes precedence over their own care."

Because BRUNAP treats women with HIV as family units, not individual patients, doctors and nurses arm themselves with information about child care, pediatricians, free transportation, and social services. Dr. Peter Smith, associate professor of medicine and director of Rhode Island Hospital's hematology center and pediatric AIDS program, treats both mothers and children with HIV. In the mid-1980s, he cofounded FACTS House – the Family AIDS Center for Treatment and Support – which offers short-term shelter, a nursery, and medical care. Dr. Kevin Vigilante, assistant professor of medicine and a physician at Miriam, recently received funding to start a storefront clinic in Providence that will cater to HIV-negative women just released from prison. The free medical care for women and their children and social-service referrals, he hopes, will keep them away from drugs and prostitution, and, in the end, HIV.

But if a woman does contract the virus, what happens to her children? When Donna Keegan discovered she was carrying HIV, her first thought was for her child, not herself. "What went through my mind immediately was, 'Oh my God, I'm not going to see my daughter graduate from high school,' " she remembers. "Then it was, 'Oh my God, I'm going to die.' "

"I think women handle this much as they do breast cancer," Carpenter muses. "If a woman with kids in high school gets breast cancer, she will undergo any kind of therapy to see those kids through college."

But some women don't live that long. In an article they wrote for *Scientific American* last year, Carpenter and Mayer called AIDS a "grandmother's disease," because mothers dying of AIDS in Africa often depend on *their* mothers to raise their orphaned children. In the United States, however, grandmothers aren't always there to help, since fewer extended families live close together and families often shun a relative with HIV or AIDS. Marianne (not her real name), a patient of Carpenter's who contracted HIV eight years ago, says her mother pushed her down a flight of stairs and disowned her when she disclosed her HIV-positive status. Marianne's daughter is twenty, with a baby and an independent life, but her son, fifteen, is still in school and has no other relatives to turn to. Marianne has no idea what will happen to him when she dies. "It's such a crucial age for a kid to have a mom," she says. "I wish I could be sure he'll be taken care of, but I'm not."

Despite the fact that many women with HIV won't live to see their children grow up, some are eager to get pregnant. One-quarter of the women treated by BRUNAP doctors, when asked if they would go through with a pregnancy even if their baby could be born HIV-positive, said yes. "It doesn't surprise me, because we all know the desire for children, for family, is strong," Mayer says. "But it underscores in my mind why we're going to have such a hard time controlling this epidemic." The statistics vary, but between one-sixth and one-third of all babies born to HIV-infected mothers become infected themselves. Dr. Gail Skowron, assistant professor of medicine and an infectious-disease specialist at Roger Williams Medical Center in Providence, is researching why the virus travels between some mothers and babies but not others, and at what point during the course of pregnancy and birth the transfer occurs. "It doesn't make sense to us yet," she warns. "I'm not sure the answers are close at hand at all." For some women, however, the risk is worth taking. "Having a child can be a very life-affirming thing," says Mayer. "The women might be denying their illness. It might also reflect their optimism. HIV or no HIV, children sometimes play a role in making relationships more real, and people with HIV have the same needs as anyone else not to feel alone in the world. We certainly don't want to dehumanize the people we care for; we just want them to be aware of the implications."

Until recently, pregnancy would disqualify a woman from many trials for AIDS-related drugs and other medications, primarily because drug manufacturers feared lawsuits if their product caused birth defects. While Brown doctors say they understand the companies' point of view, they make sure their drug trials are open to anyone who wants to participate. "Women shouldn't be punished for being pregnant," Cu-Uvin insists.

"Our first duty, as medical professionals," Mayer adds, "is to protect the life of the woman, and she has the right to choose whether she wants to take drugs for the HIV. Our responsibility is to provide her with the best data possible so she can make an informed choice. That's where we come down. The drug companies come down just covering their rears."

It's that kind of closed-mindedness that Donna Keegan wants to change. She has turned her terminal illness into a crusade against ignorance and discrimination, transformed an affliction into activism. Her calendar, she says, is a sea of meetings and appointments. She goes into high schools to talk about HIV, sometimes alone and sometimes accompanied by medical students studying with BRUNAP doctors. She also represents central Massachusetts on an AIDS advisory board for the state Department of Public Health and serves on the board of directors of the nonprofit Massachusetts AIDS Discrimination Initiative. During the summer she traveled to Washington, D.C., where she, with Carpenter, participated in a National Institutes of Health conference, providing a consumer's viewpoint to HIV drug researchers. "It's actually a selfish thing," Keegan claims. "People say, 'Oh, it's so wonderful that you're doing all this.' I say it's self-preservation. I refuse to hang my head in shame for something I didn't ask for."

Keegan knows she is one of the fortunate. Her health, for now, is stable. She takes anti-retroviral medication, although, because the prescription comes as part of a research project, she doesn't know which one. She deals with the occasional headaches, skin rashes, and bowel problems – "nothing major," she says. And she talks with her daughter about the future. "For the first six months, she wouldn't discuss my HIV, wouldn't even listen to me talk about it," Keegan says. "But we talk about bizarre things now, like where I'll be buried and what I'll wear. It's weird and it's painful, but it's healthy. It's reality." ■

OCT 2 8 1993

STATE OF FLORIDA
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

October 25, 1993

Call placed 11/2 no return

Kristine Gebbie, R.N., M.N., F.A.A.N.
National AIDS Policy Coordinator
Executive Office of the President
The White House
Washington, D.C. 20500

Dear Ms. Gebbie:

I am writing to advise you that HRS is in the process of re-examining the issue of confidential HIV infection reporting by name and to request your assistance in this deliberation.

Specifically, I have been asked to prepare a decision memo on mandatory HIV infection reporting for presentation to the new HRS Secretary, James Towey. If such reporting is recommended, it would clearly be confidential, either by name or other unique identifier.

We are attempting to list all of the possible pros and cons, with documentation for all arguments presented on this important issue. I believe that in order to develop a comprehensive analysis of all of the relevant perspectives and issues, it is vital that we have your input. I would appreciate a written opinion from you by November 5. If it is more convenient for you, please feel free to FAX your response to me at (904) 487-3729.

In order to be as comprehensive as possible in our analysis, I will seek the input of other individuals who are close to or part of the affected community. If you know of specific individuals who would be able to provide us with additional facts and opinions, please send me their names and addresses by October 29, or kindly share a copy of this letter with them.

I look forward to hearing from you in the near future. Since you have already given much time and effort to this concept, you may be certain that your thoughtful response will be given very careful consideration.

Thank you once again for your efforts in helping Florida cope with its HIV/AIDS epidemic.

Sincerely,

Paul T. Boisvert
Charles S. Mahan, M.D.
for State Health Officer

1317 WINEWOOD BLVD. • TALLAHASSEE, FL 32399-0700

LAWTON CHILES, GOVERNOR

Carlos rpt'g
Bob Moran needs to see also

December 9, 1993

DEC 14 1993

Christopher Strobel
Office of Congressman Norman Y. Mineta
Rayburn House Office Building, 2221
Washington, D.C. 20515

Dear Chris:

I am writing to follow-up on our discussion earlier this year to address the problem with the Centers for Disease Control and Prevention policy for AIDS surveillance data collection as it pertains to the Asian and Pacific Islander (API) communities.

Through our research, we have that there is currently specific computer systems by state and local health surveillance departments that would allow for easy collection of AIDS cases by racial/ethnic groups in the API communities. I have enclosed a copy of the HIV AIDS Reporting System (HARS) screen for your review. This system would allow local, state and federal surveillance departments the progress of AIDS in the API communities. Currently the CDC does not make it mandatory for state health departments to compile this information. This information is vital for API HIV/AIDS agencies to understand and conduct HIV prevention efforts and provide culturally and linguistically competent services to this under-served population. As you know without numbers, HIV education and funding cannot reach these key communities and the agencies that serve them.

On behalf of A/PAC, I am formally requesting the assistance of Congressman Mineta, in seeking an administrative resolution to this long standing problem. If an administrative solution cannot be reached, I would ask your continued assistance in seeking a legislative remedy to this discriminatory practice. Our office is ready to assist in any way in order to resolve this vital issue.

As always, if you have any questions or comments, please feel free to contact our office at your earliest convenience.

Sincerely,

Rafael

Rafael M. Chang
Public Policy Director

Enclosure

cc: James W. Curran, MD, MPH - Centers for Disease Control and Prevention
Kristine Gebbie, RN, MN - National AIDS Program Office
Dennis Hayashi, Office of Civil Rights
Dr. Philip R. Lee, MD - Department of Health and Human Services

A / P A C Asian / Pacific AIDS Coalition Dept 513, P.O.Box 597004, San Francisco, CA 94159
Admin. Office: 995 Market St., Ste. 1112, San Francisco, CA 94103 Tel. 415/243-8909 Fax 415/243-8628

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001. screen shot	re: Demographic Information; [Pesonally Identifiable Information] [Partial] (1 page)	12/14/1993	b(6)

COLLECTION:
Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbie
OA/Box Number: 8300

FOLDER TITLE:
[Miscellaneous Correspondence] [loose] [1]

2018-0756-F
jp4855

RESTRICTION CODES

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(b)(6)

01 Hispanic	02 Central Amer.	03 Cuban	04 Dominican
05 Mexican	06 Puerto Rican	07 South American	08 Spain/Portugal
21 Asian	22 Chinese	23 Filipino	24 Japanese
25 Korean	26 Asian Indian	27 Vietnamese	28 Loatian
29 Thai	30 Cambodian	31 Pakistani	32 Indonesian
33 Hmong	34 Burmese	35 Bangladeshi	36 Sri Lankan
37 East Indian	38 Malayan	39 Okianowan	40 Taiwanese
41 Singaporean	51 Pacific Islnd	52 Hawaiian	53 Samoan
54 Tongan	55 Tahitian	56 Guamanian Isl.	57 North Mariana
58 Palauan	59 Fijian	60 Micronesian	61 Alaskan Native
62 Aleut	63 Eskimo Indian	71 Amer. Indian	81 Cajun
88 Other	99 Not specified		

xrace

[001]

Asian/Pacific AIDS Coalition
995 Market Street, Suite 1120
San Francisco, CA 94103

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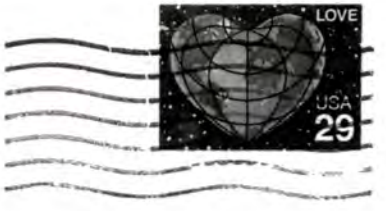

Kristine Gebbie, RN, MN
DHHS - Nati.AIDS Program Off.
Hubert Humphrey Bldg. Rm 738G
200 Independence Avenue, S.W.
Washington, D.C. 20201

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Kristine Gebbie
OA/Box Number: 8300

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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 American College of Obstetricians and Gynecologists

hold for mtg
P McGuire mtg

January 31, 1994

Ms. Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Ms. Gebbie:

On behalf of the American College of Obstetricians and Gynecologists (ACOG), an organization representing more than 34,000 physicians dedicated to improving the health care of women, I am writing to express our interest in working with you and the other primary care specialties to improve the counseling that women receive in their physicians' offices.

