### AIDS PREVENTION IN THE U.S.A.

Second Report to the
"Bundeszentrale für gesundheitliche Aufklärung"
Köln-Merheim

Update
October 15, 1987

**VOLUME TWO** 

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### VI. AIDS PREVENTION IN NEW YORK

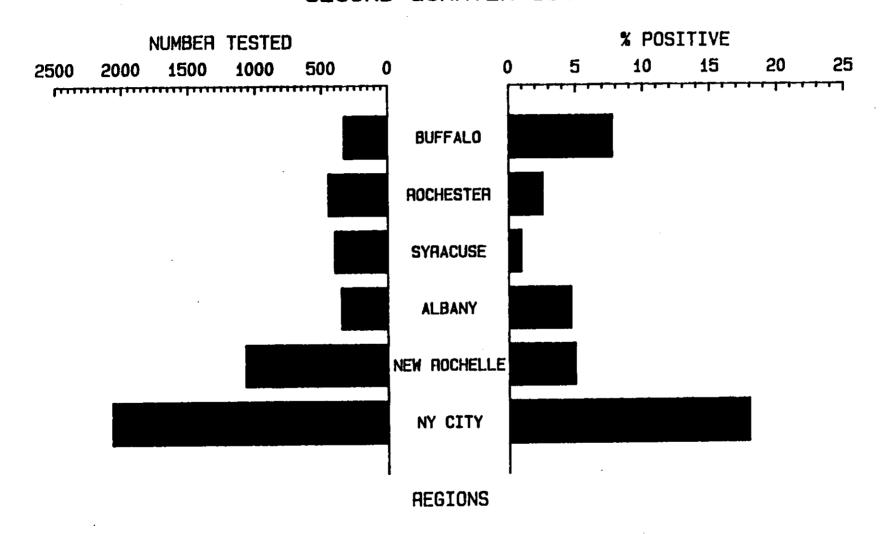
### THE STATE OF NEW YORK

When researching my previous report of April 30, 1987 it did not prove possible to obtain any documentation from the AIDS Institute on its multiple activities. However, on the occasion of the second visit the author went to the Institute headquarters in Albany and succeeded in obtaining a wealth of material, most of which is attached under separate cover to the present report (see Printed Material, II, 2).

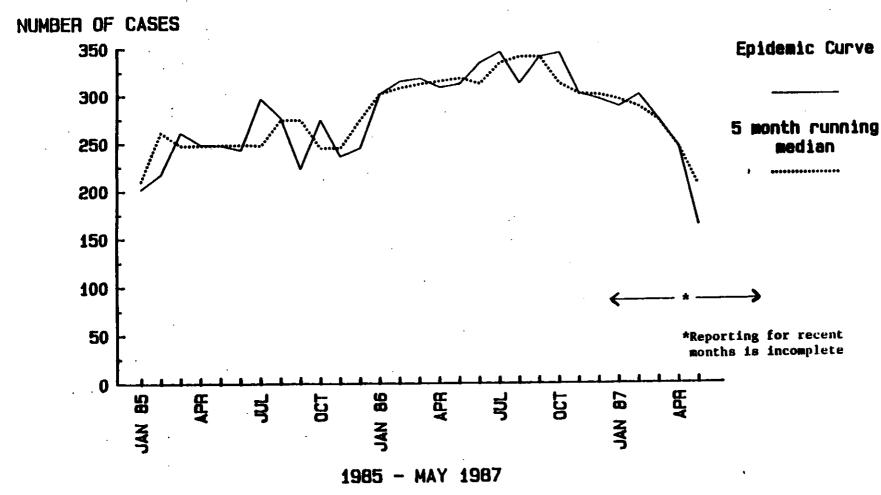
In its totality, this material conveys an adequate impression of the enormous efforts the State of New York has made in catching up with its AIDS epidemic. Indeed, the work of the New York State AIDS Institute can serve as a model for other states and other countries. Especially the careful study of a key document is strongly recommended to anyone planning general AIDS strategies: The Expenditure Plan 1987-1988. Another very informative document is The Legislative Perspective and Agenda prepared by the Majority Task Force on AIDS of the New York Senate.

In order to put these ambitious programs in perspective the following pages offer some general epidemiological data for the state of New York. This is followed by two documents prepared by the AIDS Institute outlining the management of State AIDS Centers and the education of service providers.

## ALTERNATE SITE TESTS AND POSITIVITY RATES SECOND QUARTER 1987



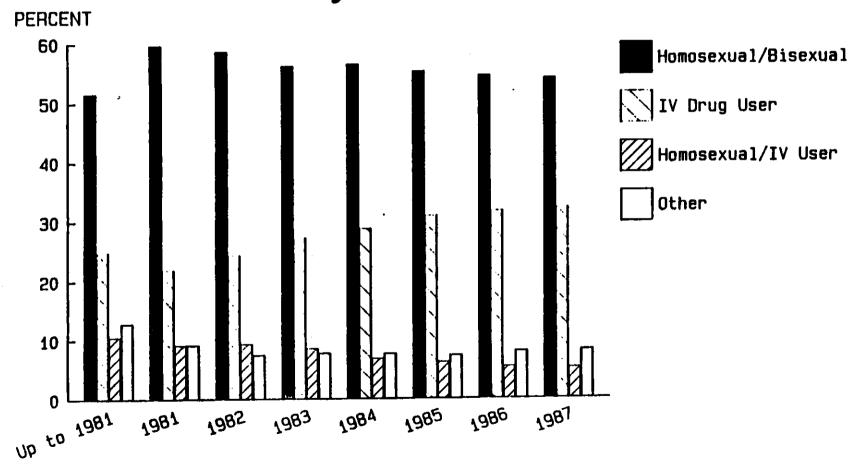
# AIDS CASES REPORTED AMONG N.Y.S. RESIDENTS BY MONTH OF DIAGNOSIS JANUARY 1985 - MAY 1987



The epi curve shows wide fluctuations in monthly incidence. The 5-mth running median shows data smoothed to reveal underlying trends.

