



STATE OF CALIFORNIA

SENATE

SACRAMENTO, CALIFORNIA 95814

DAVID ROBERTI
PRESIDENT PRO TEMPORE

TO: AIDS Service Organizations &
Community Leaders

FROM: Stan Hadden

RE: Comprehensive AIDS Plan

DATE: October 15, 1985

A requirement in the state budget approved last June was for the State Department of Health Services to develop a comprehensive plan to address the information and education, testing, mental health, research, and treatment needs resulting from the AIDS epidemic.

On November 8th the department will present the plan to the state AIDS Advisory Committee, members of the Legislature and representatives of the executive branch. Teams with expertise in AIDS research, treatment, and prevention will also review the plan and submit input. A draft of the outline that is being used is attached for your information.

I have also enclosed notes for your review from one meeting that has already taken place to develop input into the state's plan. I am very interested in your comments on these ideas.

Plans developed by state agencies go through extensive departmental review. Often, portions of reports that suggested additional funding is needed are eliminated by the department before the report is released. In order to address issues that may not be fully covered by the department's plan, the Senate Health Committee has scheduled hearings in Los Angeles on December 16th entitled "AIDS: Implications for Health, Treatment and Long Term Care." Additional information on this hearing will be sent to you in the near future.

I am interested in any written comments you might have on the items in the attached outline and memo, or suggestions for additional areas to be addressed. Please contact me if you have any questions.

— Bell Long Day —
Who will open AIDS FDN.

TO: Robert Anderson, M.D. Robert Benjamin, M.D.
Larry Bye Marcus Conant, M.D.
Bill Filante, M.D. Martin Finn, M.D.
Donald Francis, M.D. Neil Schram, M.D.

FROM: Stan Hadden

RE: STATEWIDE AIDS PLAN

DATE: October 7, 1985

These are my notes from our planning session to assist in the development of a statewide California AIDS strategic plan. We agreed to discuss these items further with our associates, with a goal of developing and prioritizing recommendations that can be addressed at community and county levels throughout the state. The programs and priorities established in California should serve as a model for other states, and for the federal government. Please let me know of additional information or changes you would like to make to this document.

COUNTY PLANS - County governments will bear the largest financial impact from AIDS for some time to come. Some county health departments have implemented education and patient care programs, others have been thwarted by county supervisors who are unwilling to take responsibility in addressing AIDS.

Recommendation: Class "A" counties (high incidence of AIDS) should be charged with producing and implementing comprehensive prevention, public education, care and ~~community planning~~ *Dieline* Class "B" or "C" counties (medium or low AIDS incidence) should be provided with a plan by the state. Standards should be set for local program elements. Inter-county cooperation for resource *SHARING* and program development should be engineered for Class "B" and "C" counties. Policy and recommendations from the state to counties should be developed, and funding necessary to implement programs should be ~~provided by the state~~ *provided by the state - Counties* *Both the*

TRANSMIT INFO FROM CLASS A COUNTIES TO REST OF STATE

OR

STATE RESPONSIBILITY - The approach to AIDS by the state, to date, has been largely reactive. Research and education efforts have been funded, but comprehensive, proactive programs have not been developed. Each day, there are conflicting messages coming from different state and federal agencies which promote unwarranted fear of AIDS in the general public. What can the state do to better educate people that is not being done now?

US

Recommendation: A Governor's cabinet level position should be established, responsible for coordination of AIDS policy among all state agencies. The position must have access to the legislature and the Governor, with enough authority to develop and implement interdepartmental policy coordination.

Not CABINET LEVEL
DESIGN DIRECTOR OF HS

NONE OF THESE WOULD BE EFFECTIVE.
ONE MUST USE INFORMAL HORIZONTAL STRUCTURES
TO SPREAD WORD --

COUNTER PUBLIC HYSTERIA

Bull PUBLIC EDUCATION - There are effective communication channels that are not being used to promote prevention & healthy living or public education about AIDS. These include public service announcements, media inserts, political mailings, junior and community college adult education courses.

AND ELSEWHERE
The issue of casual contact in schools must be addressed, both from the standpoint of students with AIDS and teachers who are in high risk groups. Active programs for crisis intervention are needed at all schools and hospitals before problems arise. **OK**

Bull Recommendation: The most effective approach to public education would be sophisticated public service announcements. Local health educators should meet with publishers and editors to discuss pertinent problem area, solicit input and learn what messages are acceptable to mass media outlets. People with communications expertise should be pulled together to develop messages. Issues about AIDS in the workplace need to be addressed.

PREVENTION & TRANSMISSION INTERVENTION - What is the best scientific approach for stopping the spread of AIDS? Present belief is that 10% of those exposed to the virus may contract AIDS. Another 25% of those exposed may exhibit symptoms, and the remainder of exposed people may remain asymptomatic, but probably infectious.

Recommendation: Prevention messages must address extended populations -- not just current high risk groups. Children today will be the at-risk populations of tomorrow.

Program design must include target audience evaluation and feedback from the biomedical community. Different messages for each audience are needed.

High Risk Individual Prevention - A continued increase (approximately 10% per year) of seroconversion showing exposure to the AIDS virus in San Francisco and Los Angeles research cohorts indicates that although people are having fewer sexual partners, they are not always having safe sex. Therefore, existing prevention efforts have been inadequate. Much data indicates enormously high behavior changes regarding the number of sexual partners, but the seroconversion rates show this is not enough. Physicians continue to see patients experiencing denial and engaging in high-risk sexual behavior. If we simply tell people to have safe sex, we are deceiving ourselves. Can people sustain long term safe sex practices? Can people be better motivated to avoid disease transmission?