This is an issue that we have been concerned with for some time. Recent surveys of both our members and the general public reveal that physicians are not doing as well as we would like in this area. Although AIDS is your primary interest we think other areas warrant concern as well. For example, we have placed a major emphasis on identification of and counseling about domestic violence. Again, we appreciate your leadership in this area and look forward to the opportunity to meet with you.

Sincerely,

Ralph W. Hale, MD
Executive Director

RWH:B:ng

409 12th Street, SW, Washington, DC 20024-2188 (202)638-5577

(b)(6)

Pat Nea Steele

Paulene Barfield

(b)(6)

213/2.

[002]

Wants meeting.

Attn: Jeff Perkins
total pages - 2

Hi Jeff!

Here is another endorsement that I thought would be of interest to Kristine. It was really nice talking to you!

Talk to you soon!

Lisa Geng
516.431.0969
516.431.5662 - fax

The Foundation for Children with AIDS

Geneva Woodruff, Ph.D.
Executive Director

1800 Columbus Avenue, Boston, MA 02119
(617) 442-7442 FAX (617) 442-1705

February 24, 1994

Lisa Geng
"You N' Me"
79 Kerrigan Street,
Long Beach, New York 11561

Dear Ms. Geng:

I agree with Peter Hunt of The Center for Disease Control that there is a need for accurate, creative and developmentally appropriate materials for young children that deal with the issue of infectious diseases and universal precautions.

There are very few materials on the market concerning such serious subjects that have been targeted for young children who often are the most vulnerable members of society.

I commend you and Mr. Kessler for taking on such a worthy project and look forward to seeing the end product.

Best of Luck to you both.

Sincerely,

Geneva Woodruff

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Office of the Assistant Secretary
for Health
Washington DC 20201

March 30, 1994

NOTE TO: BARBARA BRADY

SUBJECT: Hygenic Corporaton Letter on Dental Dams

FROM: Research Specialist, ONAP

Attached is a copy of a letter to the Surgeon General from the Hygenic Corporation regarding dental dams, sent to Kristine Gebbie. Please note Ms. Gebbie's hand written note. Would you please advise us about the original disposition of this letter? Was the letter sent to FDA for response? If it was, would you please provide us with a copy of the response for Ms. Gebbie. If it was not, would you please forward the letter to FDA for their information.

Thank you.

Johanne G. Messore

ATTACHED - STW

NATIONAL AIDS POLICY OFFICE
OFFICE OF THE COORDINATOR

ROUTING SLIP

Rec'd from Verna 3/29 Jpm

DATE: 3/13

TO: Terry/Alice

FROM: _____ W. STEVE LEE

_____ For your information

✓ For your action forward to PDA

_____ Review and comment by (date) _____

_____ Prepare reply for Coordinator's signature

_____ Reply directly and blind copy Coordinator

_____ **Circulate/**forward to: _____

_____ File

COMMENTS: _____

T63122
+
T65896
Lorenzen
NDA

DATE: February 24, 1994

BETWEEN: Stewart Lorenzen, President
Hygienic Corporation
Akron, OH 44310-2575
(216)N 633-8460

AND: Eugene M. Berk, CSO
POS, HFZ-404

SUBJECT: Letters dated November 15, 1993 and February 14, 1994 addressed to Jocelyn Elders, MD, Surgeon General

Two letters addressed to the U.S. Surgeon General were forwarded to this office by Linda Gangloff, Office of Executive Secretariat after her discussion with me regarding the device status of Mr. Lorenzen's dental dams. I agreed to review his letters and obtain an answer to his questions. After my review of the incoming I called Mr. Lorenzen to expedite his request that we advise him as to what FDA regulatory requirements would apply to dental (oral) dams labeled for the prevention of sexually transmitted diseases (STDs).

I explained that part of the delay in obtaining an answer for him was that dental dams with STD claims could be used for oral sex. Since oral sex is illegal in some jurisdictions, I needed to have our General Counsel (GC) office advise me as to the legality/liability of this Center advising someone as to how to bring to market a product the use of which may be illegal in certain jurisdictions. I told him that our GC advised us that such advice from this Center would not be inhibited due to prohibitions against oral sex by specific state or local governments.

I told the firm that dental dams labeled for the prevention of STDs would be regulated as devices and would require the firm to comply with the provision of 21 CFR Part 807. I advised him for assistance and publications involving registration, listing and premarket submissions [510(k)s and PMAs] they could call DSMA. For specific information regarding what type of information we would like to see in a premarket submission, I gave him the phone number for the Associate Director for OB/GYN and G/U Devices.

Mr. Lorenzen thanked me and we cordially ended our conversation.

Eugene M. Berk

HYGENIC

February 14, 1994

Terry or Alice —
could someone be sure
this issue gets to
FDA — Thanks

Joycelyn Elders, MD
Surgeon General
US Public Health Service
Room 1866
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Elders:

In November of 1993, we had contacted you about a public health issue we felt was particularly important to a great many of us. In that previous communication, we discussed use of a Hygenic product, known as dental dam, and its application in the area of barrier products and sexually transmitted diseases (STD's). Based on information that was recently presented to us, we felt it was necessary to contact you again with our concern.

We have recently been made aware of two instances where our product, dental dam, was being distributed at a retail level and promoted for the purpose of an aid in prevention of the spread of STD's. In both of these cases, product was obtained by the retail outlets without our knowledge. In both of these instances, we have contacted the retailer to ask them to make their intentions known to us now that we have notified them of this situation. As of this date, we have not received a written response from either party. It is also important to note that we are unaware of the total number of instances in which our product may be similarly distributed.

This situation is of serious concern to us due to the fact that, as we indicated in our previous letter, the use of product in this fashion raises questions relating to Food and Drug Administration regulatory requirements. We believe it is of utmost importance to supply products which meet all applicable regulatory requirements. If you could provide Hygenic with direction on regulatory requirements for this product as described, we could ensure our compliance with those expectations, and at the same time provide the consumers with another option in the fight to prevent the spread of these most serious diseases.

Again, I respectfully request your assistance. We would appreciate it if you could respond to us by February 28. Thank you for your consideration, and we look forward to hearing from you.

Sincerely,

Stewart Lorenzen
President

SL/pf
cc: Ms. Christine Gebbie, RN
National Aids Policy Coordinator

HARVARD AIDS INSTITUTE

bcc: Terry Beswick FYI

Chairman
M. Essex, DVM, PhD

Executive Director
Richard Marlink, MD

BY FAX: 1 PAGE
202-690-6960

RECEIVED
APR 20 1994

April 18, 1994

8
Story
Street
Cambridge
Massachusetts
02138

617 495-0478
FAX: 617 495-2863

Dr. Philip Lee
Assistant Secretary for Health
Department of Health and Human Services
Hubert H. Humphrey Building, Rm. 716G
200 Independence Avenue, SW
Washington, DC 20201

Dear Dr. Lee:

Thank you for your response to the draft of the FDAR-The Madison Project report to date. We have now finalized the report, but will not have a printed version by the time the newly-formed Drug Development Task Force meets this month.

I would like to emphasize that the seven subject areas that evolved out of our working groups and plenary sessions brought up suggestions that should not be considered as one package. That is, each of the seven areas would seem to stand on their own as an area worth pursuing or a suggestion for consideration. The formation of the Drug Development Task Force is such an example. I would hope that each suggestion could be considered to stand alone, as individual ideas worth pursuing.

We all look forward to the important work you have taken on with the Drug Development Task Force and hope to help in any way possible to ensure its success overcoming the complex issues involved in bringing truly effective therapies to fruition.

Most sincerely,

Richard Marlink, MD

WOODCRAFT RANGERS

2111 PARK GROVE AVENUE
LOS ANGELES, CA 90007-2099
PHONE: (213) 749-3031
FAX: (213) 749-0409

BUILDING CHARACTER IN TODAY'S YOUTH

August 11, 1994

Andrew Barrer
Senior Advisor, Office of the National AIDS
Policy Coordinator
750 17th Street, N.W. Suite 1060
Washington, DC 20503

COPY FOR YOUR INFORMATION

COPY

Dear Andrew Barrer:

President Clinton recently announced that you would be one of the representatives of the Non-Profit Liaison Network. He explained that you would handle communications with Non-Profits and arrange collaborations with them.

The Woodcraft Rangers is a Community Based Organization that provides afterschool youth services and camp based self esteem programs for children from low income, multi-cultural neighborhoods in Los Angeles. I have enclosed some brochures on our programs.

We would be very interested in participating in policy discussions effecting inner-city youth, program funding opportunities, service delivery options, information sharing and strategies for reaching common goals. We specifically request to be placed on any mailing list your office maintains regarding grants, contracts, RFP's and other funding opportunities.

We would also like to receive any newsletters or other materials that might be relevant to serving our young people. Last year the Woodcraft Rangers provided 25,000 children with camp based programs and 5,000 more with school linked services. The enclosed materials will describe our services in detail. I would be happy to answer any questions you may have about our services.

Working in Los Angeles, with riots, floods, earthquakes and fires is a challenge for any organization. We are proud that Woodcraft has been serving low income, minority communities since the 30's. The Federal Government has recognized our role by placing Vista volunteers with us and seeking our help after the quake to successfully design an additional Vista project at 7 schools damaged by the quake. I hope we can join with your agency in working to provide real opportunities for growth for our youth in the L.A. area.

Thank you for taking the time to serve as a Non-Profit Liaison.

Sincerely,

Jim Van Hoven

Jim Van Hoven
Executive Director

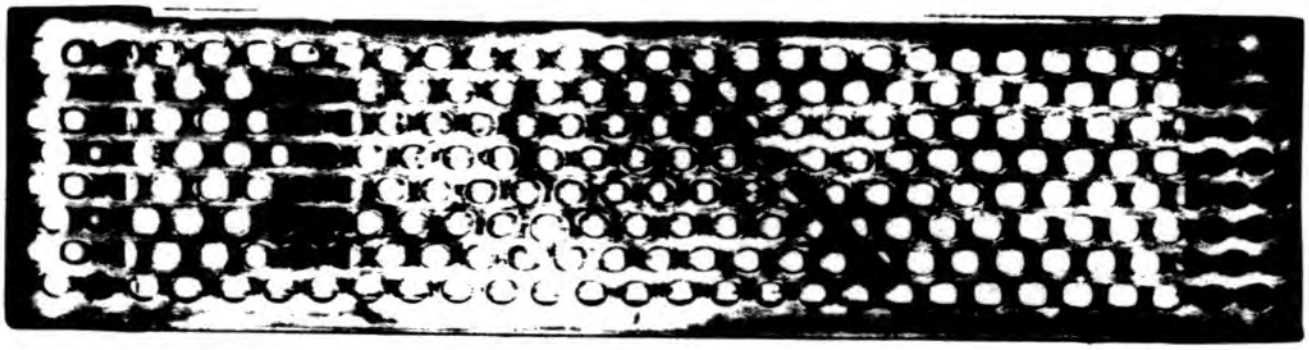
THE WHITE HOUSE

Dear Dorothy –

Thanks for writing. I'm looking forward to the Conference in September –

See you then

Kristine



Mayo Foundation Rochester, Minnesota 55905 Telephone 507 284-2511

Department of Nursing

July 2, 1993

Kristine M. Gebbie, RN, MN, FAAN
606 Lilly Road NE, #723
Olympia, WA 98506

Dear Kristine,

Congratulations on your appointment and new challenge! Your appointment is a public affirmation of your talents and abilities, and a very good choice on the part of the administration.

