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THE WHITE HOUSE

WASHINGTON

April 13, 1994

Nancy Hedin, Executive Director
Portland City Club
317 S. W. Alder Street
Suite 1050
Portland, Oregon 97204

Dear Ms. Hedin:

This letter confirms the appearance of Kristine M. Gebbie, National AIDS Policy Coordinator, at The Portland City Club, on Friday, April 15, 1994.

Ms. Gebbie plans to present:

> Observations and thoughts on the status and direction of national AIDS policy. In 1988, when Ms. Gebbie last addressed the City Club, she talked about Oregon and the AIDS epidemic -- what has happened in Oregon to-date and how does that relate to the country. In addition, Ms. Gebbie will address the need for greater community leadership, empowerment, and broad-based citizen participation necessary to end the epidemic.

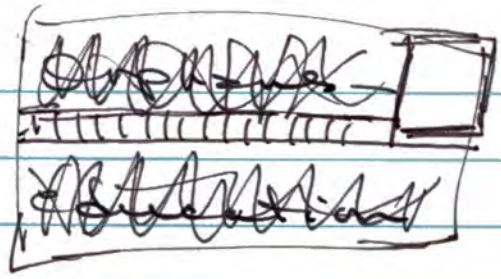
Please call me at (202) 632-1090 with any questions or for further clarification. I am enclosing a biographical sketch for your reference.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to the
National AIDS Policy Coordinator

Enclosure



HIV - Oregon & the Nation

This disease continues to be a problem

when I spoke to City Club 1988 - 323 cases AIDS
now 2525 at end of 1983

then 3% of cases = heterosexual drug users
now 10%

here as in nation, AIDS kills young group that should live —
mult.Co leading cause of death in men 25-44
statewide - 2nd leading cause

Despite interest & action
4% IV drug users +
now 18% + in public sites

Major problem continues to be denial / division
talk about "infected groups" as if they were mutually & exclusive
homosexual men
drug users
hemophiliacs
women
people of color

while hemophiliacs are not women, nor are gay men, all other intersections possible

National policy —

Research —

til we find the answers.

full range of biological → social sciences

basic & applied studies

examples: how immune system works / how to restore it

how young people learn sexual roles/

how to help with choices

Services —

early diagnosis / full range of services

Health Reform —

non-discriminatory / non cancellable

good planning / management of resources

chronic disease model

continued Ryan White funding —

support services tailored to community

substance abuse services

Prevention —

key behavior changes —

① no sharing of injection equipment —

street drugs or steroids

② sexual choices —

(3)

The local nature of actions / decisions

it is a university's decision to reward
leadership in HIV research,
not hide it

it is a community's decision to make
acknowledgment of infection easier
by accessible testing / non-discriminatory

it is a community decision to give young
people all the factual & value info
needed to save lives –
& support it fully

Is it a norm that employees get info –
ex: fed'l employee education –
personal, management, program options

Is it an expectation that leaders are
~~who~~ attending to decisions

Who is at the planning table –
Oregon leadership in health reform debate
is there that level in Ryan White process
Community prevention planning

We can stop HIV ...
connect with the reality that head knowledge ~~is~~
right behavior
honest / open communication & commitment

One of my strongest beliefs is that our response to this epidemic will be measured not by how fast we found the virus or a vaccine but in large part by the degree to which we acknowledge our community & our mutual responsibility ....

Only collective attention to our own behavior will be effective in stopping this epidemic.

THE WHITE HOUSE

WASHINGTON

December 23, 1993

John J. Ulwelling, Executive Vice President
Oregon Foundation For Medical Excellence
4000 Kruse Way Place, Building 2, Suite 100
Lake Oswego, OR 97035

Dear John:

This letter confirms the appearance of Kristine M. Gebbie, National AIDS Policy Coordinator, at the Portland City Club to present the Oregon State Board of Medical Examiners 1994 Ralph Crawshaw, M.D., Lectureship, on Friday, April 15, 1994. I do, however, appreciate your and Nancy Hedin's patience in trying to reschedule this appearance.

Ms. Gebbie plans to arrive the evening of Thursday, April 14, 1994, and to deliver the speech, "Responding to AIDS: The Government and the Public" over lunch at the Marriott Hotel on April 15, 1994. I will forward the outline and biographical material, and let you know the physical data of the trip by March 15, 1994.

Please call me at (202) 632-1090 with any questions or for further clarification.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to the
National AIDS Policy Coordinator

cc: Nancy Hedin

OREGON FOUNDATION FOR MEDICAL EXCELLENCE
4000 KRUSE WAY PL., BLDG. 2, SUITE 100, LAKE OSWEGO, OR 97035, (503) 636-2234

2295770

October 4, 1993

Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street, NW, Suite 1060
Washington, D.C. 20503

Dear Kris:

We all are very pleased that you have agreed to be the Oregon Foundation For Medical Excellence (OFME) - Oregon State Board of Medical Examiners (OBME) 1994 presenter for the Ralph Crawshaw, M.D., Lectureship.

The presentation will be given on Friday, April 15, 1994 in Portland, Oregon. For your information, I purposely scheduled you on Friday rather than Thursday, so that we might be able to do a joint presentation with the City Club of Portland. I have discussed this with Mary McWilliams, the President of the City Club of Portland, and also CEO of the Sisters of Providence Health Plans in Oregon. She thinks it would be great to have the City Club co-sponsor you. As you know, all such requests must be filtered through their committee structure.

What should the title of your presentation be? All of us would appreciate an update on AIDS in this country as well as what can be anticipated regarding the impact of AIDS in the future for physicians and the public.

