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THE WHITE HOUSE

WASHINGTON

March 15, 1994

Karen L. Lawler-Roy
5481 Landis Avenue
Port Orange, Florida 32127

Dear Ms. Lawler-Roy:

Thank you for your recent communication regarding your interest in dietary supplements. Since 1990, the Food and Drug Administration (FDA) has been authorized to allow health claims on dietary supplements and have interpreted this to require that they take whatever steps are necessary to assure that such claims are reasonably accurate and have some basis in fact as demonstrated by some kind of scientific studies. In my opinion, the FDA has done or said nothing that indicates they are interested in restricting the availability of the products; only the claims that are made on labels for such products.

The final regulations, which were published in the Federal Register on January 4, 1994, will go into effect on July 1, 1994 unless Congress acts before that date. Legislation under consideration in Congress proposes to substantially alter, and/or remove the responsibility of the FDA in this regard and the Department of Health and Human Services is working closely with Congress to try and find appropriate language which will allow us to meet three shared objectives: 1) continued availability of the products, 2) some degree of control over the accuracy of the information that is used to market such products, so people can exercise their freedom of choice on the basis of reasonably sound information, and 3) avoiding a regulatory burden that is not justified in order to protect the health of the public.

Since the HIV/AIDS community is my primary area of responsibility, I have been involved in this issue to protect the particular needs and interests of that community. As you know any product that has the potential to maintain health or increase immune competence is of particular interest to those with HIV infection and their advocates. At present, I do not believe that there is any threat to availability of dietary

supplements and I will do what I can to assure that it continues to be true. I also believe that, like any other individuals with life threatening illness, individuals with HIV/AIDS may be more vulnerable to claims being made for products that may have no beneficial effects and I am committed to insure that the information that they have is reasonably accurate--only with such information can freedom of choice be meaningfully exercised.

I appreciate your interest in this complex and vital area.

Sincerely,

Kristine Gebbie

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

ECHO = Karen L. Lawler-Roy - Secretary - 5481 Landis Avenue, Port Orange, FL. 32127

Dear Ms Gebbie,

Please encourage the President to sign into law S. 784/H. 1709

Enclosed is information on these bills.

Please don't let the FDA take away my right to wellness.

Karen L. Lawler-Roy

Allergy nurse Consultant

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NCIH
NATIONAL COUNCIL FOR IMPROVED HEALTH

1555 W. Seminole St.
San Marcos, CA 92069
(619) 471-5090

HEALTH FREEDOM UPDATE

Vol. 5, Number 1 | *Working To Protect Your Health Freedoms* | *Spring, 1993*

FDA STILL SMUG, DESPITE SCRUTINY

Despite the fact that the FDA is under increasing surveillance by Congress and that more Americans are concerned about its one-sided, over-zealous police powers in which nutrients are "dirties" while drugs remain "clean," the federal agency has no intention of easing up in the "compliance" area. This reality is clear from recent actions:

- In July of 1992 an FDA-funded study on the "safety of amino acids used as dietary supplements" suggests the federal agency will not only not restore L-Tryptophan to the U.S. market but may seek to regulate all amino acids in general.

- In November, the FDA was involved in a federal-state-local raid on the nutritional therapy office of naturopath Dr. Vera Joan Allison of Reno, a records-confiscating, patient-alarming "S.W.A.T." operation which has at least temporarily put one of Nevada's best known healers out of business on the grounds of "practicing medicine without a license," "furnishing dangerous drugs (progesterone, thyroid extract, heparin sodium, human growth hormone) without a prescription" and similar vague charges.

- On January 1, 1993, special FDA "criminal investigation" units aimed at "compliance" were set up in whole or part in San Diego, Miami, Kansas City, Chicago, New York and Washington.

In the January issue of *Health Store News,* writer Max Ricketts, reporting on the FDA L-Tryptophan study, argues that perhaps all amino acids, and many

FDA SMUG, continued on page 2

NUTRITIONAL HEALTH FREEDOMS MUST BE ADVANCED

A REPORT BY KIRKPATRICK DILLING, NCIH GENERAL COUNSEL

The resistance of our people to infectious diseases would be greatly increased by a vastly improved and more wholesome diet. Our example would be followed by the civilized world and thus bring to the whole universe the benefits which our own people had received.

We would have been spared the ignominy and disgrace of great scientific men bending their efforts to defeat the purpose of one of the greatest laws ever enacted for the protection of the public welfare.

So wrote Dr. Harvey Wiley, the first director of the FDA, a crusader and mentor of the 1906 Foods and Drugs Act which preceded the present Food and Drug statutes. Before the turn of the century, Dr. Wiley had observed the extent to which certain interests purveying patent medicines, dangerous products and other detrimental substances had created a national situation which cried out for remedial legislation. With his "poison squads" and publicizing of the situation Dr. Wiley was able to secure passage by Congress of the Foods and Drugs Act of 1906. However, to his great disappointment, he witnessed over the years the perversion of the new laws by those they had been intended to control, such as Coca Cola and bleached flour interests.

Although FDA currently purports to honor Dr. Wiley, in truth it continues the perversion of the principles for which he stood. For many years the Agency, under the guise of "protecting the American consumer" and "saving" him from spending his money for the "wrong" purposes, has sought to promulgate dietary products now and for many years past sold competitively in the open marketplace throughout the United States. These FDA proposals would, if successful, in effect substitute a "diet dictation," as administered from Washington, for the freedom of choice exercised by American citizens as to their diets, and arbitrarily bar them from freely employing such products. This "diet dictation" would obviously be in excess of any authority granted by Congress and in violation of various provisions of the United States Constitution as well.

FDA's actions inevitably favor interests detrimental to best National nutrition. FDA meanwhile issues deceptive statements intended to divert public attention from what is transpiring. FDA Commissioner Kessler recently stated, for example: "It is not our business to tell people what to eat."

Recent FDA actions concerning the protein amino acid L-Tryptophan provide a good example of current FDA anti-nutrition activities. L-Tryptophan is an essential nutrient. Since late 1989 FDA has conducted an intensive campaign of "trial by publicity" to convince the public that L-Tryptophan is "dangerous" and should not be consumed. Responsible FDA officials have carefully chosen to ignore the facts, also failing to advise that there is no government regulation "banning" L-Tryptophan, nor has there ever been a Judicial decision against it.

These FDA officials have known all along that there has never been any safety problem with L-Tryptophan, even with its consumption by millions of people for decades. L-Tryptophan is an important component of the food we eat, and is required by everyone for health, even life

FREEDOMS ADVANCED, continued on page 2

THE WHITE HOUSE
WASHINGTON

March 15, 1994

Thomas S. Inui, Sc.M., M.D.
Director
Health of the Public: An Academic Challenge
Suite 200
126 Brookline Avenue
Boston, Massachusetts 02215

Dear Tom:

Unfortunately my schedule does not permit me to participate in the annual meeting of the Health of Public Program. I look forward to catching up with this year's activities at some point. If you're ever in D.C., maybe we could grab a cup of coffee or lunch together? Let me know.

Sincerely,

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

Health of the Public
An Academic Challenge

Thomas S. Inui, Sc.M., M.D.
Director
Boston, MA
Tel: (617) 421-6011
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Co-Director
San Francisco, CA
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Fax: (415) 476-3429

February 24, 1994

NATIONAL PROGRAM OFFICE NOTES

does this look possible ?
regrets.

Dear Colleagues:

Calendar year 1994 may be a watershed for U.S. medicine in general and the Health of the Public Program in particular. I am certain that each of you has noted, as we in the National Program Office have, the striking relevance of the HOP mission to health care reform and even the political salience of our message. Many of us in the HOP network have become participants in reinvigorated institutional mission discussions, development of system-of-care restructuring strategies, and high-level executive decision-making at our own academic health centers. Some Health of the Public Program community/academic health center partnerships have been used as examples of the future of academic health centers in integrated systems for care. We hope you are making full use of these opportunities while maintaining clarity about the purposes of our HOP projects. In the midst of growing AHC enthusiasm for acquisitions and increased "market presence," we need to posit emphatically the centrality of the public's health as a primary consideration in all of our actions and plans.

HOP MEETING

The next annual meeting of the Health of the Public Program will be held in Chicago, May 25-27, 1994. The theme of the meeting is "Community Partnerships: An Essential Component for the Health of the Public." Please place these dates on your calendar now. Information regarding agenda, specific location, and travel arrangements will be forthcoming closer to the time of the meeting itself. The National Program Office budget will reimburse two participants' travel expenses for each program. We suggest that one of these two participants be a community partner. We welcome other HOP attendees, beyond the number directly supported by the National Program Office, but their expenses need to be reimbursed from other sources.

KEY INTERACTIONS

Health of the Public Program presentations have been made to the ACGME, the organization of residency review boards from all formally declared specialties of medicine. Our message at the ACGME was how the Health of the Public Program perspectives could be used to identify important "new competencies" for training programs and program trainees, enhancing the residency review committees' capacity to distinguish especially high-quality programs when reconsidering program eligibility for public support.

The Health of the Public Program was also represented at the meeting (in Thailand) of the International Clinical Epidemiology Network (INCLEN), where a presentation of the

development of community-based programs of education and research for medical students was made. In the discussion that followed, the presence of a University of Pennsylvania medical student in the audience who had been a participant in the West Philadelphia project provided a real-life context to the discussion! At the meeting, small grants were made on a competitive basis to six international schools in Asia, Southeast Asia, Africa, and South America, sponsoring programs of student activities in communities. These grants, referred to as "Health of the Public Program Projects" were provided by the Rockefeller Foundation and are intended to produce an interaction among several networks with common goals - INCLEN, HOP, and the Network of Community-Oriented Educational Institutions for Health Sciences. More information on this topic will be forthcoming at a later date in collaboration with Dr. Alan Cross of HOP, INCLEN, and the University of North Carolina, Chapel Hill. A description from the Network's newsletter of the NCOEIHS's analogous project for student activities, called the "University Partnerships Project," is attached to this mailing.

RESOURCES OF INTEREST

A thoroughly remarkable volume from the World Bank, "*World Development Report 1993: Investing in Health*," became available late in calendar year '93. This report, a perspective on the role of health in social development globally, contains new data on the health status of national populations, the relationship of social programs to health, and the cost-effectiveness of alternative approaches to enhancing health. It is available for a modest price ($19.95) from the World Bank Offices in Philadelphia (202-473-1155).

A monograph of papers from the First Congress of Health Professions Educators entitled "Health Professions Educators Confront a New Era" became available from the Association of Academic Health Centers late in 1993. The Congress was held in June of 1993 and contains several papers of relevance to the Health of the Public Program. A perspective from the CEO of the Rush Presbyterian-St. Luke's Medical Center is representative (attached). We also enclose a table of contents from this volume. The entire volume can be ordered by contacting the AAHC (202-265-9600).

A reframing of social philosophies referred to as "communitarianism" has piqued the interest of many persons, since this word entered the vocabulary of the Clinton administration. Certain Health of the Public Program principals, e.g. Dr. Christine Cassel of the University of Chicago were authors of the communitarian perspective at its origins. The Amitai Etzioni book the *Spirit of Community* is worth reading. We enclose the publication face page and an "In Conclusion" summary chapter for your interest.

The Council on Health Research for Development is articulating the "Health of the Public Program Perspective" in placing its emphasis on "essential national research." We enclose a copy of a brochure from COHRED for your information and encourage you to write or otherwise request supplementary materials for your greater information.

HOP IN THE NEWS

Many of you may not know that the first program of the eight-program series on PBS

entitled "Medicine at the Crossroads" featured a Health of the Public Program activity at Johns Hopkins. Those of you who have an opportunity to see this first episode should look for the segment describing the Heart, Body, and Soul Program in East Baltimore, including a side shot of Dr. Daniel Ford taking a patient's blood pressure in a church-based health screening clinic. We will bring a copy of this video segment to the next national meeting.

The Health of the Public Program casebook has been distributed to thousands of readers in the information dissemination network of HOP nationally. If you wish to arrange for a specific supplementary institutional distribution, contact the San Francisco office.

An important paper by Steve Miles, Nicole Lurie, Elliot Fisher, and David Haugen appeared in *Academic Medicine* in September, 1993, explicating the relevance of academic health centers to health care reform. Please continue to alert the National Program Office to new HOP publications.

For two consecutive years HOP perspectives and our program's activities have been featured in the Chair's address to the Association of American Medical Colleges. At the AAMC national meeting in November, Dr. Spencer Foreman of Montefiore Medical Center devoted his address to "Social Responsibility and the Academic Medical Center." A synopsis of his address is enclosed with this mailing. The National Program Office has a copy of the audiotape. Dr. Foreman's framing of the issues of social responsibility, description of how academic health centers can make progress ("begin by assuming real responsibility for a defined population, assessing the health status of the population..."), and some of his most striking examples of how AHCs can fulfill these responsibilities (the Rush community clinic system, the Welch Center at Johns Hopkins, the Cambridge/Harvard Medical School Health of the City Program) focussed directly on Health of the Public Program-related activities. Dr. Foreman's address was followed by an invited presentation from Dr. Mark R. Chassin, Commissioner of Health of New York State ("Health Reform, Public Health, and Academic Medicine: Strange Bedfellows?"). Dr. Chassin outlined the dimensions of AHC responsibility for assuring access and the appropriateness of health services for the populations they serve by drawing the audience's attention to HOP: "I welcome the Health of the Public initiative that was begun by the Pew and Rockefeller Foundations. I hope it broadens and deepens. I urge you to look at the specific accomplishments of the institutions that have participated in that initiative that begin to spell out the specific steps what can be done... to address this crucial agenda."

WORK GROUPS

We proffer thanks to all of you who participated in the formation of HOP work groups. We now know that we have participants *and* leadership for eleven work groups:

Community health assessment

Sustaining AHC/community partnerships

Multidisciplinary/training

HOP opportunities and responsibilities in health care reform

HOP in rural settings

Evaluation and assessment of HOP initiatives

Curricular innovation

Teaching population-based research

Institutional strategies for change

International initiatives

representing HOP activities at other national meetings

These work groups will meet at the national meeting in May. Other groups need to acquire leadership or dissolve. Program principals will receive a current version of the work group membership list with this mailing. We ask that you be certain that your preferences, and those of others from your site who may attend our meetings, have been placed properly on this list. Any individual intending to participate in a group that currently lacks a volunteer leader may step forward to assume the leader's position by simply notifying the National Program Office in Boston.

We hope that you are well, challenged, and happy in your work as we enter this new year. We look forward to seeing many of you in Chicago.

Best regards,

Thomas S. Inui, Sc.M., M.D.

Enclosures

TSI\sm
g:\shared\294\22\notes

Health of the Public

Annual Meeting

C h i c a g o

May 25-27, 1994

"Community Partnership:
An Essential Component for the
Health of the Public."

University Partnerships Project (UPP): Leaders Meet at McMaster University

From August 15 - 20, 1993, twenty-five hard-working colleagues met at McMaster University in Hamilton, Canada. All were associated with the Network's demonstration project: "University Partnerships in Essential Health Research" (UPP), a project funded by the International Development Research Centre (IDRC). The project is now in the second year of a 4-year implementation phase, following a 2-year development component. This was the third working conference for the UPP institutional project leaders; the first conference was held in Yogyakarta, Indonesia in October 1990, and the second in Sweden in October, 1992. Representatives from fifteen of the eighteen participating universities attended, along with members of the UPP Advisory Committee, and several other guests. These included a very active delegation (including two students) from the Universiti Sains Malaysia, representing a fine student project initiative.

The overall goal of the project is: To improve the relevance of health professions education by enhancing the ability of graduates to help identify and solve the problems of communities in which they serve. It is to be achieved by having students participate in health research in a systematic way and as an integral part of their training. The framework for this training is a new system of partnership among universities, governments and communities, the focus of which is a programme of essential national health research.

The specific purposes of the this conference were: to further develop the specific "partnership-derived" projects in each location; to work on some of the institutional capacities related to the project; and to evaluate progress on the overall project to date. Highlights of the working conference included:

- workshops on research project development; information and communication skills (the use of electronic mail, and of CD-ROM's); partnership development, and leadership;
- presentations of institutional action plans by project leaders, based on what had been learned during the week;
- contributions and suggestions regarding ways in which the general UPP project can be monitored and evaluated;
- joint activities with the 80 delegates who attended the concurrent workshop: "Three Days at McMaster"; these included a trip to Niagara Falls (and a picnic near by); community site visits; and a closing banquet highlighted by a presentation by Ms. Iona Campagnola, former Canadian government cabinet member.

Proceedings of the working conference can be obtained by contacting:

Kim Vine, Project Secretary, UPP McMaster Coordinating Centre, Centre for International Health, McMaster University, 1200 Main Street West, Hamilton, Ontario, CANADA L8N 3Z5.

Vic Neufeld, Centre for International Health, McMaster University, 1200 Main Street West, Hamilton, Ontario L8N 3Z5, Canada

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In Newsletter No. 16 (December 1991) the Network Book Project was first introduced to the Newsletter readers. So far, some progress has been made and the project contact person (Richard Christiansen) reports the following update. In one of the 1994 issues of the Newsletter more attention will be paid to this subject.

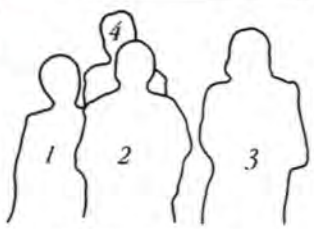
Book Project Update

A list of new textbooks, that could be sent to Network members without charge for the books, was submitted to the Network by Blackwell Scientific Publications Ltd. The Network sent Blackwell a list of member schools that needed these textbooks. The schools on the list should be receiving the new books soon.

Richard Christiansen, University of Illinois, College of Medicine at Rockford, 1601 Parkview Avenue, Rockford, Illinois 61107-1897, USA

Call to Action: Interest Group for Women's Issues in Health Sciences Education

After the Ilorin Conference, the recent initiative of the Women's Health Group at the 8th Biennial Network Conference at Sherbrooke has provided me with the encouragement to write about the outcome of the discussions in the two sessions held with the aim of putting forth to the Executive Committee a defined plan of action for the coming year. The plan developed by the group includes goals and a request to the Network for commitment in addition to funding the group's activities. Through this column, I must first acknowledge and appreciate the support of the "Women and Health: Leadership Training for Health and Development Project" of the McMaster Centre for International Health, Canada, particularly for funding my participation to chair the Special Interest Group on Women's Health. Moreover, my sincere appreciation to the small but dedicated group who worked hard in developing the plan, as well as for entrusting me with the task of the Coordinator.