Recommendation: Prevention messages must be stated loud and clear -- do not allow individuals to continue denial. One to one sexual behavior information counseling is needed, not just distribution of brochures. This information must come from physicians or counselors. Pro-active programs such as focused target media and interpersonal approaches for gay and bisexual males must be funded.

What messages can be used for gay and bisexual men, intravenous drug users, hemophiliacs, blood transfusion recipients, prostitutes, sexual partners of high risk or seropositive individuals and people with multiple sexual partners? Can people be categorized into "high, medium & low risk" groups?

Current public perception is that infection is not that serious. As high risk individuals stop having multiple partners and settle into primary relationships the issue of safe sex within relationships must be addressed. All high risk individuals currently in relationships and those forming new relationships must understand that HTLV-III infection is serious.

Guidelines to date have categorized "safe", "possibly safe" and "unsafe" sexual activities. Fundamental positive messages that empower people must be developed. Messages must be both informational and motivational; nothing is achieved by telling people what to do. If people are engaging in sex, the safety of sexual activity can be improved through the use of condoms and through development of serostatus guidelines. **Recommendations:** Drop the "possibly safe" category of sexual activities because of confusion regarding sharing of body fluids, continued denial and continued seroconversion rates.

Prevention messages:

- (1) HTLV-III infection will have a profound, terrible impact on your life.
- (2) We are losing the battle against AIDS.
- (3) We can/must do something to stop AIDS virus transmission.
- (4) If you are not infected, keep from getting infected. If you are infected, don't pass the virus to others and don't create additional exposure for yourself.
- (5) If you want to avoid AIDS or other sexually transmitted diseases, avoid sex. Be celibate or have safe sex with antibody/virus negative people. If you are antibody negative and cannot sustain safe sex practices, find an uninfected partner.

Does low risk sexual behavior work? People are capable of cutting down on the number of partners, but it is difficult to sustain "low risk" sex. Data on low risk sexual activity is soft. Are options such as sex with the protection of a condom and sex with antibody/virus negative people really safe?

Prostitutes & Their Clients - Do not moralize on the rightness or wrongness of prostitution -- present the message that exposure to AIDS is deadly. The history of female-to-male transmission is not clear. However, messages to prostitutes should be:

- (1) Continued high-risk sex is not good for your health
- (2) If high-risk sex is continued, a condom should be used.

Message to clients should be:

- (1) Some prostitutes are infected with HTLV-III virus.
- (2) To avoid exposure, don't use prostitutes.

Intravenous Drug/Needle Transmission - will require better financial resources to institute an effective approach.

Mother/Infant Transmission - the decision to undergo prenatal testing for women who may have been exposed should be made between the woman and her physician. There is little data on the prevalence of the virus in children. Educating pediatricians about AIDS should help develop a larger body of knowledge in this area.

Donor Transmission (Blood, Semen, Organs) - testing for exposure to AIDS virus in these settings.

HEALTH CARE PROVIDER EDUCATION - The Hospital Council of Southern California is working to train 600 individuals who could then provide training to 77,000 health professionals in Southern California. Many physicians are not well educated on examination issues related to AIDS, and certainly are not well educated on policy or treatment issues. Educated physicians should help develop better statistics and data.

Recommendation: Education for health professionals should include case management of people with AIDS both in and out of the hospital. In-house AIDS committees at all hospitals should be formed. Training should take place at hospitals before any AIDS-related problems arise.

SURVEILLANCE & TESTING - Is testing a realistic process for interrupting transmission of the disease? Should every high risk person be tested? How should such a testing program be implemented, and how should this information be used? People must understand the value of the test and denial that exists should be overcome.

Surveillance is passive (the reporting of AIDS cases) in all but three counties of the state. In San Francisco, Los Angeles and Orange counties active surveillance is taking place through investigation of hospital admissions, laboratory work, etc.

Recommendation: A plan for state and county surveillance of AIDS cases, ARC cases and incidence of seropositive people should be developed. A trend line establishing a risk assessment for California's population would be important. This basic demographic data could be used in developing prevention and education programs.

Active serologic surveillance should be undertaken at all blood banks, VD clinics, methadone clinics, and within selected populations (i.e. prostitutes, gay organizations) to accumulate additional information. Data on seropositive rates would not require any personal identifiers. A state databank would include only demographic data such as zip code, sex, date of birth, sexual orientation. Serologic surveillance would be done in a research context. If large scale anonymous screening takes place, more people would become part of surveillance program. For groups with high seropositive rates counseling and education would be necessary. Screening for exposure could be an important motivational factor.

Attitudes toward testing are changing, but there is resistance to testing from some gay community leaders. If we advocate testing, we must ensure that civil rights are protected. Anonymous testing must continue, with counseling for seropositives. Moving ahead with testing may divide people into "positive" and "negative" groups, but could stimulate the push for vaccine development and antiviral drug trials.

Large numbers of gay men are not always having safe sex. These men should be counseled and tested, in hopes that it may make a difference in behavior. A public health and gay community goal must be to keep uninfected people uninfected.

At the federal level, National Institutes of Health, program people are under pressure to push into basic research, vaccine development, and immunomodulator areas. Additional support will be needed for surveillance. It is the responsibility of public health officials to know how widespread AIDS infection has become.