Please let me know what your travel arrangements will be. Where would you like to stay? I would recommend the Alexis Hotel, which is located downtown by the river and is lovely. Do you need your expenses covered? Honorarium? Please let me know.

We are all very pleased that you are returning to God's country (others have called it a remote province of the American Empire) to talk about a very important subject.

Warm regards,

John J. Ulwelling
Executive Vice President

JJU:jlm

cc: OFME Board of Directors
BME
Ralph Crawshaw, M.D.

CITY CLUB OF PORTLAND

1050 Loyalty Building
317 SW Alder Street
Portland, Oregon 97204
503-228-7231
Fax 503-228-8840

October 15, 1993

RECEIVED

NOV 22 1993

Dr. Kristine Gebbie
National Aids Policy Coordinator
750 17th Street N.W., Suite 1060
Washington D C, 20503

Dear Dr. Gebbie:

I am delighted that you have agreed to be luncheon speaker for City Club on Friday, April 15, 1994. I look forward to hearing your perspective on the current status of our national fight against AIDS as well as your prognosis for our winning the battle. We are interested in hearing your views on the impact of AIDS on the community in general, and physicians, in particular. As you know, this program will be co-sponsored by the Oregon Foundation for Medical Execellence and the Oregon Board of Medical Examiners as the Ralph Crawshaw, M.D., Lecture for 1994.

As you know, your City Club audience will be well-informed and welcomes controversy and challenge. Your prepared presentation should run about 20-25 minutes after which there will be approximately 15-20 minutes of questions from the audience.

The program on April 15 will be held in the Ballroom of the Marriott Hotel in downtown Portland. Please plan to arrive at the hotel by 11:45 am so that you will have time to enjoy lunch. The program will begin at 12:15 pm and adjourn at 1:15 pm. The program will be broadcast live statewide over Oregon Public Broadcasting and aired the following week on area cable television.

I will need biographical information and a paragraph from you which outlines the substance of your talk for purposes of developing promotional program copy as well as an introduction. Please forward this information as soon as possible and not later than March 15, 1994. We will also be preparing a program announcement within two weeks of the event and may be contacting your office then regarding the details of what you will cover.

We are honored to have the opportunity to co-host this program and to have you at our podium. If you have questions or need further information in the meantime, please call me; Otherwise I look forward to the program and to seeing you on April 15.

Sincerely,

Nancy K. Hedin
Executive Director

C Ralph Crawshaw, M. D.
John J. Ulwelling, Executive Vice President OFME

CITY CLUB
OF PORTLAND

1050 Loyalty Building
317 SW Alder Street
Portland, Oregon 97204

Dr. Kristine Gebbie
Natinal AIDS Policy Coordinator
750 17th Street N. W., Suite 1060
Washington D. C ~~20006~~

750 17 50512510 ** ER 0005
***** AUTOMATED MAIL (NUM) *****
750 17TH ST NW
WASHINGTON DC ~~20006-4607~~
20520

Keep this for when
I prepare my PDX
speech

DEC - 7 1993

THE WHITE HOUSE

Ralph —

Thanks for writing — Sin looking forward to April — & will try to live up to your hopes! Your encouragement for the real voice of people means a great deal to me — Best time

PRACTICE LIMITED TO
PSYCHIATRY

PHONE: 223-8811

RALPH CRAWSHAW, M. D.
PHYSICIAN
2525 N. W. LOVEJOY STREET
SUITE 404
PORTLAND, OREGON 97210

October 29, 1993

Kristine Gebbie, R.N, Ph.D.
National AIDS Policy Coordinator
750 17th Street N.W., Suite 1060
Washington, D.C. 20503

Dear Kris,

Word has filtered back to me that you will give the lecture to the City Club on April 15th. Three Cheers.

I do not know what you wish to say but encourage you to say it. However, it might be a help for you to know what some of us wish to hear. I, for one, would like to know what the citizen's contribution can be expected to be in time, money and suffering? What level of citizen/government organization is unacceptable, acceptable and optimal? Is there a place for the health decisions process in what is unfolding around AIDS?

It will be great to have you back to show us what an Oregonian has accomplished with the kind of support you received in Oregon. Read me clearly, for you and I have experienced some similar responses in Oregon to the idea there is more to being a citizen in this beautiful state than passing judgement on California's short comings. In the words of Harry Truman, "Giv'em hell."

Lastly, how does anyone survive in Washington? In all the reform hubbub I have been trying to get an idea across that the citizen should be heard and the government should ante up a pittance to facility the voice of the people. Congressional crowd seemed to have lost their hearing but Koop and Phil Lee nodded approval.

Great good fortune with your new assignment.

Cordially,

Ralph Crawshaw, M.D.

Who is Going To Solve My Plumber's Health Care Problem?

In my opinion you, the lay citizen, can solve my plumber's health care problem, as a matter of fact you may be the only one that can. After fixing a leaky faucet in the basement he shoved back his cap and said, "Doc, I got a health care problem?" He went on, "I have been coming by your place for a number of years so you know we moved to Portland just so my wife could get good medical care for her emphysema. She has a chronic problem and we lucked out when we found a clinic and a good doctor in that clinic, that is until last month."

"The last time she went in for her regular check up with Dr. Barbonne she was told by the receptionist she would see Dr. Swift instead. 'Why,' she asks and the receptionist says Dr. Barbonne is no longer with the clinic. When my wife asked more the receptionist turned her off with some story about him going to get more training."