1 = Ms. Miriam Priya Abraham
2 = Mrs. Nighat Huda
3 = Dr. Rogayah Jaafar
4 = Dr. Barbara Carpio

Sherbrooke Meeting: Women's Health Issues in Education

Although the Network had scheduled only one session of the Women's Health Group, on the last day of the

HEALTH PROFESSIONS EDUCATORS CONFRONT A NEW ERA

PROCEEDINGS OF THE

1ST CONGRESS OF HEALTH PROFESSIONS EDUCATORS

MARIAN OSTERWEIS
ELAINE R. RUBIN

EDITORS

ASSOCIATION OF ACADEMIC HEALTH CENTERS

The Association of Academic Health Centers (AHC) is a national, nonprofit organization comprising more than 100 institutional members in the United States and Canada that are the health complexes of the major universities of these nations. Academic health centers consist of an allopathic or osteopathic school of medicine, at least one other health professions school or program, and one or more teaching hospitals. These institutions are the primary resources for education in the health professions, biomedical and health services research, and many aspects of patient care services.

The AHC seeks to influence public dialogue on significant health and science policy issues, to advance education for health professionals, to promote biomedical and health services research and to enhance patient care. The AHC is dedicated to improving the health of the people through leadership and cooperative action with others.

* * * * * * * * * * * * * * * *

The Congress and the preparation and publication of this book were supported by grants from the Burroughs Wellcome Co., the Josiah Macy, Jr. Foundation, and the National Fund for Medical Education of The Pew Charitable Trusts Center for the Health Professions.

Copies of this book may be obtained from:
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Suite 410
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202/265-9600
Fax: 202/265-7514

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CONTENTS

ACADEMIC HEALTH CENTERS: FACING THE CHALLENGES OF THE FUTURE

LEO M. HENIKOFF

I am going to look at the academic health center relative to the one major societal change that I think is having the most effect on us. That change is consumerism. Consumerism is affecting us not just in our health care delivery; it's affecting us in education and even in how we approach research. Consumerism is directing some of our basic science research, it's focusing us on research in AIDS, and it's also directing what other kinds of research we undertake. Consumerism on the research front is going to direct a strong focus on health services research, something that academic health centers do very poorly today.

On the education side, consumerism has always played a role in determining which educational programs we conduct and in what quantity. Over the years we have balanced our educational programs to respond to the need for nurses, physical therapists, medical technologists, and others. But today we're seeing new demands for health care professionals, and of course for primary care services. This is not just a medical demand but a very broad health professions demand. Clearly, that is going to affect what we do over the next decade.

As health care professionals, we're all familiar with proposed legislation and directions that health care is taking. It's clear to me that these changes are going to take place with or without legislation, because the major forces that are changing health care have nothing to do with what may or may not be legislated by Congress. They are powerful, they have been developing for some time now, and there is an inexorable march in their direction.

I list two major forces: First, our health care system is rapidly becoming a consumer-driven system rather than a provider-driven system. Think about how we managed the health care system five or ten years ago--the providers would get together around a table and decide what to provide, in what quantity, in what location, and how to provide those services. The consumers now are dictating what to provide, in what quantity, and in which locations.

The second major force in health care delivery is pushing down risk in the system. What do I mean? As we look at how health care is delivered today, we have seen a trend over the past five years toward capitated programs--Health Maintenance Organizations (HMOs), if you will, although the term HMO is becoming diffuse. Accountable health plans look to me like HMOs by another name, and so do some other structures. These mechanisms that accept a capitated premium and then distribute it are becoming more prominent in health care delivery. The number of

people in our country who are covered by capitated mechanisms is growing. It's growing without legislation, forcing consumers into that mode.

The capitated mechanisms themselves have had very poor experience with the risk that they have accepted. Anyone who accepts capitation is an insurance company by definition. An HMO is an insurance company. These insurance companies have been burned, so they are gradually pushing such risks onto the provider with whom they contract.

How do we see that? Examine how HMOs have contracted with physicians historically. Initially they contracted with a physician on a fee-for-service basis with the physician giving the HMO a discounted fee. HMOs today prefer to contract with physicians on a capitated basis. They take a piece of the capitation that they receive and give that to the physician; the physician is then responsible for all services for a group of patients for that capitated amount. All of a sudden, the HMO no longer carries any risk for those services. A successful HMO will capitate all its services; the hospitals will be getting capitation and taking risk; physicians will be getting capitation and taking risk. Thus, the HMO has stopped being an insurance company; it's simply a jobber of health care. It is a distributer, a middleman. The risk is pushed down onto the provider.

There is no question that these two major forces are taking place, and that they are increasing in magnitude--there is more consumerism, and there is more risk being pushed down on the providers. Health care institutions are becoming the insurance mechanism, and we in academic health centers are responsible for some of those health care institutions.

Let's look a little more at consumerism in health care. Clearly, what we want as consumers are cost reduction, quality, and access. Cost reduction and quality are the two components of the value equation, because value in health care is directly proportional to quality and inversely proportional to cost--a simple equation.

If we pay piecework, if we pay a given amount for each particular service (such as an office visit or an X-ray or a laboratory test), we are in a system that is volume-driven, even if there are price controls. Total costs are not contained, because as volume increases, total expenditures increase, even in a situation of price control. The incentive in piecework payment is to overserve. We have been dealing with that factor for many years in health care.

In a capitated situation, by comparison there is a simple payment for all services, and the incentive is to underserve. The question is, how do we deal at academic health centers with these two incentives? Today, at each of our institutions, some of our patients are covered by piecework payment, and others are covered by capitated payment. So we are schizophrenic, because we have an incentive to

maximize the number of pieces of piecework for some patients and to reduce the number of services for capitated patients.

Let's look at the managed competition scenario, which in the pure Jackson Hole form is the ultimate in capitated payments. In that scenario, which I don't think anyone believes is going to be legislated, everyone in the country would be covered by an accountable health plan or HMO, and everyone would be on a capitated payment system.

Taking that pure thought backwards, we can look at the development of markets in the United States today that look very much like a managed competition scenario, where a large number of patients--more than 50 percent of those in the marketplace--are covered by capitated systems. We see that in Minneapolis, in California, and in other places in the country.

These systems obviously need primary care practitioners of one kind or another to act as entry points for the people that they serve. As was mentioned in an earlier discussion, there just isn't the health manpower available to staff these systems for their primary care needs. That lack of availability is going to come home to rest on the shoulders of the academic health centers, which are the manpower generators, and we are going to have to adapt in order to respond to this consumerism, this requirement for primary care practitioners.

We have to have a cultural change in medical schools, because primary care has not been a priority of most medical schools in this country. In fact, even today it's not uncommon to have a bright student derided by faculty for going into primary care (the assumption being that you don't have to be bright to do primary care).

I can tell you that as a pediatric cardiologist I have tunnel vision. The primary care practitioner has a much greater academic challenge in understanding the needs of patients and finding out what to do about their problems. We have to change our culture in academic health centers, in medical schools, and we have to give primary care its due as an academic enterprise, as an academic challenge.

We are doing some things at Rush that I find terribly exciting. We are not a community-based, primary care medical school, as are a number of schools in this country. But we are refocusing. First, there are nine community service initiatives that our students are involved with from the very beginning of medical school. These put them in touch with families, family needs, and family care. They started as student-originated programs, and we incorporated them into the curriculum.

Second, we're creating a primary care institute. This is intriguing, because we have six other institutes, all of which are high-science, high-superspecialty institutes. But the primary care institute at Rush-Presbyterian-St. Luke's has several purposes in its development. It will provide a focus for the culture change that I mentioned,

giving primary care the academic credibility and the respect in the institution that it needs to compete for students in our atmosphere. We also look at this institute as the focus for health services research. The kind of institutions we operate make them good homes for health services research. Finally, as retooling for specialists becomes necessary in the future, the institute will be the locus for that kind of educational activity for physicians already in practice.

The government is going to give us no choice in this matter. I think it's very clear that something is going to change, wherein the government is going to control residency slots. It's going to control residency slots through financing mechanisms and, clearly, it will not continue to allow the health care dollar to be spent on the education and training of so many specialists. So one of the ways that we'll change is in how we approach graduate medical education and the distribution of that activity between primary care and specialty care.

Health services research is going to play a big part in our future. Study the proposed legislative activities, such as managed competition. Health services research plays a key role, because it is how the output of these programs will be objectively measured. Those objective outcome measures are going to be the marketing tools of accountable health plans, of HMOs, and of the any of the groups seeking to contract with health alliances.

It's clear that we ought to be out in front in creating those measurements and that this health services research activity is going to be important. I think nursing will play a large role in health services research, because nursing leadership seems to be the most interested right now and because there is a lot of talent in the nursing field in the health services research line.

For academic health centers in the future, survival itself will be a challenge. Forty years ago, that might not have been true, even if the scenario changed as it's changing today, because we were less dependent upon health care delivery. Over the past 40 years, the funding of academic health centers has changed considerably. A good portion of that funding comes out of the practice of medicine in our medical practice plans. We found out in the early 1980s that the hospital was no longer a clinical laboratory for our use, whose costs were automatically met by payments. We found that our hospitals were in a competitive business environment. Quite a shakeout developed in the last eight or nine years in the relationship of our hospitals to our medical centers. Some academic health centers divested their institutions of their hospitals, some put hospitals in a separate corporation, and some focused strongly on our hospitals to make them competitive players in a competitive marketplace.

It's important that we look at what kind of systems are evolving. We must be players. If we accept patients who are capitated in our health care institutions and academic health centers, by definition these patients are part of somebody's system. It's clear that for our own survival, we're going to have to play in that environment;

we're going to have to play with capitated patients. That means that we are going to have to be part of a system or many systems. Of course, under the pure managed competition model, we would be allowed to be a part of only one system. Currently, the way we are conducting ourselves, we participate in many systems.

Let's look at the systems. There are two extremes. One is a provider-owned system. As you heard from Judy Feder, the legislation that is being proposed will drive us towards provider-run, provider-owned systems. Rush is one example of a provider-owned system in that we have corporately integrated six hospitals, two HMOs, a PPO, and some other activities. It is a geographically comprehensive system.

On the other end of the spectrum is what I would call a network contracting system, where the individual or entity that controls the system is an insurance mechanism. That entity will go out on the "spot market" in health care and buy services. It will buy a liver transplant from me and coronary artery bypass surgery from you, basing those decisions on cost and quality. It will have short-term contracts, only a year. Then it will market to its potential enrollees the system it has put together by contracting with multiple providers. Of course, the next year, if your liver transplant of the same quality is less costly because you want the business, I won't get the contract for transplants, you'll get it.

This network contracting model has a lot of implications for us in academic health centers. Look at the ability to cross-subsidize under a network contracting model. If you're an academic health center and you're big on liver transplants and the two major systems in your area have contracted with someone else, you're going to be very prone to reduce your price to get that business the next year. You will reduce your price down to the minimum acceptable price, either cost or cost plus a little bit. That's fine. That's the intent of managed competition, isn't it?

Yet, in that scenario, if you were supporting a number of losers out of that liver transplant program through cost-shifting, you will no longer be able to do that. What are the losers? I think we all know what they are. We run a poison control center for northern Illinois with no reimbursement from the state. It is a $300 thousand bottom line loss--no income. Chronic ventilator patients in our institutions--I bet we're all losing a lot of money on chronic ventilator patients. We support that out of fees of patients for whom the revenues exceed the expenses.

I'm talking about a different kind of cost-shifting. We're aware of the classic cost-shifting from Medicare-Medicaid to private patients, a hidden tax that the government imposes, we're the tax collector, of course. That's classic. There's cost-shifting from education and research to health care, and we're all aware of that.

But probably the greatest pain and the deepest wound would be inflicted by our inability to cost shift between services, something that we haven't given a lot of

thought. We are all supporting a number of losing, needed health care services on the backs of those services where we make "a profit."

The question is, how will a network contracting environment influence our ability to sustain our mission (if we feel that indeed it *is* our mission to provide this broad array of services to the population)? How will we be able to maintain it? I don't have the answer to that one.

I'm very bothered by the prospect that we are going to be in competitive systems. This is the proposed legislation that supposedly will bid down our prices until we eke out survival. If Medicaid is pushed through the same system, it's uncertain whether it's going to pay the same price as the others coming from industry and individuals. If this happens, there will no longer be the ability to cost shift, and whether we can accept government patients at a reduced rate in that situation is questionable.

My final concern for the future has to do with the ethic with which we deliver services, not just at academic health centers but in health care nationally. If these models of health care delivery say a gall bladder is a gall bladder is a gall bladder, you will have to prove to me by outcomes research that your cholecystectomy is better than the one next door. Otherwise, all gall bladders are the same, and then we're simply going to go out and buy that standardized product at the lowest cost.

Today, we don't believe in our heart of hearts, as providers or consumers, that health care is a standardized product. Do you really think that the patients in this country believe that a gall bladder is a gall bladder is a gall bladder? Our patients are more likely to say, "I have the best doctor, and I went to the best hospital." Patients firmly believe we are delivering a non-standardized product.

The change to the managed competition scenario is a change that will tend to force people into a situation in which the product is a standardized thing, unless there is evidence to the contrary. In that situation, what is the ethic with which that product is sold? Is it a professional ethic that says the patient's needs come first? Is it a business ethic that says, "If you can sell it and remain honorable, you will sell it." Or does it say, "Sell the product as much as you can, and buyer beware"? The responsibility is on the part of the buyer to make the judgments about the quality of the product. That's a real danger for our system, as we go forward in an era of consumerism. Consumerism brings with it the ethics of sales that are pertinent to other industries and other types of buyer and consumer relationships.

I think academic health centers have great challenges for the future. We have an economic challenge and we have an ethical challenge to maintain the professional ethic despite the business forces coming from the outside that are tending to push us into a mode that people really don't want in health care delivery. Our work is clearly

to preserve the mission of our institutions and to protect the ethic by which we deliver our health care.

The Spirit of Community

RIGHTS, RESPONSIBILITIES, AND THE COMMUNITARIAN AGENDA

Amitai Etzioni

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First Edition

In Conclusion

"WHAT is Communitarianism?" we are frequently asked. We are a social movement aiming at shoring up the moral, social, and political environment. Part change of heart, part renewal of social bonds, part reform of public life.

Change of heart is the most basic. Without stronger moral voices, public authorities are overburdened and markets don't work. Without moral commitments, people act without any consideration for one another. In recent years too many of us have been reluctant to lay moral claims on one another. It is a mistaken notion that just because we desire to be free from governmental controls we should also be free from responsibilities to the commons, indifferent to the community.

Which values should the renewed moral voices reaffirm? Let's start with those we all share. Nobody seriously maintains that lying is better than truth telling (other than under some rather peculiar circumstances philosophers argue about). Using force to push around other fellow human beings—whether it is a police officer indiscriminately clubbing a civilian who is already shackled or rioters pulling innocent people out of their cars—is something we deem to be unacceptable. Sexual harassment occurs, and although we may disagree about what exactly is encompassed by this term, we all agree

that it should be considered morally inappropriate. And so on.

In the fifties we had a well-established society, but it was unfair to women and minorities and a bit authoritarian. In the sixties we undermined the established society and its values. In the eighties we were told that the unbridled pursuit of self-interest was virtuous. By the nineties we have seen the cumulative results. There is now near universal agreement that the resulting world of massive street violence, the failing war against illegal drugs, unbridled greed, and so on—our well-worn list of ills—is not one we wish for our children or, for that matter, ourselves. Where do we turn from here?

To shore up the moral foundations of our society, we start with the family. The family was always entrusted with laying the foundations of moral education. In the renewed communities we envision, raising children is a job not for mothers alone, but for both parents. There is no contradiction between treating women and men as equals and calling for greater attention to, investment in, and, above all, a higher valuation of children.

Second in line are the schools. They are more than places in which people acquire skills and knowledge: they are places in which to acquire—or fail to acquire—education. Education includes the reinforcement of values gained at home and the introduction of values to those children whose parents neglected their character formation and moral upbringing.

Third are the social webs that communities provide, in neighborhoods, at work, and in ethnic clubs and associations, the webs that bind individuals, who would otherwise be on their own, into groups of people who care for one another and who help maintain a civic, social, and moral order. However, for these communities to be able to make their contributions, they themselves need to be shored up. This requires a new respect for the role that institutions, such as local schools, have in sustaining communities. Government needs to refrain from usurping their functions; planners need to make spaces more community-friendly; and all of us need to invest more of ourselves in one another.

Fourth, the national society must ensure that local communities will not lock in values that we, as a more encompassing and overriding community, abhor—such as burning books. And the national society should seek to maintain encompassing bonds that keep the many vying groups from turning hateful and violent to-

ward one another. We can readily accommodate, indeed be enriched, by the cuisines, music, and religious practices of the great variety of subcultures that make up America. But all of these subgroups must subscribe to a set of overarching values: specifically the democratic process, the Constitution and its Bill of Rights, and the commitment to be respectful of one another.

As our moral order is shored up, we need to concern ourselves with the civic order. Individuals' rights are to be matched with social responsibilities. If people want to be tried before juries of their peers, they must be willing to serve on them. If they want elected officials that respond to their values and needs, they must involve themselves in the primaries in which the candidates are chosen. Voting is not enough. They will also have to dedicate more time and energy to participating in local politics and institutions, from the community hospital to the local school board.

We need to remind one another that no rights are absolute. Even the freedom of speech, we all know, is refused to people who shout fire in a crowded theater, unless there is a fire. Testing those who have the lives of others directly in their hands for drugs, setting up sobriety checkpoints to stop murderous drunk drivers, and asking people whose blood is being tested to allow it to be checked for the HIV virus are all reasonable responses to new massive threats we must deal with in order to make the society work again.

Finally, complaining about special interests is not good enough. Don't get mad; get going. Special interests must be countered, and their money bags must be kept from corrupting our elected officials. The political energy required to reform the political system and restore the public interest to the central place it belongs cannot come from anywhere but aggrieved citizens banding together to clean up politics.

During a dinner discussion of the Communitarian agenda, Dr. Joan W. Konner, dean of the School of Journalism at Columbia University, puzzled over Communitarianism. "It appeared to be one part church sermon, one part reassertion of old values, one part political campaign, and one part social movement," she said. I could not have put it better myself. Our agenda, by necessity, is as complex and encompassing as the problems we face: beware of politicians promising simple solutions. We aim to change values, to

alter mind-sets, and to promote public policy that serves the commons.

As encompassing as the new Communitarian agenda is, it requires much experimentation and elaboration. This book is only a preliminary exploration of its ideas and practicalities. Above all, the agenda requires more good people and leaders who will join with one another to further develop the messages and form the social movement without which no basic change of direction is possible.

We do not have all the answers. But we are engaged in a genuine, shared undertaking. Many of these answers must evolve out of the give and take among those who make the Communitarian movement their social, civic, and moral home. It is, I assure you, a mighty fine place to start. May we hear from you?