90

### New York State AIDS Risk Groups Percent Distribution by Year July 17, 1987



TIME

Source: AIDS Epidemiology Program, Bureau of Communicable Disease Control, Division of Epidemiology, NYSDOH.

### AIDS CENTER DESIGNATION/ AIDS INTERVENTION MANAGEMENT SYSTEM

### I. Designated Centers

In January of 1986, New York State amended Part 405 of Title 10 of the New York State Codes, Rules and Regulations to include Section 405.40 of 10 NYCRR to ensure the provision of health care services for patients with Acquired Immune Deficiency Syndrome (AIDS). This section entitled "AIDS Centers" detail the regulations hospitals must comply with in order to be designated as an AIDS Center. An AIDS Center is required to provide and/or arrange for all levels of care and services including inpatient, ambulatory, home health, personal care services, psychiatric, psychological services, housing, legal and financial arrangements and as appropriate hospice and residential health care services. This program will provide access for people with AIDS to essential health care community resources so AIDS patients will be to maintain the quality of their lives in a home The AIDS Centers vill environment as long as possible. receive discreet inpatient and outpatient medicaid reimbursement rates in order to provide coordinated and comprehensive services and programs.

The Designated AIDS Center program is not intended to relieve non-designated hospitals of their responsibility for the care and treatment of persons with AIDS nor is it intended to inhibit patient freedom of choice in seeking access to care in non-AIDS Centers.

On March 24, 1986, Department of Health Memorandum 86-32 was issued to the New York State hospital community. This memorandum requested applications from general hospital licensed under Article 28 of the Public Health Law to become Designated AIDS Centers. The "Request for Proposal" cutlined the following thirteen requirements for hospitals seeking designation as an AIDS Center:

Standard 1. Integrated and comprehensive inpatient services must be provided on-site through a discreet unit model. A scatter bed approach would be approved on an exception basis only.

- <u>Standard</u> 2. Ambulatory/outpatient services available for screening diagnostic and treatment services specifically for AIDS patients.
- Standard 3. Emergency services available 24 hours a day for treatment and identification of AIDS patients.
- Standard 4. Home Care services must be provided or assured through a home care agency certified under Article 36 of the Public Health Law.
- Standard 5. Other health care services must be provided or assured such as residential Health Care Services, Hospice Services, Residential living programs, etc.
- Standard 6. Availability of diagnostic and therapeutic radiology services and other specialized services.
- Standard 7. Inservice education programs which address the medical, psychological and social needs specific to AIDS patients are conducted for all hospital personnel caring for AIDS inpatients.
- Standard 8. Infection control policies and procedures specific to AIDS are developed and implemented as an integral part of the hospital-wide infection control program.
- Standard 9. A quality assurance program which includes a review of the appropriateness of care of patients with AIDS is developed and implemented as an integral part of the overall quality assurance program.
- Standard 10. At the request of the Department of Health, the AIDS center participates in clinical research programs approved by the hospital's Institutional Review Board.
- Standard 11. Resource information about AIDS is made available to the public and educational programs are provided for particular high-risk populations.
- Standard 12. A crisis intervention program is made available in coordination with other existing potentially services.

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- Standard 13. The AIDS Center is required to ensure that each AIDS patient has a care management plan which specifically addresses the patient's post-hospital care needs. The care management plan should be accomplished through the following program elements:
  - A. a multi-disciplinary team, whose composition reflects inpatient and outpatient care services, to include as appropriate to the patient's needs, medical, nursing, nutritional, mental health and social work services, is responsible for each AIDS patient and, whenever possible, the AIDS patient is assigned to the same multi-disciplinary team for all health care services;
  - B. a case manager is designated from the multi-disciplinary team to be responsible for coordinating the health care services and plan for each AIDS patient;
  - C. a mechanism is established to assure periodic reviews and updates of the patient management plan in conjunction with other agencies involved with, or responsible for, the care of AIDS patient; particularly the home health agency or health related facility which will participate in the patient's continuum of care as well as appropriate representative(s) of community support groups; and
  - D. a comprehensive patient management plan is developed by a multi-disciplinary professional team, the patient, and when appropriate, home health care or other non-acute long term care representatives, in consultation with the patient's family and other individuals with significant personal ties to the patient.

In response to the Request for Application which the New York State Department of Health received 26 Certificate of Need Applications.