"His leaving seemed too sudden. He was not the kind of doctor who just disappears without say something to his patients I looked up his home telephone number and gave him a call. He knew me right away. When I asked why he left the clinic, straight out he said it was because of a disagreement. I did not want to get into it but he went on to explain that he was seeing 25 patients a day and the clinic management told him he would have to up it to 45. When he said he could not do a proper job seeing 45 patients a day it was out. He was replaced with a new guy who would see 45 patients a day. That is not good for my wife so we are looking for a doctor we can trust to take the time wife needs. Do you know any?

I gave him some names of good doctors I knew but his problem and the public's problem is not solved by a transfer within the system. The system needs to be addressed by grass roots lay people. A line must be drawn on how much money will be squeezed out of patient care by top down reform plans. Oh, some reformers will claim they improve quality while they reduce cost but what chance do the people like my plumber have of knowing the odds or setting the standards on getting what they want for their tax dollars and insurance premiums, their definition of quality? Is the public expected to give up believing that their doctor should have time to stop and listen to their concerns, to known them, before reaching for the prescription blank?

Granted it is difficult for a plumber, a shoe sales man, or a homemaker to come to grips with the complex language and involved bioethical issues presently emerging from health reform. But with all these citizen tax dollars going for health care reform it is plain common sense to put aside a bit for the public to learn something about the issues and values involved in making intelligent choices?

You can help my plumber with his health care delivery problem of finding a trustworthy doctor with enough time to listen by writing your congressman or woman to set aside a small amount, in the range

2525 N. W. LOVEJOY STREET
SUITE 404
PORTLAND, OREGON 97210

PORTLAND, OR 972
PM
1 NOV
1993

Kristine Gebbie, R.N., Ph.D.
National AIDS Policy Coordinator
750 17th Street,N.W. Suite 1060
Washington, D.C. 20503

Kristine Gebbie
Health Division
February 19, 1988

AIDS IN '88

HIV infection has presented immense challenges to the citizens of Oregon, the citizens of our nation, and the citizens of the world. Some of these issues have been apparent to me for a number of months, thanks in large measure to excellent tutoring by Oregonians - physicians, local health departments, community based AIDS organizations, individuals with AIDS and their families and friends. I have become more conscious of others because of my recent involvement with the Presidential Commission on the HIV epidemic. The process of understanding the challenges presented by this infection, and figuring out solutions, is going to require careful work by many individuals. I am pleased to share some thoughts with you today and explore how you, as concerned and involved Portland people, can participate. You have already taken a step forward with the work of your AIDS Committee and the publication of a first report.

To briefly recap what you have probably heard on the 6 o'clock news or read in the paper, AIDS is the most severe form of infection with the retrovirus known as HIV (Human Immunodeficiency virus).This virus attacks cells controlling the body's ability to respond to infections, leaving a person vulnerable to conditions which occur almost unnoticed in healthy individuals. While easy to kill outside the body, a retrovirus is hard to reach once inside; no cure is yet available. The virus goes where it is put - wherever infected blood or semen carry it (a word of caution - although the virus has been found in other body fluids, it is in low concentration, and all epidemiologic evidence points to blood and semen as the transmitters of the disease). Rather than a disease of chance (I was sneezed on in the bus today) it is a disease of choices - we put ourselves in the path of the virus by our choices of sexual and drug behavior.

The sudden appearance of AIDS and the challenge of responding to the epidemic have revealed a number of things about our society - things which are problems, which may not be new, and which interfere with our response. Among those which have surfaced include:

1) Our societal confusion about sexuality. We live in an era of double or triple standards about sex. Our federal administrative leadership talks about the family and fidelity as if they were a universal way of life, our televisions broadcast show after show of couples merrily hopping in and out of beds with no consequences and our children are left to guess how their bodies work, what the raging emotions of adolescence mean and what values and standards are most appropriate for them. We get sidetracked by the red herring of whether "the C word" (condom) is suitable for public discourse rather than be honest that many young people grow up unable to have an open discussion with caring adults who can talk both about the facts of sexual behavior and the consequences of the choices that might be made.

2) Drug use and abuse. While we are aware that the abuse of drugs has increased, many of us have successfully avoided an appreciation of how many people are trapped in a life dominated by the injection of heroin or in ways of life associated with illicit drugs. The selling of one's body to pay for drugs, prostitution, is a major contributor to spread of HIV infection in some parts of the country already. We may not have New York City's shooting galleries, with 100 users per needle per day, but we can't ignore the issue. We have more people asking for care than our drug programs can enroll today.

3) Illness care coordination and financing - Anyone who has had a long term illness can describe the problem of finding alternatives to hospitalization when acute care is no longer needed. Adequate support for extended care services, in-home care, and assistance with basic household tasks become a problem for persons who have AIDS. The pieces of the system don't fall together automatically. Programs struggling to coordinate services for other population groups don't drop everything to serve AIDS patients.

AIDS community based organizations do not come into being without support and effort. Neither will it come as any surprise to those who have been concerned about provision of care to the uninsured and under-insured, that our system of paying for illness treatment is at best, confusing and at worst, a disaster. Most persons are insured only while working; if you become too ill to continue to pay a premium you are out of luck. Many people may have coverage for acute care but are left to self finance less expensive and more appropriate forms of care in the home or in a community setting. A person may be eligible for publicly funded care but because the public program pays only a small percentage of the actual costs, may find service doors closed. Poor mothers on welfare, the severely handicapped, the frail elderly have experienced these problems for years; we have now added a new population to the affected.

4) Discrimination. Attack on any epidemic depends on members of a society working together.