TREATMENT & CARE - Eighty eight percent of Medi-Cal cost is for hospital care. If people with AIDS or ARC can be cared for out of the hospital, less will be spent. Medi-Cal's current position is that if person has to be hospitalized because of illness, the cost of hospitalization would be covered. However, the cost of admission is not covered if the person is admitted to the hospital in order to receive experimental treatments.

Recommendations: The medical definition of AIDS should be broadened to include anyone with evidence of infection that is disabled. The state should approve Medi-Cal payment for experimental drugs. Funding to pay for hospital care when trying experimental drugs should be a necessary part of research funding. There should be independent diagnostic codes for AIDS and ARC. Symptoms could be divided into severe, moderate and mild.

What should be done for individuals with lymphadenopathy? Lymphadenopathy often indicates that the person has been infected and the body is fighting the virus. Before people become symptomatic, what type of care is needed? What can be done for seropositive individuals? Early clinical intervention is better than late -- planning must begin. Seropositive individuals represent a vague area. They must be included as target groups for positive, healthy lifestyle promotion, just as is done with people with high cholesterol, smokers, drug users, etc.

Care in non-hospital facilities such as extended care facilities, skilled nursing facilities, hospice and in-home nursing care must be provided. Of current Medi-Cal expenditures, 1% is for home health care. Can AIDS be used politically to impact long term care? Contracting for Medi-Cal on a community basis is helpful.

Mental Health - Because of the high morbidity of the illness, stress and mental health issues affect those who are sick, those who are in at risk groups and are worried, and health care providers. Burn out among providers will be a problem of increasing proportion. Patients in terminal stages of the disease often have impaired central nervous systems. What sort of care will these people need? Planning must take place and programs must be developed.

Recommendation: Mental health programs and support for asymptomatic carriers or seropositive individuals are needed. Programs must also be developed for health care providers and patients.

RESEARCH - State research funds are allocated through the University of California. State funding for research is unusual. The UC process must be more accountable -- what are UC's priorities? UC does not want to be accountable to the legislature. They want the money with no strings attached.

Recommendation: UC should prioritize research proposals received and report on where the money is spent. UC must be approached to solicit their suggestions and involve them in this planning process.

Vaccine Development - Companies are moving slowly on vaccine development. The Center for Disease Control is not likely to request such a purchase order from the current federal administration. The state might approve a purchase order for vaccines if a spending limit is set. The money would not be spent immediately and we have the numbers of people who could benefit from a vaccine, such as prison populations, other institutionalized populations, health care workers, high risk groups. All would likely be eager to participate once vaccine efficacy is established.

Liability and indemnification are problems that must be addressed. California Trial Lawyers Assn. is currently working on problems of several and joint liability -- once this area is settled the gates for responsible private research should open up.

Recommendation: An incentive for vaccine development at state and federal levels must be established. This could be done through a state or federal purchase order for a specified number of safe vaccine at \$100 each. A purchase order would stimulate the vaccine & pharmaceutical industry, which currently consider development of and AIDS vaccine as a high risk venture with an unknown market.

AIDS Memo
October 7, 1985
Page 8

Antiviral Drug Trials - Laboratories lacking facilities for culturing the virus are going to hold up drug trials in California. Approximately \$300,000 would be sufficient to make necessary improvements in state laboratories for viral cultures.

cc:	Bruce Decker	Michael Roth, M.D.
	Sal Roselli	Michael Gottlieb, M.D.
	Dick Pabich	Richard Hamilton, M.D.
	James Chin, M.D.	State AIDS Contractors

OUTLINE: AIDS COMPREHENSIVE PLAN

10/25/85
11/1/85

I. Background

- A. Mandate for the Report
- B. Current Status of the AIDS Problem
 - 1. Incidence and Prevalence
 - 2. Risk Groups
- C. Strategies and Interventions
 - 1. Prevention/Community Education
 - 2. HTLV III Antibody Alternative Test Site Program
 - 3. Diagnosis and Treatment Services
 - a. Medical
 - b. Mental Health
 - c. Other
 - 4. Research and Surveillance

II. Prevention and Community Education

- A. Description of Services
 - 1. Health Education for Target Groups
 - 2. Professional Education for Health Care Providers
 - 3. Education for the General Public
- B. Trends in State Funding (FY 83/84 - FY 85/86)
- C. Impact of Services/Unmet Needs
- D. Recommendations

III. HTLV III Antibody Alternative Test Site Program

- A. Status of Program Efforts
 - 1. State/Federal Funding
 - 2. Operational Sites/Persons Tested
 - 3. Reimbursement to Counties
- B. Status - California's Blood Supply

DRAFT

1. Percentage of Positive Results
2. Notification of Positive Blood Donors

C. Policy Issues

1. Confidentiality of Test Results
2. HTLV III Antibody Test as a Screening Device

D. Impact of Services/Unmet Need

E. Recommendations

IV. Diagnosis and Treatment Services

A. Diagnosis

B. Outpatient Care

C. Acute Care (Hospital)

1. Service Trends/Utilization
2. Cost of Care/Reimbursement
4. Availability of Facilities

D. Long Term Care

1. Service Trends/Utilization
2. Cost of Care/Reimbursement
3. Availability of Facilities

D. Home Care

1. Home Health Care
2. In Home Support Services
3. Cost of Care/Reimbursement
4. Availability of Facilities

E. Hospice Care

1. Service Trends/Utilization
2. Cost of Care/Reimbursement
3. Availability of Facilities

E. Recommendations

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V. Research and Surveillance

- A. Epidemiological Research
- B. Vaccine Development
- C. Clinical Research
- D. State and Federal Roles/Funding
- E. Unmet Need
- F. Recommendations

United States Senate

WASHINGTON, D.C. 20510

January 31, 1985

Honorable Dianne Feinstein
Mayor of San Francisco
San Francisco, California

Dear Dianne,

Many thanks for your comments and kind words about my efforts regarding federal funding for treatment, prevention, and education programs for AIDS.