### II. AIDS Intervention Management System (AIMS)

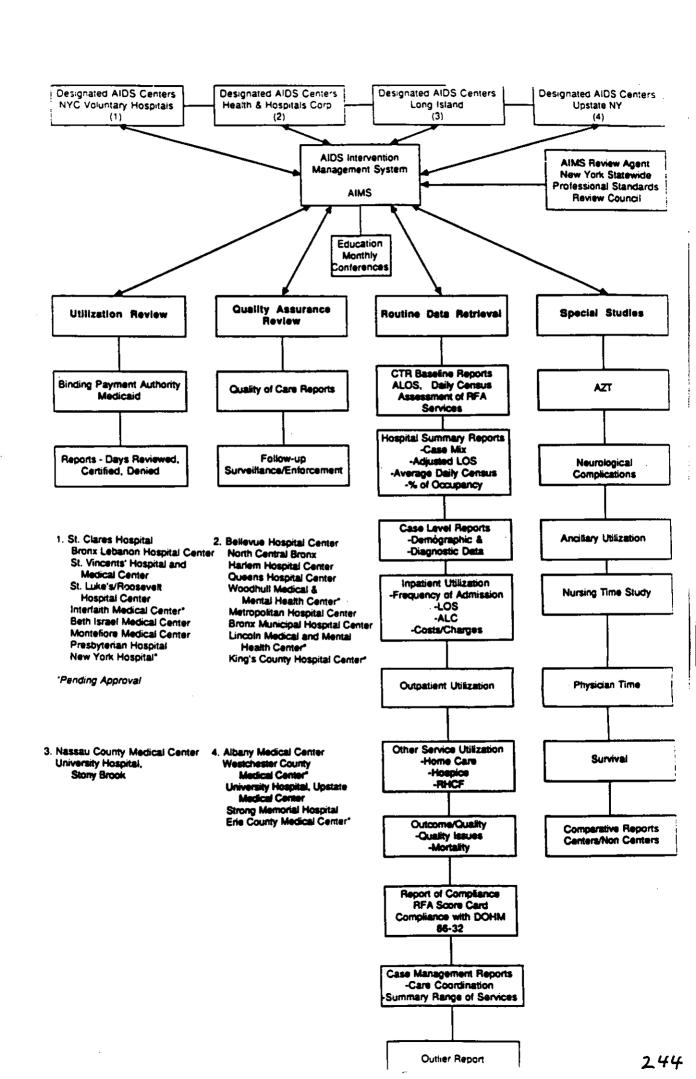
In conjunction with the AIDS center process, New York State solicited competitive applications from qualified organizations for the design, implementation, and operation of an oversight system. This system will review the performance of the comprehensive AIDS Centers and also conduct a comparative review of AIDS patient management in non-designated hospitals. The organization selected, the New York Statewide Professional Standards Review Council, Inc., will have the responsibility to ensure that appropriate standards of utilization review, quality assurance, and case management are established and met for patients receiving care under the designated center program. This oversight system is referred to as the AIDS Intervention Management System (AIMS).

Through AIMS, the New York State Department of Health will be able to centrally coordinate the retrieval of data from the multihospital treatment of AIDS patients. Routine data reports are to include hospital length of stay, average daily census, inpatient and outpatient utilization, demographic and diagnostic data, quality of care, and case management assessment.

Through the analysis of data retrieved from the review of a broad range of services, special studies such as inpatient and outpatient ancillary utilization and cost, neurological complications, AZT effect, nursing time, physician time and survival from the onset of illness will be conducted.

In addition, the AIMS Agent will be coordinating bi-monthly conferences to discuss pertinent AIDS topics with the Designated Centers. The objective of these conferences is to assist facilities in developing "best practice" models of care in the areas of case management, discharge planning, research management, addiction disorders, infection control, teaching methodologies, etc.

The Designated AIDS Center Program in conjunction with AIMS, will provide current information concerning the impact of AIDS and HIV related illness on the health care delivery system. These programs will be enable New York State to plan policy, identify service gaps and coordinate care for those persons affected with HIV related illnesses.



## Education and Training AIDS Institute New York State Department of Health

Program Status Report September, 1987

Program Area: Education and Training

Goals/Objectives:

Through the five units of the Education and Training Section, (see attached unit status reports) to accomplish the following goals:

- Training Unit: to develop standard and speciality courses on AIDS related issues; to provide technical assistance, training of trainers and primary direct training to a variety of audiences.
- Field Operations Unit: to deliver regionally based training courses statewide, collect data for program evaluation and to provide technical assistance on a local basis.
- Evaluation Unit: to design survey instruments to measure AIDS-related knowledge, attitudes and behaviors; to analyze data collected from the field; to issue reports to be used to adjust programmatic goals and objectives; and to manage education and risk reduction research projects (e.g. the Men's Project).
- Educational Resource Unit: to develop/purchase education and training materials for general and specialty audiences and insure their appropriate distribution; to monitor contracts with HEAPS and the statewide hotline located at Roswell Park; and to maintain a resource/lending library of AIDS related materials.
- Minority Education Unit: to develop culturally relevant education and training programs for ethnic minorities; and to oversee the development and implementation of the Minority Trainer Development Program.

Current Status
Significant Activities:

Education and Training Section (ETS) is responsible for the coordination of state funded AIDS/HIV education and training initiatives. In addition, the ETS manages several federal grants that address primary prevention of AIDS. The ETS has experienced rapid growth as the state and federal governments have increased their role in the reduction of the spread of AIDS through education and training.

The ETS has recently completed several searches and interviews and has hired staff for existing vacancies. Programmatic activities for the coming year will include; an educational program for migrant workers; training and evaluation of HIV counselors in community health access points (STD, family planning clinics and community health centers); the establishment of local "Prevention Centers" through an RFA process; increased training of health and human service providers; increased training and technical assistance for State agencies (e.g. SED, DSS, DOCS); and the continuing expansion of a statewide regional training program.

#### Issues/Problem Areas

AIDS education is complicated by the fact that risk reduction and transmission is primarily related to sexual and drug using behaviors. Demonstrating program effectiveness and efficiency requires a combination of epidemiological and behavioral methods. In the coming year, the ETS will be required to significantly increase the numbers and types of educational programs available to both the general public and specialized subsets of professional and at-risk populations.