While good laws, and Oregon has good public health laws, are needed, cooperative effort is the key to success. When any group within the society fears discrimination (especially if there is actual evidence of its existence) members of that group will not come forward to participate in the needed cooperative response. In the course of history, many diseases have been "leprosies". Tuberculosis was once a shameful condition. Cancer was not mentioned in obituaries. Any one of us might be reluctant to see our physician if we thought that intimate facts might be broadcast or the result of that visit would be shared with our employer, or our landlord and result in firing or eviction. The group most affected by this epidemic in Oregon and generally nationwide, is a group already unsure of a welcome reception in the community. Many gay men have specific experiences of negativism. For these men, the request to "trust your friendly health department" or to identify themselves as at risk of this disease has seemed very risky indeed.

Despite all of these problems, we have come a long way in both understanding the disease and in identifying what can be done. The facts about AIDS in Oregon are:

- as of today, 323 individuals living in Oregon have been diagnosed as having AIDS. (There are over 50,000 cases nationally, and Oregon ranks 20th in the rate of the disease.)
- An additional 29 persons have died of AIDS in Oregon, though originally diagnosed elsewhere.
- From what is known, we project that perhaps 15,000 Oregonians are infected with the HIV virus. We do know from our alternate testing sites, from the blood banks and elsewhere the additional facts that -
  - of those individuals seeking testing who have used IV drugs, about 4% are infected.
  - of the population entering our prisons, approximately 1% are infected.
  - of those seeking to enroll in the military from Oregon, 5 of each thousand applicants are infected.

Both the disease and the infection are spread across Oregon, although it is predominantly an urban condition (77% of cases have come from the tri-county area). As with many west coast states, the majority of those infected and diagnosed with AIDS so far have been gay men, but there are infected individuals who are users of drugs, who are hemophiliac, who have been infected through blood transfusions, who have been born to infected women. They are male and female, young and old. Many of these individuals are sexually active; only a portion of them are homosexual. One of the peculiar discussions about this epidemic has been the question of risk to "the general public" as contrasted with the "them" who are at highest risk. "They" are part of "the public" and no redefinition of "risk groups" can separate them from us, their parents, children, spouses, lovers, friends, neighbors.

I have been asked often "why keep on about AIDS? It's been on the news so much, surely everyone knows what they need to know - let's get on to something else". Not quite true. There is still plenty to do.

We must understand this disease as a disease of behavior. It is not something to which we are subject by the casual whims of people around us. It is a disease for which we are at risk by the choices we make: a decision to change sexual partners, to have sex with a partner whose sexual history we do not know, a decision to use drugs with a needle that's been used elsewhere. One of the easier options is to think that all of those are behavior choices made "out there" by some other people who are nasty, dirty, poor, of a different colored skin, of a different sexual orientation. But the fact is, those are behavior choices that are made by lots of Oregonians every day, even, perhaps by a member or two of the City Club.

As we confront our behavior, and acknowledge that the behavior which puts people at risk of HIV is scattered throughout our community, we must acknowledge our community. We must admit the impossibility of defining those involved with this virus out of our community and into some other group which can be isolated, separated, dealt with without bothering us.

It won't work that way. We are all "us", whether we are the majority or the minority, whether we are gay or straight, whether we are using drugs or not, whether we are a child or an adult. One of my strongest beliefs is that our response to this epidemic will be measured not by how fast we found the virus or a vaccine but in large part by the degree to which we acknowledge our community and our mutual responsibility.

After admitting our community, we start committing our resources and I mean far more than dollars. Oregon is spending $1,800,000 in this fiscal year on preventing further HIV infection. That's a lot of money. The first set of resources we need are those for education.Having become personally informed, we must use all of the settings we can identify to educate others. The workplace, the hospital, the doctor's office, the school, youth groups . . . the list is endless. The choices we make as informed adults are ours to live with.

Our next generation of Oregonians, those kids in school who are not yet sexually active or who have not yet decided to use drugs, must receive the information necessary to make wise choices, wiser choices than some of the adults around them have made. That means starting early. In 1987, 113 teenagers under 15 became pregnant. The youngest was 12. It means starting with accurate and straightforward information and it means providing that information in an atmosphere of trust and support so that a kid who's having a problem doesn't feel a need to go off and make unwise choices alone. That means while the school may be the place for some of the factual information, the home, the social club, the sports team, the church, all of those other places where kids can be found must become a part of the support for wise decision-making. That will happen only with the personal commitment of time by informed caring adults. Much of what is needed is not AIDS specific.

These are the same kinds of support and structures that kids need to make wise decisions about avoidance of pregnancy as a teenager, about avoidance of substance abuse, about using seatbelts, choosing to finish school rather than be a dropout, all of those things to which we are committed. The response of school boards, parents, teachers to the new AIDS curriculum is a good marker of progress.

Second, we must make a commitment to care. This means caring about those who are ill, but it also means caring about those who are infected and caring about those who are frightened of becoming infected. It means allowing services for the treatment of drug abusers or hospices for those infected into our neighborhoods: we cannot afford a "not-in-my-backyard" syndrome on this one. It means tackling head-on the problems in paying for illness care. I do not think we can have a system in which people with AIDS are given better treatment than anybody else. But neither should they be edged out or receive worse care. If the system is not working for anybody, then we have to find ways to fix it.

The burden of several hundred AIDS patients may be more than a broken system can absorb. If the system is working, but not for those who are HIV infected, we must correct the access problem. Long term care facilities have not been open to accepting AIDS patients; nationally, dental care seems hard to find. Since there are no technical or infection control reasons those types of care should be inaccessible, the answer may be in the problem of "the AIDS twitch" - a fear of the unknown, of sexuality or homosexuality, of "them". Those are resolvable concerns, if we want to fix them. As new community based organizations have been developed to aid those affected, we need to give them support such as we give the traditional disease, cancer, diabetes, birth defects.We must assure every Oregonian, regardless of sexual orientation, that we will not allow discrimination, just as we extended that assurance to racial and ethnic minorities in the past. Knowing that the law alone is not enough, we must back it up with fair and equitable treatment.