I share your view* that prevention and education must be integral components of our efforts to combat AIDS. Although I believe that the greatest resources should be allocated to research, because that is our only real hope for bringing an end to this epidemic, public information and education are essential to preventing the further spread of the disease and to avoiding misunderstanding of it and hysteria in reaction to it.

In FY 1985, \$2.845 million is available from the Centers for Disease Control for education programs on AIDS. These funds were appropriated as a result of the amendment I offered last year to add \$15 million to the Labor, HHS, Education, and Related Agencies Appropriations Act to increase FY 1985 Public Health Service funding for AIDS activities. Of this \$2.845 million, \$2.5 million was intended to be used for education programs of state and local health departments; \$140,000 for the U.S. Conference of Mayors; \$125,000 for education programs of the National Hemophilia Foundation; and \$80,000 for the establishment of an AIDS reporting network among state and local health departments.

In addition, the Preventive Health Amendments of 1984 (Public Law 98-555) authorized appropriations of \$3.5 million for FY 1985, \$5 million for FY 1986, and \$6.5 million for FY 1987 for grants to public and non-profit private organizations for information and education programs about AIDS and for diagnosis and prevention, and -- as such efforts become possible -- for treatment of the disease. It was intended that these project grants should go primarily to the cities -- such as San Francisco -- with the highest incidence of AIDS. Unfortunately, no such funds have yet been appropriated because this measure was not signed into law until after Congress adjourned last year. I plan to seek funding

through supplemental FY 1985 appropriations as well as FY 1986 appropriations (although I must note that in the present "freeze" environment this may be difficult to achieve).

With regard to our previous correspondence concerning presumptive SSI eligibility, I have been informed by the Social Security Administration that the Office of Management and Budget finally approved the proposed regulations but conditioned the approval upon inclusion of a provision that would eliminate presumptive status for AIDS victims after an effective treatment of the disease is developed. However, I was also informed that final action on the regulations is not expected until late winter or early spring. I am very dissatisfied with the length of time it is taking for the Administration to issue these regulations and have, therefore, written to HHS Secretary Heckler urging her to expedite this process (a copy of my letter is enclosed). My letter also presses her on a number of other vital concerns regarding AIDS.

Finally, I am enclosing a copy of a letter I am sending today to the Mobilization Against AIDS, as well as copies of other letters discussed in that letter.

Dianne, I appreciate your sharing your concerns with me. I hope that we can continue to work closely together in this area. Also, congratulations for your excellent appointment of Dr. Philip Lee as the President of the San Francisco Health Commission. I have already been consulting with Phil on the AIDS problem and plan to stay in close touch with him.

With warm regards,

Cordially,


Alan Cranston

Enclosures

cc: Members, U.S. Conference of Mayors Task Force on AIDS
Honorable Sala Burton
Honorable Barbara Boxer

United States Senate

WASHINGTON, D.C. 20510

January 30, 1985

Honorable Orrin Hatch
Chairman
Honorable Edward M. Kennedy
Ranking Minority Member
Committee on Labor and Human Resources
United States Senate
Washington, D. C. 20510

Dear Orrin and Ted,

I am writing to urge you to include in your Committee's hearing schedule, as early this year as is practical, the subject of federal activities and policies regarding acquired immune deficiency syndrome (AIDS). A number of my constituents, as well as others, have raised questions regarding those activities and policies that I believe should be publicly aired in order to facilitate the development of sound policy and clarify the facts regarding the implementation of existing policies.

The following issues are among those that I recommend be covered in any such hearings on AIDS:

- The conduct of public information and education programs: I believe that adequate information and education programs are essential in order to help prevent hysteria in reaction to news of the spread of the disease and to ensure that individuals in high-risk groups, such as homosexual males, are not subjected to discrimination, rejection, or isolation in their communities as a result of ignorance about AIDS and how the disease is transmitted. In addition, the conduct of blood-screening tests (discussed further, below), which is expected to commence next month, will create an urgent need for educational efforts to respond to the needs and concerns of those who test positive.
- The conduct and adequacy of preventive health-care programs aimed at reducing the incidence of AIDS: Preventive measures are essential to halting the rapid increase in the incidence of AIDS that has been manifested over the past few years and shows no sign of abating.

● In connection with the foregoing two points, the need for appropriations in FY 1985 and future years for programs of AIDS information, education, diagnosis, and prevention under the Preventive Health Amendments of 1984: I have written today to Senator Weicker, Chairman of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies and a member of your Committee as well, about this need (a copy of my letter is enclosed). Also, in order to help meet this need, I urge that your Committee include the modest but important AIDS funding authorized by that measure for FY 1985 and FY 1986 in your FY 1986 report of budget views and estimates to the Budget Committee. I do not believe that our very great concern about cutting the projected federal deficit should stop us from continuing to do what is needed to deal with this devastating epidemic -- the most serious faced by this country since the outbreak of polio.

● Issues arising in the context of the administration of blood-screening tests to individuals donating blood: It is expected that blood-screening tests, which can detect antibodies to HTLV-III, the viral cause of AIDS, will begin to be administered next month. Testing of all donated blood is vital to protect the nation's blood supply. However, such testing may also present some significant needs and problems.