Contact Person:

Jane C. Holmes, Director Telephone (518) 486-1320

### Program Status Report

Program Area: Field Operations

### Goals/Objectives:

- to participate in data collection for ongoing assessment of knowledge, attitudes, and beliefs about AIDS/HIV infection
- to provide education and training for health providers and other professionals who work with individuals at risk for HIV infection
- to provide an ongoing and highly effective health promotion/disease prevention and risk reduction educational campaign
- to encourage those who may be at elevated risk to participate in HIV counseling and testing
- to refer persons to community agencies to reinforce and support behavioral changes which reduce risk of infection
- to alleviate unvarranted fears and misconceptions about AIDS
- to collect data for evaluation of the quality and efficacy of all programmatic activities
- to continue to distribute material and literature

### Current Status

### Significant Activities:

- cumulative total of 681 presentations to 23,999 persons in New York State
- audience breakdown includes
  - e schools
  - health care, providers
  - social service agencies
  - e city/county corrections
  - New York State corrections
  - private industry
  - churches
- interagency coordination/consultation with the Department of Substance Abuse Services, Department of Corrections and Department of Parole

Program Status Report Angel Roca Page 2

- HIV counselor training to Family Planning Clinics, Sexually Transmitted Disease Clinics, Prenatal Care and Nutrition Programs
- assisting with the development of modules to be taught

### Issues/Problem Areas:

- overwhelming need for presentations
- balance two needs within the presentations
  - 1. statewide standardized clear/consistent message about AIDS/HIV statewide
  - tailoring the presentation to the particular regional/agency needs
- disparate expectations for the training specialists between the regional and central offices

### New Initiatives

- regional training network to professionals in New York
   State (eight modules have/will be taught)
- to present training courses for providers serving minority populations
- to train HIV counselors in community health centers, designated care centers, and other local health agencies
- to implement the minority Trainer Development Project
- to implement an educational program for migrant workers
- to participate in ongoing staff development

### Contact Person:

Angel Roca Field Coordinator

### Program Status Report

Program Area: Education Resource Unit

### Goals/Objectives:

- development of AIDS related educational materials for general public and specific audiences (minorities, pregnant women, etc.)
- review of educational resources (printed and audio visual) from other agencies, companies, etc.
- purchasing of necessary resources (videos, printed materials, condoms)
- create training materials in conjunction with curriculum developers
- monitor HEAPS contract, meet regularly with Public Affairs Group
- consult with other New York State agencies developing AIDS materials
- limited resource distribution
- public speaking/special projects

### Current Status

### Significant Activities:

The addition of two staff members should help with the backlog of materials currently waiting to be developed. Recent activities include: development and production of ADAP materials, printing certificates of recognition for CSP volunteers and the research and development of a bilingual brochure on condoms for pregnant women.

### Issues/Problem Areas:

Due to tremendous demand for publications, quite frequently items are out of stock. Additionally once orders are placed, shipping time can be quite lengthly, due to delays in processing at the warehouse.

Funding for printed materials may prove to be an issue this year as it was last but cannot be predicted at this time.

### Program Status Report - continued

### New Initiatives

During the coming months Education Resource initiatives will include the following: Production of educational materials targeted to minority and bilingual populations, increased emphasis on staff development and education through monthly mailings to field staff, and development of prevention materials in conjunction with Men's Project.

### Contact Person:

Joe Anarella Education Resource Coordinator 474-3045

### Program Status Report

### Program Area:

The Men's Project

### Goals/Objectives:

- (1) To measure AIDS-related attitudes, knowledge and behavior in a cohort of gay/bisexual mean from a low-incidence area for AIDS;
- (2) To compare behavioral and psychosocial responses to the AIDS threat of high- and low-incidence area cohorts;
- (3) To evaluate the efficacy of HIV-ab counseling and other intervention strategies on attitudes, risk behavior and health care practices;
- (4) To monitor change in cohort seroprevalence over at least a 4-year period;
- (5) To participate in the development of a multi-city longitudinal data set for monitoring behavior change and incidence of HIV infection among gay and bisexual men.

### Current Status/

Significant Activities:

- (1) ongoing recruitment of gay and bisexual men, 18 or older, not presently diagnosed with AIDS
- (2) questionnaire development for annual 3-4 hour confidential interviews with study participants
- (3) HIV testing and counseling of study participants
- (4) design and implementation of intervention activities
- (5) development of HIV resource directory for targeted population
- (6) coding and cleaning of data, data analysis, report writing

### Issues/Problem Areas:

- (1) Recruitment and follow-up of gay/bisexual men from an invisible community with low seroprevalence continues to be a formidable problem.
- (2) Data analysis is complex and time-consuming and often exceeds the capabilities of our small staff.
- (3) The negotiation of a s atisfactory working relationship with the local community service program continues to be problematic.

### Contact Person:

Dr. Carolyn Beeker, Project Director and Principal Investigator Tom Rose, MSW, Project Field Director

### THE NEW YORK CITY DEPARTMENT OF HEALTH

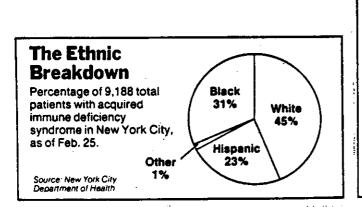
My previous report of April 30, 1987, and its attached supporting material already contains an adequate accounting of New York City's AIDS prevention programs. Since then, the New York City Department of Health AIDS Education Unit has expanded and moved to new, larger quarters. One interesting new development is the hiring of a new educator whose duties include establishing contact with the "sex industry" (publishers of sexually explicit materials, owners of sex clubs and sex video arcades). Otherwise, the Department's programs are developing along the lines previously indicated.

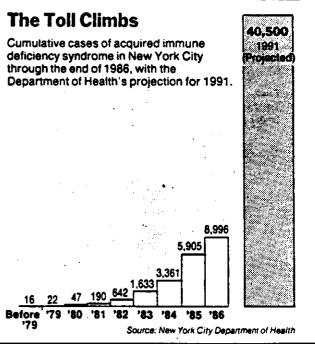
As far as the spread of the disease itself is concerned, it seems to be sufficient at this time to provide a simple epidemiological update.

In addition, the following pages offer a copy of a recent newspaper report on AIDS in New York which rounds out the previously reported dry statistics.

An especially instructive document is reprinted here in full: an outreach and education program for heterosexuals at risk.

(It does not seem necessary to provide additional information on the Gay Men's Health Crisis. See previous report of April 30, 1987).