And finally, we need a commitment to research. We must continue to find ways to educate better, to support care givers better, to treat the virus, to treat those infected with the virus, to possibly, some day, have a vaccine. I put research last because it is an easy one for many people to support. We often do better raising money and community emotion for shiny things and scientific solutions than for the person-intensive tasks mentioned earlier.

The clearest message I can bring you about this epidemic is that this is an epidemic that can be stopped, but it is one that will not be halted by a new shiny silver bullet. If you have any doubts about that, you have only to look at the syphilis epidemic in Oregon in this last year. We have a silver bullet for syphilis; the antibiotics to treat the disease have been available for many decades. No baby needs to be born infected, no adult need spread the infection. But we have failed to connect that readily available silver bullet with those who are practicing behaviors that put themselves at risk. The methods of transmission are very like the methods of transmitting HIV.

Last year five Oregon babies were born with congenital syphilis and over 300 adults got a new case of this old disease. That is as many adults as will get a new case of AIDS in 1988 in Oregon. Only collective attention to our own behavior will be effective in stopping this epidemic. Thank you.

1:30 c Fqzios

LANE
POWELL
SPEARS
LUBERSKY

March 28, 1994

Steve
Did we schedule anything?

BY TELEFAX AND MAIL

Kristine M. Gebbie, RN, MN
Office of National AIDS Policy
Executive Offices of the President
750 17th Street NW, Suite 1060
Washington, DC 20503

Re: Epitope, Inc.
Our File No. 702322-2

Dear Kristine:

Attached is a story about you from the front page of today's *Oregonian*. I thought you would like to see how the home town press treats you.

I have not yet heard from your office about scheduling a time for you to visit Epitope when you are here next month. I hope we can pin this down soon.

Very truly yours,

Theodore C. Falk

Enclosures

cc w/enc. by telefax and mail:
Andrew Goldstein, Vice President
Steve Weiner, Readmore Communications

LPPORT1 J:\CG1\TCF\12683TCF.LTR

Law Offices

520 S.W. Yamhill Street Suite 800 Portland, OR 97204-1383

(503) 226-6151

Facsimile: (503) 224-0388

A Partnership Including Professional Corporations

WHO IS SHE?

Kristine Moore Gebbie

- **Born:** June 26, 1943, in Sioux City, Iowa
- **Occupation:** national AIDS policy coordinator
- **Salary:** $112,000 annually
- **Education:** B.S. in nursing, St. Olaf College, Northfield, Minn., 1965; master's in nursing, UCLA, 1968; doctorate candidate at University of Michigan School of Public Health.
- **Professional history:** assistant director of nursing, St. Louis University, 1976-78; administrator, Oregon Health Division, 1978-89; secretary, Washington State Department of Health, 1989-1993; member, Presidential Commission on HIV Epidemic, 1987-88; appointed President Clinton's national AIDS policy coordinator on June 26, 1993.
- **Personal:** Divorced, mother of 3.
- **Children:** Anna, 22; Sharon, 20; and Eric, 17
- **Hobbies:** speed walking, classical music
- **How admirers describe Gebbie:** Works hard, mediates well, shows compassion, listens to all sides.
- **How critics describe Gebbie:** Fails to lead, dodges tough fights, sometimes talks before thinking, lacks passion.

MATT MENDELSOHN/for The Oregonian

White House AIDS policy director Kristine M. Gebbie finds herself in the cross hairs of Washington critics who say she isn't doing enough to find a cure to stop the disease.

AIDS czar Kristine Gebbie is either compassionate and open or aloof and hesitant. It depends on whom you talk to

By ROSE ELLEN O'CONNOR
of The Oregonian staff

WASHINGTON — About 200 activists crowded into a stuffy Capitol Hill meeting room last June to celebrate the long-awaited appointment of a national AIDS czar.

But as Kristine M. Gebbie made her way to the microphone, radical Act-Up AIDS activists unfurled a banner and shouted her down. Their chants demanded a war on the epidemic — a war that would tap the nation's scientific resources with the same vigor used during World War II to build the atomic bomb.

Gebbie rejects the notion of a centralized "Manhattan Project" for AIDS. But she stopped her speech in midsentence and, unruffled, gave up the floor. She never engaged with the protesters. But after security guards dragged out the most vocal man in handcuffs, Gebbie asked an aide to pass on her wishes that he not be arrested. She left the decision to organizers of the celebration, she said in a recent interview.

The story is one of the most often told about Gebbie as AIDS czar, but the interpretations vary widely. It demonstrates compassion and an ardor to hear everyone, or aloofness and a propensity to let others lead, depending on who tells the story.

The duality seems to exist no matter who is asked about Gebbie, former chief health officer for Oregon and Washington.

The nearly two dozen people interviewed about her praised her — but almost all of them also expressed disappointment, too.

Gebbie admirers cite coalition building, efforts to focus federal research and the launching of an AIDS education program for all federal workers — aimed at providing greater

Please turn to GEBBIE, Page A7

Gebbie: After 9 months, no AIDS policy

■ Continued from Page One

sensitivity in the workplace — as examples of her accomplishments.