First, as noted above, educational and counseling services will be needed for those who test positive. Although these tests will detect the presence of antibodies to the AIDS virus in prospective donors, a positive test result does not necessarily indicate that the individual has AIDS -- only that he or she has been exposed to the virus. Steps must be taken to educate those who test positive about the nature of the test, the meaning of the results, and the possible need for further diagnostic examination. These efforts are extremely important not only to encourage test-positive individuals to have regular medical examinations in order to detect symptoms that could confirm the onset of the disease, if it occurs, but also to help the individual minimize and cope with the anxiety which might follow from an incomplete understanding of the test result.

Second, the question arises as to how the needs of test-positive individuals for psychological counseling and further diagnostic services will be met -- especially for those who lack the necessary resources.

Third, alternative testing sites may be warranted for individuals in high-risk groups who are interested in having their blood tested. The current plans to conduct all testing at blood-collection sites has lead to much concern that, without alternative sites, many individuals in high-risk groups will apply to donate blood in order to get the test. Thus, the availability of the test only at blood-collection

sites could produce a large increase in the number of high-risk donors. Since the HTLV-III virus will be present in some cases with negative test results, the acceptance of blood from such false-negative individuals who are attracted by the test could diminish substantially the benefits of the screening.

- The current status of research into the causes, treatment, and prevention of AIDS: The Administration's early response to the need for AIDS research has been slow and sporadic, and it has refused to provide the Congress and the American people with a comprehensive plan. The most complete document in this regard of which I am aware was the May 25, 1984, memorandum from the then-Assistant Secretary for Health, Dr. Edward N. Brandt, Jr., to HHS Secretary Margaret Heckler setting forth Public Health Service agencies' funding needs for AIDS activities in FY 1984 and FY 1985.

Secretary Heckler disapproved the recommendations in this memorandum. Nevertheless, based on this document, I was able to secure an increase of \$38.5 million in FY 1985 funding for Public Health Service agencies' AIDS activities -- an increase of 70 percent over the Administration's original request -- for a total of \$93 million. This history of slow and inadequate Administration initiatives has raised very deep concerns among for those who see the urgency of the AIDS crisis as to whether the principal science and health policy makers in the Administration attach sufficient priority to combatting this epidemic and conquering the disease. I believe that hearings are needed to respond to those concerns and, if necessary, to find the means to ensure that these efforts get the priority for action that they warrant.

- The protection of the confidentiality of AIDS patients and research subjects and of those who have positive blood-screening results: In any area in which a diagnosis or other indication of exposure to a disease can be seriously stigmatizing, the need for strict confidentiality of treatment and research information identifying individuals is extremely important. Thus, it seems to me that legislation -- such as provisions along the lines of section 333 of the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970 (42 U.S.C. 4582) and section 408 of the Drug Abuse Office and Treatment Act of 1972 (21 U.S.C. 1175) -- would help to ensure that a fear of inappropriate disclosure does not impede AIDS research involving human subjects, deter from seeking diagnostic or treatment services those who need them, or deter from seeking to give blood those who would otherwise do so.

Dealing effectively with AIDS is a public health imperative of nationwide significance. As of January 21, 1985, according to the CDC, 7,981 cases have been reported, with a mortality rate of 49 percent and no recoveries. Over 1 percent of AIDS victims are children, 2 percent are hemophiliacs or the recipients of blood transfusions, 3 percent are Haitians, 17 percent are intravenous drug users, and 72 percent are homosexual or bisexual men. Moreover, initial results from testing donated blood with new blood-screening tests indicate that hundreds of thousands of persons may have been exposed to the HTLV-III virus and are therefore at risk of becoming victims of the disease in the future. Additionally, patients who are not members of known risk groups are now beginning to develop AIDS.

Some people seem to think that the AIDS epidemic is an important concern only to persons in the high-risk groups and those who are exposed to the disease through contact with those carrying the virus. That is not the case. Despite all the precautions we may take, no screening test is ever totally effective. Thus, every American who may have to rely on the safety of our nation's blood supply has a stake in conquering AIDS.

I hope you will agree with me, Orrin and Ted, that there are a number of extremely important issues relating to the AIDS epidemic and the federal government's response thus far that need to be covered in Senate hearings. I would greatly appreciate your letting me know, at your earliest convenience, your reaction to this letter and whether such hearings will be held and, if so, when. Needless to say, many of my constituents are enormously concerned about this matter and the actions your Committee takes.

Cordially,


Alan Cranston

Enclosure

cc: Honorable Lowell Weicker

United States Senate

WASHINGTON, D.C. 20510

January 31, 1985

Mr. John Lorenzini
Mr. Paul Boneberg
Mobilization Against AIDS
647-A Castro Street
San Francisco, California 94114

Dear Mr. Lorenzini and Mr. Boneberg,

Thank you and the Mobilization Against AIDS for your letter and enclosed petition and for sharing with me the concerns that you and the signers of the petition have regarding AIDS. I, too, am deeply concerned about the AIDS epidemic and the tragedy of so many lost lives. Since the outbreak of the epidemic, I have devoted much time and effort to trying to ensure that the federal government makes all possible efforts to find the means to treat and, hopefully, to cure and prevent this deadly disease.

I believe that our greatest hope lies in research. Only by understanding the cause of AIDS and how it destroys the immune system can we find a means for treating and preventing the disease. The Reagan Administration was slow in recognizing the breadth and depth of the crisis, and its response has been inadequate. Moreover, the Administration has consistently refused to put forward a comprehensive plan for research and public health programs. Despite the alarming rate of the continued increase in the number of AIDS cases, the Administration budget request for AIDS activities for FY 1985 decreased by \$2.5 million from the amount appropriated for FY 1984.