THE COUNCIL ON HEALTH RESEARCH FOR DEVELOPMENT (COHRED)

At the end of its mandate, the Task Force and the countries that were actively involved in implementing the Strategy, assessed progress and recommended the continuation of the facilitation of ENHR. This recommendation was endorsed by the eighty-eight participants from forty countries, agencies and organizations at the Second International Conference on Health Research for Development in Geneva, Switzerland on March 8 and 9, 1993. The strong endorsement led a group of individuals from ten countries and three agencies to establish the Council on Health Research for Development (COHRED) as a long-term mechanism to carry forward the implementation of ENHR and the other recommendations of the Commission.

COHRED was formally established as a non-governmental organization on 10 March, 1993. It consists of member countries, agencies, organizations and a Board of eighteen individuals. The majority of Board members are from developing countries. COHRED's headquarters and secretariat are located in Geneva Switzerland, within the United Nations Development Programme.

COHRED's goal is to assist countries to achieve better health and quality of life for all their people. COHRED serves as a means by which countries, agencies and organizations (governmental and non-governmental) can work together to promote, facilitate and support **Essential National Health Research** and to address health issues of international priority requiring joint action. COHRED can provide "seed" funding and technical assistance for the planning and organization of a country's ENHR initiative.

COHRED works with countries to strengthen their research capacity, to identify their major health problems and to find the solutions which are most appropriate for them. COHRED helps countries build strong links between researchers, health care providers, decision makers and the people at all levels of the health system. These links are crucial to carry out the research necessary for informed and intelligent decision making and to institute the appropriate action. COHRED also works closely with international research programs, United Nations Agencies and other international organizations working towards health and equity.

THE COHRED SECRETARIAT

A small secretariat in Geneva, Switzerland supports the operation of COHRED.

COHRED will work in partnership with any country interested in applying the ENHR Strategy and with international agencies and organizations wishing to help countries to achieve this. Countries, agencies or organizations interested in becoming members of COHRED, or that wish further information about COHRED and Essential National Health Research, please contact:

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COHRED

March 1993

ESSENTIAL NATIONAL HEALTH RESEARCH

COHRED

COUNCIL ON HEALTH RESEARCH FOR DEVELOPMENT

BACKGROUND

The Commission on Health Research for Development was established in 1987 to recommend how research might improve the health and well-being of the peoples of the developing world. Following a world-wide analysis of health conditions and health research, the Commission released its Report at the Karolinska Nobel Conference in February 1990.

The Commission concluded that research is an essential but often neglected link between human aspiration and action, and that there are many ways that research should be applied to improve human health. Research to support informed and intelligent decision making for health action was of highest priority and good health was a driving force for development based upon equity and social justice.

The focus of health research should be national, and each country no matter how poor, should have a health research base which will enable it to understand its own problems and enhance the impact of limited resources. The process of setting priorities for national health research must be inclusive and involve scientists, decision makers and representatives of the people as equal partners. The resulting national health research agendas should serve as a starting point for global research efforts. The Commission called this concept Essential National Health Research (ENHR).

The Task Force on Health Research for Development was formed in late 1990 to implement the Commission's recommendations and promote the ENHR Strategy. Eighteen countries began to apply the Strategy between January 1991 and March 1993. At that time, the Council on Health Research for Development (COHRED), was established to continue the work of the Commission and the Task Force, especially the facilitation of ENHR.

WHAT IS ENHR?

ENHR is an integrated strategy for organizing and managing research, whose special characteristics include its goal, focus, content and mode of operation.

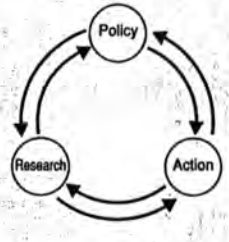
- **The goal** is to promote health and development on the basis of equity and social justice.

- **The Focus** is national and country specific. A country may choose to apply the ENHR strategy at the sub-national or district level in its efforts to use resources most effectively. The goal of equity and effective allocation of limited resources makes the ENHR strategy just as relevant to developed as to developing countries.

- **The Content** includes many types of research such as epidemiological, human behavioral, clinical and bio-medical, health systems, policy analysis, operational, management and communications research. However, the research disciplines and methodologies used evolve from the problems and research questions identified through the process. Usually the research requires the involvement of a number of disciplines.

- **The Mode of Operation or Process** is characterized by inclusiveness. It involves scientists, policy and decision makers (including health care providers) and representatives of the community. All three constituencies are crucial for setting priorities and for planning, promoting and implementing research and action programs. Effective linkages must be established among the constituencies to enable each to participate as an equal partner in the decisions and actions leading to Equity in Health. In this way, the process ensures that the results of research are translated into action.

The ENHR Loop



ENHR establishes a dynamic relationship among the policy, action and research sectors and spurs researchers, decision makers and community representatives to use scientific methods to analyze health situations, identify problems and solve them. ENHR aims to improve health and equity, and this makes it an essential component of both primary health care and human development.

Progress in the Implementation of ENHR

By March 1993, eighteen countries were implementing the Strategy and another eighteen were seriously considering doing so. Each country which adopts the Strategy evolves its own particular ENHR process and plan. Experience has shown that most countries follow a series of steps which usually, but not always, follow in sequence.

- The formation of a working group to promote the Strategy and assess its national applicability;
- A two to four day Workshop including represen tatives of the three constituencies to consider the value and feasibility of ENHR;
- The institutionalization of the ENHR process and the production of the ENHR plan;
- Networking with other countries carrying out their own ENHR process;
- National acceptance of the ENHR plan and the organization of its implementation and financing;
- Implementation, monitoring and evaluation of the ENHR plan and the continuation of the process.

Countries have carried out the above steps using different national organizations and procedures. The variations relate to the individuals and their organizations who become the initial promoters or "primemovers" of the Strategy. These have come from Ministries, academic institutions and national non-governmental organizations. Some national groups submitted proposals to the Task Force Secretariat for "seed" funding to support the cost of planning workshops and rapidly established a working group to develop a national ENHR plan. In a number of countries, ENHR was built up from the community by NGO's, while others started centrally with either academic or governmental institutions taking the lead. In all cases, the consultations at many different levels were the key to success and these always take time. Free and open debate among communities, researchers, health care providers and decision makers is always crucial to the success of an ENHR initiative.

COUNTRIES WORKING TOWARDS AN ENHR PLAN (March 1993)

Bangladesh • Benin • Anglophone Caribbean States
Egypt • Ghana • Guinea • India • Kenya • Mexico
Mozambique • Nicaragua • Nigeria • Pakistan
Philippines • Tanzania
Thailand • Uganda • Zimbabwe

STEVEN H. MILES, MD, NICOLE LURIE, MD, MSPH,
ELLIOT S. FISHER, MD, MPH, and DAVID HAUGEN, MA

Academic Health Centers and Health Care Reform

Abstract—There is increasing support for the proposition that academic health centers have a duty to accept broad responsibility for the health of their communities. The Health of the Public program has proposed that centers become directly involved in the social–political process as advocates for reform of the health care system. Such engagement raises important issues about the roles and responsibilities of centers and their faculties. To address these issues, the authors draw upon the available literature and their experiences in recent health care reform efforts in Minnesota and Vermont in which academic health center faculty participated. The authors discuss (1) the problematic balance between academic objectivity and social advocacy that faculty must attempt when they engage in the health care reform process; (2) the management of the sometimes divergent interests of academic health centers, some of their faculty, and society (including giving faculty permission to engage in reform efforts and developing a tacit understanding that distinguishes faculty positions on reform issues from the center's position on such issues); and (3) the challenge for centers to develop infrastructure support for health reform activities. The authors maintain that academic health centers' participation in the process of health care reform helps them fulfill the trust of the public that they are obligated to and ultimately depend on. *Acad. Med.* 68(1993):648–653.

There is increasing support for the proposition that academic health centers serve a public trust and have a corresponding duty to accept broad responsibility for the health of their communities.[1–9] Private foundations are supporting innovative programs to foster community engagement by academic health centers on behalf of the broadest health needs of their communities. Although most interest has focused on providing services to defined (usually underserved) populations and on teaching students about population health issues, the Health of the Public program (supported by The Pew Charitable Trusts, the Rockefeller Foundation, and The Robert Wood Johnson Foundation) has proposed that academic health centers also become directly involved in the social–political process as advocates for health care reform.[9]

Historically, academic health centers have not participated widely or directly in the process of seeking changes in public policy to promote health care reform. The proposal that they seek such participation raises important issues about the roles and responsibilities of centers and their faculties. In this article, we seek to provide insight on these issues by reviewing the history of recent health care reform legislation that was promoted by academic health centers. Specifically, in both Minnesota and Vermont, major health care reform laws were recently enacted, and faculty (ourselves included) at the University of Minnesota Medical School and at Dartmouth Medical School participated in the processes that produced these reforms. Drawing on our own experiences during the debates leading to these reforms, and consulting the available literature on the general issues involved, we examine the role of academic health centers and faculty in this kind of political process.

We focus on three issues. The first is the problem of striking a balance between academic objectivity and social advocacy that a faculty member must face when engaged in health care reform. The second is the management of the sometimes divergent interests of academic health centers, their individual faculty members, and society. The third is the challenge to academic health centers to develop infrastructure support for their health reform activities.

MINNESOTA'S RECENT REFORMS

In Minnesota, a bill to create a state-subsidized health care insurance plan for uninsured Minnesotans was proposed in 1989. The legislature and the governor concluded that the proposed plan lacked sufficient supporting analysis and would not reform the health care system. Legislation then created the bipartisan Health Care Access Commission to study the problem of the uninsured and provide the legislature with a recommended course. In 1991, the Commission proposed that the legislature focus on the cause of deteriorating access by introducing a new state health plan, reforming private insurance practices, and developing statewide cost-containment mechanisms rather than simply creating a program for the uninsured. The lengthy legislative debate included the veto of one bill, after which a bipartisan task force representing the legislature and the governor introduced HealthRight, Minnesota's recent health care reform legislation, which was debated, amended, and finally enacted on April 23, 1992.[10]

The major features of this law are designed to reform insurance underwriting and rating practices, provide for regional health care planning,

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support fragile rural health care delivery systems, reduce the need for defensive medicine, introduce practice guidelines, and consolidate the health care bureaucracy. The law also establishes a state-subsidized, sliding-scale health care insurance plan for Minnesotans with incomes up to 275% higher than the federal poverty level who are ineligible for Medicare or Medicaid. The plan emphasizes primary and preventive outpatient care (including mental health) with a modest hospital benefit.

VERMONT'S RECENT REFORMS

Between 1988 and 1991, health care reform was a prominent issue for the legislature and in statewide election campaigns. A substantial deficit and the potentially high cost of expanding access limited the scope of the legislative response. During the 1992 legislative session, consensus was reached on two positions: first, that cost containment could be achieved only through aggressive regulation of spending and investment in health care; and second, that universal access implied comprehensive benefits and a common benefits package for all.

The bill that emerged from the legislature takes major steps in some areas and modest steps in others.[11] A new agency, the Vermont Health Care Authority, was established to streamline and strengthen health care planning and to establish a budget within which total public and private spending for health care would be controlled. Measures were adopted to enhance the government's ability to manage health care resources, including mandatory budget review for hospitals and expenditure targets for physicians' and other providers' services. The bill also included health care insurance reforms, substantial malpractice reforms that are to be implemented when the universal health care program is adopted, and an expansion of Medicaid eligibility. Universal access is not immediately assured. Instead, the Health Care Authority plans to develop two versions of a universal access plan, one to be based mainly on private funding of health care through highly regulated insurers, the other on a publicly financed system similar to Canada's. Two plans are to be submitted to the legislature in 1993; achieving universal access thus awaits and depends on future legislative action.

REFORM EFFORTS OF FACULTY AT TWO CENTERS

Participation by academic health centers or their faculty in health care reform may be described within the traditional triad framework of research, education, and service. To illustrate this, we summarize some of the activities regarding health care reform that were undertaken in Vermont and Minnesota by academic health center faculty.

Research

The conduct and analysis of research is a traditional role for academic health center faculty. At the University of Minnesota Medical School, the main studies of uninsured, out-of-pocket health care expenses, employment insurance coverage, and citizens' preferences for services were commissioned by the legislature, were conducted by academic health center faculty, and ultimately influenced the design of legislation.[12] Separate, additional analyses were performed at the request of state departments, legislators, or advocacy organizations, or because of the researchers' interests. For example, a private advocacy group, the Children's Defense Fund, requested an analysis of data from the state-funded studies pertaining to the needs of children, to be used in developing their legislative agenda. The Minnesota Chapter of the National Organization of Women requested information about women's access to care and out-of-pocket expenses and used the findings to raise community awareness about the discrepancies in insurance premiums for men and women. Data about urban–rural differences in insurance and access to care were analyzed because of researchers' interests.[13]

While at the University of Vermont in the 1970s, John Wennberg developed the concepts and methodology of small-area analysis.[14,15] The state continued to use this methodology to inform public policy. Dartmouth Medical School faculty built on this work. They reanalyzed state data to show the sizes of financial cross-subsidies between areas with high and low hospital-use rates. Data from other states were used to argue that the resources tied up in excess beds could be used to fund improved access to care.[16] Dartmouth faculty used data from other states to supplement the Vermont findings and to argue that controlling the level of investment in health care was essential to controlling costs.

Findings from such studies were introduced into the policy process and public discussion in several ways. Researchers presented findings to legislative commissions and committees, to key legislators and their staffs, and to senior staff members in relevant offices of state government. Summaries of key research findings were broadly disseminated to legislators and to the public by the legislative bodies. Faculty at both Minnesota and Dartmouth also presented findings to their community groups, who used this information within the communities and at the legislature to focus their legislative priorities. Community groups disseminated research findings through press releases and alerted the public to their implications for policy. Findings were also reported in the lay media and in media outlets of the health care industry. In Minnesota, they were discussed by faculty and policymakers on talk shows as the legislation developed.

Education

Both universities participated in major symposia on health care reform policy. Dartmouth Medical School faculty and senior administrators of the academic health center participated in a two-day, statewide invitational conference on health care reform. In Minnesota, the Health of the

Public's Health Priorities Council brought together faculty, legislators, labor consumers, graduate students, and key medical industry leaders to examine how health care allocation priorities could be defined. The Center for Biomedical Ethics of the University of Minnesota created an important collaboration of academicians, payers, providers, and policymakers to develop a "values framework" for analyzing health care reforms.[17]

Minnesota and Dartmouth faculty participated in numerous public debates and forums with community groups, churches, consumer advocacy groups, businesses, insurers, and health professional organizations. These addressed topics ranging from overviews of the health care system to numerous specific topics about health care reform. In Minnesota, health science faculty wrote "op-ed" pieces and letters to the editor, met with editorial and news staffs, and served as commentators on radio and television in talk show and interview formats before legislation was introduced, as it was being debated, and after it was passed. Some of these interactions were initiated by reporters or editors; others were initiated by faculty members, departments, or organizations that invited faculty spokespersons.

In both Vermont and Minnesota, faculty met with lobbying or interest groups such as the state medical association or business organizations. Some faculty took an information resource role only, did not openly express a "political" conclusion, and restricted themselves to conveying research data pertaining to the views of these organizations. Others spoke as identified advocates of particular points of view.

Minnesota and Dartmouth faculty disseminated information about the research findings and about the health care policy reform developments in peer-reviewed publications and presentations at professional meetings.[10,12,18–20] Some of these faculty are periodically engaged as consultants on health care reform in other states.

Service

Minnesota and Dartmouth health science faculty played important service roles in the development of policy options. Minnesota faculty served the governor's and legislature's Health Care Access Commission as consultants and members, and one faculty member was the chair of a major committee. In these roles they helped define the research agenda for state-sponsored research; addressed ways to increase the numbers of rural and primary care practitioners; discussed insurance benefit designs and consumer preferences, delivery mechanisms, managed care, and managed competition; made presentation on efforts in other states; and discussed the ethical values underlying the health care system. To varying degrees, faculty from each university acted as consultants to the state administration, to legislative members, and to committees throughout the legislative session. Some reviewed drafts of the evolving bills and suggested revisions to legislators or their staffs. After passage of the legislation, Minnesota faculty advised the executive branch on technical issues of implementing it.

Faculty also played a significant role in securing additional resources to aid health care reform. Minnesota faculty from the departments of internal medicine, family practice, and pediatrics worked closely with government officials to prepare, write, and support state efforts to obtain funding from private foundations for health care reform.

DISCUSSION

Our experiences in Minnesota and Vermont highlight the complex challenges inherent in the disarmingly simple call for academic health centers to become involved in health care reform. Three of these challenges strike us as being particularly significant: maintaining "academic objectivity," establishing an appropriate distinction between the individual faculty member's reform activities and the center's and/or university's agenda, and developing an infrastructure within the academic health center to support reform-related activities.

Academic Objectivity

The ideal image of the faculty participant in health care reform is as an expert who constructively informs a public and political consensus upon which the policy reform is based. Based on the Minnesota and Vermont experiences, we can state that in the early stages of health care reform, faculty participation most closely resembles this model and the conventional forms of research and education. At this stage, faculty who are able to frame health care reform in terms of the broad view of the public interest can work well with groups inside and outside government to identify and address the tasks of health care reform.

Such neutrality is short-lived. The fact, for example, that out-of-pocket spending for health care is higher for rural citizens than urban dwellers has political ramifications, and policy responses will potentially affect the pocketbooks of many interest groups. Responding to interest groups' requests to reanalyze state data files to determine rural and urban out-of-pocket expenses, and reporting the findings to interest groups or to political bodies pose difficult issues for faculty researchers, who believe that their reputation for academic objectivity requires that they not be identified as aiding any political interest group. The ideal of political "neutrality" becomes increasingly difficult as the political process proceeds from research, to defining problems and their causes, and to developing and finally choosing policy options for legislation.

In this process, where ideas and information become increasingly controversial and politicized, the claim of academic neutrality and objectivity becomes increasingly difficult to maintain as partisans and opponents of ideas, conclusions, and legislative

solutions all try to claim the rational high ground. Though science cannot define the correct policy option, faculty who wish to play a policy role will be called upon to make judgements and commit themselves for or against specific policy options.

Faculty have several possible ways to handle this problem. They may disclose their own policy conclusions as they try to present a balanced assessment of the issue they are working on. They may conceal their own views as they try to present both sides of each issue fairly without drawing conclusions. Some may disengage from the policy process at some point in order to maintain the appearance of objectivity. The latter two options deprive the public and legislative debate of experienced and credible experts at the time that special interests are having greater opportunities to manipulate the policy process when amendments (both constructive and mischievous) are being rapidly proposed and evaluated for inclusion in "reform" bills. The difference between academic faculty involvement and that of special interests is worth considering. While neither may claim "scientific objectivity," faculty are responsible for scientific rigor in their interpretation and representation of data and for valuing the broader public interest. The legitimacy of faculty in the policy process thus rests not only on their academic credentials and intellectual integrity but also on the degree to which they are perceived as unconstrained by a special interest agenda.