We are looking forward to having you here at the Quest for Quality '93 conference in September.

Sincerely,

Dorothy Bell, RN, MS
Nursing Education Specialist
Education and Professional Development Section
Marian Hall 7

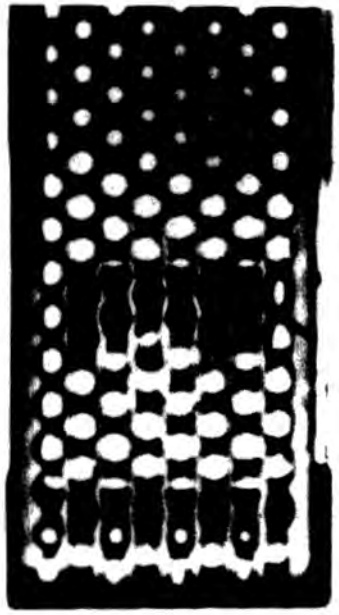
sb

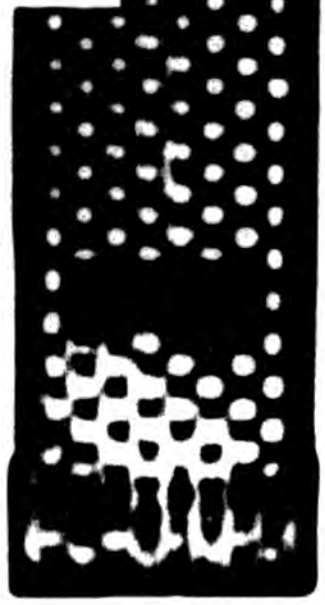
THE WHITE HOUSE

Dear Mr Maloney -

Thank you for taking time to write and share your concerns. The AIDS Clinical Trials Group is an important part of our effort, and I will make note of the dates. Best wishes to you, and all for whom you write —

Kristine Gebbie

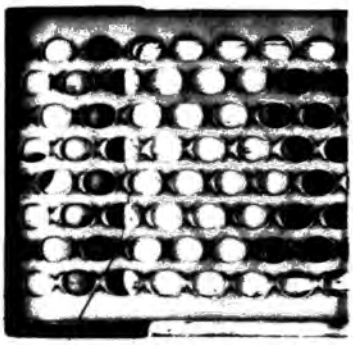




AMS

For Dec. 5-8

8 Pond St.
Seymour CT
June 27, 1993



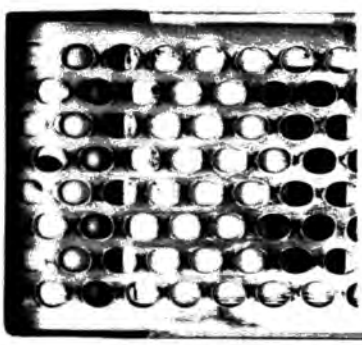
Ms. Kristine Gebbie
"AIDS Czarina"
The White House
Washington DC 20500

Dear Ms. Gebbie;

Welcome to your new position as AIDS Czarina! People's lives literally depend on you, so I certainly wish you all the best.

As you know, throughout the years of official neglect of this crisis, many organizations have developed to deal with various aspects of AIDS: research, treatment, services, and advocacy. You start your job with a major advantage: having this infrastructure in place. Your challenge is to make effective use of it.

I have one specific suggestion. The next full meeting of the AIDS



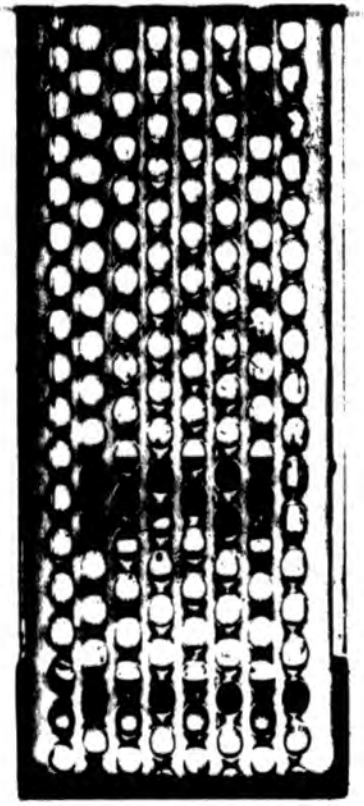
Clinical Trials Group will be December 5-8 in Washington. Both you and President Clinton should be there to speak to the gathering of researchers, clinicians and activists and show your support for their work. Of course that would be an ideal time and place to announce any new initiatives in AIDS research or care.

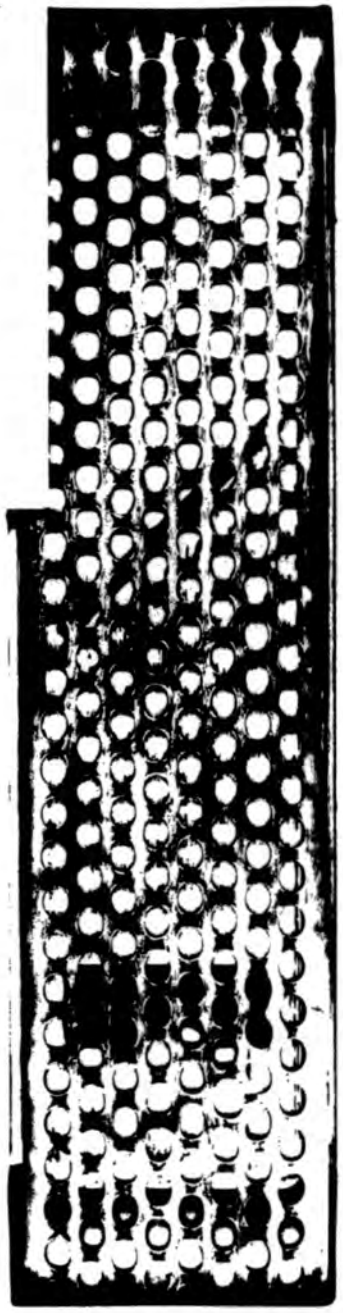
The hopes of me and people too sick to write letters are with you.

Sincerely,
Vincent Maloney

Vincent Maloney
8 Pond St
Seymour CT 06483

Ms Kristine Gebbie
"AIDS Czarina"
The White House
Washington DC
20500





THE WHITE HOUSE

WASHINGTON

John —

If the President has time, World AIDS Day might be a good time for a follow up call to Randy Jacobs in Port Townsend, whose wife Mary died of AIDS earlier this year —

The two phone numbers I have for Randy are 206-385-3500 or 206-385-5525.

Thanks —

Christine

THE WHITE HOUSE

Dear Bernie & Sylvia —

Thank you for caring and sharing — I appreciate the copy of Unconditional Love as a symbol of the voice we are all trying to give this epidemic. I shall try to live up to your standard —

Kristine

Mr. And Mrs. Bernie Goldstraub
Apartment 404
6515 Kensington Lane
Debay, Florida 33446

THE WHITE HOUSE

Dear Bernie & Sylvia —

Thank you for caring and sharing — I ~~appreciate~~ the copy of Unconditional Love as a symbol of the voice we are all trying to give this epidemic. I shall try to live up to your standard —

Kristine

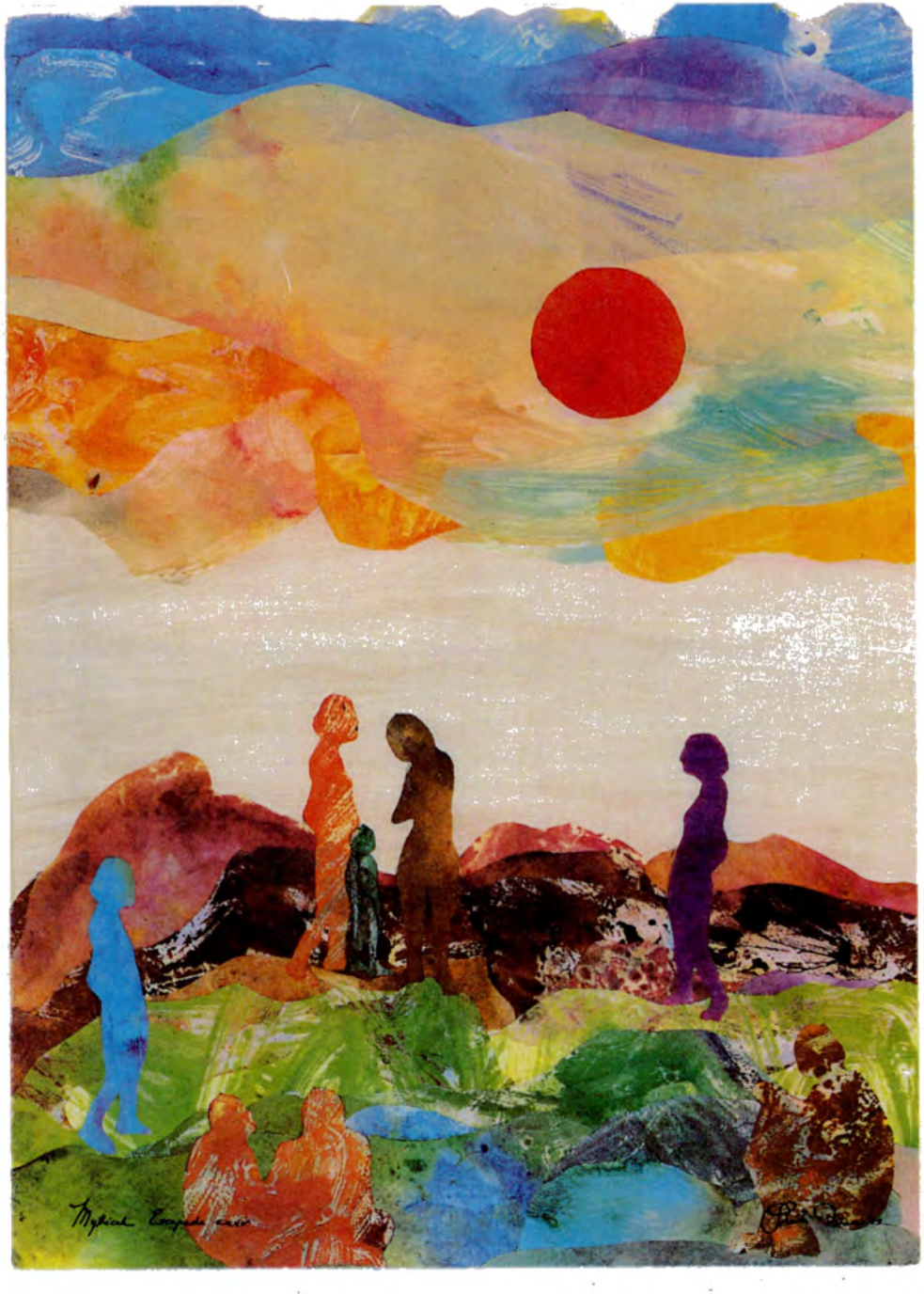
Mr. And Mrs. Bernie Goldstraub
Apartment 404
6515 Kensington Lane
Debay, Florida 33446

Mothers' Voices is an awareness program created in 1992 by people dedicated to ending the AIDS crisis. We seek to mobilize one of the greatest resources of our country, our nation's mothers, together with their families and friends, to advocate for compassion and respect for those living with the AIDS virus, as well as effective AIDS education, access to quality care and accelerated research for a cure.