On the one occasion when a high Administration official put forward a coordinated strategy -- the May 25, 1984, memorandum from then Assistant Secretary of Health Dr. Edward N. Brandt, Jr., to Health and Human Services Secretary Margaret Heckler describing the AIDS research and public-health activities program that needed to be undertaken and urging that a request for appropriations for those activities be submitted to the Congress -- Secretary Heckler rejected the recommendations.

To help ensure that adequate funds were made available, throughout 1983 and 1984 I led Senate efforts which succeeded in appropriating \$48.4 million more than the Administration requested to combat the AIDS epidemic. Specifically, I was a principal sponsor, with Senator Moynihan, of a successful amendment to add \$10 million

to the Administration's request for FY 1984 AIDS research funding and the Senate sponsor of legislation, enacted in 1983, to establish the Public Health Emergency Fund to help ensure the availability of funding for swift and effective responses to public health emergencies. After I obtained a copy of Dr. Brandt's memorandum, I authored two amendments securing a total of \$38.4 million in additional FY 1985 funding, above the Administration's request for research and public health activities regarding AIDS, so that the plan in Dr. Brandt's memorandum could be implemented. The additional FY 1985 funding consisted of \$18.037 million for the National Institutes of Health, \$11.2 million for the Centers for Disease Control, \$822,000 for the Alcohol, Drug Abuse, and Mental Health Administration, and \$8.35 million for the Food and Drug Administration (FDA). Although the \$8.35 million for the FDA was held up by the Administration from October through January, I am happy to report that Secretary Heckler on January 15, 1985, informed me that the official budget request releasing those funds will be forthcoming in the President's budget submission for fiscal years 1985 and 1986.

It is reassuring that scientists have begun to make important strides in understanding AIDS, and I will closely monitor the FY 1986 AIDS research budget and am prepared to seek Congressional add-ons where necessary to ensure adequate funding for AIDS research.

I also realize that public information and education are essential to preventing the further spread of the disease. In FY 1985, \$2.845 million is available from the Centers for Disease Control for education programs on AIDS. These funds were appropriated as a result of one of my amendments, which I noted earlier, to increase FY 1985 funding for AIDS activities.

In addition, the Preventive Health Amendments of 1984 (Public Law 98-555) authorized appropriations for grants to public and non-profit private organizations for information and education programs about AIDS and for diagnosis and prevention, and -- as such efforts become possible -- for treatment of the disease. As my good friend and colleague from California, Representative Henry Waxman, noted at the time of final House passage of Public Law 98-555 (Congressional Record, October 9, 1984, page H 11679), priority in the award of the grants should be given to cities and areas with the highest incidence of AIDS. This would, of course, include San Francisco. Unfortunately, because this measure was not enacted until after the Congress had adjourned last year, no funds have as yet been appropriated for these grants. In an effort to see that this funding is provided at the earliest opportunity -- through FY 1985 supplemental appropriations -- I have urged the Appropriations Committee to provide that supplemental funding as well as full funding for FY 1986 (a copy of my letter is enclosed).

I share fully your concerns that the many issues and concerns that have arisen with respect to federal activities and policies regarding AIDS be dealt with in Congressional hearings. Therefore, I have urged the Chairman and the Ranking Minority Member of the Labor and Human Resources Committee to hold hearings on AIDS programs within that Committee's jurisdiction (a copy of my letter is enclosed). I believe that it is essential to discuss the many issues surrounding AIDS -- such as, research, public education, blood testing, and confidentiality -- in a public forum. Such hearings could contribute significantly to the understanding and sound development of federal policies and programs in this area.

Finally, I have also advocated to HHS Secretary Heckler (a copy of my letter to her is also enclosed) that she expedite the issuance of regulations establishing presumptive Supplemental Security Income (SSI) eligibility for AIDS victims. It is critical that patients diagnosed with AIDS be granted SSI eligibility presumptively so as to ensure categorical Medicaid eligibility and receipt of benefits promptly. I have been informed by the Social Security Administration that the Office of Management and Budget finally approved the proposed regulations but conditioned the approval upon inclusion of a provision that would eliminate presumptive status for AIDS victims after an effective treatment of the disease is developed. However, I was also informed that final action on the regulations is not expected until late winter or early spring. I see no good reason why it should take this length of time for the Administration to issue these regulations.

In my letter to Secretary Heckler, I also pressed her to seek FY 1985 and FY 1986 full funding for AIDS public information and education programs and requested the Department's views on various concerns regarding blood-screening tests and certain confidentiality issues.

I hope that this summary of the actions I have taken will assure you that I place a high priority on efforts to help the victims of AIDS and to find a means to prevent and cure that disease. It is without question the most serious epidemic we have faced since polio and warrants a full commitment of our nation's resources. I intend to continue doing all I can to ensure that that commitment is made.

I appreciate your contacting me on this issue of great mutual concern and major importance to the nation as well as California. I hope that you will try to find a way to share with the many individuals who signed the petition the information that I have set forth in this letter.