New York Times March 14, 1987

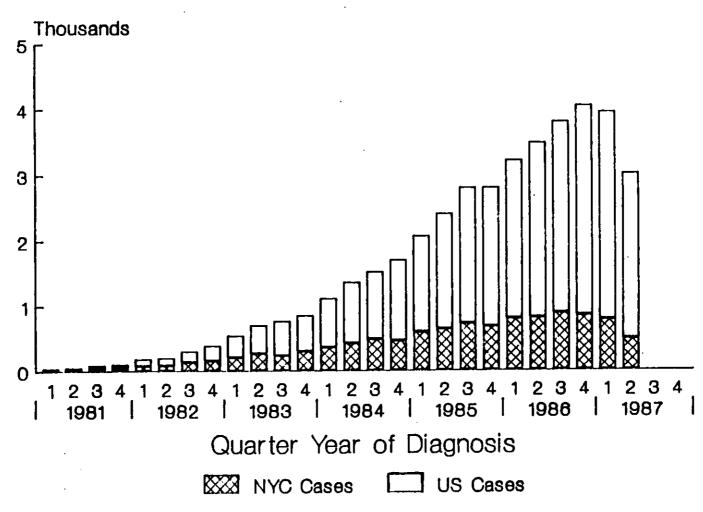
### **New York City AIDS Cases: Patient Profiles**

Number of cases of acquired immune deficiency syndrome as of Feb. 25 by patient group and percentage of total cases.

Patient Category	Males	Females	Total
	Cases (%	) - Cases (%)	Cases (%)
Homosexual/bisexual, not intravenous drug user	<b>5,101</b> (55.5	0 (0.0)	<b>5,101</b> (55.5)
Homosexual/bisexual, I.V. drug use unknown	<b>138</b> (1.5	0 (0.0)	<b>138</b> (1.5)
Homosexual/bisexual, I.V. drug user	. <b>45</b> 1 (4.9	) 18 (0.2)	469 (5.1)
I.V. drug user, heterosexual	2,086 (22.7	) <b>544</b> (5.9)	2,630(28.6)
I.V. drug user, sexual orientation unknown	93 (1.0	) 11 (0.1)	104 (1.1)
Born in country where heterosexual transmission is believed common	159 (1.7	) 39 (0.4)	198 (2.2)
Transfusion-associated	38 (0.4	) 35 (0.4)	73 (0.8)
Hemophiliac, or other blood-factor deficiency	- 17 (0.2	) 2 (0.0)	19 (0.2)
Sex partner of person from known risk-group	4 (0.0	) 209 (2.3)	213 (2.3)
Interviewed, no risk factor determined	44 (0.5	) 23 (0.3)	67 (0.7)
Unable to interview adequately	51 (0.6	) 24 (0.3)	75 (0.8)
Under investigation	74 (0.8	) 27 (0.3)	101 (1.1)
TOTAL	<b>8,256</b> (89.8	932 (10.2)	9,188 (100)

Source: New York City Department of Health

## AIDS INCIDENCE 1981-1987 Total US and New York City



Cases reported as of August 1987

NEW YORK CITY SURVEILLANCE - REPORTING PERIOD: June 13 - July 14, 1987

MALES	New Cases	Cases to Date	_(%)_
Kaposi's sarcoma (KS) Pneumocystis carinii	36	2273	
pneumonia (PCP) without KS	160	5871	
Other opportunistic infections (001)			
without KS or PCP	_33	<u>1690</u>	4
Total Males	229	9834	(89)
FEMALES			
KS	2	31	
PCP	37	845	
001	_9	<u> 293</u>	
Total Females	46	1169	(11)
TOTAL ADULTS	256	11,003	
TOTAL CHILDREN	7	214	
TOTAL CASES	263	11,217 (27% )	US cases)

CDC National Surveillance - Total U.S. cases reported as of 7/13/87: 41,776

### AIDS CASES BY DATE OF DIAGNOSIS AND BY DATE OF REPORT, NEW YORK CITY

<u>Month</u>	Number Diagnosed*	Number Reported**
1982		
average no./mo.	39	31
<u>1983</u>		•
average no./mo.	83	79
<u>1984</u>		
average no./mo.	145	123
1985		
average no./mo.	215	201
<u>1986</u>		
average no./mo.	281	284
<u>1987</u>		
lst half	251	301
July	145	_ 284
August	<b>15</b> ·	115

<sup>\*</sup>Reflects the number of cases diagnosed. Lag time between diagnosis and report to Dept. of Health is usually under 6 mo., but has been as long as 24 mo.

<sup>\*\*</sup>Reflects trends in reporting. Cases reported in a given month may have been diagnosed that month or at any earlier time.

### AIDS IN AMERICA / A SPECIAL REPORT

# New York Wasn't Prepared

# Grim Predictions of Epidemic Have Come True

By Randy Shilts Chronicle Correspondent

New York

It was nothing more than a gesture, really, but one that spoke volumes about life in a city where AIDS has hit harder than anywhere else in the western world.

Author Larry Kramer ran into an actor on Fifth Avenue and mentioned that both a prominent theater director and a well-known stage designer were in the hospital.

"What with?" the actor asked.

Kramer just nodded his head.

"Oh," said the friend sadly, understanding instantly what the nod meant. "That's terrible."

More than 10,600 people are dead or dying of AIDS in New York City, where more cases have been reported than in any other city in the world. Nearly one in three AIDS sufferers in the United States lives in this metropolitan area.

In no other city in North America has the AIDS epidemic appeared in so many disparate

forms and posed such complex issues of public policy and planning. No American city has allowed itself to be less prepared to deal with a situation that is rapidly shifting from desperate to catastrophic.

The disease rages from the trendy gay neighborhoods, where the nation's first AIDS victims fell ill nearly a decade ago, to the sprawling slums of the Bronx, where the major portion of the city's estimated 250,000 intravenous drug users live.

As a result. New York City is left to play a game of catch-up.