Mothers' Voices is a program of People Taking Action Against AIDS, a non-profit organization founded in 1987 to raise funds and awareness in the fight against AIDS.

Speaking from the Heart about AIDS

MOTHERS' VOICES



MYTHICAL ESCAPADE SERIES, 1993
Collage on paper by Sheila Isham, donated as part of her personal contribution to end AIDS

Manufactured by DESIGNER GREETING, INC., S.I.N.Y. 10314

Sylvia Goldstaut
author
"Unconditional Love:
"Mom! Dad! Love me!
Please!"

AIDS THRIVES ON
= =
SILENCE.
=

JOIN OUR FAMILY

in the fight to end AIDS.

The new Administration, committed to
leadership and change, has promised
better funded and better organized AIDS research,
AIDS education programs that recognize the realities of people's lives,
adequate health care for all, and
an end to discrimination against people living with HIV/AIDS.

Please, work to fulfill the promise!

NAME: Bernie & Sylvia Goldstaut

ADDRESS: 6515 Kensington Lane #404
Delray Beach, Fla.
33446

407-498-8614

THE WHITE HOUSE

Dear Lili –

Thank you for adopting me into the Mother's Voices family. I take that inclusion seriously, and look forward to a positive collaboration –

Laura Bush

Ms. Lili Rundback
2774 Red Oak Circle
Bethlehem, Pennsylvania 18107

THE WHITE HOUSE

Dear Lili –

Thank you for adopting me into the Mother's Voices family. I take that inclusion seriously, and look forward to a positive collaboration –

Kristine Gebbie

Ms. Lili Rundback
2774 Red Oak Circle
Bethlehem, Pennsylvania 18107

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MOTHERS' VOICES

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Collage on paper by Sheila Isham, donated as part of her personal contribution to end AIDS

Manufactured by DESIGNER GREETING, INC., S.I.N.Y. 10314

9/13/97

Ms. Gebbie,

As a co-founder of Mothers' Voices, I consider you an honorary member of our team and extended family. With up to 300,000 + families who we have communicated with, I urge you to do the right thing and fight for the lives of all of us, healthy and sick! We need you now. Seize the moment.

Lili Rundback
Co-FOUNDER/MOTHERS VOICES

JOIN OUR FAMILY

in the fight to end AIDS.

The new Administration, committed to leadership and change, has promised better funded and better organized AIDS research, AIDS education programs that recognize the realities of people's lives, adequate health care for all, and an end to discrimination against people living with HIV/AIDS.

Please, work to fulfill the promise!

NAME: Lili Rundback

ADDRESS: 2774 Red Oak Circle
Bethlehem, PA 18017

Speaking from the Heart about AIDS

150 West 26 Street
Suite 603
New York, NY 10001
Phone: 212-366-9217
Fax: 212-366-0679
Home #: 215-882-0626
fax: 215-882-5656
Lili Rundback

Speaking from the Heart about AIDS

150 West 26 Street
Suite 603
New York, NY 10001
Phone: 212-366-9217
Fax: 212-366-0679
Lili Rundback
(Home) 215-882-0626
#
(FAX) 215-882-5686

Note for some Dallas trip - I need to visit her — —
K.

MOTHERS' VOICES
Speaking from the Heart about AIDS
150 West 26 Street
Suite 603
New York, NY 10001
Phone: 212-366-9217
Fax: 212-366-0679

Dorothy C FEASINS
2713 KNIGHT ST
DALLAS TEXAS 75241
214-5593946

THE WHITE HOUSE

Dear Dorothy —

I look forward to seeing you again, & meeting the Kids at Bryan House —

Thank you for your dedication —

Kristine Gebbie

Ms. Dorothy C. Feagins
6840 Carioca Circle
Dallas, Texas 75241

THE WHITE HOUSE

Dear Dorothy —

I look forward to seeing you again, & meeting the kids at Bryan House —

Thank you for your dedication —

Barbara Bush

Ms. Dorothy C. Feagins
6840 Carioca Circle
Dallas, Texas 75241

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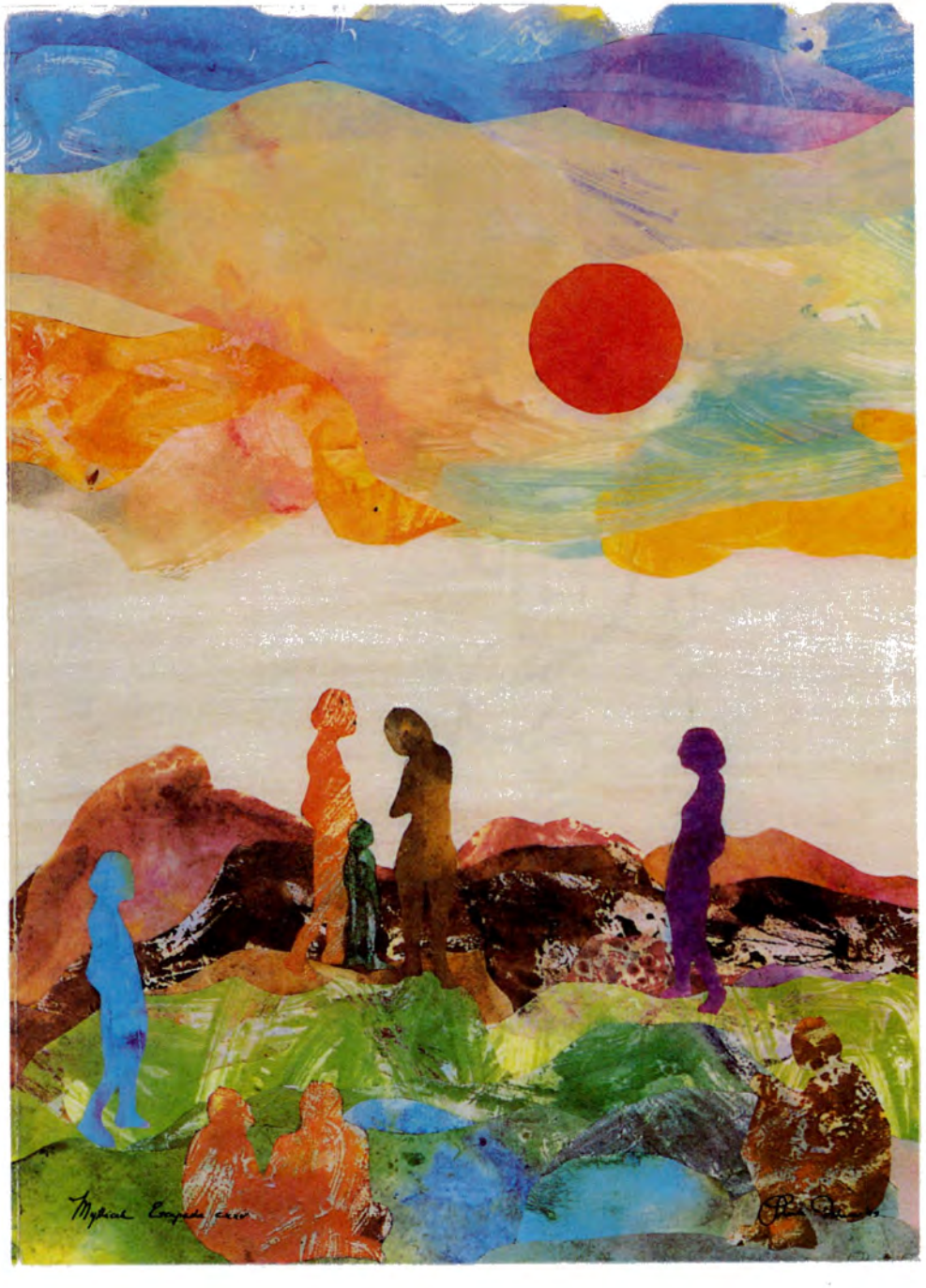
Speaking from the Heart about AIDS

MOTHERS' VOICES



MYTHICAL ESCAPADE SERIES, 1993
Collage on paper by Sheila Isham, donated as part of her personal contribution to end AIDS

Manufactured by DESIGNER GREETING, INC., S.I.N.Y. 10314

This CArd is A Reminder of All the Mother AND Children of the World we Hope you will do something to Help us with word to the Presdints. so He will Keep His words ON Help us.

From
All the Kid At
Boyan House
2713 Knight St
Dallas Tex 75215
214-559 5546
Love / Lindsay Cushingberry Age
Liveing with Aids

ME
Dorothy C Feasins
6840 Carioca Cir
Dallas Texas 75241
214-371 2755-

JOIN OUR FAMILY

in the fight to end AIDS.

The new Administration, committed to
leadership and change, has promised
better funded and better organized AIDS research,
AIDS education programs that recognize the realities of people's lives,
adequate health care for all, and
an end to discrimination against people living with HIV/AIDS.

Please, work to fulfill the promise!

NAME: _____

ADDRESS: _____

_____

THE WHITE HOUSE

Dear Dorry –

I'm watching the appropriation process closely – we do need the Ryan White money and we do NOT need any amendments! I'm glad to have begun our dialogue and look forward to future collaboration.

Kristine Gebbie

Ms. Dorry Bless
26 West 20th Street
New York, New York 10011

Speaking from the Heart about AIDS
MOTHERS' VOICES

150 West 26 Street
Suite 603
New York, NY 10001
Phone: 212-366-9217
Fax: 212-366-0679

Dorry Bless
h # 212 - 929 - 2734

THE WHITE HOUSE

Dear Dorry —

I'm watching the appropriation process closely - we do need the Ryan White money and we do NOT need any amendments! I'm glad to have begun our dialogue and look forward to future collaboration.

Warmest Regards

Ms. Dorry Bless
26 West 20th Street
New York, New York 10011

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Speaking from the Heart about AIDS

MOTHERS' VOICES

MYTHICAL ESCAPADE SERIES, 1993
Collage on paper by Sheila Isham, donated as part of her personal contribution to end AIDS

Manufactured by DESIGNER GREETING, INC., S.I.N.Y. 10314

9.13.93

Ms. Gebbie:

Please make sure the Ryan White Act is completely funded and when the bills go to conference & to be appropriated that NO negative ammendments are added to the bills!!!

As a co-founder of Mothers' Voices we hope that you will be a true leader in the fight to end AIDS. Let this meeting be the beginning of a collaborative effort to put an end to this pandemic.

Dorry Bless

JOIN OUR FAMILY

in the fight to end AIDS.

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Please, work to fulfill the promise!

NAME: DORRY BLESS

ADDRESS: 26 WEST 20TH ST.