Gebbie, who was appointed to the post of White House AIDS policy director one day before her 50th birthday, was a nurse before she entered public life. She works long hours, often getting to her office before dawn and leaving after dark. When she's not on the road meeting with AIDS groups around the country, she returns all of her own phone calls, staffers say, whether they're from an angry activist or a frightened AIDS patient.

Courting controversy?

Nine months into her tenure, however, Gebbie still has no national plan for combating AIDS, although she says a brief policy outline is being drafted. Critics say Gebbie has courted unnecessary controversy while opting out on important fights, most noticeably the battle for more money to fight the disease.

Her heart is in the right place, says one Congressional observer. It just isn't beating fast enough.

Even her harshest critics concede that no one could live up to the expectations raised by candidate Bill Clinton's promise of an AIDS czar. Gebbie complains that the term —and the expectations — are creations of the media.

"I laugh about that title a little bit. It continues to imply power that's unrealistic in our structure of government," Gebbie said.

Jim Graham, among the most prominent AIDS activists in Washington, D.C., and director of the city's first AIDS treatment center agrees.

"They wanted a General Patton, a George C. Marshall," Graham said. "In the realities of federal government, it's a naive proposition."

In her cramped office above a McDonald's restaurant and across the street from the White House executive office building, Gebbie looks more schoolteacher than czar. She wears patent leather pumps, a gray skirt and glasses that pinch the end of her nose. Her tone is occasionally dismissive.

Her job should be a temporary one only until AIDS policies are integrated throughout the government, Gebbie insists. She disagrees with the concerns of AIDS activists who interpret that view as a lack of long-term commitment.

"I'm very reluctant to build a disease of the month if you will or, in this case, disease of the decade —separate organizational structures —because in the long run that doesn't work well," Gebbie said.

Activists and congressional aides most often cite the president's latest budget when asked to explain their disappointment with Gebbie. Clinton is proposing to increase overall spending on AIDS programs by about 5 percent to $3.8 billion next year.

The increase is less dramatic than the AIDS community had hoped to see under a president who gave the epidemic such a high profile during his campaign. The president is recommending increases in research and care but no increase in spending for AIDS prevention.

Gebbie said she was disappointed in the lack of additional money for prevention but that "some pretty hard choices had to be made."

Gebbie said she and the president exchanged budget materials and that her staff worked closely with Budget Director Leon Panetta's office before the spending proposal was drafted.

Results disappoint many

Whatever the process, many were disappointed with the results.

Doug Nelson, who has run the Milwaukee-based AIDS Resource Center of Wisconsin for six years, is among them. He no longer keeps count of the clients who have died. And the president's proposed 16 percent increase in spending to help care programs such as his, won't even keep pace with the new faces he sees each week.

Nelson said he sympathizes with Gebbie because some of the anger directed at her stems from things over which she has no control. Resentment lingers over what the AIDS community saw as the past administrations' refusal to address the disease because of its association with gay men and drug users.

"That anger is placed unfairly on the doorstep of Kristine Gebbie," Nelson said. "But there's also anger that her office in Washington isn't more powerful. What I do think we expect is very aggressive leadership, a certain amount of agitation.

"A strong AIDS czar within the councils of the Clinton administration would say that no increase in AIDS prevention dollars is unacceptable for this administration."

More telling than the criticism of activists is the response from Capitol Hill.

When members of the Senate Budget Committee decided they wanted more money for AIDS next year, Gebbie was not even consulted. First-term Democrat Patty Murray, who represents Gebbie's home state of Washington, went instead to other senators with cities similar to Seattle, one of the nation's hardest hit by AIDS.

On Friday, at the prodding of Murray and other budget committee members, the Senate voted to double the increase the president had recommended for AIDS care programs.

Under the Senate-approved budget, the government would spend $800 million to help public and private care providers. For the first time, it would provide all of the funding called for under a 4-year-old federal law, the Ryan White CARE Act, named after a teen-age hemophiliac who died from AIDS.

Gebbie, meanwhile, gets mixed reviews for coalition building.

Some activists credit her with bringing together diverse groups for the first time under the auspices of the White House. They cite meetings with religious leaders and AIDS activists as especially effective.

Some also say Gebbie has shown savvy in dealing with the tensions created by a new law funneling all federal research money through a central AIDS office at the National Institutes of Health. Scientists at the agency's various divisions fought the change, arguing that it would stifle their independence and introduce politics into their research.

Insider heads office

Gebbie pushed for an NIH insider to head the AIDS office, a move that some of those who assisted in the search say has eased resistance to the change. Dr. William Paul also appeals to activists who complain that government AIDS research is mired in agency politics and old approaches. Although Paul has been a scientist at the agency for 30 years, his specialty is immunology and thus he won't "bring old baggage" to the new office, as one administration official put it.

But Gebbie also has alienated people, sometimes even her supporters, with controversial statements she has later clarified.

This winter Gebbie broke an agreement not to discuss the government's new public service announcements urging condom use until support was lined up for the new ad campaign, according to several privy to the discussions. Gebbie upstaged a news conference scheduled to announce the ads when she talked about them at two out-of-town appearances. What most infuriated those trying to lay the groundwork for the new ads were Gebbie's inflammatory references to potential opposition as "weird" and "right wing."

A few months earlier Gebbie became fodder for radio talk shows and drew criticism even from allies when she complained that the nation is a "repressed Victorian society" that "denies sexuality."

Softer image

Gebbie's image has softened considerably since her days as Oregon's public health director, when her curtness with staff members was legendary. One career public servant in Salem during the budget-cutting days of the 1980s recalled learning that his job had been wiped out during an offhand hallway conversation with Gebbie. But his former boss has grown through her sometimes rocky tenures in Oregon and Washington, he said.