Roberts and King describe such active faculty participants in health care reform as "policy entrepreneurs." They are outside government and "introduce, translate, and help implement new ideas" into public policy.[21] They facilitate policy breakthroughs by generating ideas; defining problems; cultivating relationships between advocates, community leaders, and politicians; assisting with obtaining media attention and support; and disseminating ideas. In this role, faculty may be able to facilitate dialogue between parties of opposing views and broaden public support for health reform efforts.

The role of policy entrepreneur should not eclipse other valuable roles for faculty in health care reform. For example, some faculty may participate purely as researchers or as academic informational resources on the literature pertaining to insurance reform, organization of delivery systems, technology assessment, etc. Some may simply convene discussions between citizen groups and/or policymakers to address health care reform. Individual Dartmouth and Minnesota health center faculty played all these roles and others during their respective states' reform processes. (For a list of these roles, see the boxed text.)

Individuals and the Institution

The degree to which faculty participate in reform policymaking is linked to some degree to how strongly their academic health center supports health reform. At the least, there must be (1) a tacit acknowledgment by deans and department heads that the health care system is failing to meet critical public needs and failing to provide equitable, affordable access to health services, and (2) permission for faculty to engage in reform efforts.

There are at least two built-in conflicts between the institutional interest of the academic health center and the engagement of faculty in health care reform, and both require careful attention. First, faculty activity on behalf of health care reform falls outside the carefully cultivated and defined lobbying relationships between academic health centers and legislators. Second, to some degree the interests of academic health centers mirror the problems of the American health care system. Academic health centers may see few benefits and many costs to reforms that, for example, would expand primary care, slow the emphasis on new costly technology or specialists, or mandate the assignment of government fee schedules. Although academic health care centers may acknowledge that their long-term interests are best served by a fiscally viable health care system that meets the public's needs in a satisfactory and respected manner, conflicts between their short-term interests and specific elements of reform pose a challenge to their broader mission.

Support for faculty engagement in health care reform thus requires a tacit understanding that distinguishes faculty activities and positions on legislative matters from the positions of academic health centers on these matters. Though faculty will be identified as such, their positions on reform issues should not be presented as the positions of the academic community or of the university. This distinction is especially important in the later stages of controversial legislative debates, when intense professional and peer interests may encourage faculty to modify their positions or even their participation in health care reform. Institutional consensus on reform proposals would require complex, difficult, and time-consuming negotiations within the academic health center that cannot usually be accomplished on a legislative timetable.

The processes of creating this tacit understanding are unique and linked to the characteristics and situation of each institution. Creating this understanding begins with a personal commitment by the leadership of the academic center to the importance and necessity of scholarly work that enhances the health of the public, either by biological or nonbiological research or by involvement in policy work that will improve the population's health. This commitment must be strong enough to support the engagement of faculty during the inevitable controversies and to support junior faculty as they learn how to properly engage in health care reform issues. The commitment requires trust in the expertise and intellectual fairness of faculty who participate in health care reform. It also requires a recognition of—and comfort with—the fact that controversies about health care reform differ from those

Examples of Off-campus Activities Concerning Health Care Reform Carried out by Faculty of Two Academic Health Centers

The following activities to promote health reform were recently undertaken by faculty at the University of Minnesota Medical School (for Minnesota reforms) and faculty at Dartmouth Medical School (for Vermont reforms).

Research for the policy-making process

Undertook research of the uninsured, of out-of-pocket health care expenses in rural and urban areas, of preferences for services, of sources of high health care costs, and (via employers) of insurance coverage of workers

Made special analyses of specific issues for government and advocacy groups

Gave research presentations, summaries, and testimony to legislators and members of the executive branch

Education

Community-based

- Gave interviews to reporters and editorial boards
- Wrote editorials and letters to the editor
- Spoke at public meetings and debated
- Consulted with private health reform organizations
- Sponsored and participated in university-based reform symposia for public and/or leadership groups

Professional

- Peer-reviewed papers pertaining to health care reform for publications and for meetings of professional organizations
- Presented papers at meetings of professional organizations
- Consulted with experts in other states

Service

Policy development

- Served on state reform commission
- Consulted with and testified before legislators
- Consulted with and testified before members of the executive branch

Mobilization on specific legislation

- Gave speeches and interviews
- Wrote op-ed pieces
- Served as spokespersons for advocacy organizations
- Served as spokespersons for health-professionals' associations

State grant development

- Helped develop grant proposals to foundations to fund state activities related to health care reform

in the biological health sciences in that there are a broader array of engaged parties and different and more elusive standards of proof.

Infrastructure

Considerable support by the institution must precede the engagement by faculty or academic health centers in health care reform. The most basic is support for faculty education at conferences and grand rounds on the need and options for health care reform. A more complex commitment is identifying and encouraging individual faculty who have the interest and aptitude for this kind of scholarship. This might, for example, involve encouraging faculty involved in medical ethics, epidemiology, or primary care to consider conducting research or performing analytic work that has a direct bearing on health care reform in the center's state or region, or to consider establishing working relationships with key policymakers. The most complex commitment is establishing a health care reform policy center or delegating such a function to an established center of ethics, health law, or health policy. This may entail requesting legislative support for a major university initiative.

Whatever supporting role academic health centers take, it is becoming more widely understood that they must support faculty who participate in health care reform. The kind of support will vary with the role of the faculty and with the characteristics of the institution. Protected time is essential. Deans and department chairs must also understand that academic publication about reform events and ideas will often occur only after wide public discussion of reform ideas rather than before. Even research findings will need to be disseminated through media, legislative, or community venues according to the legislature's deadlines rather than those of peer-reviewed publications. This issue may pose special challenges for editors of medical publications.

Finally, extramural funding is essential, both to assure sufficient protected time for scholarship, community education, and legislative involvement and to provide validation within the academic center of these activities. Public education, testimony, most consultation with community groups, reviewing legislation for government personnel, and background reading take large amounts of time and are non-remunerative. Grants pay for the substantial amount of faculty time and provide validating "recognition" of the worth of the faculty effort. They also provide a rationale to legislators or other groups as to how faculty have time for this kind of activity and thus make the faculty less suspect as lobbyists. Extramural funding is especially necessary, given the decreasing availability of internal funds for non-remuner-

ated activities. The development of additional sources of private donor support for these kinds of activities is urgently required.

CONCLUSIONS

The engagement by academic health centers in health care reform is a complex but not altogether unprecedented challenge. Other university colleges or divisions, such as those devoted to foreign policy or social service administration, have experience with active engagement in public policy. In such units, an accommodation has been reached that enables and evaluates faculty participation in public policy-making. This accommodation addresses the problems of objectivity, neutrality, and advocacy and, with experience, develops standards for faculty excellence. There are many elements for successful participation in health reform policy making. These include developing faculty expertise in population-based health care, in health policy, and in the understanding of how to play an effective public role in health care reform; developing agreements and understandings that insulate faculty activities from parochial institutional interests; and fostering support for faculty and a tolerance for their somewhat experimental and controversial activities. The difficulty of meeting this challenge does not diminish its necessity.

Health care reform is under way. Hopefully, the outcome will be a better health care system. It will certainly also affect the stature of the health care profession and that of academic health centers. By participating in this process, academic health centers are fulfilling the trust of the public that they are obligated to and ultimately depend on.

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THE FOURTH MISSION: CARING FOR COMMUNITIES

By Patricia Shea, M.A.

AAMC Chair Spencer Foreman, M.D.

The message that academic medicine must revitalize its responsiveness to the nation's needy communities underpinned many health care reform discussions at the November AAMC Annual Meeting. Strongly reinforced by the remarks of guest speakers and the presentation of the first AAMC Award for Outstanding Community Service, Association Chair Spencer Foreman, M.D., called for heightened social responsibility in his plenary address.

Dr. Foreman acknowledged that academic medicine has contributed much to the nation's health, but society's glaring needs demand that medical schools, hospitals and physicians do more. "Despite our immense and incomparable success, a grateful nation seems not to lie at our feet," he said. "There's a sense that academic medicine may somehow have failed to deliver on important parts of our social contract."

Dr. Foreman said this discontent is evident in public policy decisions that "have gradually chipped away at the supports that built and sustained the academic enterprise for decades." Coupled with this signal of disapproval are growing national crises that society increasingly expects academic medicine to help address—the growing number of uninsured Americans, the shortage of health care professionals in thousands of communities and the spreading social scourges of poverty, homelessness, crime and isolation that undermine health.

Academic medical centers now must define themselves not only by the programs and science conducted within their institutions, but by the services they provide to the surrounding community. "The challenge to us is nothing less than to undertake the building of the medical infrastructure now missing in America's most deprived communities," he said. "We have the talent, the expertise, the physical resources, the management strength and, more often than not, the investment capital. . . . If [we] do not accept responsibility for the health of [our] neighbors, who will?"

Dr. Foreman's vision of academic medicine's role in social change extends beyond merely catalytic to that of permanent leadership. "It's an aggressive role in which academic medical centers must make a major institutional commitment to building and sustaining community-based delivery systems which, in addition to providing basic health care, are capable of dealing with the complex special problems of the disadvantaged," he said.

First, each academic medical center should identify and take "real responsibility" for an underserved community, creating health care delivery systems that recognize and address the special challenges poor communities face, he said. Schools, churches, welfare hotels and homeless shelters as well as the more traditional community-based primary care facilities should be access sites for such services as health and nutrition education, substance abuse management, mental health counseling, HIV screening and TB treatment.

Institutions also must work to ensure that they become effective and motivational training grounds for an enlarged cadre of primary care physicians interested in serving poor or rural populations. Achieving this, Dr. Foreman said, will require medical schools to assemble community-based faculty dedicated to working and teaching in medically underserved settings. Institutions actively must support and nurture these faculty, particularly by linking them to academic centers that offer educational and research opportunities and membership in a scholarly community. "To avoid a revolving door, there must be the clinical and intellectual infrastructure necessary to sustain them there," he said.

Educating more community-based primary care physicians will require medical education reform, said Dr. Foreman. "This means . . . providing real-life experiences in targeted com-

munities and side-by-side exposure to committed role models. It means integrating into the curriculum behavioral and population-based sciences, exposing students to the social, environmental and cultural influences which impact on health and disease."

Graduate medical education should reinforce medical students' experiences by enabling residents to work with physician role models committed to inner-city or rural practice. "It means demonstrating to these young physicians that a long-term commitment to practice in difficult or isolated areas is possible, and that burnout and isolation are preventable with a properly constructed support system," said Dr. Foreman. "We need to . . . learn how to support, and not squander, the socially responsible inclinations most medical students bring with them at the start of their education."

An invigorated research agenda, launched in the community setting, should complement and advance these medical education and training efforts, he said. By expanding their venue for scientific inquiry outside the laboratory and into surrounding communities, institutions can provide better solutions to the health concerns that aggravate the nation's most difficult social problems. "We need epidemiological studies and

(continued on page 8)

Miami Wins First AAMC Community Service Award

From left, Ira Clark, President, Jackson Memorial Hospital; Nester de la Cruz-Muñoz, a fourth-year student at Miami and student council president; Bernard J. Fogel, M.D., dean, Miami; Spencer Foreman, M.D.; and Robert G. Petersdorf, M.D.

The University of Miami School of Medicine received the Associations' first Award for Outstanding Community Service Nov. 7 at the AAMC Annual Meeting. The AAMC established the annual award this year to recognize medical schools and teaching hospitals for long-standing service to their communities.

Miami and its affiliated public teaching hospital, Jackson Memorial Hospital, were selected from more than 40 nominated institutions for the commitment and scope of their efforts to benefit medically underserved communities throughout southern Florida. Dade County voters even authorized a sales tax increase to support expanded hospital programs to meet community health needs, including the county's only trauma unit, a pediatric AIDS unit and a special neonatology unit. Ongoing outreach programs include mobile mammography screening and pediatric care for indigent women and children and the Debbie School, a national model program for children with developmental disabilities. Teams of faculty, staff and students played key roles in helping victims of Hurricane Andrew in the days and months following the storm.

Medical education is tied closely to Miami's service efforts through the unique Community Clinical Experience Program. The entire freshman and sophomore classes are assigned to more than 70 community sites where they give physical exams and assist in patient follow-up one afternoon a week. Third-year students complete a required one-week rotation at the Camillus Health Concern, an ambulatory clinic located at a homeless shelter which provides 25,000 patient encounters each year. On their own time, students stage health fairs at public schools and community centers in underserved areas of the Florida Keys.

"Practicing medicine is a privilege, not a right, and giving something back to the community through service is part of that," said Nestor de la Cruz-Muñoz, a fourth-year medical student at Miami. "I think our students will carry community service into their practices long after they leave here."

"This award probably is the most significant recognition our school of medicine could receive. For our faculty and students who have worked so hard in the community, I am extremely pleased," said Bernard J. Fogel, M.D., senior VP for Medical Affairs and dean. "Community service long has been a major mission of our school, and it is gratifying to be recognized for it."

Johns Hopkins University Medical Institutions and the University of California-San Francisco School of Medicine were award finalists.

CHANGING THE CONTEXT

Dr. Weldon (left) with Janet Bickel, AAMC assistant VP for Women's Programs

"I would wager that virtually every one of us here today has found ourselves in a situation where we have been marginalized. . . . This is not an ivory tower debate—this is reality for millions of American women," said Virginia Weldon, M.D., at the annual Women in Medicine Lunch.

Dr. Weldon, VP for Public Policy at Monsanto and 1985-86 AAMC chair, pointed to the strides women have made in academic medicine and elsewhere, but noted, "For the vast majority of American women, the reality of the workplace has not changed a great deal." Dr. Weldon cited the "troubling" findings of a recent Families and Work Institute study in which more than half of those surveyed said they would rather work alongside people of their own race, culture and gender. In addition, the study showed that far more women managers rated their personal career opportunities as "poor" or "fair" than did their male counterparts. "What all of these findings suggest to me is that the so-called 'Year of the Woman' may be something of a myth," said Dr. Weldon.

Employers ignore workforce diversity at their own expense, she warned. For example, studies show that diverse employee teams outperform homogenous teams of any composition. "Diversity is an asset we've been hiding from ourselves; a neglected resource we have not used," she said. She illustrated her point with a story about the recent peace negotiations in Norway between Israel and the PLO which, instead of taking place in the customary formal meeting halls, were held in the home of foreign minister Johan Jorgen Holst and his wife, Marianne Heiberg. The secret talks went on for 18 months, and when communication would break down, Ms. Heiberg would invite her four-year old son into the room to ask the negotiators to play. "These men, hardened toward each other by literally centuries of history and hate, played together on the floor."

While the activity certainly released tension, said Dr. Weldon, it also made the critical point that children's futures were at stake. "Marianne Heiberg did something very powerful and very much like a women," she said. "She changed the context. . . . That is a vital and often overlooked strength that women bring to the workplace in our corporations and in our medical centers."

The Women in Medicine Lunch took place at the Washington Hilton Nov. 9 during the Association's Annual Meeting.

"THE FOURTH MISSION" *(continued from page 7)*

clinical research, particularly on conditions that disproportionately affect disadvantaged communities," said Dr. Foreman, "and we need to put our emphasis on studies done in community settings to advance what we know about managing illness there."

Creating such community-based systems of patient care, medical education and research will require a dedicated faculty and institutional mission. "It will also mean a commitment of substantial institutional resources, because the start-up costs can be very significant," Dr. Foreman said. However, between patient care revenue, Title VII and other grants, graduate medical education payments and foundation support, funding sources do exist, he said. "We need to go after them and use them to build a case for what we hope to accomplish."

Dr. Foreman urged AAMC members to join their many colleagues who have pioneered this new agenda of social responsibility, despite its challenges. He cited Parkland Memorial Hospital; the Johns Hopkins Health System; Montefiore Medical Center; Rush-Presbyterian-St. Luke's Medical Center; and the medical schools at Dartmouth, Minnesota and Miami among the many institutions across the country that successfully have implemented parts of this agenda in recent years. "The unmet need in these underserved areas is among the most compelling problems that academic medicine could seek to remedy. If we do not undertake this responsibility, a critical job will go undone and a huge opportunity will have been missed. And all of us . . . will be the poorer for it."

2-15-94

SUBJECT "A.I.D.S."

DEAR KRISTINE;

I'M A RETIRED MECH. ENGR HAVING, IN 1949, EARNED MY B.S.M.E. FROM THE UNIVERSITY OF MICH.

THIS IS THE PROBLEM. HOW CAN AN ENGINEER SOLVE A WORLD WIDE DISEASE, A.I.D.S.. I BELIEVE I HAVE.

FOR OVER 2 YEARS I'VE BEEN TRYING TO GET A SEROLOGIC VACCINE TESTED WITH NO LUCK.

I'LL MENTION A FEW INFLUENTIAL PEOPLE I'VE CONTACTED.

1. GEORGE AND BARBARA BUSH.
2. PRESIDENT CLINTON AND THE FIRST LADY, HILLARY.
3. THE HEADS OF 4 PHARMACEUTICAL CO'S. THE COMPANIES ARE UPJOHN, ELI LILLY, MERCK AND BRISTOL MEYERS SQUIBB.
4. POPE JOHN PAUL II IS INTERESTED IN A.I.D.S. SO I WROTE HIM.
5. ARTHUR ASHE FOUNDATION
6. DOCTORS AND A RETIRED DENTIST.
7. THE JONAS SALK INSTITUTE.
8. ELIZABETH TAYLOR.
9. ELTON JOHN
10. AND MORE.

IF YOU ANSWER ME IN A POSITIVE WAY I'LL GIVE YOU THE DETAILS ON HOW TO MAKE THE MEDICINE. I'LL ALSO TELL YOU WHY I FEEL THAT I HAVE A CURE.

IF THIS SERUM IS USED NATION WIDE. MEDICAL COSTS WILL DECREASE, HOW MUCH, I DON'T KNOW, BUT A SUBSTANTIAL AMOUNT.

PEOPLE WHO ARE H.I.V. POSITIVE, AND KNOW, FIGURE THEY'VE BEEN GIVEN A DEATH WARRANT.

I'VE DRANK ABOUT 40 C.C. WITH NO ILL EFFECTS. I FEEL I AM NOW IMMUNE TO H.I.V.

HOPING TO HEAR FROM YOU. LETS MAKE IT A BELATED HAPPY 1994 FOR WORLD WIDE SUFFERERS.