NY, NY 10011

THE WHITE HOUSE

Dear Jim -

Thanks again for the kind letter, the "Bobby Beagle" word on your efforts in San Francisco. I'm a Gebbie by acquisition (a former spouse of that name) only, but my children will be interested in the history. I look forward to ~~not~~ meeting you on a San Francisco trip one day —

Best wishes

Mr. James C. Gebbie
3215 Harrison Street
San Francisco, California 94110

MEALS WITH LOVE FOR PEOPLE WITH AIDS
PROJECT
OPEN HAND

JAMES C. GEBBIE
Manager, Telefunding

2720 17TH STREET
SAN FRANCISCO
CALIFORNIA 94110
415 771-7409
VOICEMAIL 415 255-4355

THE WHITE HOUSE

Dear Jim -

Thanks again for the kind letter, the "Dolly Dingle" word on your efforts in San Francisco. I'm a Gebbie by acquisition (a former spouse of that name) only, but my children will be interested in the inventory. I look forward to meeting you on a San Francisco trip one day —

Kindest

Mr. James C. Gebbie
3215 Harrison Street
San Francisco, California 94110

3215 Harrison St.
San Francisco, CA 94110
September 13, 1993

Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street
Washington, DC 20500

Dear "Cousin" Gebbie:

From one Gebbie to another, I want to congratulate you on being appointed by President Clinton to the important post of overseer of the federal AIDS masterplan. It is a tremendously vital position--but one that will, no doubt, be impossible to satisfy all special interest groups. I wish you all the luck in the world. I know you will do the name Gebbie proud.

I, too, work in AIDS support here in San Francisco. I am a fund-raiser for Project Open Hand, a sort of "Meals on Wheels" for people living with AIDS. Founded in 1985, Open Hand is now feeding hot dinners every evening to nearly 1,900 men, women and children. Our food bank distributes bags of groceries to another 950 people. My card is included.

Concerning our Gebbie roots, I have tracked our family back to a small town not far from Glasgow, Scotland, called Darvel. There are more Gebbies there than you could imagine. And it seems before we were Gebbies, we were called "Gebbricht," and our ancestor(s) came from Flanders. Most have been lace makers. I've enclosed a copy of a story I wrote about tracing my roots. If you have time (which I doubt), you might enjoy reading it.

As a bit of amusing history, Grace Gebbie Drayton was an illustrator who invented the children's character "Dolly Dingle." Dolly was a "paper dolly," and children could cut out clothes and attach them to the round-faced little cherub. Enclosed is a "Red Cross Dolly Dingle" postcard. Grace also created the more well-known Campbell Soup kids.

Again, congratulations and good luck to the most famous Gebbie in the American clan.

Best wishes,

Jim Gebbie

James C. Gebbie

YOU AND YOURS. WILL WE BE SEEING YOU IN L.A. SOON? THAT WOULD BE NICE.
'TILL THEN STAY HAPPY.
LOVE,
T.Q.

Dolly Dingle™
House of Global Art

Grace Gebbie Drayton, the creator of Dolly Dingle, was born in Philadelphia on October 4, 1876. From childhood, she enjoyed drawing the roly-poly children which she said were based on her own image in the mirror. Educated at the Convent of Notre Dame In Philadelphia and the Convent of Eden Hall in nearby Torresdale, Grace was a talented and prolific illustrator and writer. Dolly Dingle was created as a paper doll in 1913 and appeared in the women's magazine Pictorial Review for 20 years. During that time, Grace designed more than 200 paper dolls for the series. Remembered primarily for her drawings of adorable children, Grace also illustrated fashion pages, magazines and calendars with elegant, sophisticated ladies. She designed toy banks, feeding dishes, door stops, stuffed animals, dolls, and post cards.

FLOWERS
FROM THE ARTWORK BY GRACE G. DAYTON
PUBLISHED AND DISTRIBUTED BY PORTAL PUBLICATIONS, LTD.,
CORTE MADERA, CALIFORNIA

85 DD005
LITHO IN U.S.A.

Well, some of them were Scots

By Jim Gebbie
Special to The Examiner

EVER SINCE Alex Haley's "Roots" was serialized for television five years ago, Americans have been a little nutty about climbing their ancestral trees. From Africa to England, everyone seems to be zipping off in search of long lost relatives. Even Ma Bell and the airlines have jumped on the band wagon, and "geneanostalgic" commercials beckon us to call or visit our faraway families in Italy, Germany, Japan and other patriarchal homelands. It took me awhile, but last year I caught the roots bug.

My ancestral homeland is Scotland — or so my father told when I was a kid. According to him, Scottish blood came down to me from both sides of the family — Gebbie on his side, McClure on my mother's. Those Scottish genes gave me visions of relatives wearing kilts, playing bagpipes, pinching pennies and tossing the caber (whatever that was). To be Scottish was more than liking a wee bit of Scotch whisky, it was — like Scott and Burns — well, poetic.

But as a youngster, I didn't think my name sounded very Scottish. Why wasn't it MacGebbie like all the other big Macs were called in the Highlands?

Last fall I decided to do something about tracing my Scottish roots. It started in London, where I found five Gebbies listed in the phone book. Five! It was a veritable gang of Gebbies. I didn't bother my London kin, thinking I'd wait until I got farther north.

On a rainy night at the Saddle Inn in York, one of Europe's best-kept medieval cities, I started my research. I was sitting at the bar, bored with the rain, and I decided to see if any shirttail cousins were listed in the phone book. A certain Walter Gebbie was and his address looked to be near. I gave him a call, explaining I was a Gebbie from America trying to trace my roots. He was curious and invited me to his home on Hellington Lane.

Over beer and meatloaf sandwiches served by his wife, Bess, he told me what he knew about the family.

According to his family tree, there had been two Gebbie brothers, both lace makers, who came from Belgium or Holland in the 1700s and settled at Darvel, a small town near Glasgow. One of the brothers was killed fighting for Bonny Prince Charlie, and therefore the Scottish Gebbies must have descended from the surviving brother. Walter, a retired policeman, said there is no Gebbie tartan, but his family had adopted the one of the Buchanan clan.

So, we weren't Scottish after all — at least not until after the 18th century.

Walter said I should look up a Dr. Hugh Gebbie in Edinburgh, who was more knowledgeable about the family history.

It was still raining when the Britrail train pulled into Edinburgh's Waverly Station and I took a big black taxi to a small hotel off Abercrombie Place. I had just missed the Edinburgh Festival, so the next day I explored a city relatively empty of tourists.

Edinburgh is divided into two parts: "New Town," which is gray-stone Georgian terraces all neatly laid out, and Old Town, a 16th-century collection of three- and four-story buildings that meander down the Royal Mile from Edinburgh Castle.

Along the Royal Mile, I bought a tie of the Buchanan tartan, which turned out to be quite garish. Many shops on this street, as well as on Princes Street, the main thoroughfare, sell ties, scarves, kilts and other woolen items made from plaids of the different clans.

A plaque at the Scottish National War Museum in Edinburgh led an American to an honored soldier

I tried to call Dr. Hugh Gebbie but was told he was on holiday. I went back to the trusty phone book and found 10 other Gebbies, including my namesake James. Fortunately, James said he and his wife were free that evening and they would meet me at the Caledonian Hotel on the west end of Princes Street. Over a "bladder" of beer, James more or less verified Walter Gebbie's story. The Gebbies had come from Holland in the late 16th or early 17th century and had settled in Ayrshire. James, an Edinburgh physiotherapist, had been born in Darvel, where he knew the family had lived since the 1800s, if not before.

I asked him about our tartan and he said we had none. "I wouldn't be too disappointed though," he said. "We're Lowlanders. The Highlanders, the ones with the tartans, were something like your American hillbillies. The Gebbies have been bankers and physicians, tradesmen and weavers." He reconfirmed the lace maker story and suggested that the brothers came to Scotland to escape the persecution of Protestants on the Continent. He urged me to visit Darvel and check the parish records.

I took a train to Glasgow the next day and found 32 Gebbies listed in the phone book. The gang had increased to a mob. From Glasgow I took another train and then a bus to cover the 17 miles to Darvel.

Darvel turned out to be a pleasant little town (population 3,300), nestled among rolling, green hills. My first stop, naturally, was a red phone booth. Finding no directory, I stopped a passerby who said there'd be one at the post office on the main street. There I found nine Gebbies. A woman behind the window asked if she could help me. I explained my quest and she said, "Ah, got a touch of the old roots, eh? As a matter of fact, you look a bit like Bobby Gebbie, or maybe an older version of his son Grant."

I couldn't track down Bobby, but I did call a James J. He was a busy textiles man, but he had time to volunteer that our ancestors were from Flanders. His father had seen an old family Bible, and the original spelling of the name was Gebbricht. Most of the Gebbies had been hand-loom weavers, he said.

Someone suggested that I look up James C. Gebbie, who was working at the Bashford Dyers, just off the main street. At the "Enquiries" office of the old red brick building, I told a young woman, "I'd like to see Jim C. Gebbie."

"And may I say who's calling?"

"Jim C. Gebbie," I said.

I guess she didn't think I heard correctly. "No, who are you?" she asked. "I'm Jim Gebbie — too," I said.

"Oooooh. I'll tell him."

When Jim arrived, he suggested that we meet for a drink at the Turf Hotel when he got off work. At the hotel, he explained that there were many Gebbies in Darvel, but he'd never met an American one. While we were talking, a Robert Gebbie walked in. "Are you the American Gebbie who's searching his roots?" he said. "I'd like to buy you a drink."

Over glasses of Scotch whisky and lager, my distant cousins again pieced together the story about two brothers who came from Belgium (or perhaps Norman France) and how they started the lace trade in Darvel. Jim said his great grandfather had owned and "drank away" the Bashford weaving factory. Jim and Robert, coming from different lines of the family, had always thought of each other as "those other Gebbies." They hardly felt related, but having an American in their small town with the same name made them realize that we all were some kind of cousins.

Robert wanted me to stay overnight and said he'd invite all the Gebbies in town to have a "clan" roots meeting. Unfortunately, I had to catch the bus and train back to Edinburgh.

Maybe I'll get a little nutty about my ancestral tree in a year or two, then we can have that clan meeting.

Note: For other clansmen and women, the best place to trace your roots is at the General Register Office for Scotland near "Woolies" (Woolworth's), just off Princes Street. Here, for a fee of about $8 a day, you can search records of births, deaths, marriages and adoptions kept since 1855. For another fee of about $6 per day, you can get access to pre-1855 parish registers and census records of 1841-1891. You must have a name and birthdate or date of marriage (something concrete) to start with, and then the search becomes a matter of leapfrogging through relatives on your family tree.