In New York City, AIDS is the leading

#### NEW YORK CITY 8,300,000 Population: 10,601 AIDS cases: 6,125 AIDS deaths: National rank: 1 Pct. Major risk group Сазез 55% Gay/bisexual 5,885 Heterosexual 30% 3,160 IV drug user Gay/Bisexual 489 4% IV drug user Heterosexual 245 2% contact Children of 199 2% risk group ■ Hospital beds for AIDS patients: About 1,000/day ■ Total spending on AIDS programs: \$334 million in federal, state, city, foundation and private money

Figures as of June 6

Sources: New York City Department of Health, Chronicle research cause of death among all men from the ages of 25 to 44; it has been for several years. Just last month, health officials said AIDS had also surpassed cancer as the leading cause of death among women between the ages of 25 and 34.

With conditions as bad as they are, AIDS experts cringe when they consider the future of AIDS in New York City, because the present is already so bad.

### **Conditions Like Zaire**

When Dr. Ernest Drucker talks about the future of acquired immune deficiency syndrome in New York City, he mentions six of the newer patients being treated at Montefiore Hospital in the Bronx. All are teenagers, ages 17 to 19; their combined sexual activity amounted to 58 sexual contacts.

- Drucker figures a typical young, sexually active heterosexual in the Bronx has at least a 1-in-10 chance of being infected with the AIDS virus during any one year. The odds may be as bad as one in five, he adds.
- "We're beginning to see 18year-olds with (AIDS) symptoms," says Drucker, director of community health at Montefiore. "The numhers approach what you'd expect to see in Kinshasa, Zaire."
- Pulling out a map of the Bronx, Drucker draws his finger around the neighborhoods that have become the personification of American poverty. Ten to 20 percent of the people in those areas are drug addicts, he says, and at least half of them are infected with the AIDS virus.

"The implications of these numbers are fairly obvious and very frightening," says Drucker.

One-half of the AIDS cases among heterosexual intravenous drug users in the country have been reported in New York City alone. These cases represent only a fraction of those who are infected with the AIDS virus and may be spreading it heterosexually.

The slums, such as those of the Bronx, are where the real problem of heterosexual AIDS in America is centered, not in the singles bars of Manhattan's Upper East Side or San Francisco's Union Street.

One-third of the nation's female AIDS patients, most of whom contracted the disease from drugusing male sexual contacts, live in New York. More than half are black, another 35 percent are Hispanic and almost all are poor.

These statistics make New York City the home to nearly 200 AIDS-stricken babies, about half the nation's total, who are born to infected women.

The city recently announced new initiatives to fight the spread of AIDS among addicts, but, even the most optimistic concede that educational campaigns which urge white, middle-class homosexuals to change their sexual behavior will have far less success in the Bronx.

"It's hard to convince a junkie, who is killing himself anyway, that he shouldn't kill himself by sharing needles," says Lee Jones, a spokesman for Mayor Edward Koch.

### Too Little, Too Late

People who have long pressured the Koch administration insist the AIDS problem in New York today would be far less substantial if the city had moved faster against the epidemic. For the first four years of the epidemic, the city resisted calls to start long-term planning and steadfastly refused to allocate funds for AIDS education.

Even some of Koch's harshest critics, however, credit New York with a dramatic turnaround in its handling of AIDS in the past year.

As of 1985, for example, the city had spent only about \$40,000 on AIDS prevention and patient support programs. In the next fiscal year, the city will spend about \$12 million for such efforts, more than twice the city funds for comparable projects in San Francisco.

Still, just about everyone involved with the epidemic in New York agrees that efforts against the disease may be too little, too late, given the dimensions of the prob-

The city health department estimates that 400,000 New Yorkers are infected with the virus. At least 40,000 are expected to be diagnosed with AIDS in the next four years.

Just caring for the city's current caseload consumes \$334 million in city, state and federal funds. Beyond the concern of cost, there is substantial concern about where all these sick people are going to be put.

### **AIDS Hospital**

When St. Clare's Hospital opened its Cardinal Spellman Unit for the Treatment of HIV Infections in September 1985, its five-year plan called for expanding from seven to 40 beds for AIDS patients by 1990. By then, the hospital figured its clinic also would be handling 250 outpatients.

Now, less than two years later, the patient demand is so great that the hospital has filled five wards with a total of 60 beds, and another 700 people are being treated at the hospital's outpatient clinic.

Administrators cannot renovate rooms fast enough to keep up with the demand. Plans call for expanding to 125 to 150 AIDS beds within a year, including a separate locked unit to house 25 state prisoners suffering from the disease.

"I don't think New York will ever be ahead of the game, because planning started so late," says Terry Miles, coordinator of the Spellman Unit.

"I have to admit that when I got to New York two years ago, I was disgusted that there seemed to be no planning whatsoever about what was going to happen around AIDS. Somebody else was supposed to be doing it, but nobody ever said who that somebody else was supposed to be."

On any given day, the St. Clare's wards are home to twice the AIDS patients typically at San Francisco General Hospital—and all the new facilities can barely make a dent in the city's AIDS caseload.

"I don't know what the city expects to do in one or two years, when the patient load is so much greater," says Miles. "I'm not sure if the city knows, either."

The despair engendered by the avalanche of AIDS cases is measured in part by the number of gay doctors who have decided to change careers rather than spend their lives doing little more than caring for the dead or dying.

Richard Dunne, executive director of Gay Men's Health Crisis, tells the story of one Manhattan gay physician who recently shut down his office to become a became a real estate developer. "He said he'd never practice medicine again — it was too painful," Dunne said.

### **Body Catching**

When AIDS educator Rodger McFarlane talks about the problems of health care delivery to AIDS patients in New York City, he recalls the story of a Hispanic prostitute suffering from a yeast infection that had spread from her mouth into her throat.