SINCERELY

Henry Kahn

HENRY KAHN
19655 RENO, APT. #4
DETROIT, MICH.
48205

TEL. 1-313-8396249

THE WHITE HOUSE
WASHINGTON

March 15, 1994

The Honorable E. Clay Shaw
U.S. House of Representatives
2267 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Shaw:

For your information, I am enclosing a copy of the letter I recently sent to your constituent, Ken Consentino.

Please let me know if you have any questions.

Sincerely,

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

Enclosure

I thought this would be of interest to you.

Clay.

E. CLAY SHAW, JR.
U.S. House of Representatives
2338 Rayburn House Building
Washington, D.C. 20515
(202) 225-3026

E. CLAY SHAW
22D DISTRICT, FLORIDA

2267 RAYBURN HOUSE OFFICE BUILDING
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Congress of the United States
House of Representatives
Washington, DC 20515-0922

March 1, 1994

Mr. Ken Consentino
National Coordinator
National Health Registry to Prevent AIDS
P.O. Box 350510
Fort Lauderdale, Florida 33335-0510

Dear Mr. Consentino:

I received your recent letter and enclosures in support of in-home HIV testing.

I appreciate knowing of your service. I have noted that you are seeking the "government to endorse us and assist in implementing" this program. While I am not able to personally do that, I have forwarded a copy of your suggestion to Ms. Kristine Gebbie, the President's National AIDS Policy Coordinator. I hope this is helpful to you.

I appreciate having the benefit of your thoughts.

Sincerely,

E. Clay Shaw, Jr.
Member of Congress

ECS:maw
cc: Kristine Gebbie, National AIDS Policy Coordinator

366318 |mw

NATIONAL HEALTH REGISTRY
to Prevent AIDS
1 (800) HALT-HIV

DEAR REPRESENTATIVE SHAW,

THESE MATERIALS AND THE PROGRAM DESCRIBED WITHIN SHOULD BE CAREFULLY READ, THOROUGHLY EXAMINED AND COMPLETELY UNDERSTOOD.

THIS PROGRAM REPRESENTS AND IS THE MOST VIABLE AND EFFECTIVE SOLUTION FOR THIS COUNTRY TO GREATLY EFFECT AND CONTROL THE SPREAD OF HIV/AIDS.

THE PURPOSE OF CONTACTING YOUR OFFICE IS TO INFORM YOU AND GAIN YOUR COMMITTED SUPPORT, AND TO ASK THAT YOU USE YOUR POSITION AND INFLUENCE AND DIRECT IT TO THE PROPER PERSON, PERSONS OR AGENCY TO PERSUADE EITHER THE FEDERAL GOVERNMENT OR INITIALLY THE STATE OF FLORIDA TO ASSIST US IN CERTAIN IMPORTANT AREAS THAT WILL INSURE THIS PROGRAMS COMPLETE SUCCESS.

DESCRIPTION:

HIV NEGATIVE TEST "REGISTRY SERVICE".

* Enables two HIV negative tested persons to expeditiously verify that each other has in fact tested negative for the HIV virus, thereby reducing their risk of contracting HIV/AIDS.

* This program offers to arrange convenient in-home HIV testing that will to a great extent relieve the hesitation and procrastination that is indicative of present attitudes toward HIV testing.

* This concept is simple and offers substantial "risk reduction" combined with convenience which will promote the essential HIV testing that is desperately needed in order to provide any type of effective solution short of a vaccine or cure.

* Discrimination is not a problem factor or issue because no HIV/AIDS infected persons will be publicly identified or exposed in any way.

P.O. Box 350510 • Ft. Lauderdale, FL 33335-0510 • Fax Number (305) 766-8470

NATIONAL HEALTH REGISTRY
to Prevent AIDS
1 (800) HALT-HIV

FEBRUARY 3, 1994

FLORIDA CONGRESSIONAL DELEGATION
UNITED STATES REPRESENTATIVE
E. CLAY SHAW, JR.
2267 RAYBURN
HOUSE OFFICE BUILDING
WASHINGTON, D.C. 20515

DEAR REPRESENTATIVE SHAW,

The National Health Registry to prevent AIDS is an organization dedicated to preventing the ravaging spread of AIDS! We have developed and are close to a start date in implementing our program that absolutely has the potential to substantially reduce the risk of contracting HIV, and will ultimately impact the over-all spread and devastation of this disease.

Until now most people have not wanted to or have not had a compelling reason to be tested for HIV because they feel their life would be completely devastated since there is no cure. Since it generally takes ten years or more for HIV to produce symptoms from the point of infection, an infected person will probably unknowingly infect many other people in that long period of time, which is the precise reason AIDS is likely to be spreading in geometric proportions.

There is no way to know just how fast or how wide AIDS has spread to date. Given the nature of AIDS and the possibility of geometric growth of infection, all published estimates are mostly based on irrelevant data, and information that leaves a tremendous potential for drastic gross inaccuracies in the number of people reportedly thought to be infected with HIV, which then would result in grossly inaccurate reports in the actual rate of its spread. There will be a compounding increase in future infection and devastation for every day, week, month and year that this dreadful disease is permitted to continue its spread. The truth is; the world will not know the true impact of AIDS for many years to come.

The only responsible action and immediate solution short of a cure is for the government to endorse and assist us in implementing our plan which will entice and

promote the essential widespread HIV testing that is desperately needed, and will then offer an effective way for people to avoid contact with HIV. This program will accomplish this easily and effectively, without discriminating against or exposing those people who are already infected.

Our program offers those at risk that "compelling" reason to want to be tested. Participation enables each person to interact with another person who they can easily verify has also tested negative for the HIV virus and the exact date of their most recent test, therefore greatly reducing their chance of contracting HIV/AIDS.

Participants are encouraged to maximize their protection within this program by requesting that each new sexual partner re-test prior to any sexual involvement. Now that people have a "compelling" reason to be tested we firmly believe most will want to take advantage of the included attractive simplicity within this unique program of being tested for HIV in the convenience of their own home or at their place of work. However, even if there is not a request for a participant to re-test and to provide a current result, at the very least it will be extremely valuable for that person to know that their potential sexual partner has tested HIV negative at the beginning of their membership period, and that they could not have been an HIV carrier for a prolonged period of time. Since the vast majority of HIV infected persons have been infected for a prolonged period of time, this program will be extremely effective in not permitting the largest percentage of all HIV infected persons from participating.

Within this program the level of risk is immediately reduced to only include those persons who have become infected with HIV and have been tested too soon before the virus could produce enough HIV antibodies to be detected by the test, which represents only a small fraction of present and all future HIV infected persons. (The HIV virus is generally detected by an HIV test within 2-12 weeks from the point of infection). In the scope of the AIDS epidemic and its spread there of, immediately eliminating roughly eighty to ninety percent or higher of all HIV infected persons from participating or interacting with participating uninfected persons, is certainly a dramatic reduction in risk that must not be ignored.

Many people in this country strongly support mandatory HIV testing for everyone and public disclosure of the test results. As effective as that would be, discrimination prevents its application and the moral and ethical questions it could raise. This program does not discriminate or expose infected persons, yet it provides a very similar degree of

protection as mandatory testing would offer. Even with mandatory testing, in addition to the window period causing a problem in detecting 100% of all HIV infected persons, the possibility still exists that an uninfected person will foolishly choose to interact with an infected person and then without malice of forethought infect other uninfected persons, ridiculous, yet possible! Therefore mandatory testing would not provide guaranteed protection either. The point is; no one can have complete control over everyone's actions and there will always be foolish people who do unthinkably foolish things. In light of that, we should still absolutely not ignore the dramatic potential for risk reduction within this program only because it cannot offer guaranteed protection. There is no better solution short of a cure that can guarantee protection, this is as close as it gets!

Aside from abstinence and maybe condoms, there is simply no other effective means of reducing the risk and spread of HIV/AIDS. Abstinence is not a realistic expectation and condoms are questionable because of the low percentage of use, the alarming percentage of leakage, breakage and improper use, and in addition condoms must be used and relied on for each and every act WITHOUT FAIL. Nevertheless, because there is a definite degree of protection, this program will heavily endorse and promote condom use in conjuction with this program.

This program does not match one person with another person, and is in no way a dating service of any sort, and certainly does not have any intention now or in the future to attempt to match any member with another member. Each participant will meet and interact with people in exactly the same way they always have in the past, the only major difference is they will now request for their potential sexual partner to be tested and then to "Register", if that person happens to already be participating and is registered, they can simply call to check and verify that person has tested negative for the HIV virus and the exact date of their test.

The fear that someone may become infected with HIV while participating with this program is essentially a futile fear. The fact is; people who were destined without this program to meet an infected person and unknowingly become infected, will now within this program have an excellent chance of not even meeting much less become infected by that person. However, if by some lack of detection and through no fault of our own, the infected person is enabled to participate with this program and should infect another participant, we have only failed to prevent the infection and are certainly not the cause of that infection

NATIONAL HEALTH REGISTRY
to Prevent AIDS
1 (800) HALT-HIV

because it would have occurred regardless of this "Registry Service". We must not as you should not be deterred because of the relatively few people we may not be able to save, but encourage and determined by the potential masses of people we can save!

With this nations impenetrable and complex bureaucracy, it is extremely difficult to find someone with the authority and in a position who is willing and capable to convince those necessary to make the needed decisions that will give this program the chance it deserves. We believe this programs complete and widespread success may depend on the governments assistance.

Enclosed for review:

1. Brief program description,
2. Seven pages of the exact contents to be contained in our information brochure,
3. A two page document explaining our view of the liability involved within this program,
4. Contents of a disclaimer form that must be signed by each and every participant.

Please take the time to carefully examine and understand all materials.

Contact Mr. Kenneth N. Cosentino with questions and comments at (305) 523-7479

Sincerely,

Kenneth N. Cosentino
President

NATIONAL HEALTH REGISTRY
to Prevent AIDS
1 (800) HALT-HIV

THE FOLLOWING SEVEN PAGES CONTAIN THE PROPOSED CONTENTS OF OUR "INFORMATION BROCHURE".

THIS BROCHURE WILL INFORM THE PUBLIC AT RISK OF THE EXISTING DANGER, POTENTIAL DEVASTATION AND ELUSIVE NATURE OF THE HIV VIRUS.

THE MAIN PURPOSE OF THIS BROCHURE IS TO EXPLAIN EXACTLY HOW THIS PROGRAM WILL WORK AND CLEARLY OUTLINES ITS LIMITATIONS AND OBVIOUS BENEFIT.

EACH AND EVERY PARTICIPANT WILL RECEIVE THIS INFORMATION PRIOR TO BEING REGISTERED AND PRIOR TO BEING PERMITTED TO PARTICIPATE WITHIN THIS "REGISTRY SERVICE".

P.O. Box 350510 • Ft. Lauderdale, FL 33335-0510 • Fax Number (305) 766-8470

THE SOLUTION!

A SIMPLE AND EFFECTIVE WAY TO REDUCE YOUR RISK OF BECOMING INFECTED WITH HIV/AIDS!

CHECK AND VERIFY THAT YOUR POTENTIAL SEXUAL PARTNER HAS IN FACT TESTED NEGATIVE FOR THE HIV VIRUS BEFORE ANY SEXUAL CONTACT.

YOU WILL SUBSTANTIALLY REDUCE YOUR RISK OF CONTRACTING HIV!

Once you have been tested for HIV and have tested negative - we will obtain and verify the negative test result and enter your name and the exact date of the test into our computer based "Registry Service". You will be issued a personal ID# and ID card which will be promptly sent to you along with important membership information.

When you meet someone who is not yet "Registered", you should explain that you have registered your negative HIV test result with a "Service" that enables each of you to call and verify that the other has tested negative for the virus. Suggest that it is important and a good idea that they also Register! (WE CAN ARRANGE CONVENIENT IN HOME TESTING AND "REGISTER A PERSON WITHIN JUST A FEW DAYS.) *Give them our registration telephone number (1-800-HALT-HIV) and explain how simple and convenient it is to "Register, not to mention potentially life saving! The person you request this of will certainly respect your sense of responsibility and will very likely also want to "Register".*

Once that person is also "Registered", or; if the person you meet and are interested in is already "Registered", for only a $2.00 toll you will be able to call our verification telephone number to check and verify that persons HIV test result information.

When calling to check and verify HIV test information, you will be instructed to first enter in your own identification number, and then to enter in the other persons identification number who you wish to verify. Once both ID#s are entered properly you will listen to a computer verify and announce the other persons name and that they have tested negative for the HIV virus along with the exact date of their most recent negative HIV test result.

If the person you are interested in declines your request and does not wish to "Register" you should make a wise decision and also decline to persue a sexual relationship with that person.

However, since most people are very concerned and fearful of contracting HIV/AIDS, we strongly believe people will eagerly welcome the suggestion and opportunity, and want to "Register"!

FOR THIS TO WORK

" DON'T WE NEED EVERYONE TO REGISTER "?

NO! WHETHER TWO PERSONS OR TENS OF MILLIONS OF PERSONS PARTICIPATE WITHIN THIS "REGISTRY SERVICE", THERE IS NO DIFFERENCE IN THE AMOUNT OF PROTECTION RECEIVED. YOU ONLY NEED THE PERSON YOU INTEND TO PERSUE SEXUALLY TO BE "REGISTERED"! YOU SHOULD NOT BE CONCERNED ABOUT ANYONE ELSE EXCEPT YOURSELF AND YOUR POTENTIAL SEXUAL PARTNER!

PLEASE BE INFORMED THAT THE NATIONAL HEALTH REGISTRY CANNOT "GUARANTEE" PROTECTION AGAINST BECOMING INFECTED WITH HIV!

However, this "Registry Service" will provide you with valuable information that will "REDUCE" your risk and chance of becoming infected with the HIV virus!

The National Health Registry CANNOT GUARANTEE that any person participating with this "Registry Service" who tests negative for the HIV virus will currently be free of HIV. The NHR also CANNOT GUARANTEE that a person will not become infected with HIV while participating with this "Registry Service". If you decide to participate with this "Registry Service" you must understand that we can only 'REDUCE' your chances of contracting HIV and that we do not have control over how responsible a registered member will choose to be while participating with this "Registry Service".

You should continue to use condoms while participating with this "Service", and you should always inquire about your partners recent sexual history at least since their last negative HIV test. If your partner has not had a sexual relationship since their last negative HIV test, you are obviously at considerably less risk than if they had.

Your decision to engage in a sexual relationship should not be solely based on the information you receive from this "Registry Service".

THE FACT IS:

Even though we cannot guarantee 100% protection against HIV and after informing you of all the facts and existing risk;

IT IS ABSOLUTELY INDISPUTABLE THAT IT IS OF GREAT VALUE AND BY FAR BETTER TO KNOW THAT THE PERSON YOU ARE INTERESTED IN SEXUALLY HAS TESTED NEGATIVE FOR THE HIV VIRUS AND THE EXACT DATE OF THAT TEST,

RATHER THAN NOT KNOWING AT ALL!

Each NHR member will have the option to re-test and re-register as often as desired under these same terms, charges, and conditions.

When checking and verifying the HIV test information of another member, each NHR member has the responsibility to decide if you are sufficiently satisfied that the verified test date is current enough and whether or not you should request for that person to re-test and re-register before any initial sexual contact.

Regardless, each NHR member is required to re-test and re-register after expiration of the initial six month period. Thereafter each member will be required to re-test and re-register at least every twelve months.

You will be notified just prior to the expiration date of your membership.

* HIV TESTING *

According to the Federal Agency CDC (Center For Disease Control) in some areas around the country going to a doctor for counselling and an HIV test can cost more than $200.00

Most people are uncomfortable and anxious about making a doctor appointment or going to a crowded public health facility for the purpose of getting an HIV test.

* FOR THIS REASON WE HAVE MADE IT SIMPLE!

* WE CAN ARRANGE CONVENIENT TESTING FOR YOU!

THIS IS HOW IT WORKS:

TO REGISTER:

Choose one of the three test options on the following page and send a check or money order in the amount of the option chosen, made payable to; National Health Registry, P.O. BOX 350510 Fort Lauderdale, Florida 33335-0510

Be sure to include name, telephone number with area code and complete mailing address. Please specify option chosen.

* OR YOU CAN CALL

(1-800-HALT-HIV)

(1-800-425-8448)

OPTION I: COST $75.00- *(Includes HIV test and entry into the "Registry Service" with a negative test result).*

YOU WILL HAVE THE CHOICE AND CONVENIENCE OF BEING TESTED IN YOUR OWN HOME OR AT YOUR PLACE OF WORK.

If you choose this option a licensed professional paramedic will contact you and set an appointment at your convenience in your home or place of work in order to obtain a blood sample. The blood sample will be professionally handled and shipped to (Center For Laboratory Services) one of the largest and most respected laboratories in the country. Each HIV test result will be held confidentially and transferred to (SAMI) a respected counselling company staffed with physicians who will professionally contact and counsel any positive test result. All negative HIV test results will be held confidentially and transferred directly to National Health Registry for the purpose of registering only the HIV negative test results into our "Registry Service" along with the exact date of the HIV test.

OPTION II: COST $50.00- *(Includes HIV test and entry into the "Registry Service" with a negative test result).*

YOU WILL BE TESTED AT A PARTICIPATING PARAMEDICAL TESTING FACILITY NEAR YOU.

If you choose this option we will send you a requisition form listing all of the participating testing facilities in your area. By simply presenting the requisition form at any of the listed locations will entitle you to receive an HIV test at no additional charge. Any HIV positive tested person will be contacted and counselled the same as in Option I. All negative HIV test results will be held confidentially and transferred directly to National Health Registry for the purpose of registering only the HIV negative test results into our "Registry Service" along with the exact date of the HIV test.

OPTION III: COST $25.00- *(Does not include HIV test)*

THIS OPTION INCLUDES ENTRY INTO THE "REGISTRY SERVICE" ONLY WITH A NEGATIVE HIV TEST RESULT.

You can choose to be tested for HIV by your personal doctor or a testing facility of your choice at your own expense. If you choose to be tested on your own it is important to make sure the doctor or testing facility you choose can and will test you 'confidentially' not 'anonomously'. You must request for the facility to place your full name and address directly on the test form. When you choose this option you will receive a "Register Kit" containing all of the needed information and a medical release form that will enable us to obtain and verify the negative HIV test result. With a negative HIV test result we will enter you into our "Registry Service" along with the exact date of the HIV test.

SOME PEOPLE SAY

" I DON'T NEED THIS "

REGISTRY SERVICE

" BECAUSE I WILL JUST BE TESTED TOGETHER WITH MY NEW PARTNER WHEN I MEET THEM "

THE FACT IS; *The awkwardness of mentioning that you both be tested together, along with the inconvenience of making an appointment that agrees with both of your schedules, and then actually arranging to be tested when the relationship is new and just beginning,* USUALLY IS NOT THE CASE! *This "Registry" takes the awkwardness out of asking and puts the words in your mouth for you. This gives you an unawkward unoffensive way to suggest that you both find out each others* HIV test status BEFORE ANYTHING ELSE!