JAMES C. GEBBIE
3215 Harrison St.
San Francisco, CA 94110

738
44

Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street
Washington, DC 20500

MEALS WITH LOVE FOR PEOPLE WITH AIDS
PROJECT
OPEN HAND

JAMES C. GEBBIE
Manager, Telefunding

2720 17TH STREET
SAN FRANCISCO
CALIFORNIA 94110
415 771-7409
VOICEMAIL 415 255-4355

THE WHITE HOUSE

Dear Jim -

Thanks again for the kind letter, the "Dolly Dingle" word on your efforts in San Francisco. I'm a Gebbie by acquisition (a former spouse of that name) only, but my children will be interested in the lineage. I look forward to ~~meeting~~ meeting you on a San Francisco trip one day —

Ronnie

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Best wishes

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Best wishes

THE WHITE HOUSE

Dear Lisa -

Thank you - for sharing your story, for your own fight against the virus, for all you do. It is an honor to know you & I take the charge to work for you seriously -

Kristine

Ms. Lisa S. Vincent
341-B Hilltopper Drive
Bowling Green, Kentucky 42101

THE WHITE HOUSE

Dear Lisa -

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Kristine

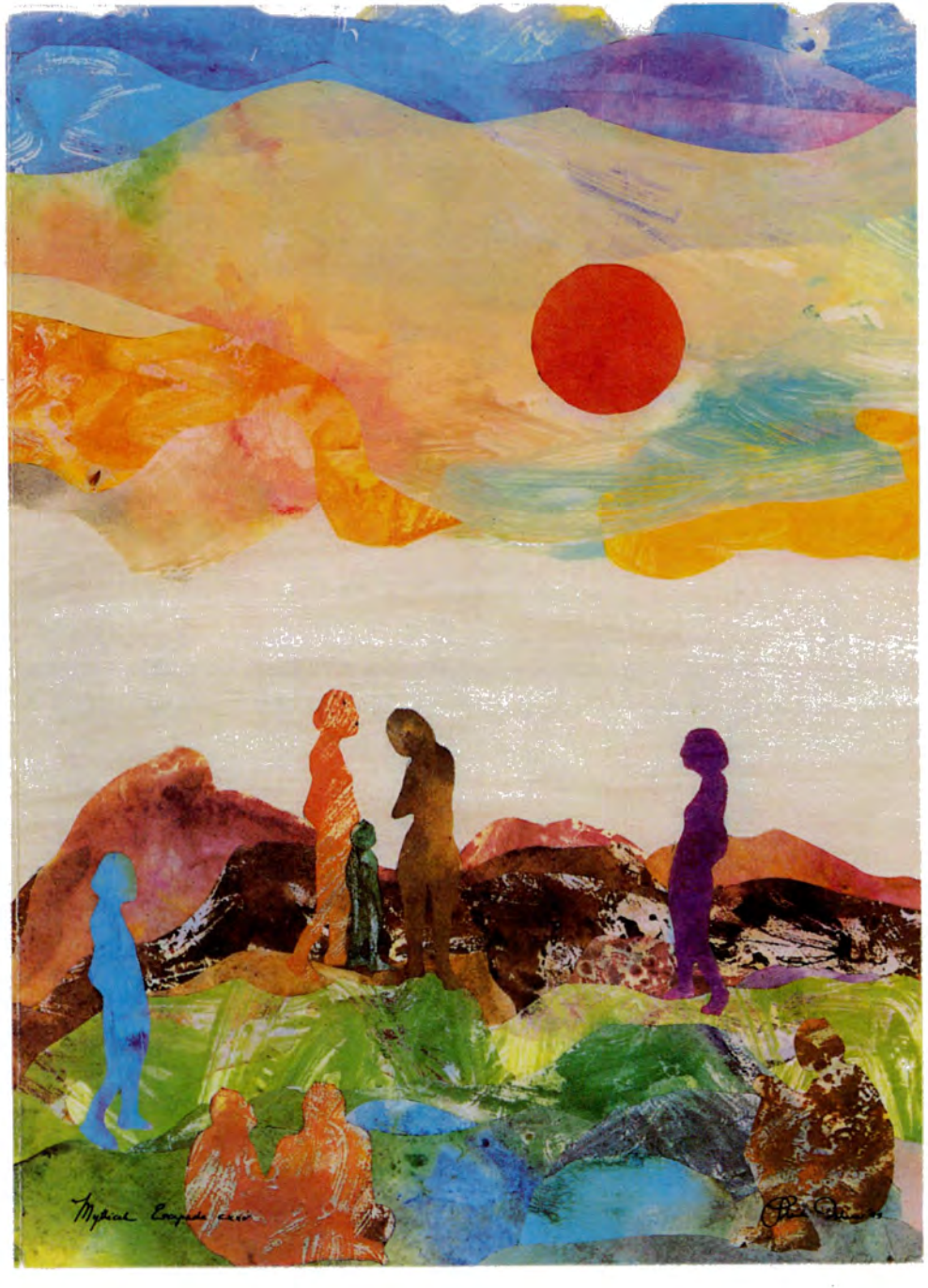
Ms. Lisa S. Vincent
341-B Hilltopper Drive
Bowling Green, Kentucky 42101

Mothers' Voices is an awareness program created in 1992 by people dedicated to ending the AIDS crisis. We seek to mobilize one of the greatest resources of our country, our nation's mothers, together with their families and friends, to advocate for compassion and respect for those living with the AIDS virus, as well as effective AIDS education, access to quality care and accelerated research for a cure.

Mothers' Voices is a program of People Taking Action Against AIDS, a non-profit organization founded in 1987 to raise funds and awareness in the fight against AIDS.

Speaking from the Heart about AIDS

MOTHERS' VOICES



MYTHICAL ESCAPADE SERIES, 1993
Collage on paper by Sheila Isham, donated as part of her personal contribution to end AIDS

Manufactured by DESIGNER GREETING, INC., S.I.N.Y. 10314

9-13-93

Ms. Gebbie,

As a mother living with AIDS who has lost a husband to AIDS - I have confidence that you will do your job and speak out for all of us who are infected and/or affected by HIV/AIDS.

It's an honor to meet you and please feel free to contact me anytime

JOIN OUR FAMILY

in the fight to end AIDS.

The new Administration, committed to
leadership and change, has promised
better funded and better organized AIDS research,
AIDS education programs that recognize the realities of people's lives,
adequate health care for all, and
an end to discrimination against people living with HIV/AIDS.

Please, work to fulfill the promise!

NAME: Lisa S. Vincent

ADDRESS: 341-B Hilltopper Drive
Bowling Green, Ky. 42101

(502) 782-1365 - home
(502) 842-5833 - AIDS Southern Ky.

150 West 26 Street
Suite 603
New York, NY 10001
Phone: 212-366-9217
Fax: 212-366-0679

Lisa S. Vincent →

Lisa S. Vincent
341-B Hilltopper Dr.
Bowling Green, Ky. 42101
(502) 782-1365

THE WHITE HOUSE

Dear Harry –

Miss Manners would not approve of my slowness in acknowledging your kind note last June – I'm slow but sure, I guess! It is fun to get settled in this Washington, & I'm encouraged by the support I'm getting from many quarters.

Hope to see you soon – Kristine

Lawrence S. Lewin
9302 Lee Highway
Fairfax, Virginia 22031

June 27, 1993

Dear Kristine,

What a lovely birthday present from the President! Congratulations and welcome to "our" Washington.

I know how thrilled Marion is to have one of her PEW alumna in such a critically important job and we all look forward to your leadership.

All the best, and I hope we'll have a chance to see you soon.

Sincerely,

Larry

P.S. Marion send you her love.

THE WHITE HOUSE

Dear Lois —

I'm only 3 months behind in writing — but haven't been standing still! This is quite a challenge! One of my priorities is health reform, as needed by HIV infected persons. I hope NANDA & its members are actively participating in work on data & documentation in the new system — a critical area.

Thank you for the good wishes — Hillary

N.A.N.D.A., 1211 Locust Street, Philadelphia, Pennsylvania (800) 647-9002

July 6, 1993

Kristine Gebbie, RN, MN, FAAN
606 Lilly Road N.E. #723
Olympia, Washington 98504

Dear Ms. Gebbie: Kris

Congratulations on your Presidential appointment to the position of AIDS policy coordinator for the U.S. Government! It is a comfort to have someone with your outstanding abilities recognized. We in NANDA were aware of your talents long ago. If our organization can be of service to you in this new task, let us know.

Sincerely,

Lois

Lois M. Hoskins, RN, PhD
President

THE WHITE HOUSE

Dear Drew —

So I'm 3 months behind in my correspondence! My apologies — Thank you for the note - I've appreciated the support from my Oregon friends.

Best wishes —

Drew Fletcher
President
Oregon AFL-CIO
1900 ~~Hines~~ Hines St., S.E.
Salem, Oregon 97302

POR

From
IRV FLETCHER
President

Oregon
AFL-CIO

7/4/93

Kristine..

Congratulations... Let
me know if I can be
of help!

Jim

THE WHITE HOUSE

Dear Dorothy —

In the hectic early weeks on this new job, I think I failed to send you my warm good wishes on your retirement from the Region X health administrator's position. It was fun being colleagues all those years - in a great part of the country. I know you'll be busy with lots of things - hope we can squeeze in a visit now & then —

Kristine

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Region X
M/S _____
2201 Sixth Avenue
Seattle, WA 98121

June 2, 1993

to Dorothy Mann
c/o Region X office

Kristine M. Gebbie
606 Lilly Road #723
Olympia, Washington 98506

Dear Ms. Gebbie,

The staff of US Public Health Service, Region X, invites you to celebrate with us the retirement, after 33 years of federal service, of our Regional Health Administrator, Dorothy H. Mann. The reception will be held on June 25, 1993, from 2:00 PM to 4:00 PM in the Blanchard Plaza Bldg., Room 205, 2201-6th Ave. Seattle, Washington 98121.

At the beginning of the reception we will provide a few minutes for Dorothy's co-workers and other friends to acknowledge her service. If you wish to participate in this recognition ceremony, please contact David Hutchinson at (206) 553-0215.

We look forward to having you join us.

Sincerely,

Chuck Smith for

The Retirement Planning Committee

THE WHITE HOUSE

Alex —

good luck in your new international ventures — and do, please, stay in touch — I'd like to hear how it goes —

All the best —

Ronald Reagan

THIS CARD IS PRINTED ON CHLORINE FREE PAPER

GC168 Published by Roger la Borde
Printed in England

Dear Kristine,

I wanted to thank you for offering me a position in the Office. I was honored. As you know, I had also been offered a position with the Office of International Health / AID. This was an very difficult decision. After weighing many different issues and perspectives, I decided to pursue my interest in international health. For me, I needed a change and the opportunity affords me a chance to explore this area while remaining a PHS employee.

I'm sorry we didn't get a chance to touch base after I made my decision. I tried on a few occasions to get in touch but ours schedules both were enough to miss one another.

I look forward to remaining in touch and helping in any way I can. I will continue to work with HIV (and other) issues in the Bureau for Africa.

Again, thankyou very much for thinking of me and best of luck in your work with the Office.

Sincerely,

Alex Ross

Alex Ross
8915 Sudbury Rd
Silver Spring MD 20901

WASHINGTON, DC 200
PM
8 OCT
1993

Personal

Ms. Kristine Gebbie
Office of National AIDS Policy Coordinator
Executive Office of the President
750 17th St, NW
suite 1060
Washington, DC 20503

THE WHITE HOUSE
WASHINGTON

Ms. Debra Faser-How
Black Leadership Commission on AIDS
105 East 22nd Street
New York, New York 10010

THE WHITE HOUSE

Debra —

just a quick "thank you" for last week's meeting with BLCOA — it was a great learning event for me — I've started some follow-up & you'll get a more formal letter, but this is my hug to you —

Kristine

THE BLACK LEADERSHIP COMMISSION
BLCA
on
AIDS

SEP 2 2 1993

There's another letter from her around this one needs to get connected with the other

13 September 1993

Ms. Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, NW, Suite 1060
Washington, DC 20500

Dear Ms. Gebbie:

On behalf of the Board of Commissioners of the Black Leadership Commission on AIDS, I would like to thank you again for taking the time to meet with us regarding the Clinton Administration's plans for combating and policies regarding HIV/AIDS in communities of African descent. Having a place at the table is the first step in halting the devastating impact HIV/AIDS is having in African American/Caribbean communities.