Today's staff of 30 describes a very different boss. Buck Buckingham, who worked under Gebbie for six months, said she mothered him, often nagging him to go home on time or take a real lunch and forego junk food. Buckingham, who has AIDS, left the office in February because he found it too stressful.

Buckingham founded and directed an AIDS service program in Dallas before coming to Washington, D.C., but says his White House job was far more difficult. Most AIDS activists have no inkling of the stress Gebbie and her staff face, he said.

"The further you get from the front lines the harder it is to know for sure that what you did today is going to trickle down and make a difference," Buckingham said.

"The stress comes from the fact that people's expectations for this office were in the stratosphere but their faith in any part of government was in the subbasement."

Gebbie lives in a well-to-do Northwest Washington neighborhood. She has two grown daughters and a teenage son who lives with her ex-husband in Portland. Gebbie acknowledges the distance is difficult although she doesn't elaborate other than to say she spends a lot of time on the phone.

Gebbie acknowledges that sometimes the job is overwhelming. She has dragged herself home on occasion and told herself "it's never going to work," she said, but only on a couple of the worst days. She has never regretted taking the job.

Despite disappointment, some critics say they are still hopeful that Gebbie will be an effective leader in the AIDS fight. Nelson said she impressed him with her sincerity when she visited Milwaukee, Wis., a few months ago even though her performance on the budget left him with doubts.

"I don't think she has a lot of time to prove herself," Nelson said. "She listens. I think she understands. But does she have the ability to go back to Washington and translate that into action?"

GEBBIE AT A GLANCE

WHAT GEBBIE SAYS ABOUT:

Her opposition to "Manhattan Project" for AIDS:

"We're not building a bomb. We're not building a single technological thing. We're dealing with some very complex human disease and health questions and with a much sketchier basic science base."

Criticism over her lack of a national AIDS plan:

"I have an antipathy to federal plans that are 48 volumes long and have all kinds of sub-objectives and footnotes and live for the sake of the paper they're printed on...It's become clear that people need a document to hold onto to compare me to and so we've got that document in preparation."

Anger sometimes directed her way from AIDS activists:

"If I were to be infected with this virus, to not feel a recognized part of a power structure, to be concerned that nobody was hearing me, I would probably bevery angry too."

How she cautioned her own teen-ager about AIDS:

"He would have been — what — 7 when this started. So all of his pre-teen and teen years have been in a household where the issues of our understanding of the virus, the discussions of whether or not we talk about condoms in public were dinner table conversations. So it wasn't a matter of deciding now it's time to educate Eric about HIV."

On where she goes from here:

"In my lifetime the next interesting job has always turned up, sometimes even when I didn't think it was there. I don't know where I'll go next. I don't have time to think about it."

WHAT OTHERS SAY ABOUT HER:

"I never came to the office when she wasn't already there. I never left when she wasn't going to be there for at least another hour. She will move heaven and earth to be available to visit with, to listen, to debate."

Buck Buckingham,
former assistant

"There's a great deal of disappointment over Gebbie's not taking a strong leadership position in the government response to AIDS...I think the question is whether she's doing what the White House wants her to do. I think at some point the responsibility has to go back to the president."

Jeff Levi,
AIDS Action Foundation

The Oregonian

THE WHITE HOUSE

WASHINGTON

April 22, 1994

Nancy Hedin, Executive Director
Portland City Club
317 S. W. Alder Street
Suite 1050
Portland, Oregon 97204

Dear Ms. Hedin:

At the request of National AIDS Policy Kristine M. Gebbie, I am enclosing a copy of her remarks before The Portland City Club, on Friday, April 15, 1994.

Please call me at (202) 632-1090 with any questions or for further clarification.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to the
National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

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

Speech before

The Portland City Club
April 15, 1994

"HIV -- Oregon and the Nation"

The last time I spoke about HIV and AIDS to the City Club was in 1988. The disease continues to be a problem, but some things have changed. At that time, there had been 323 cases of AIDS diagnosed in Oregon; at the end of 1993, there had been 2525. In 1988, 3% of the cases were in heterosexual drug users; today, about 10% of the cases are from that route of transmission.

In Oregon, as in the nation, AIDS kills a generation that should live. In Multnomah County it is the leading cause of death of young men between the ages of 25 and 44; statewide, it is the second leading cause of death. While it has not achieved that level in women, it is steadily rising.

And despite interest and action, the rate of infection grows in a number of groups. In 1988, about 4% of injecting drug users tested in public sites were HIV+; today that number is about 18% in Oregon.

The major problem with this infection continues to be denial and division. We persist in talking about various "infected groups" as if they were mutually exclusive, and unrelated to one another. The list often includes homosexual men, drug users, hemophiliacs, women, people of color. It is certainly true that hemophiliacs are not women, nor are gay men. But with those exceptions, all intersections of the listed groups are possible: there are women who are drug users and there are gay men of color. The intersecting circles of interaction in our society mean that all of those exposed to or at risk of HIV infection are indeed a part of our community, our family, and we must be concerned.

So what are our national policies to deal with this epidemic? They are in three areas: research; services; prevention.

In research, we are committed to seeking until we find the answers. This means a national commitment to the full range of biological, biophysical, physiological, psychological and sociological sciences as they apply to this disease and our experience of it. It means doing both basic and applied studies in all of these areas. For example, we need to study both how the immune system works in general, AND how to restore it after it is damaged by this particular virus. We need to study how young people learn sexual roles AND how to help with choices in the face of this epidemic.

There is no single, technical "fix" out there which will resolve this disease easily: we are going to be helping people live with a chronic disease, for a long time, and that will take a lot of information we do not yet have.