YOU DO NEED THIS "REGISTRY SERVICE"!

" COMMON MYTH "

Many people mistakenly think that if you are infected with HIV, *an* HIV *test may not detect the* AIDS *virus for years.*

THAT IS ABSOLUTELY FALSE!

ACCORDING TO THE CDC

According to the CDC *(Center For Disease Control)* "ALMOST ALL PEOPLE WHO ARE INFECTED WITH HIV WILL DEVELOP THE HIV ANTIBODIES AND TEST POSITIVE WITHIN 2 TO 12 WEEKS FROM THE POINT OF INFECTION". *In rare cases it can take as long as six months to detect from the point of infection. It is almost* UNHEARD OF *for the virus to go undetected by an* HIV *test longer than six months.*

TEN YEARS TO PRODUCE SYMPTOMS!

People confuse the fact that once someone is infected with the HIV *virus, it will likely take up to ten years or more to develop into "full blown* AIDS". FULL BLOWN AIDS IS GENERALLY WHEN SYMPTOMS FIRST OCCUR THAT PROMPT THE PERSON TO FINALLY GET TESTED AND THEN THEY ARE FINALLY DIAGNOSED. *Before an* HIV *infected person gets tested or finally gets sick, there is simply no sign to warn them they are* HIV *positive! For this reason, during that long period of time that person will unknowingly expose any sexual partner to the* HIV *virus!*

THREE EASY STEPS TO REDUCE YOUR RISK:

1.) TEST — YOU GET TESTED OR LET US ARRANGE CONVENIENT TESTING FOR YOU.

2.) REGISTER — ONCE WE VERIFY YOUR NEGATIVE HIV TEST RESULT, WE WILL AUTOMATICALLY REGISTER YOU INTO OUR "REGISTRY SERVICE".

3.) VERIFY — CALL TO VERIFY THAT YOUR PARTNER HAS TESTED NEGATIVE FOR THE HIV VIRUS AND THE EXACT DATE OF THEIR MOST RECENT TEST PRIOR TO ANY SEXUAL CONTACT.

To further reduce your risk: inquire about their recent sexual history and suggest they re-test and re-register if they have been sexually active with someone who has not recently tested negative for the HIV virus, or is not currently "Registered".

CONDOM USE

In order to maximize your protection against the HIV virus, it is highly recommended that you continue to use latex condoms while participating with this "Registry Service"! However we should also inform you that condoms alone are not sufficient protection because of the reported risk of condom breakage, leakage, and improper use. It is substantially safer to use a condom with someone who you know has tested negative for the HIV virus, as opposed to using a condom with someone who has not tested at all with the risk and possibility of having the condom fail in any way.

YOU CAN NOW CHECK YOUR PHYSICIANS OR DENTISTS HIV TEST STATUS

You can now easily check to see if your physician or dentist is "registered" with the NHR. Physicians and dentists all across the country are registering their HIV test result in order to ease their patients and potential patients fear that they may be infected with HIV in this manner. IT IS SIMPLE AND FREE TO CALL AND CHECK THIS INFORMATION! SIMPLY CALL (1-800-NEGATIVE), (1-800-634-2848) and enter any physicians or dentists complete ten digit telephone number.
(If your doctor is not yet "Registered", it is possible they are not aware that this service is now available. Please inform them and request that they "Register"!

"AIDS"

THE FRIGHTENING THING IS:

The nature of AIDS is such that most infected people are not aware that they have been exposed to HIV, in many cases they may go ten years or more before they start having symptoms, or finally get sick and finally get tested.

When AIDS was discovered in the United States in 1981, only a few cases were reported and confirmed. The numbers have continued to rise month by month, year by year in FRIGHTENING proportions.

It is truly frightening to think that there is a massive number of americans that have ABSOLUTELY NO IDEA THEY ARE INFECTED WITH THE HIV VIRUS.

And since it takes so long to produce symptoms that will finally prompt a person to get tested, each person out of that massive number of americans may go many years probably infecting other people who also may go many years probably infecting other people and so on. It is a form of geometric progression where the numbers can keep doubling, or growing geometrically. For example, when 10,000 infected people each only infect 1 person that number doubles to 20,000 people. Again, each one of those people infect just one person the number doubles again to 40,000 people, then to 80,000, then to 160,000, to 320,000, to 640,000, to 1,280,000, to 2,560,000 to 5,120,000, to 10,240,000, you get the idea. The numbers will keep growing geometrically until something is done to stop it. How long will it take to reach you? MUCH SOONER THAN YOU THINK!!

Keep in mind that this is happening to people without their knowing it!!!

Because of this it is extremely difficult to even begin to predict the number of people who are presently infected and more disturbingly how many more people will go on to be unknowingly infected!

Aids is already a leading killer of men and women ages 15 to 44 in this country.

As reported in the Surgeon Generals Report To The American Public On HIV And Aids, "about 1 american out of every 250 is currently infected with the HIV virus", and these are only the figures reflecting the people who have actually taken an HIV test and tested positive. It is anyones FRIGHTENING guess what the true numbers of HIV positive people really are!

ANOTHER TROUBLING TREND:

Teenagers seem to think they are not as at risk because they do not see many of their friends sick, but the fact is most people being diagnosed now are in their 20s and early 30s, that means the majority of those people were teenagers when they were infected.

NATIONAL HEALTH REGISTRY
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EACH AND EVERY PERSON WHO CHOOSES TO PARTICIPATE WITHIN THIS "REGISTRY SERVICE" WILL BE REQUIRED TO SIGN AND AGREE TO THE FOLLOWING DISCLAIMER STATEMENT PRIOR TO ANY PARTICIPATION WHAT SO EVER.

DISCLAIMER STATEMENT

I agree not to hold National Health Registry or any of its officers, directors, employees or agents, including specifically any third party with whom it may contract to perform any portion of the functions of the Registry Service (collectively "the Registry") responsible or legally liable should I become HIV positive while participating in the Registry Service and further agree to indemnify and hold harmless the Registry from any claims by myself or others arising out of myself or others becoming HIV positive.

P.O. Box 350510 • Ft. Lauderdale, FL 33335-0510 • Fax Number (305) 766-8470

NATIONAL HEALTH REGISTRY

to Prevent AIDS

I (800) HALT-HIV

This "Registry Service" program has been designed with limiting liability as our first priority and concern.

Each and every person who registers with our "Registry Service" will receive our information brochure (enclosed for review) which informs in detail and is unmistakable that this "Registry Service" cannot guarantee protection against HIV infection. Our claims are clear that participating with this service will only reduce a persons chance of becoming infected with HIV.

Before any person is permitted to participate with our "Registry Service" they are required to sign a disclaimer statement form that will be kept on file with the National Health Registry. In addition, when a registered member calls to check and verify the negative HIV test result of another NHR registered member, the announcement will remind and inform them that "this negative HIV test result cannot guarantee that the person tested is currently free of HIV".

This program permits and encourages each member to update their negative HIV test result as often as they want or feel they need to, which is important because it puts the responsibility of letting each registered member decide if the test date of their potential sexual partners HIV test is current enough. They can now make their decision of whether or not to become sexually active with that person based on how current the test is, or they can request for that person to re-test and re-register in order to up-date the test information to be more current. In effect, each person will control their own degree of risk. However, the NHR requires each member to up-date their negative HIV test result initially after six months and there after at least every twelve months.

Through our information brochure, which each and every member receives, they are instructed to use condoms while participating within this "Registry Service". They are also instructed to use caution and inquire about a potential partners sexual history at least since their last recent negative HIV test. They are further directed not to make the decision to engage in a sexual relationship based solely on the information they receive from this "Registry Service".

It is important to note that the National Health Registry will only permit NHR registered members to participate with our "Registry Service". Only NHR registered members can receive verification of another registered members negative HIV test result information. This enables us to inform each and every participant properly and also enables us to obtain from each participant a disclaimer statement signature. In order for a person to access test information from our verification service, all callers will be instructed that they must first enter in their own identification number and then the identification number of the person they wish to check and verify. The announcement will instruct the caller to hang up if they are not an NHR registered member.

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This program does not permit any of the general public who are not registered with the NHR to participate or to call and verify any NHR members test information which eliminates the liability that would be incurred by having people participate who were not informed properly, as well as eliminating the liability from not being able to obtain a signed disclaimer statement on file from each participant.

Registered members will be the only people participating within this program who will be very well informed of the facts and their remaining risk that is beyond our control while participating within this "Registry Service".

Because of the enormous economic strain caused by AIDS to many facets of our society especially the insurance industry due to increased health care and life insurance claims. This program represents a windfall and sure salvation for many of the effected companies, as well as the american public who ultimately has to pay for the rising cost of premiums. AIDS will surely be the economic downfall of this country if not stopped soon!

Because of the intentional structure of this program and the close attention paid to limiting the liability involved, the actual risk in liability is far less than may initially appear.

Please take your time to study and understand all aspects of this program.

Direct questions and comments to Mr. Kenneth N. Cosentino at (305)523-7479

Sincerely,

Mr. Kenneth N. Cosentino
President

P.O. Box 350510 • Ft. Lauderdale, FL 33335-0510 • Fax Number (305) 766-8470

THE WHITE HOUSE

WASHINGTON

March 15, 1994

W. J. Comey
37 Bridgeport Street
Dana Point, California 92629

Dear W. J. Comey:

Thank you for writing me with your comments. It is important for people to realize that HIV is not spread solely through gay male sexual intercourse. HIV is spread by people of all sexual orientations during unprotected sexual intercourse and through the sharing of needles by injecting drug use. In fact, the fastest rising rate of HIV infection is among heterosexual women.

HIV and AIDS affects everyone, not just one segment of the population. We must all work together to put an end to this epidemic. One step in that work is to educate people on ways to protect themselves against contracting HIV. That means spending money on education programs and public relations efforts to teach people about HIV, abstinence, and safer sex practices. I believe money spent to save lives is money well spent.

Thank you again for your comments.

Sincerely,

Kristine Gebbie

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

we have kick
similar - pull
for reply

January 9 94

Ms Czar

Look,

You eliminate drunk driving accidents by not driving while drinking.

You reduce lung cancer deaths by not smoking.

You reduce heart attack risk by limiting fat intake.

And you end the risk of AIDS by ending sex between males. (Not by emptying the national treasury)

Is that so complicated?

WJ Comey

37 Bridgeport St
Dana Point CA 92629

PS Enclosed a copy of the article on you in a recent addition of the local paper. You can add it to your scrapbook.

Focus on Health
THE ORANGE COUNTY REGISTER FRIDAY, JAN. 28, 1994

Acting against AIDS

PEOPLE: AIDS czar Kristine Gebbie says she's determined to focus on 'realism,' despite criticism from activists.

By PATRICIA ANSTETT
Knight-Ridder Newspapers

They still haven't put out the welcome mat for Kristine Gebbie.

They may never.

Not with more than 204,000 Americans dead of AIDS and 340,000 more diagnosed with the disease.

Not with an uncertain, if not gloomy, national mood.

Not with the lack of a cure or even a treatment breakthrough.

Many people on the front lines of the epidemic are too concerned with who she is — and isn't.

"To the very active AIDS advocacy groups, particularly those on the East Coast, I'm an uninfected, straight white woman from the Northwest," said Gebbie, the nation's first federal coordinator on acquired immune deficiency syndrome.

"How could I possibly be their hero in this epidemic?"

Gebbie, a nurse and former chief of the state health departments in Oregon and Washington, knows she wasn't President Clinton's first choice for the job.

"I was the last one standing," she has said of her appointment five months ago. Most recently, she served as chairwoman of an AIDS advisory panel for the federal Centers for Disease Control and Prevention in Atlanta.

Still, she's excited about the possibility of changing the course of the AIDS response, which she says was often poorly navigated during 12 years of Republican leadership.

"I would never have been here in the Bush or Reagan administration. They weren't interested in AIDS," she said.

Gebbie's evidence that the Clinton administration cares about AIDS includes:

- A soon-to-be appointed federal AIDS research coordinator, a new position.
- A new requirement that federal employees receive AIDS prevention and awareness training.
- An initiative to get each federal agency to do more about AIDS, such as encouraging more young children to pursue research careers.
- Millions more dollars proposed for AIDS research and treatment. About $227 million more is proposed for research, bringing the total to $1.3 billion, and a $300 million increase is proposed for treatment.

Gebbie, who is pursuing a doctorate at the University of Michigan School of Public Health, heads an office of 30 people, five of whom, including herself, have White House office space. She sits in on Cabinet meetings and says she has the president's ear frequently.

Knight-Ridder Tribune

CLINTON'S AIDS CZAR: Kristine Gebbie, the nation's first federal AIDS coordinator, has developed the first federally funded public-service ads to mention condoms.

Ask AIDS activists how Gebbie is doing and the answers vary widely.

"She's a very wise, seasoned bureaucrat," said Randy Pope, who directs AIDS programs for Michigan's Health Department — the closest thing the state has to an AIDS czar. He asks others to give her time and not blame her for "all the things not done in the last 10 years."

Jeff Levi, director of public policy for the AIDS Action Foundation, a Washington, D.C., group, faults Gebbie for not developing a national strategic AIDS plan or setting up, as promised, an AIDS advisory committee.

He also found disappointing her recent comments in a New York Times Magazine interview that "part of her mission ... is to help people keep their expectations within reality."

"There's some disappointment in her not reaching far enough," Levi said. "For a community waiting so long for an appropriate and compassionate response to the epidemic, it's disappointing to hear the point person in the administration talk about lowering expectations, rather than rolling up our sleeves and doing as much as we can, as quickly as we can."

Gebbie takes the heat in stride, including criticism of her remarks about expectations. In fact, she said, others praised her "sense of realism."

"I really believe in hope ... but I think false hope is a delusion," she said.

She says she's making progress on setting up a 21-person advisory committee, noting that starting such a committee in less than a year is considered "something just less than a miracle" by die-hard federal bureaucrats.

She has plans, too, to issue a strategic plan, though she adds, "I don't want my office to turn into someplace that just prints plans ... the kind that take a year to write and then they sit there."

"The question is, is she tough enough?" Pope said. "I hope so. The issue is, you have to separate the personal attacks from the professional attacks.

"I don't think Kristine is the problem. I think there still is a lot of denial in the Cabinet" that keeps the Clinton administration from more forcefully addressing such issues as condom distribution at schools, gays in the military and other issues, he said. "To a certain extent she's playing a difficult balancing act that's not well understood by the activists."

Gebbie, meanwhile, remains focused on the future.

She has high hopes for a new federal task force to coordinate AIDS research, and another intercompany pharmaceutical effort to share information on AIDS drugs.

"We've got to break through the denial," she said. "People come up with a thousand and one ways not to admit to the reality of this disease and not to admit to the reality of adolescent sexuality. What I've said is, the fight about condoms is the wrong fight to have. Just handing someone a condom in no way ensures they know when and why to use it, or they'll feel empowered enough to see that it is used.

"The debate has to be at a much earlier stage. If you are a 13-year-old with surging hormones, what do you need to know about your bod? What do you need to know about this thing called sex? What do you need to know about your eventual sexuality as an adult that might help you with some healthy decisions while you are still a teen-ager?"

KRISTINE GEBBIE

AGE: 50

PERSONAL: Divorced, has children, 23, 20 and 17. Walks three to four miles each morning. Likes to read, mostly mysteries. Enjoys knitting, going to the theater, visiting museums.

PROFESSION: Registered nurse.

PREVIOUS JOBS: Vice president of St. Louis University Hospitals; state health department chief in Oregon and Washington; teacher at universities in Missouri, Oregon and Washington.

VOLUNTEER DUTIES: Has served on numerous federal AIDS advisory committees, as well as the executive board of the American Public Health Association; member of the federal Institute of Medicine, a prestigious research agency.

EDUCATION: Bachelor of Science nursing degree, St. Olaf College, Minnesota; master of nursing degree, University of California School of Nursing, Los Angeles; now completing a doctorate in public health.

DISSERTATION: A case study of the 1989 reorganization of the state health department in Washington.

Source: Knight-Ridder Tribune

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Jody Huckaby
Bering Community Service Foundation
1440 Harold
Houston, Texas 77006

Dear Mr. Huckaby:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about the Bering Community Service Foundation, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Charles Domingues
President
HIV Service Providers, Inc.
Suite 811
3400 Montrose
Houston, Texas 77006

Dear Mr. Domingues:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about HIV Service Providers, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Chris Jimmerson
Director
Houston Clinical Research Network
Post Office Box 66251
Houston, Texas 77266

Dear Mr. Jimmerson:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about the Houston Clinical Research Network, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Ms. Margo Morris
Executive Director
Omega House
616 Branard
Houston, Texas 77006

Dear Ms. Morris:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about Omega House, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Ms. Claudia Commo
Director of Patient Services
Omega House
616 Branard
Houston, Texas 77006

Dear Ms. Commo:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about Omega House, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Ms. Carolyn Barrett, R.N., B.S.N.
Director
Thomas Street Clinic
2015 Thomas Street
Houston, Texas 77009

Dear Ms. Barrett:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about the Thomas Street Clinic, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Richard Elbein
President of the Board
AVES, Inc.
Suite 100
2510 Broad Street
Houston, Texas 77087

Dear Mr. Elbein:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about AVES, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Ms. Angela Mora
Executive Director
AVES, Inc.
Suite 100
2510 Broad Street
Houston, Texas 77087

Dear Ms. Mora:

Thank you so much for your warm hospitality during my visit to Houston. I appreciated the chance to learn about AVES, and hear of your concerns, hopes, and plans.

My best wishes for your continuing work.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Howard Schell Reilly, Esq.
Director of Litigation
Mid-Hudson Legal Services, Inc.
54 Noxon Street
Poughkeepsie, New York 12601

Dear Mr. Schell Reilly:

Thank you for submitting your recommendation for membership on the President's National HIV/AIDS Advisory Council. Your contribution to the selection process was very helpful.

President Clinton will soon choose an Advisory Council that reflects the diversity of the HIV-affected community, including many people with HIV/AIDS. I hope those not chosen will continue to be a part of our efforts, and I will look for ways to include them.

Again, thank you for taking the time to write me. Your input is always appreciated.

Sincerely,

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

Mid-Hudson
Legal Services, Inc.