With best wishes,

Sincerely,


Alan Cranston

Enclosures

United States Senate

WASHINGTON, D.C. 20510

January 30, 1985

Honorable Lowell P. Weicker, Jr.
Chairman
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, D. C. 20510

Dear Lowell,

I'm writing to urge that your Subcommittee include in the FY 1985 supplemental appropriations bill and the FY 1986 Labor/HHS appropriations bill funds authorized specifically for AIDS public health and education programs by section 3 of the Preventive Health Amendments of 1984 (Public Law 98-555). ^{1/} The Director of the Centers for Disease Control would use the funds to make grants to public and non-profit private entities for information and education programs about AIDS.

As you will recall, Public Law 98-555, which authorizes appropriations within the sexually-transmitted diseases categorical grant program for AIDS information, education, diagnosis, prevention, and control, was not signed into law until after the 98th Congress adjourned. That measure includes an authorization of appropriations for FY 1985 (as well as authorizations for FY 1986 and FY 1987), and I believe that the need for the funding for these AIDS activities is most urgent.

^{1/} More specifically, section 3 of that law provides an authorization of appropriations of \$57 million for FY 1985 for sexually-transmitted diseases grants, with the specification that, to the extent actual appropriations exceed \$50 million, one-half of the amount above \$50 million shall be available "for information and education programs on, and for the diagnosis, prevention, and control of, acquired immune deficiency syndrome." However, the law also provides that this is not the exclusive authority for grants for AIDS activities, and, thus, as a matter of discretion CDC could use part of the first \$50 million for AIDS activities; also, of course, Congress can under this authority earmark specifically for AIDS activities amounts within the first \$50 million.

Lowell, you have already been most supportive of efforts to try to ensure that adequate funds are made available to deal with the AIDS health crisis, and my constituents and I are very grateful for your actions. As you know, most of the funds thus far appropriated have been directed to biomedical research. Although research holds the key to our ultimately being able to conquer AIDS, public information and education are essential to preventing the further spread of the disease and to avoiding misunderstanding and hysteria in reaction to it.

Because adequate research funds have been appropriated for FY 1984 and FY 1985, progress in understanding the disease is advancing rapidly. One very significant achievement has been the development of blood-screening tests, which should be commercially available in the very near future. Although the tests will detect the presence of antibodies to the AIDS virus in prospective donors, a positive test result does not necessarily indicate that the individual has AIDS -- only that he or she has been exposed to the virus. Steps must be taken to educate those who test positive about the nature of the test, the meaning of the results, and the possible need for further diagnostic examination. These efforts are extremely important not only to encourage test-positive individuals to have regular medical examinations in order to detect symptoms that could confirm the onset of the disease, if it occurs, but also to help the individual minimize and cope with the anxiety which might follow from an incomplete understanding of the test result.

Education is also our best preventive measure at this time. We should ensure that information regarding the disease, its transmission, and new developments associated with it is disseminated quickly and efficiently to people at high risk.

I would also note that under the new law these grants can also be made for the education of health professionals and others who work with the disease and with the patients who have it. Such efforts would help alleviate many of the fears associated with providing care and treatment to AIDS patients and thus improve the quality of care provided.

The need for accurate and effective information and education programs is an extremely urgent part of the effort to bring the AIDS crisis to an end. As of January 21, 1985, according to the CDC, 7,981 cases have been reported, with a mortality rate of 49 percent and no recoveries. Over 1 percent of AIDS victims are children, 2 percent are hemophiliacs or the recipients of blood transfusions, 3 percent are Haitians, 17 percent are intravenous drug users, and 72 percent are homosexual or bisexual men. Moreover, initial results from testing donated blood with new blood-screening tests indicate that hundreds of thousands of persons may have been exposed to the HTLV-III virus and are therefore at risk of becoming victims of the disease in the future. Additionally, patients who are not members of known risk groups are now beginning to develop AIDS.

Some people seem to think that the AIDS epidemic is an important concern only to persons in the high-risk groups and those who are exposed to the disease through contact with those carrying the virus. That is not the case. Despite all the precautions we may take, no screening test is ever totally effective. Thus, every American who may have to rely on the safety of our nation's blood supply has a stake in conquering AIDS.

The modest amounts targeted by Public Law 98-555 on AIDS -- \$3.5 million for FY 1985 and \$5 million for FY 1986 -- could go a long way toward educating and informing individuals in high-risk groups, health-care workers, and the general public. Thus, I strongly urge you to do all you can to include these funds for this new program in the first FY 1985 supplemental appropriations bill and the FY 1986 appropriations bill.

As in the past, Lowell, I hope we can work closely and cooperatively together on this. I look forward to your early response.

With warm regards,

Cordially,


Alan Cranston

cc: Honorable William Proxmire
Honorable Mark O. Hatfield
Honorable John C. Stennis

United States Senate

WASHINGTON, D.C. 20510

January 31, 1985

Honorable Margaret M. Heckler
Secretary of Health and
Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Margaret,

I am writing in connection with a number of matters of urgent concern regarding the spread of acquired immune deficiency syndrome (AIDS).

First, regarding regulations to provide for presumptive supplemental security income (SSI) eligibility for individuals suffering from AIDS, it is my understanding that the Office of Management and Budget has approved the HHS-proposed regulations on the condition that they be amended to provide for the elimination of presumptive eligibility following the development of an effective treatment. Although this would seem to clear the way for swift promulgation of the regulations, the Social Security Administration has advised that final action on them is, unfortunately, not scheduled until late winter or early spring.

The same reasons that warrant presumptive eligibility should result in the issuance of the regulations without the 8 or more additional weeks' delay that seems to be contemplated. In addition to ensuring, in an appropriate way, the prompt availability of SSI cash benefits, the determination of SSI eligibility carries with it categorical Medicaid eligibility, a matter of equal or greater concern to many needy AIDS victims. The sooner the regulations are prescribed, the sooner Medicaid eligibility will be extended to those who have recently applied and who will be applying for SSI.