We greatly appreciate your concern for and awareness of our growing numbers in the epidemic and look forward to working with you in developing sound, humane and workable policies to deal with this terrible disease. We hope you will agree that BLCA's national replication plan is just one action step on which we can work together.

I will be in contact with you shortly to further discuss BLCA's national replication plan and other ways in which we might work together. I am enclosing a copy of a briefing paper that was prepared at the time BLCA met with members of the President's transition team which outlines some concrete ways we can move forward.

Again, many thanks for taking time out of your hectic schedule to meet with us. Your candor and graciousness are greatly appreciated.

Sincerely,

Debra Fraser-Howze.

Debra Fraser-Howze
Executive Director/CEO

105 EAST 22ND STREET NEW YORK, N.Y. 10010 TELEPHONE: 212-614-0023, FACSIMILE: 212-614-0057

Briefing Paper
Black Leadership Commission on AIDS, Inc.
Clinton-Gore Transition Team
Wednesday, January 13, 1993

BLCA HISTORY

The Black Leadership Commission on AIDS, Inc, (BLCA) is a not-for-for profit organization in New York City, comprised of 67 African American leaders. Founded in 1987, BLCA's mission is to promote organized leadership and education on AIDS-related issues within African-American communities, to enhance the capacity of service providers, and to give communities of colors a visible presence wherever public policy is formulated and resources allocated. Our goal is not to compete with, but to assist and enhance community-based organizations providing direct service to people with HIV/AIDS. To date BLCA has helped the Black community access more than $11 million in new funding for direct care, served more than 1500 organizations and institutions, and remains unprecedented in the development of programs and services through the Black Church.

STATEMENT OF NEED

During the first twelve months of President-Elect Clinton's new administration, it is estimated that there will be 80,000 new AIDS infections in this country. The majority of these cases will be Blacks and Latinos.

The National Commission on AIDS Report, released January 11, 1993, states that Blacks and Latinos constitute fully half of all Americans living with HIV disease. Between 1990 and 1991, the reported number of AIDS cases increased 11.5 percent among Hispanics, and 10.5 percent among Blacks, but fell 0.5 percent among whites.

Dr. June Osburn, Chair of the Commission, stated "The AIDS epidemic has impacted communities of color with a special fury, converging on the turbulent effects of poverty, poor access to health care, and the twin epidemic of substance abuse..." The lead article in **The New York Times** reports that "Racism Contributes to AIDS Spread."

New reports released by the Health Systems Agency in New York City show an alarming increase in new AIDS cases for women, children and heterosexuals between 1991 and 1992. In New York, African Americans and Latinos constitute 64 percent of all AIDS cases. AIDS remains the number one cause of death for Black women of child-bearing age in New York and New Jersey. The United Hospital Fund estimates that as many as 30,000 motherless children and teenagers and an additional 25,000 young adults (18 to 25 years of age), will come from the five boroughs of New York City. 90 percent of all children with AIDS are Black and Latino. These statistics are preview of the rest of the nation.

Issues and Recommendations

Policy and Leadership

To date, Blacks and Latinos constitute fully half of all Americans living with HIV disease. For the past 12 years of this epidemic, the Black and Latino communities have been locked out of the major AIDS policy and decision-making efforts in this nation. The Black and Latino Community is fast-becoming the dominant population of People With AIDS in this nation. In many urban centers, these two ethnic groups have comprised more than 50 percent of all People With AIDS for several years. Especially hard hit are our women, young adults, teenagers, new born babies, and, too often, entire families. We acknowledge and respect the great work of those advocates who were the majority infected in the first wave of this epidemic. Black Leadership, however, must refuse to continue to apologize for not having been the first in the fight against AIDS. We must have a place at the table, and create new tables where needed.

"The challenge within Communities of Color, and especially for those who would be leaders, is that of continued, rapid mobilization against this epidemic, both in promotion of major prevention initiatives, as well as providing compassionate care for those who are infected," as stated by Eunice Diaz, of the National Commission on AIDS.

Recommendations

- **Establish the Black Leadership Commission on AIDS in the 15 cities hardest hit by this epidemic.**

The National Caucus of Black State Legislators, comprised of 500 Black elected state officials throughout the nation, voted to use the model of the Black Leadership Commission on AIDS for national replication. We are asking the Clinton Administration to support these efforts to allow similar Black Leadership Commissions to be established. The Black Leadership Commission on AIDS in New York City has been designated the National Affiliate for this critical policy initiative. A National Replication Plan targeting 15 Black communities across the nation hardest-hit by this epidemic is in the final planning stage for implementation. Our leadership model has been replicated by the Latino community in New York, and Black communities in other upstate regions. Funding for this effort can come from a special allocation from the Centers for Disease Control (CDC) and the Division of Health and Human Services. We are prepared to meet this mandate of mobilization and reorganization of the Black Leadership and People With AIDS in our communities, to promote rapid and effective change and assist community organizations

The Black Leadership Commission on AIDS is not a direct-service organization. Our mission is to improve the health care, education, and delivery of service to Blacks through the provision of technical assistance, to the organizations that serve them.

We are committed to ensuring that the multi-service and new AIDS service delivery agencies in the Black community acquire the resources needed to ensure the development of their infrastructure, and allow them to improve the quality and quantity of services they deliver.

- **Increase Funding to the Black Church for Delivery of AIDS Services.**

For the past five years, Black religious leaders in New York City have played an active and highly effective role in AIDS education and services. The Black Clergy have pioneered in efforts to raise the consciousness of our community, establish trust, and provide direct services through operating AIDS housing, and other care programs.

Developing programs in the Black Church is unquestionably cost-effective. The alarming increase in new infections among Black women and children, enhances the viability of the Black Church as a valuable AIDS service provider. Involvement of the Black Church will allow for immediate family intervention, planning of care and services, and create an existing, compassionate and culturally appropriate system to respond to the more than 80,000 children who will be left motherless in this country due to AIDS within five years.

Efforts by the Centers for Disease Control to involve the Black Church have been sporadic, uncoordinated, lacking the necessary resources and limited to only a few providers. We recommend that a new initiative be established to provide the Black Church with the necessary funding to forge a credible service response to this epidemic, particularly in New York City. We recommend that a National Advisory Council of Black Religious Leaders be established to oversee funding for AIDS education and service programs to the Black Church.

The Black Leadership Commission has had the most successful record in working with and establishing a response for the Black Church community in the nation, with no funding from the CDC. Much of the perceived resistance of the Black Church to be involved in this epidemic is attributed to the issues of homosexuality and drug use. While we admit that some resistance exists, particularly among conservative religious constituencies, this is <u>not</u> a phenomenon confined to the Black Church. Many Black Church leaders have more than demonstrated their willingness and capacity to provide community-based services in this epidemic to our men, women, and children. To continue

to exclude them as providers of service is to continue to deny Blacks the opportunity to develop a credible response to this epidemic.

We would like the Black Leadership Commission AIDS to receive funding to broaden it's efforts to provide technical assistance, training, and assistance in program development to the Black Church. This effort will also enable us to lend our expertise to a national initiative that will insure the success of this process.

- **Create an emergency prevention act that resembles the Ryan White Care Act, that will render allocations to cites and states for prevention programs and risk reduction.**

"The relative impoverishment of African-Americans, Hispanics/Latinos, Native Americans, and many Asian Americans/Pacific Islanders...bears testament to the enduring nature of yesterday's burdens, and the difficulty of playing catch-up at a time when the dominant society is apt to discount matters of race," according to the National Commission on AIDS. The alarming increase of new infections among Blacks and Latinos, as well as those estimated for Native Americans and Asian Pacific Islanders will continue to rise without an emergency act that resembles the Ryan White Care Act. We must end, at all cost, the disparity in the interpretation of any such legislation that may cause a funding battle between the cities and the states. Legislation and full funding for an "emergency prevention act," must be planned and developed in the first 100 days of the new administration. Any response from the new administration that does not include such emergency measures will promote the growing concerns that prevention education has become the stepchild of the AIDS epidemic, and that communities color who are most in need of these new interventions are dispensable.

- **Increase funding for Drug Abuse Treatment and Prevention.**

The nation has identified needle exchange as **one** approach to reducing transmission of the HIV virus among intravenous drug users. The Black Leadership Commission on AIDS, Inc. has also reversed it's decision and is in support of these efforts, if linked to drug treatment, care and education, as a means risk reduction. BLCA has also been a constant advisor to Communities of Color around the nation who are experiencing resistance to this controversial method.

In the Black and Latino communities, injection drug use has played a significant role in the rise of infection and disproportionate impact of AIDS. "The proportion of AIDS attributable directly to injection drug use among African-Americans and Latinos is four times that of whites, which is 40 percent as opposed to 9 percent," as stated in the

Commission Report. Clearly, needle exchange cannot remain the sole answer to these astounding numbers.

Treatment on demand is **essential**, and the need is immediate. Racism is clearly apparent in this segment of the AIDS epidemic. Treatment on demand can no longer be viewed as too encumbering or expensive while the lives of Blacks and Latinos hang in the balance of the debate.

In addition, the abuse of crack cocaine has created a massive resurgence of sex in exchange for drugs. A staggering increase in oral gonorrhea in urban centers is attributed to a new phenomenon of "head bankers," young women who exchange oral sex for drugs in crack houses, and must "bank their heads" until the crack house proprietor considers their debt paid in full.

Treatment on demand must address **all** illicit drug use and provide a wide range of alternative treatments for people in need. We recommend increased funding to all agencies in the federal government to allocate funds for drug abuse treatment and related services. We also recommend that special, gender-appropriate services be funded for the care and special needs of women and children.

Funding for drug treatment and services must be provided to city and state correctional facilities, to address an immediate emergency. Also, the general philosophy that addresses drug treatment as a criminal intervention is inappropriate. The new administration must change it's approach for drug abuse treatment to one of public, clinical and mental health. The health care community is the appropriate place for drug treatment which has before been treated through the criminal justice system.

Advisory Boards and Commissions

Advisory boards and commissions established to council the administration on AIDS policies and programs must reflect the ethnicity, gender, geographic and risk factor profiles of this country's epidemic. People with AIDS and service providers from these communities that have the willingness and capacity to serve on such boards must be actively recruited to do so . We further recommend that a credible percentage of all such appointments (determined by the infected and affected community), be standard practice for this administration across all such boards and councils. Having People With AIDS and providers from these communities serve in such capacities is essential to planning for their needs.

Research and Clinical Trials

No where in this epidemic has an apartheid system been more evident than in AIDS research and clinical trials. Of the billions spent on AIDS research to date the profile of people with HIV/AIDS involved in protocols in absolutely unacceptable.

The attempt to answer questions of accruals by individuals in policy positions who bear no resemblance to the people they are trying to engage must cease immediately. Provision of treatment education among to Black and Latino communities have been dismal and foster the feelings of many in our communities that AIDS is biological germ warfare created in a test tube to eliminate the people of color. The genocide theory, research and the question of accruals can only be answered through providing credible institutions with clinical personnel and leadership, that resemble these communities and who have gained their trust, to become appropriately engaged in the process.