The infection is a classic AIDS-related disease and the woman was rapidly wasting away, but when she went to 16 city hospitals, she was told by 16 doctors that she was not seriously ill and only suffering from malnutrition.

By the time the woman could convince a hospital she was sick enough to deserve admission, she was suffering from tuberculosis and deadly AIDS pneumonia.

"That story is more typical of AIDS in this city than that of a nice white gay man who calls his doctor as soon as he gets shortness of breath and gets smoothly admitted to a room that has his medication waiting," says McFarlane.

There are not enough doctors to give decent treatment to all the poor people coming into emergency rooms with strange infections, Mc Fariane notes, and there aren't enough rooms to put them in once the treatment is found.

People who understood the epidemic had warned the city that this would be the shape of AIDS in New York City in 1987. McFarlane war one of the people who did so most aggressively as far back as 1982 when he served as the first director of the Gay Men's Health Crisis, or GMHC.

Now that the future he predicted has come, McFarlane remains at the center of the crisis, training employees of New York City's mental health system about how to care for AIDS patients.

Given the future volume of AIDS patients, McFarlane doesn't think programs like the AIDS facilities at St. Clare's Hospital are the ultimate answer. Every hospital in New York will, to some extent, have to be an AIDS hospital.

McFariane says there is a lessor in this for the rest of the country.

"The whole health care system needs to gear up to help carry the load," says McFarlane.

"The future is imminently predictable here, as it is everywhere else," he says. "We can go into any city and tell them how many cases they will have in five years. Still. nobody seems to be planning about how to take care of the huge numbers ahead. It will happen here in New York first, but it will also happen in San Francisco and a lot of other cities. I don't know if anyone is prepared."

As part of a program sponsored by the city, GMHC and Memorial Sloan-Kettering Cancer Center. McFarlane has trained 4,000 workers in municipal hospitals and community mental health agencies to prepare the health system to handle the shock of AIDS.

Like so many working on AIDS in New York City, however, McFarlane says that current efforts are only a fraction of what is needed.

"I don't shout and scream any more that the city has to come to grips with it," says McFarlane wearily. "The sheer inevitability of the epidemic will force it. They're going to change when the bodies are piled up on the door step. Until then, all we can do in the health system is catch bodies."

### OUTREACH AND EDUCATION

### PROJECT 2: HETEROSEXUALS AT RISK

### Introduction

Last year, the Public Health Service projected that new cases of AIDS in men and women acquired through heterosexual contacts would increase from 1,100 cases nationwide in 1986 to almost 7,000 in 1991. Although there is a broad spectrum of opinion about the extent of the likely spread in the United States of HIV infection in the heterosexual population, there is strong agreement that, whatever the efficiency of heterosexual transmission, the infection will continue to be amplified among heterosexual populations in regions with a high prevalence of infection and where intravenous drug use is high.

National data suggest that sexual contact has been the route of transmission of HIV in over 75% of the cases. Male-to-male sexual transmission has been documented to be the most common mode of sexual transmission, followed by male-to-female transmission. Female-to-male transmission occurs but probably less frequently, while female-to-female transmission remains rare.

The risk of acquiring HIV appears to depend on three variables: the number of sexual contacts with an infected partner; the type of sexual contacts; and the likelihood of transmission of infection during sexual contact with an infected person.

In New York City, we conclude that these factors will account for a substantial increase in HIV infections in the heterosexual population over the next 5 to 10 years and that these cases will occur predominantly in those subgroups of the population at risk for other sexually transmitted diseases. We therefore propose an AIDS prevention program directed at heterosexuals with

multiple sexual partners, specifically those who engage in sex with prostitutes or in other ways access the "sex industry". Through education, advertising and materials distribution we hope to reach these individuals and influence their behavior.

### Current Activities

To date, MYCDOH's AIDS Education Unit has provided the following related services:

Informational and educational sessions have been conducted for the public through community organizations.

Individual and group counseling has been available at select DOH STD clinics for this clientele deemed at high risk for HIV infection.

Training has been conducted with many who serve the public, e.g. MYC Housing Authority residence managers, community boards, etc.

Educational brochures and video productions geared to the needs and concerns of the public have been distributed/viewed through education and training sessions, clinics, private practices, community centers, etc.

Subway car cards and posters have been installed throughout the city, one series targeting women at risk.

Outreach work has served to get the AIDS prevention message out to the heterosexual partners of some at risk.

The AIDS Hotline and public service announcements/flyers designed to promote it have reached large numbers of the public with information designed to assist in assessing one's individual risk.

These activities, though directed at a broader audience than we propose to reach through this proposal, have undoubtedly had some impact on heterosexuals with multiple sexual partners. It is the intent of this proposal, however, to direct educational resources more specifically at those heterosexual New Yorkers who are served by the sex industry and are thus at risk.

### **Objective**

To develop a citywide AIDS prevention program targeting heterosexuals with multiple sexual partners who will be reached through establishments and at locations known to cater to such heterosexuals.

### New Activities

This proposal requests funding to develop and implement an outreach and education program that will decrease the transmission of HIV by teaching AIDS prevention to adult and juvenile heterosexuals with multiple sexual partners. This program differs from the existing AIDS education efforts that target the public in that it will 1) bring information to this population through the businesses and other locations that cater to heterosexuals with multiple sexual encounters: singles clubs, bars, massage parlors, escort services, street corners, adult newspapers and magazines, adult movie theatres, health clubs, etc.; 2) train the staff of service organizations (eg. Consumer Affairs) already reaching these locations in AIDS prevention; 3) and, as appropriate, deliver AIDS education directly to proprietors and clients of establishments which promote or permit high risk sexual activity.