It would seem to me that these regulations (at least interim regulations) could be issued with no significant further delay if a sufficient priority were to be attached to them. Therefore, I urge you to give this matter your personal attention with a view toward ensuring that the necessary operative regulations are promulgated and made effective at the earliest possible time.

Second, a number of issues have arisen in the context of the administration of blood-screening tests to individuals donating blood. It is expected that blood-screening tests, which can detect antibodies to HTLV-III, the viral cause of AIDS, will begin to be administered next month. Testing of all donated blood is vital to protect the nation's blood supply. However, such testing may also present some significant needs and problems.

Educational and counseling services will be needed for those who test positive. Although the tests will detect the presence of antibodies to the AIDS virus in prospective donors, a positive test result does not necessarily indicate that the individual has AIDS -- only that he or she has been exposed to the virus. Steps must be taken to educate those who test positive about the nature of the test, the meaning of the results, and the possible need for further diagnostic examination. These efforts are extremely important not only to encourage test-positive individuals to have regular medical examinations in order to detect symptoms that could confirm the onset of the disease, if it occurs, but also to help the individual minimize and cope with the anxiety which might follow from an incomplete understanding of the test result.

Also, the question arises as to how the needs of test-positive individuals for psychological counseling and further diagnostic services will be met -- especially for those who lack the necessary resources.

In addition, it seems to me that alternative testing sites may be warranted for individuals in high-risk groups who are interested in having their blood tested. The current plans to conduct all testing at blood-collection sites has led to much concern that, without alternative test sites, many individuals in high-risk groups will apply to donate blood in order to get the test. Thus, the availability of the test only at blood-collection sites could produce a large increase in the number of high-risk donors. Since the HTLV-III virus will be present in some cases with negative test results, the acceptance of blood from such false-negative individuals who are attracted by the test could diminish substantially the benefits of the screening.

Thus, I would appreciate learning your views as to how the needs for educational and counseling services for blood donors should be met, as to whether alternative test sites should be established, and what actions you are planning in these areas.

Third, I believe that stepped-up programs for AIDS prevention and public information and education are needed. Preventive measures are essential to halting the rapid increase in the incidence of AIDS that has been manifested over the past few years and shows no sign of abating. More adequate counseling programs are essential in order to help prevent hysteria in reaction to news of the spread of the disease and to ensure that individuals in high-risk groups, such as homosexual males, are not subjected to discrimination, rejection, or isolation in their communities as a result of ignorance about AIDS and how the disease is transmitted. In addition, as noted above, the conduct of blood-screening tests will create an urgent need for educational efforts to respond to the needs and concerns of those who test positive.

In response to these needs, Congress enacted in section 3 of the Preventive Health Amendments of 1984 specific authorizations of appropriations for AIDS information, education, diagnosis, and prevention programs for fiscal years 1985, 1986, and 1987. I have written to Senator Lowell Weicker, Chairman of the Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies, about the need for appropriations for FY 1985 and FY 1986 under this authority (a copy of my letter is enclosed). I also urge you to support these appropriations

and, if requests for these funds are not included in the President's FY 1986 budget and revised FY 1985 budget, to press for budget amendments to include this funding.

Fourth, I am concerned about the apparent need for legislation to protect the confidentiality of AIDS patients' blood-screening results. In any area in which a diagnostic or other indication of exposure to a disease can be seriously stigmatizing, the need for strict confidentiality of treatment and research information identifying individuals is extremely important. Thus, legislation -- such as provisions along the lines of section 333 of the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970 (42 U.S.C. 4582) and section 408 of the Drug Abuse Office and Treatment Act of 1972 (21 U.S.C. 1175) -- would help to ensure that a fear of inappropriate disclosure does not impede AIDS research involving human subjects, deter from seeking diagnostic or treatment services those who need them, or deter from seeking to give blood those who would otherwise do so. I would like to have your views on the desirability of such legislation.

Margaret, I view the AIDS epidemic -- the most serious faced by this country since the outbreak of polio -- as a public health imperative of nationwide significance. I would appreciate your giving these matters very prompt consideration and look forward to receiving a response at your earliest convenience.

With best personal regards,

Cordially,


Alan Granston

Enclosure

In Front of 50 United Nations Plaza
San Francisco, California 94102
November 4, 1985

Hon. John Molinari
President
San Francisco Board of Supervisors
City Hall
San Francisco, California 94102

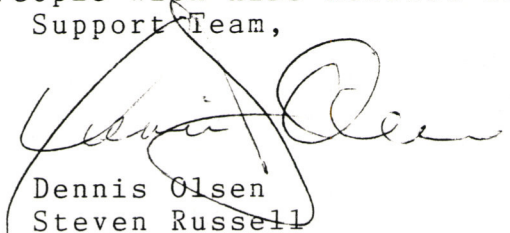
Dear Supervisor Molinari:

We, People With AIDS Related Complex, thank you for your help (as Acting Mayor) in assuring our safety from further violence, during our non-violent Vigil and Demonstration. As you know, we suffered a violent attack on Saturday night, and we are grateful for your help in preventing a recurrence.

We also hope that you can support us in our just demands, directed at all levels of Government. (Attached is a copy of those demands.)

Again, thank you for your assistance.

For the People With AIDS Related Complex
Support Team,



Dennis Olsen
Steven Russell