Law Offices

Columbia County
389 Fairview Avenue
Hudson, NY 12534

54 Noxon Street / Poughkeepsie, NY 12601 / 914/452-7911
FAX 914/485-7217 / TTY 914/471-8619

Greene County
2 Franklin Street
Catskill, NY 12414

Orange County
700 North Street
Middletown, NY 10940

Sullivan County
21 Hamilton Avenue
Monticello, NY 12701

Ulster County
276 Fair Street
Kingston, NY 12401

January 31, 1994

Ms. Kristine Gebbie, RN
National AIDS Policy Coordinator
Executive Office of the President
The White House
Washington, D.C. 20500

Re: Nomination of William E. Arnold to The Presidential HIV/AIDS Advisory Council

Dear Ms. Gebbie:

I am happy to write in support of William E. Arnold's nomination to the Presidential HIV/AIDS Advisory Council. I have known Bill Arnold since 1986 when we were both volunteers in the ARCS, (AIDS related Community Services of the Hudson Valley, our local AIDS support organization) buddy program which provides direct personal assistance to PWAs. Bill was outstanding in his energy, knowledge and dedication to the clients. He was also an "AIDS Educator" for ARCS organizing and appearing in numerous TV, radio and press appearances to educate people about AIDS and to secure needed services. His resume details the numerous organizing and management activities he has undertaken since then. You could not secure someone for the Advisory Council with a better background and record in the AIDS support field. In the area of AIDS treatment, Bill has an encyclopedic knowledge and has been an important resource for the hospitals and medical practitioners in this area.

Catherine Charuk, Esq.
Executive Director

Howard Schell Reilly, Esq.
Director of Litigation

Most important of all, Bill is a person who has felt the impact of AIDS through the personal support he has given PWAs. He has not "burned out" but has remained an untiring activist. Please give his nomination favorable consideration. If there are questions you wish answered, please do not hesitate to contact me.

Very truly,

Howard Schell Reilly
Director of Litigation

HSR:dh

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Carol Gresser, President
Board of Education
New York City Board of Education
110 Livingston Street
Room 1118
Brooklyn, New York 11201

Dear Ms. Gresser:

I understand that several questions have arisen on the Conference of Peer Educators in which I participated last month. In my view, the conference was very positive. Enclosed is letter that I sent to Ramon Cortines that may be interest to you.

If I can offer additional support or assist to the board in anyway, please let me know.

Sincerely,

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

Enclosure

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Mr. Raymond Bush
5043 West Adams
Chicago, Illinois 60644

Dear Mr. Bush:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

Kristine

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Ms. Geneva Reed
Post Office Box 12566
Chicago, Illinois 60612

Dear Ms. Reed:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Ms. Patricia Pearson Sistrunk
Apartment 602
6000 South Indiana
Chicago, Illinois 60636

Dear Ms. Pearson Sistrunk:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Ms. Kim Jane Curtis
9121 North Cherry
Morton Grove, Illinois 60053

Dear Ms. Curtis:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Ms. Sharon Getman
5226 South Marshfield
Chicago, Illinois 60609

Dear Ms. Getman:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Ms. Karen Smith
Apartment 4
1643 Mulberry Court
Elgin, Illinois 60120

Dear Ms. Smith:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

Kristine

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

THE WHITE HOUSE
WASHINGTON

March 16, 1994

Robert and Cheryl Braddock
Apartment 3-A
85 South Crystal
Elgin, Illinois 60123

Dear Mr. and Ms. Braddock:

Thank you for coming by the Second Family program to meet with me, and tell me your story of living with HIV.

The President and I are committed to helping families through this disease. You have my continuing best wishes.

Sincerely,

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

Child Welfare Services

Open Arms
6525 West North Avenue, Suite 212
Oak Park, Illinois 60302
708/445-8341
Fax: 708/445-8351

Lutheran Social Services of Illinois

March 11, 1994

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

Dear Ms. Gebbie:

Thank you so much for sharing your time with us at LSSI's Second Family program. I'm sure you must have been aware of how much your caring presence meant to these parents. They truly felt as though what they were saying to you might be going to make a difference for someone.

Those of us who work in the program also appreciated the opportunity to meet with you and share our program with you. Thank you for your suggestions regarding ongoing funding. I will contact your office when I am in town next week.

Enclosed is the list of parents who were present at the meeting with their addresses. They were pleased for you to have this information.

Sincerely,

Cathy R. Blanford

CRB:ps

Cathy R. Blanford
Program Director

Robert and Cheryl Braddock
85 S. Crystal, Apt. 3A
Elgin, IL 60123

Karen Smith
1643 Mulberry Ct., Apt. 4
Elgin, IL 60120

Sharon Getman
5226 S. Marshfield
Chicago, IL 60609

Kim Jane Curtis
9121 N. Cherry
Morton Grove, IL 60053

Patricia Pearson Sistrunk
6000 S. Indiana, Apt. 602
Chicago, IL 60636

Geneva Reed
P.O. Box 12566
Chicago, IL 60612

Raymond Bush
5043 W. Adams
Chicago, IL 60644

I think I drafted note to these folks already

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Ms. Cathy Nash, R.N.
Ball High School Primary Care Center
4115 Avenue O
Galveston, Texas 77550

Dear Ms. Nash:

Thank you for taking time to visit with me during my stay in Galveston. I am very impressed by your energy and enthusiasm. Providing health services to teens remains one of our biggest challenges; you appear to have a model that works.

My best wishes to you in your continuing efforts. Please let me know if I can be of any assistance.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Stephen Barnett, M.D.
c/o Ball High School Primary Care Center
4115 Avenue O
Galveston, Texas 77550

Dear Dr. Barnett:

Thank you for taking time to visit with me during my stay in Galveston. I am very impressed by your energy and enthusiasm. Providing health services to teens remains one of our biggest challenges; you appear to have a model that works.

My best wishes to you in your continuing efforts. Please let me know if I can be of any assistance.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

March 16, 1994

Mr. Tom Pevoto
Galveston County Health District
Post Office Box 838
Galveston, Texas 77553

Dear Mr. Pevoto:

Thank you for taking time to visit with me during my stay in Galveston. I am very impressed by your energy and enthusiasm. Providing health services to teens remains one of our biggest challenges; you appear to have a model that works.

My best wishes to you in your continuing efforts. Please let me know if I can be of any assistance.

Sincerely,

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

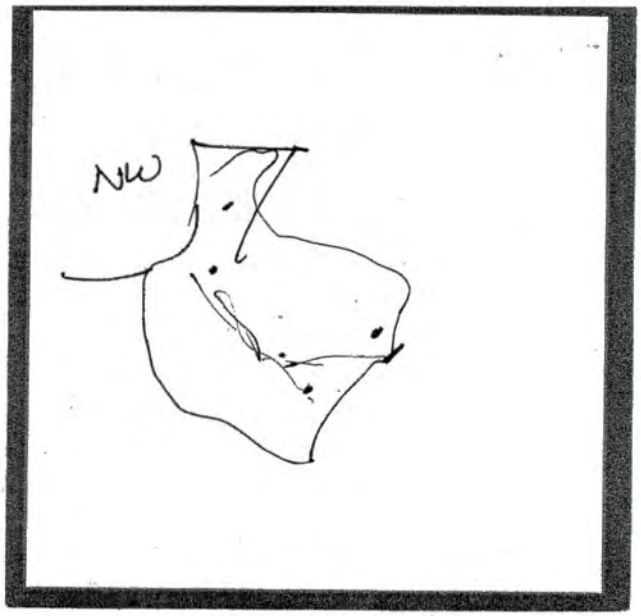
Cathy Nash – Nurse Practitioner

Tom Pevoto Galveston Co. 409-763-8531 Health Dept

Dr. Stephen Barnett UTMB

766-5751

765-2586 Ball HS Primary Care Center 409-766-5800 5700



PHOTOCOPY
PRESERVATION

MAR 16 1994

THE WHITE HOUSE

Jo Anne —

Thanks for the clipping - and for the kind notes. I can't believe how many weeks it has been since you were my taxi!! I hope all is well for you - and I do look forward to another chance to meet — Kristine Gebbie

MARCH 8, 1994

DEAR MS. GEBBIE,

RECENTLY I CAME ACROSS THIS ARTICLE WHICH I HAD MEANT TO SEND EARLIER. FROM OUR CONVERSATION IN DALLAS, I AM CONVINCED THAT YOU WILL CONTINUE TO PRESS THE AIDS AGENDA TO THE FOREFRONT. UNFORTUNATELY, BEING INVOLVED WITH AIDS BRINGS CRITICISM TO

OVER.

EACH OF US. AT THE SAME TIME, I AM CONVINCED OF YOUR CONCERN, SCOPE OF THE HEALTH CRISIS AND DETERMINATION TO AFFECT PUBLIC POLICY.

KEEP UP THE GOOD WORK. IF YOU RETURN TO DALLAS/FT. WORTH, PLEASE KNOW THAT I WILL GLADLY MEET YOU AT THE AIRPORT, AGAIN.

CORDIALLY, JoANNA KESSLER

Fighting one battle at a time

Kristine Gebbie is the lightning rod in the crusade against AIDS

By Patricia Anstett
Knight-Ridder Newspapers

They still haven't put out the welcome mat for Kristine Gebbie.

They may never.

Not with more than 204,000 Americans dead of AIDS and 340,000 more diagnosed with the disease.

Not with an uncertain, if not gloomy, national mood.

Not with the lack of a cure or even a treatment breakthrough.

Many people on the front lines of the epidemic are too concerned with who she is — and isn't.

"To the very active AIDS advocacy groups, particularly those on the East Coast, I'm an uninfected, straight white woman from the Northwest," says Ms. Gebbie, the nation's first federal AIDS coordinator.

"How could I possibly be their hero in this epidemic?"

Ms. Gebbie, a nurse and former chief of the state health departments in Oregon and Washington, knows she wasn't even President Bill Clinton's first choice for the job.

"I was the last one standing," she has said of her appointment four months ago. Most recently, she served as chairwoman of an AIDS advisory panel for the federal Centers for Disease Control and Prevention.

Still, she's excited about the possibility of changing the course of the AIDS response that she says was often poorly navigated during 12 years of Republican leadership.

"I would never have been here in the Bush or Reagan administration. They weren't interested in AIDS," she says flatly.

Ms. Gebbie's evidence that the Clinton administration cares about AIDS includes:

- A soon-to-be appointed federal AIDS research coordinator, a new position.
- A new requirement that federal employees receive AIDS prevention and awareness training.
- An initiative to get each federal agency to do more about AIDS, such as encouraging more young children to pursue research careers.
- Millions more proposed for AIDS research and treatment. About $227 million more is proposed for research,bringing the total to $1.3 billion, and a $300 million increase is proposed for treatment, for a $550 million total.
- The first federally funded public service ads to mention condoms will be unveiled soon by CDC. The campaign, first scheduled to kick off this week, now is tentatively scheduled for Jan. 4.

"The ads will be very different than anything you've ever seen before," Ms. Gebbie promises. "They reflect the changes we're going through here.

"I just didn't sign up to fill space, to fill air time," she says in a recent interview in Ann Arbor, Mich., before addressing the University of Michigan School of Public Health, where she is pursuing a doctorate.

"There definitely are some things that happen differently in government because there is an AIDS coordinator at the White House."

She heads an office of 30 people, five of whom, including herself, have White House office space. She sits in on Cabinet meetings and says she frequently has the president's ear.

Ask AIDS activists how Ms. Gebbie is doing, and the answers vary widely.

"She's a very wise, seasoned bureaucrat," says Randy Pope, who directs AIDS programs for Michigan's Health Department — the closest thing the state has to an AIDS czar. He asks others to give her time and not blame her for "all the things not done in the last 10 years."

Jeff Levi, director of public policy for the AIDS Action Foundation, a Washington, D.C., group, faults Ms. Gebbie for not developing a national strategic AIDS plan or setting up, as promised, an AIDS advisory committee.

He also found disappointing her recent comments in a *New York Times Magazine* interview that "part of her mission . . . is to help people keep their expectations within reality."

"There's some disappointment in her not reaching far enough," Mr. Levi says. "For a community waiting so long for an appropriate and compassionate response to the epidemic, it's disappointing to hear the point person in the administration talk about lowering expectations, rather than rolling up our sleeves and doing as much as we can, as quickly as we can."

Ms. Gebbie takes the heat in stride, including

Please see GEBBIE on Page 16C.

Kristine Gebbie is the nation's first federal AIDS coordinator.

Gebbie takes criticism in stride in AIDS job

Continued from Page 5C.

criticism of her remarks about expectations. In fact, she says, others praised her "sense of realism."

"I really believe in hope . . . but I think false hope is a delusion," she says.

She says she's making progress on setting up a 21-person advisory committee, noting that starting such a committee in less than a year is considered "something just less than a miracle" by die-hard federal bureaucrats.

She also intends to issue a strategic plan, though she adds: "I don't want my office to turn into some place that just prints plans . . . the kind that take a year to write, and then they sit there."

Ms. Gebbie, 50, seems steely enough for the challenge. She seems unconcerned that one AIDS activist described her as "Snow White." It doesn't seem to bother her that people have remarked on her "air of a head nurse," her erect posture, her suits and "precise and proper answers."

Might there be some sexism here? she is asked. "I don't have a very good sexism monitor," she says. "I just try to do my job."

Nor does she want to be described as a single mother, though she has been divorced for about five years and has three children, two of whom are grown; the youngest lives in Oregon with his father.

Back in the Northwest in her state health jobs, Ms. Gebbie earned a reputation as feisty and hardheaded, not the consensus builder she now must be.

Once, she followed Oregon Gov. Neil Goldschmidt to the men's room and waited outside to give him a framed AIDS poster she had printed without his permission, though she'd been told to get his approval for all promotions. "Good boys always wear their rubbers," the caption read.

Another time, on a Labor Day weekend in a tourist town crowded with visitors, she shut off the water supply when fecal material was found, rankling the area's well-heeled crowd.

"The question is, is she tough enough?" Mr. Pope says. "I hope so. The issue is, you have to separate the personal attacks from the professional attacks.

"I don't think Kristine is the problem," he says, adding, "I think there still is a lot of denial in the Cabinet" that keeps the Clinton administration from more forcefully addressing such issues as condom distribution at schools, gays in the military and other issues. "To a certain extent she's playing a difficult balancing act that's not well understood by the activists," he says.

Ms. Gebbie, meanwhile, remains focused on the future.

She has high hopes for a new federal task force to coordinate AIDS research and an inter-company pharmaceutical effort to share information on AIDS drugs. She plans to meet with church groups and others to push prevention programs.

"We've got to break through the denial," she says. "People come up with a thousand and one ways not to admit to the reality of this disease and not to admit to the reality of adolescent sexuality. What I've said is, the fight about condoms is the wrong fight to have. Just handing someone a condom in no way ensures they know when and why to use it, or they'll feel empowered enough to see that it is used.

"The debate has to be at a much earlier stage. If you are a 13-year-old with surging hormones, what do you need to know about your bod? What do you need to know about this thing called sex? What do you need to know about your eventual sexuality as an adult that might help you with some healthy decisions while you are still a teen-ager?"

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Neal F. Lane, Ph.D.
Director
National Science Foundation
4201 Wilson Boulevard
Arlington, VA 22203

Dear Dr. Lane:

The Office of National AIDS Policy has established as a primary goal to maximize our Nation's investment in the search for better treatments and better prevention methodologies for HIV/AIDS. As a part of this effort, I have directed my staff to prepare a "Compendium of Federal HIV/AIDS Research Programs." This compendium will summarize all biomedical, behavioral and resource programs in HIV/AIDS research funded in whole or in part by the Federal Government. We hope the completed compendium can be cross-referenced in a way that will enable all agencies to take better advantage of opportunities for improved coordination.

Please provide the following information for your agency:

1. A short summary of any on-going or planned HIV-related research programs, categorized by "area of emphasis," as in the "National Institutes of Health Five-Year Plan for HIV-Related Research" (enclosed). If no intramural or extramural research is funded by your agency in any category listed below, please so indicate.

   Scientific:
   - Natural History and Epidemiology
   - Etiology and Pathogenesis
   - Therapeutics
   - Vaccines
   - Behavioral Research

   Resource:
   - Training and Infrastructure
   - Dissemination of Research Findings

2. Estimated annual HIV/AIDS research budget for your

agency for fiscal years 1993 through 1995. Please indicate percentages of intramural and extramural funding, and percentages of funding awarded to private nonprofits (universities), private industry, and foreign agencies. When possible, please provide budget information categorized by above areas of emphasis.

3. Current contact information for coordinators of HIV/AIDS research programs for each relevant area of emphasis in your agency.

4. A listing of existing or planned inter-agency and inter-departmental collaborations, and a description of current planning mechanisms for establishing inter-agency collaborations (note area of emphasis if applicable).

5. A complete listing of external advisory committees chartered in whole or in part to provide consultation on planning and evaluation of HIV/AIDS research programs, or to review grant or contract applications. Please include the name and telephone number of the executive secretary or other contact for each committee (note area of emphasis if applicable).

Use existing materials where possible. Please send this information by COB April 25 to:

HIV/AIDS Research Program
Office of the National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20503

The Compendium of Federal HIV/AIDS Research Programs should be helpful to all agencies in planning and evaluating related activities. Copies of the completed compendium will be provided to your agency. For additional information, please contact Mr. Terry Beswick at (202) 690-5560. Internet: TBESWICK@OASH.SSW.DHHS.GOV.

A similar letter is being sent to all relevant Federal departments and independent agencies.

Thank you for your cooperation.

Sincerely,

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Elaine Johnson, Ph.D.
Acting Administrator
Substance Abuse and Mental Health Services Administraton
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Johnson

The Office of National AIDS Policy has established as a primary goal to maximize our Nation's investment in the search for better treatments and better prevention methodologies for HIV/AIDS. As a part of this effort, I have directed my staff to prepare a "Compendium of Federal HIV/AIDS Research Programs." This compendium will summarize all biomedical, behavioral and resource programs in HIV/AIDS research funded in whole or in part by the Federal Government. We hope the completed compendium can be cross-referenced in a way that will enable all agencies to take better advantage of opportunities for improved coordination.

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   - Therapeutics
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   - Behavioral Research

   Resource:
   - Training and Infrastructure
   - Dissemination of Research Findings

2. Estimated annual HIV/AIDS research budget for your

agency for fiscal years 1993 through 1995. Please indicate percentages of intramural and extramural funding, and percentages of funding awarded to private nonprofits (universities), private industry, and foreign agencies. When possible, please provide budget information categorized by above areas of emphasis.

3. Current contact information for coordinators of HIV/AIDS research programs for each relevant area of emphasis in your agency.

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Use existing materials where possible. Please send this information by COB April 25 to:

HIV/AIDS Research Program
Office of the National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20503

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A similar letter is being sent to all relevant Federal departments and independent agencies.

Thank you for your cooperation.