The goal in services is that anyone who is infected with this virus is diagnosed early, and has access to a full range of services that will allow him or her to live as long and full a lifetime as possible. Health reform is at the heart of this policy: without non-discriminatory, non-cancelable coverage it is impossible to build the kind of services needed. People with HIV infection are too often un-insured or under-insured, or lose their coverage just when they need it most.

But coverage for payment is not enough. We also need to build a network of services which are based on good planning and management of resources so that anyone with a chronic condition, including those living with HIV, get the care needed in a timely manner, in the most appropriate setting for his or her circumstances and health status.

The funding called Ryan White must also be continued, not only to assure a safety net during transition to a reformed system, but continuously, to provide those needed services which are not part of insured benefit packages. These services, which include transportation, child care, housing, food and the like, must be planned and organized by each community, to fit the resources and needs of the population.

Somewhere between services and prevention comes substance abuse prevention and services. Preventing and treating substance abuse IS HIV prevention. This not only applied to any form of injecting substances, but to any abuse which clouds judgement and can leave individuals in risky circumstances. The administration is committed to increasing resources for substance abuse treatment, and has asked for over 300 million additional dollars

in the FY95 budget.

Finally, prevention of any further cases of HIV, using the best available knowledge, is a central part of the national policy. It is simple to describe the behavior changes which must be achieved: no one should ever share injecting equipment, ever, for any purpose. No one should engage in sexual activity outside of a mutually monogamous, lifetime relationship, unless a latex condom is used consistently and correctly for each sexual act. Those two behavior changes are simple to state, but very hard to achieve in practice. It is especially difficult because we have trouble talking about sexual behavior, and do not really understand what it takes to help a young person develop a sexual identity, understand his or her sexual orientation, and then make decisions about what, if any, sexual activities are appropriate.

In considering these policies, I am struck over and over by the local nature of the decisions needed to translate any of these policies into effective actions against HIV infection and AIDS. No matter what is done in Washington, no matter how firm the commitment of the President and the administration (and the commitment is firm), your actions in the community will make the real difference for people.

A few examples. No matter how much money is available for HIV-related research, it is a university's decision whether to reward leadership in AIDS research, or to hide it by failure to recognize those who do it, or placing it in the most obscure corner of the campus without signs on the door. It is a community decision to make it easier for those who are or might be infected to acknowledge their infection, by making testing readily available AND by committing to non-discrimination in all settings. It is a community decision to give all young people the information they need to save their lives, and to support that decision firmly, not only by a school curriculum which includes comprehensive health information, but by church, service and civic club commitment to give parents and young people the support and value information to turn the facts into meaningful life decisions.

One example of how a community could support efforts to stop this disease would be through workplace HIV prevention education. The federal government has made this commitment: all 3 million civilian employees of the federal government will be getting such education. We are doing it for three reasons. We value the personal health of our employees, and want them to have the information; we know we have HIV+ employees, and we want our

supervisors to know how to manage them appropriately within the Americans with Disabilities Act; and we hope that information on the epidemic will trigger at least some individuals to reconsider how their programs can become a part of the overall prevention effort.

This community could make it a community norm that all workplaces be places of HIV information. There are some interesting resources out there. For example, there is a group of "Racers against AIDS" -- car dealerships or garages might team up with this group in developing programs. And what about the hairdressers and barbers? This is a group we once looked to for their role in mental health and crisis intervention. They are certainly in a position to talk to people about important subjects. Have we made certain that they have facts and resources to pass along?

Two other examples and possibilities. One is the expectation that community leaders are not just attending to this issue quietly, but that they are paying attention to critical public decisions, such as school board consideration of comprehensive health, sexuality and HIV education. These are often tough decisions, and the school decision makers need to know that the community leaders are there with them. And then there is the HIV planning table: first the local planning for Ryan White service dollars, and now the new planning for HIV prevention.

Oregon has been a leader in community involvement in health issues, as is evidenced by the development of the Oregon Plan and the debates on access to health care. Is the same standard of openness and involvement of all affected being applied in the HIV area? It must be, if we are to be successful.

We can stop HIV, if we connect with the reality that what we know in our heads does not automatically equal right behavior. It takes much more that the ability to pass a factual test about HIV for individuals to make healthy behavior choices for a lifetime. We need honest and open commitment, honest and open communication among ourselves if we are going to be successful. Something I said to you in 1988 still seems to be essential:

> One of my strongest beliefs is that our response to this epidemic will be measured not by how fast we found the virus or a vaccine, but in large part by the degree to which we acknowledge our community and our mutual responsibility... only collective attention to our own behavior will be

effective in stopping this epidemic.

If we can do that, we can, indeed, stop AIDS.

OREGON FOUNDATION FOR MEDICAL EXCELLENCE
4000 KRUSE WAY PL., BLDG. 2, SUITE 100, LAKE OSWEGO, OR 97035, (503) 636-2234

RECEIVED

MAR 30 1994

March 28, 1994

Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street, N.W., Suite 1060
Washington, D.C. 20503

Dear Ms. Gebbie:

This is to confirm that the Oregon Foundation For Medical Excellence has made reservations and will pay for your transportation costs for your trip to Oregon on April 14, 1994. The airline tickets were purchased without the use of federal funds and will be mailed under separate cover.

We have also made reservations for you at the Mallory Hotel (Confirmation #1067). The Foundation will be happy to cover your expenses for three nights.

If you have any questions, or if I can assist you in any way, please do not hesitate to contact me.

Sincerely,

Jan L. Murdock

Jan L. Murdock
Assistant to Mr. Ulwelling