- Increased funding must be given to Black and Latino medical institutions for development of clinical trials and research. The idea of recompetition in a clinical trial system where only powerful white educational institutions are allowed to compete is lacking integrity. Black and Latino medical schools and institutions must be removed from recompetition criteria that create barriers to funding, and directly awarded grants as sole source applicants.

- Increase the number of Black principal investigators and clinical staff across all existing trials. Of the approximately 950 research scientists working on a cure or treatment modality for AIDS, approximately eight (8) are black. The government must develop programs that target Black and Latino medical doctors and students to be involved in research. The procedure for acquiring research grants must mandate affirmative action systems in the request process. The open competitive system of research funding must mandate more than special incentives for institutions who increase the number of Black and Latino participants in their trials. Depending on the studies, it should be mandated that personnel on the protocol team, in other than clerical or entry-level positions must include people of color. Special incentives should be given to protocols that either have people of color as primary investigators or co-investigators in protocols.

Outreach and education on treatment and trials has been overwhelmingly successful when carried out on a community level. Community based organizations and patient advocates must have increased funding to broaden these efforts.

Full funding for the demonstration project entitled "PETT"--Public Education and Technical Transfer--must be enacted **now**. This project is now being established at the Division for AIDS at the NIH in conjunction with the Community Constituency Group and HERSA. The purpose of PETT is to broaden the access of clinical research information to all communities, especially communities of color.

The Black Leadership Commission on AIDS initiated the creation of the PETT Project, and it's Executive Director, serves as it's chair. Without necessary education in the infected communities, we will shorten the lives of many people of color who simply lack the education needed to make an informed decision.

The office of Minority Health MUST be reorganized and funding MUST be increased.

THE WHITE HOUSE

Dear Judy—

Yes, I do remember our visit in Colville. Attached is the letter which recently went to potential applicants ~~further~~ information will be forthcoming—

I hope you're enjoying Wyoming—

Ken Duberstein

September 28, 1993
1440 Hillcrest Drive
Lander, Wyo. 82520

Ms. Kristine Gebbie
Nt'l AIDS Policy Coordinator
Washington, D.C.

Dear Kristine,

Realizing the great responsibilities you now have, I thank you for taking the time to acknowledge my telephone call through Dr. Edwards. It was very much appreciated.

I wish to Congratulate you on receiving this most prestigous appointment; and I know you will do a fine job. You are an excellent communicator and that is a great asset.

Kristine, hopefully you will at least vaguely recall visiting in Colville, Wn. You spoke at the dedication of the new surgical wing at Mt. Carmel Hospital as well as touring our facility at an earlier date. At that time I was Dir. Pt. Care Services. Am sure you also remember Mary Selecky, Adm. of Tri-county Health Services.

I recently retired from my position and have moved to Lander. I continue to have great interest in the many varying problems in Health Care and of course in the AIDS situation.

At this time I am inquiring if any work is available in the area of assisting in your project or related areas? I would certainly appreciate any information concerning work availability.

Again Kristine, Congratulations and I wish you a triumphant journey.

Most Sincerely,

Trudy Paddleford

Trudy Paddleford

THE WHITE HOUSE

Dear Edie —

Sorry I'm so slow — thanks for your good wishes — and the update on NYU's AIDS education efforts. I wish more schools of Nursing were energetically doing AIDS-related research & teaching.

All best wishes —

Ronald Reagan

New York University
A private university in the public service

School of Education, Health, Nursing, and Arts Professions
Division of Nursing

429 Shimkin Hall
Washington Square
New York, NY 10003
Telephone: (212) 998-5300

July 8, 1993

Kristine M. Gebbie, M.N., R.N., F.A.A.N.
606 Lilly Road, N.E.
Apartment 723
Olympia, Washington 98506

Dear Kristine:

I could not let this opportunity pass without writing to congratulate you on your appointment as AIDS czar or shall I say the White House AIDS Coordinator. I am sure that you have the knowledge and expertise to measure up to all of the expectations from such an appointment. You have acknowledged that it will be a difficult task, but with your experience and positive outlook you will succeed.

It is an honor for the nursing profession that you were chosen for this position. It makes one proud to be a nurse and to share the burdens and responsibilities that confront the profession in this HIV/AIDS pandemic. We first met in Washington, D.C.in 1989 when you keynoted the Invitational Workshop on "Nursing and the HIV Epidemic: A National Agenda." Pat Hurley and I presented the background paper that we had prepared on Nursing Education at that workshop.

Since then, we have continued our HIV/AIDS education/training programs here at New York University which we began in 1986. Currently, we have a grant from the Center for Mental Health Services, DHHS, and a contract with the New York City Department of Mental Health, Mental Retardation and Alcoholism Services to train mental health care professionals regarding the neuropsychiatric and psychosocial complications associated with HIV disease. We have been proud of our efforts to date, but unfortunately so much remains to be done particularly here in New York City.

We wish you only continued success, happiness and good health in all of you future commitments. If we can ever be of any assistance to you, all you have to do is ask.

Most sincerely yours,

Erline

Erline P. McGriff, Ed.D., R.N., F.A.A.N.
Professor

THE WHITE HOUSE

Karen —

Thanks for sharing the publication on Adolescent AIDS programs. It's great! And great to have you around. I hope this is a good year for you —

Barbara Bush

Karen Hein, MD

will be on sabbatical beginning
September 1, 1993 for a year
as a

Robert Wood Johnson Health Policy Fellow

working on national health care reform

Fellowship Offices:

Institute of Medicine
National Academy of Sciences
2101 Constitution Avenue
Washington, DC 20418
202/334-1506 - phone
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Home Address (with husband Ralph Dell MD,
and daughter Molly Hein):

3905 Huntington Street, NW
Washington, DC 20015
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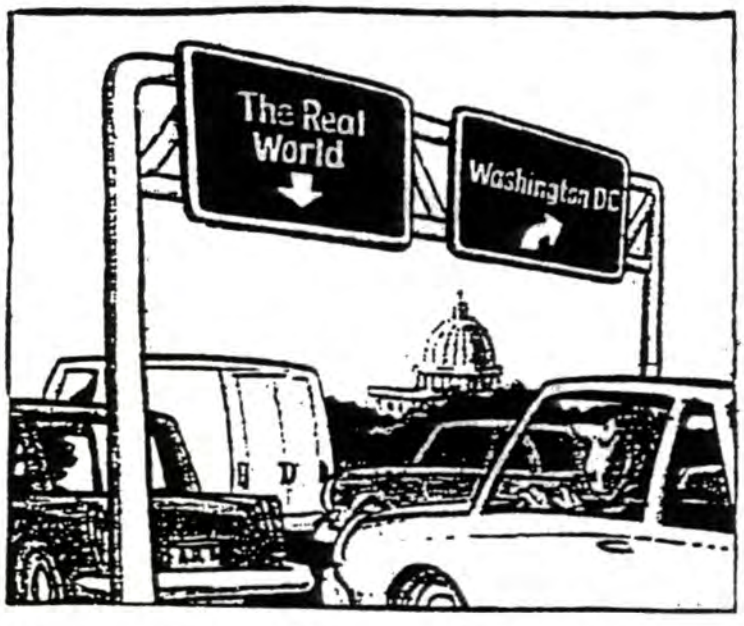
202/363-5139 - FAX

(mail and calls will be forwarded from my New York office by
my secretary, Retha Johnston @718/882-0322)



THE WHITE HOUSE

Dear Dan –

Thank you for taking time to write – I ~~appreciate~~ the words of encouragement & support. I do look forward to meeting with NYACN members again – the communication skills represented in the group can be invaluable in our fight against AIDS

~~Best~~ Wishes Kristine

OCT 18 1993

October 15, 1993

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

Dear Ms. Gebbie: Kristine:

It was a pleasure meeting you at NYACN. I'm sorry the disruption at last night's meeting made it impossible to discuss the role of communications and media in furthering the awesome tasks of your office. It was disheartening to see ACT UP's overkill of passion and urgency effectively abort any chance of progress on so important and potentially powerful an alliance.

Again, I want to let you know that there are activists of many different types within the gay and lesbian community, and all have considerable energy and organizational resources to offer.
The majority of those present were honored to have you as our guest and were extremely impressed with your bearing and candor in confronting the peculiarly chaotic energy of anguish and rage that ACT UP seems to embody.

Don't however permit these shock troops in the war against AIDS to erode your courage. You will need it, and so do we. Perhaps you may even find ways to enlist their estimable energy and channel it productively.

More importantly, don't discount the level of interest, support and commitment that exists within the lesbian and gay community, or our willingness to contribute toward the objectives we share with you and all humanity where HIV and AIDS are concerned.

Incidentally, there are more of us than you may think who recognize the political capital the President continues to expend on behalf of equal rights and equal protection for homosexuals; who can see that much is being accomplished despite the vast difficulty of simultaneously moving government, shaping public opinion, and pursuing a legal framework for lasting change. I trust you will have his continuing support to act swiftly and to accomplish more than has been done so far in pursuit of the answers and solutions the AIDS crisis demands.

I also hope you would consider returning to enlist the resources and capabilities of NYACN members, providing our leadership can design an appropriate forum where your time and presence, not to mention that of our own members, can't be arrogated and wasted as it was last night.

Sincerely,

Dane Twining

THE WHITE HOUSE

Dear Ruth -

I hope this reaches you before APHA - so you know I'll be looking for you there. My apology for being so slow in thanking you for the message of support & congratulations. I'm watching the UCHA fight closely - with concerns that there's no shift so far - looking forward to visiting with you & Hillel -

Hillary

RER

UNIVERSITY OF CALIFORNIA, LOS ANGELES

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SCHOOL OF PUBLIC HEALTH
10833 LE CONTE AVENUE
LOS ANGELES, CALIFORNIA 90024-1772

June 28, 1993

Kristine Gebbie
AIDS Policy Chief
The White House
Washington, D.C. 20500

Dear Kristine:

Congratulations on your appointment as AIDS Policy Chief! You are ideally qualified for this crucially important assignment. Congratulations should really go to President Clinton for having made such a wise choice.

Your performance on the McNeill Lehrer show on June 25th was outstanding. The photograph in the New York Times and all the news stories are wonderful. I know you are no stranger to challenging tasks; so I just want to send Milton's and my best wishes for meeting the "dragon within our gates."

As ever,

Ruth

Ruth Roemer, JD
Adjunct Professor of Health Law
Past President (1987)
American Public Health Association

rr3(kg).ltr

THE WHITE HOUSE

Dear friends—

My belated thanks for your kind message of support. I value my UCLA ties (though my letter seems to have had no effect on Chancellor Young!) and look forward to seeing you all—

Best of luck in the struggle—

Ronald Reagan

KG

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98504

KRISTINE GEBBIE RN MN
SECT. OF HEALTH
DEPT.OF HEALTH
1112 S E QUINCE ST.
OLYMPIA WA 98504

CONGRATULATIONS ON BEING APPOINTED BY PRESIDENT CLINTON AS COORDINATOR OF AIDS PROGRAMS AND SERVICES. WE ARE PLEASED AND PROUD THAT ONE OF OUR ALUMNI HAS ACHIEVED SUCH WELL DESERVED PROMINENCE AND LOOK FORAWARD TO ASSISTING YOU IN ANY WAY WE CAN.

DEAN, FACULTY AND STAFF
UCLA SCHOOL OF NURSING

Ada Lindsey, Dean