Sincerely,

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Michel E. Lincoln
Acting Director
Indian Health Service
5600 Fishers Lane
Rockville, MD 20857

Dear Mr. Lincoln:

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   - Dissemination of Research Findings

2. Estimated annual HIV/AIDS research budget for your

agency for fiscal years 1993 through 1995. Please indicate percentages of intramural and extramural funding, and percentages of funding awarded to private nonprofits (universities), private industry, and foreign agencies. When possible, please provide budget information categorized by above areas of emphasis.

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Use existing materials where possible. Please send this information by COB April 25 to:

HIV/AIDS Research Program
Office of the National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20503

The Compendium of Federal HIV/AIDS Research Programs should be helpful to all agencies in planning and evaluating related activities. Copies of the completed compendium will be provided to your agency. For additional information, please contact Mr. Terry Beswick at (202) 690-5560. Internet: TBESWICK@OASH.SSW.DHHS.GOV.

A similar letter is being sent to all relevant Federal departments and independent agencies.

Thank you for your cooperation.

Sincerely,

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Ronald H. Brown
Secretary of Commerce
14th Street & Constitution Avenue, N.W.
Washington, D.C. 20230

Dear Mr. Secretary:

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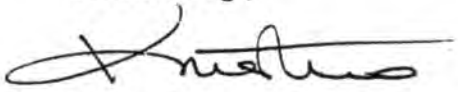

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Ciro Sumaya, M.D., Ph.D.
Administrator
Health Resources and Services Administration
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Sumaya:

The Office of National AIDS Policy has established as a primary goal to maximize our Nation's investment in the search for better treatments and better prevention methodologies for HIV/AIDS. As a part of this effort, I have directed my staff to prepare a "Compendium of Federal HIV/AIDS Research Programs." This compendium will summarize all biomedical, behavioral and resource programs in HIV/AIDS research funded in whole or in part by the Federal Government. We hope the completed compendium can be cross-referenced in a way that will enable all agencies to take better advantage of opportunities for improved coordination.

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable David Kessler, M.D.
Commissioner
Food and Drug Administration
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Kessler:

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Sincerely,

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable David Satcher, M.D., Ph.D.
Director
Centers for Disease Control and Prevention
1600 Clifton Road, N.E.
Atlanta, GA 30333

Dear Dr. Satcher:

The Office of National AIDS Policy has established as a primary goal to maximize our Nation's investment in the search for better treatments and better prevention methodologies for HIV/AIDS. As a part of this effort, I have directed my staff to prepare a "Compendium of Federal HIV/AIDS Research Programs." This compendium will summarize all biomedical, behavioral and resource programs in HIV/AIDS research funded in whole or in part by the Federal Government. We hope the completed compendium can be cross-referenced in a way that will enable all agencies to take better advantage of opportunities for improved coordination.

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable John H. Gibbons
Director
Office of Science and Technology Policy
OEOB
Washington, D.C. 20500

Dear Mr. Gibbons:

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Daniel S. Golldin
Administrator
National Aeronautics and Space Administration
400 Maryland Avenue, S.W.
Washington, DC 20546

Dear Mr. Golldin:

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable J. Brian Atwood
Administrator
U.S. Agency for International Development
320 21st Street, N.W.
Washington, DC 20523

Dear Mr. Atwood:

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Jesse Brown
Secretary of Veterans Affairs
801 I Street, N.W.
Washington, DC 20001

Dear Mr. Secretary:

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Robert B. Reich
Secretary of Labor
200 Constitution Avenue, N.W.
Washington, D.C. 20210

Dear Mr. Secretary:

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable Hazel R. O'Leary
Secretary of Energy
1000 Independence Avenue, S.W.
Washington, DC 20585

Dear Madam Secretary:

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HIV/AIDS Research Program
Office of the National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20503

The Compendium of Federal HIV/AIDS Research Programs should be helpful to all agencies in planning and evaluating related activities. Copies of the completed compendium will be provided to your Departmen. For additional information, please contact Mr. Terry Beswick at (202) 690-5560. Internet: TBESWICK@OASH.SSW.DHHS.GOV.

A similar letter is being sent to all relevant Federal departments and independent agencies.

Thank you for your cooperation.

Sincerely,

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

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

The Honorable William J. Perry
Secretary of Defense
The Pentagon
Washington, D.C. 20301

Dear Mr. Secretary:

The Office of National AIDS Policy has established as a primary goal to maximize our Nation's investment in the search for better treatments and better prevention methodologies for HIV/AIDS. As a part of this effort, I have directed my staff to prepare a "Compendium of Federal HIV/AIDS Research Programs." This compendium will summarize all biomedical, behavioral and resource programs in HIV/AIDS research funded in whole or in part by the Federal Government. We hope the completed compendium can be cross-referenced in a way that will enable all agencies to take better advantage of opportunities for improved coordination.

Please provide the following information for each agency within your Department:

1. A short summary of any on-going or planned HIV-related research programs, categorized by "area of emphasis," as in the "National Institutes of Health Five-Year Plan for HIV-Related Research" (enclosed). If no intramural or extramural research is funded by an agency in any category listed below, please so indicate.

   Scientific:
   - Natural History and Epidemiology
   - Etiology and Pathogenesis
   - Therapeutics
   - Vaccines
   - Behavioral Research

   Resource:
   - Training and Infrastructure
   - Dissemination of Research Findings

2. Estimated annual HIV/AIDS research budget for each

agency for fiscal years 1993 through 1995. Please indicate percentages of intramural and extramural funding, and percentages of funding awarded to private nonprofits (universities), private industry, and foreign agencies. When possible, please provide budget information categorized by above areas of emphasis.

3. Current contact information for coordinators of HIV/AIDS research programs for each relevant area of emphasis in each agency.

4. A listing of existing or planned inter-agency and inter-departmental collaborations, and a description of current planning mechanisms for establishing inter-agency collaborations (note area of emphasis if applicable).

5. A complete listing of external advisory committees chartered in whole or in part to provide consultation on planning and evaluation of HIV/AIDS research programs, or to review grant or contract applications. Please include the name and telephone number of the executive secretary or other contact for each committee (note area of emphasis if applicable).

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National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

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March 17, 1994

The Honorable Richard W. Riley
Secretary of Education
400 Maryland Avenue, S.W.
Washington, DC 20202

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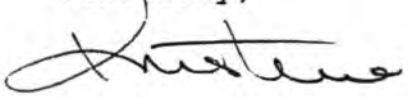

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Enclosure

THE WHITE HOUSE

WASHINGTON

March 17, 1994

Lori DeLorenzo, M.S.N., R.N.
Northern Virginia HIV Resource &
Consultation Center
2832 Juniper Street
Fairfax, Virginia 22031

Dear Ms. DeLorenzo:

Thank you for the invitation to attend the "HIV -- Meeting the Challenge: Prevention and Health Maintenance Strategies" on May 24, 1994. Unfortunately, my schedule does not permit me to participate. If you need suggestions for other speakers, or if I can assist in some other way, please let me know.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

40

December 28, 1993

Lori DeLorenzo, M.S.N., R.N.
Northern Virginia HIV Resource &
Consultation Center
2832 Juniper Street
Fairfax, VA 22031

Dear Ms. DeLorenzo:

Thank you for your invitation for Kristine M. Gebbie, National AIDS Policy Coordinator, to speak at the "HIV-Meeting the Challenge: Prevention and Health Maintenance Strategies" conference, May 24-25, 1994 at George Mason University. Your request is under consideration and I will contact you at least sixty (60) days prior to the event as to Ms. Gebbie's availability.

Thank you for your interest and patience.

Sincerely,

W. Steve Lee

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

FAIRFAX HOSPITAL
INOVA HEALTH SYSTEM

Office of HIV Services
2832 Juniper Street
Fairfax, Virginia 22031
703 204-3780
800 828-4927
FAX 703 204-3798

December 14, 1993

Steve - possible ?

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

Dear Ms. Gebbie:

It was a pleasure meeting you at the Mid-Atlantic AIDS Education and Training Advisory Committee on December 8, 1993 at the Jefferson Hotel in Richmond, VA. Your thoughts and comments were very encouraging and I look to the opportunity to once again hear you speak.

I would like to formally invite you to be the keynote speaker for our annual spring conference which is being held May 24 and 25, 1994 at George Mason University in Fairfax, Virginia. The conference entitled "HIV-Meeting the Challenge: Prevention and Health Maintenance Strategies" targets approximately 300 physicians, nurses, social workers, health educators, mental health therapists and teachers practicing throughout the Mid-Atlantic region. I have enclosed a brochure from last year's conference for you to see the depth of information presented. HCE

I extend an open invitation for you to speak on either day of the conference at a time that is convenient for you. As we are confirming speakers throughout January your prompt response would be appreciated. If you need further information related to the conference, please contact me at 703/204-3790. I look forward to hearing from you soon.

Sincerely,

Lori DeLorenzo

Lori DeLorenzo, MSN, RN
Coordinator
Northern Virginia HIV Resource &
Consultation Center

FAIRFAX HOSPITAL
INOVA HEALTH SYSTEM

Office of HIV Services
2832 Juniper Street
Fairfax, Virginia 22031
703 204-3780
800 828-4927
FAX 703 204-3798

repeats San Antonio but maybe

RECEIVED
FEB 15 1994

February 9, 1994

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

Dear Ms. Gebbie:

Thank you for your kind consideration of my letter of invitation for you to speak at the spring conference, "HIV-Meeting the Challenge: Prevention and Health Maintenance Strategies" in Fairfax County, Virginia on May 24 & 25, 1994.

In my letter, dated December 14, 1993, I offered an open-ending speaking engagement on either May 24th or May 25th. In order to engage other speakers and finalize planning, a specific day and time has been scheduled for your presentation. As the presenter for the opening keynote address, the presentation is scheduled for May 24th from 9:15 am. to 10:15 am. Slight adjustments can be made to the program schedule if you are unable to appear at this period. To make these accommodations I will need to know no later than February 21st.

I have enclosed the tentative agenda for your information. I would like to reiterate that conference attendance will approximate 300 people representing federal, state and local agencies and community based programs.

I look forward to hearing from you in the coming weeks. Should you need further information on the conference, please contact me at (703) 204-3790.

Very truly yours,

Lori DeLorenzo, MSN
Coordinator
Northern Virginia HIV Resource
and Consultation Center

Enc.

HIV

Meeting the Challenge: Prevention & Health Maintenance Strategies

Agenda

George Mason University
Fairfax, Virginia
May 24-25, 1994

May 24, 1994	Activity	Presenter
8:00 am - 9:00 am	Registration/Refreshments	
9:00 am - 9:15 am	Welcome/Opening Remarks	Sharon Brodeur, MPA
9:15 am - 10:15 am	Keynote Address: Health Care Reform and HIV	Kristine Gebbie, MS
10:15 am - 10:30 am	Break	
10:30 am - 12:00 pm	Women's Panel	**Cheryl Nesbitt,** Paula Fenner, Diane O'Koneski, Amalie Zurn Celia Maxwell, MD, Marianne Banzoff
12:00 pm - 1:15 pm	Luncheon Address: New Approach to HIV Education: Ventriloquism	Willy and Woody
1:15 pm - 2:45 pm	Workshop A	
Clinical	1A Early Management of HIV Infection	Lisa Kaplowitz, MD
Adolescents/Pediatrics	2A. Psychosocial Considerations for the HIV-Infected Child and Family	Lori Wiener, PhD

Substance Abuse	3A.	Risk Assessment of the Dually-Diagnosed Client	Kathy Schmidt-Morris, RN, MS, CAAC
Multicultural	4A.	Cultural Diversity Issues	Terry Tafoya, PhD
Psychosocial	5A.	Counseling/Testing Using Myers-Briggs	Henry Masters
Sexuality	6A.	Exploring Your Sexual Values: The Interface Between Your Personal and Professional Worlds	Rebecca Shaw
Education	7A.	How To Talk to College Students About AIDS	Hildegard Richardson
Intensive	8A.	Case Management--Part I	Peggy Beckman, BSN & Dawn Ivener, BSN
	9A.	Complimentary Therapies	Dolores Macklin, OSF
2:45 pm - 3:00 pm	Break		
3:00 pm - 4:30 pm	Workshop B		
Clinical	1B.	Clinical Care of the Gay/Bisexual Client	Enriquez Fernandez, MD
Adolescents/Pediatrics	2B.	Teen Prevention Measures	Bob Warfel
Substance Abuse	3B.	Sex, Drugs & HIV	Kathy Woodward, MD
Multicultural	4B.	HIV and the Latino Community	Britt Ellis, PhD, Rebecca Vargas, MD or Margerita Figueroa, MD (ST)
Psychosocial	5B.	Psychosocial Issues Across the Spectrum of Disease	Fred Boykin, MSW, LICSW
Sexuality	6B.		

Education	7B	
Intensive	8B. Case Management--Part II	Peggy Beckman, BSN & Dawn Ivener, BSN
	9B. Patient Decision-Making	Susan Thorner, MA, Joe O'Neill, MD & Moises Agosto
4:30 - 5:15 pm	Story Telling Ceremony	Terry Tafoya, PhD

May 25, 1994	**Activity**	**Presenter**
8:15 am - 8:45 am	Registration/Refreshments	
8:45 am - 9:45 am	Coping with Multiple Loss	Terry Tafoya, PhD
9:45 - 10:45 am	Plenary Session: TBD	
10:45 am - 11:00 am	Break	
11:00 am - 12:15 pm	Plenary Session: Integrating STDs and HIV	**Jeff Gilbert, MD**
12:15 pm - 1:15 pm	Lunch	
1:15 pm - 2:45 pm	Workshop C	
Clinical	1C. Clinical Manifestations of HIV Disease in Women	Mary Young, MD or Mary Schmidt, MD
Adolescents/Pediatrics	2C. Management of the Pediatric Patient	Eric Moolchan, MD or Tamara Rakusan, MD
Substance Abuse	3C.	

Multicultural	4C.	AIDS Prevention Education Targeted to the African-American Community	Darlene Washington
Psychosocial	5C.	Caring for the Care-Giver	Gayle Crandell Sherman
Sexuality	6C.	Targeting Heterosexual Men for HIV Prevention	Wayne Pawlowski, LCSW
Education	7C.	Model Program for Teens--Pine Bluff, Ark. "Take Charge"	Henry Masters
Intensive	8C.	Closing the Circle: Ceremonies for Health Loss-Part I	Susan Thorner, MA and Kevin Shipman, MA
	9C.	Workplace Issues: Ethical and Personal Perspectives	Steve Rowett, BSN, RN, CCRN
2:45 pm - 3:00 pm	Break		
3:00 pm - 4:30 pm	Workshop D		
Clinical	1D.	MAC & TB	Richard Chaisson, MD or Fred Gordin, MD
Adolescents/Pediatrics	2D.	Is Your Organization Adolescent-Friendly?	Elizabeth Hagaman, MEd
Substance Abuse	3D.	Pain Management and the Substance Abuser	Zail Berry, MD
Multicultural	4D.	HIV and the Homeless	Laura Gillis
Psychosocial	5D.	Peoplechange	Joan Garrity
Sexuality	6D.		
Education	7D.	Combating the Media's Mixed Messages: Art, Music and Storytelling	Cheryl Nesbitt

Intensive	8D.	Closing the Circle: Ceremonies for Healing Loss	Susan Thorner, MA & Kevin Shipman
	9D.	Second Decade: Women and Children	Pat Lincoln

FAIRFAX HOSPITAL SYSTEM
A DIVISION OF INOVA HEALTH SYSTEMS

8001 Braddock Road
Springfield, Virginia 22151
703 321-4200

December 14, 1993

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

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Sincerely,

Lori DeLorenzo, MSN, RN
Coordinator
Northern Virginia HIV Resource &
Consultation Center

THE WHITE HOUSE

WASHINGTON

March 18, 1994

Ms. Rose M. Jansen
7067 South 3480 West
West Jordan, Utah 84084

Dear Rose:

I want to express my appreciation for your active interest in the sharing of AIDS information. I certainly agree that access to AIDS information is critically important in stopping the spread of HIV.

The AIDS Education General Information System (AEGIS) is a valuable resource, and continues to provide a variety of AIDS information to a diverse population. We have worked proactively within the Federal system to assist Sister Mary Elizabeth in her efforts in acquiring Federal information. While AEGIS is comprehensive, there are also other information sources, which are free to the public (i.e., the AIDSDRUGS, AIDSTRIALS, AIDSLINE, DIRLINE at the National Library of Medicine.)

There are many AIDS information systems which have been developed by individuals and privately funded organizations; they all understand that they must assume responsibility for their administrative expenses. The PHS cannot selectively fund an 800 number for one system, to the exclusion of others. In order to undertake funding of such activities requires program authority, availability of funds, public announcement for competition for funds, grant review, etc.

Please understand that we are working within the Federal system to facilitate free access to AIDS information using creative and innovative approaches. Sister Mary Elizabeth and AEGIS are certainly considered in the development of these solutions, as are other systems.

Thank you for your interest in AIDS information dissemination. We appreciate opinions from individuals like you.

Sincerely,

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

February 18, 1994

Vesta Swift Fogg

Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
Washington, D.C. 20503

Dear Ms. Gebbie,

Are you aware of the AIDS Education General Information System (AEGIS), computer bulletin board service sponsored by the Sisters of St. Elizabeth in San Juan Capistrano? Because it fills a very important need in a unique way....it is gaining a reputation as one of the best sources of AIDS "on-line" information/support in the nation.

It is unfortunate that many cannot access this information because they are unable to pay the long distance phone charges. I am certain you agree that one of the best defenses against AIDS is information. The benefits of funding an 800 number for AEGIS would far outweigh the cost.

If you have not signed on to AEGIS, please do so and see for yourself....the unique service they provide. Their "on-line" number is (714)248-2836.

AEGIS needs an 800 number. Please help it become a reality!

Sincerely,
Rose M. Jansen
Rose M. Jansen

Rose M. Jansen
7067 South 3480 West
West Jordan, UT 84084

ref: Sisters of St. Elizabeth of Hungary
AEGIS
P.O. Box 184
San Juan Capistrano, CA 92693-0184

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Sincerely,

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

Prepared by: VJones 3/17/94 690-6248

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

FILE COPY

NATIONAL AIDS POLICY OFFICE
OFFICE OF THE COORDINATOR

ROUTING SLIP

DATE: 3/13

TO: Vesta

FROM: ✓ W. STEVE LEE

____ For your information

✓ For your action

____ Review and comment by (date) ____

✓ Prepare reply for Coordinator's signature

____ Reply directly and blind copy Coordinator

____ **Circulate/**forward to: ____

____ File

COMMENTS: by 3/21

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National AIDS Policy Coordinator

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE
	VJ	3/17						

Prepared by:VJones:3/17/94:690-6248

FILE COPY

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Office of the Assistant Secretary
for Health
Washington DC 20201

February 18, 1994

FEB 23 1994

Vesta
draft #2

Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
Washington, D.C. 20503

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