The objective of the Citywide AIDS Prevention Education Program targeting haterosexuals at risk is to prevent the spread of AIDS. This will be done by providing a variety of educational opportunities for this population to learn about the disease and be motivated to make necessary behavior changes. A report in MANNER documented that this approach can be effective; when AIDS education was made available to a "swinger's club" in the mid-West where two members were also found to be seropositive, the club was disbanded. The following activities will be conducted as part of the MYC effort:

### Community Outreach Work

The staff will reach out to this at-risk population in the locations/businesses that cater to them. The objectives of this activity will be to establish a rapport with these businesses, find appropriate sites for the distribution of materials and to recruit "gate-keepers", or those individuals who can provide access to this population, both the staff and the clients. These include managers of singles bars, massage parlors, escort services, adult movie houses etc. The program will encourage the adoption of risk-reduction behavior among prostitutes.

While direct counseling of large numbers of individuals is unlikely, it is expected that the our staff will come into direct contact with many people at risk. Materials will be handed out and referrals for counseling and other services will be made.

### Advertisements

Certain publications which promote high risk sexual activity through advertisements of sex clubs, massage parlors, escort services etc. offer an opportunity to reach those at greatest risk. The DOH will regularly place advertisements concerning AIDS prevention and write articles about AIDS for these same publications.

### Condom Distribution

Short of abstinance, the latex condom is the primary preventive measure for sexual transmission of AIDS. These will be distributed by outreach workers to reinforce the prevention message.

### Training

Many City agencies and community organizations interact with the businesses (and clients) that promote or permit high risk sexual activity. These include: the Police Department; Probation Department; Office of Consumer Affairs; social service programs for runaway youth etc. The staff of these programs will be trained in AIDS information and thereby encouraged to communicate AIDS prevention in the context of their work responsibilities.

### Budget

### Personal Services

1 Public Health Educator	28,000
6 Community Associates 20 hrs @ \$10.30/hr	67,486*
1 Office Associate	18,030
PS Sub-total	113,516**

### <u>OTPS</u>

Recruitment		4,000
Office Furniture and Equipment (8)***		11,944
Office Supplies (8)		4,000
Local Travel 7 x 3 trips x \$2 x 52		2,184
Typewriter***	•	750
Car***	•	7,800
Maintenance, garage, gas		2,210
Advertising		20,000
Condoms		48,000
Space (2)		4,000
OTPS Sub-total		104,888
GRAND TOTAL		\$218,404

\*including a 10% shift differential for night work (50% of total hours)

\*\* No collective bargaining increases have been factored into this budget

\*\*\* Mon-recurring

### BUDGET JUSTIFICATION

### Public Health Educator

A public health educator will be hired to coordinate this activity. This individual's responsibilities will include: general oversight of all program activities; supervision of other staff members; program implementation; program reports and evaluations. This person will be the primary contact with other City and community agencies that have contact with the target population.

### Community Associates

Six part-time Community Associates will perform the community outreach work, establishing relationships with the businesses, distributing AIDS education materials at appropriate sites and recruiting "gate-keepers" to sustain support for AIDS prevention activities. They will be supervised by the Public Health Educator and will primary work in pairs during evening and weekend hours.

### Office Associate

This individual will handle clerical and office support activities
necessary for program operation. Responsibilities include, typing, handling
correspondence, word processing, scheduling, telephone, filing etc.

### **OTPS**

### Office Equipment and Supplies

This amount covers the non-recurring cost of desks, chairs, lamps, file cabinets, calculators, etc., for staff of the program. Cost is calculated at \$1,493.

### Office Supplies

Office supplies for all staff members are needed annually. This is calculated at \$500 per year.

### Condons

800,000 condoms will be purchased for distribution at all activities of this program.

### Car

A car is needed for use by personnel to travel between sites at night particularly to outer boroughs. Because of the geographic distance between sites and the necessary evening schedule of these activities, this item is crucial for effective program operation.

### Car Maintenance, Garage and Gas

This item is calculated at standard agency rate.

### Typewriters

The typewriter will be used by the Office Associate.

### Recruitment Costs

This amount covers the cost of advertising. Since positions in these field locations and in AIDS-related work are frequently difficult to fill, paid advertising is very important.

### Space

This amount covers space needs for 2 people at \$20 per 100 square feet.

### Advertisement

AIDS prevention ads will be placed in magazines and newspapers that promote sexual activity. (We cannot depend on public service space for this purpose)

# VII. AIDS PREVENTION IN CHICAGO

# THE STATE OF ILLINOIS

On September 22, 1987, Illinois Governor James Thompson signed a conprehensive package of AIDS legislation. This package presented a compromise between "liberal" and "conservative" legislative proposals, containing elements of both. Not surprisingly, the Governor did not succeed in entirely pleasing both sides. Even so, to outside observers it was obvious that the Governor had made a political rather than internally consistent public health decision.

In particular, a law requiring premarital testing was widely criticized by public health professionals as being practically meaningless from an epidemiological point of view and financially wasteful.

Another law requiring schools "to teach abstinence" is considered by these same professionals as a sop to conservative pressure groups without any serious effect on the prevention of HIV-infection among teenagers. Much more meaningful would be a law requiring "safe sex" education in schools, but whether such a law will be passed in the increasingly politicized climate is by no means certain.

A summary of the legislative package, together with an epidemiological chart, is reproduced on the following pages, followed by a "liberal" flier protesting against some of the laws that were passed by the legislature and demanding a veto. Apparently, this "liberal" pressure was sufficient to influence the Governor and to persuade him to "steer a middle course" with the compromise package described above. Nevertheless, the "conservative" proposals are not necessarily dead and may be reintroduced in subsequent legislative sessions. In general, the outcome of the political battle in Illinois remains uncertain.

One positive element in the continuing political struggle is a special task force called Illinois AIDS Interdisciplinary Council. Last year, this broadly based council arrived at a consensus which was summarized in a report to the Governor. The report covers the fight against AIDS in Illinois in great detail from all angles and is therefore attached in full to the present report (see Sources: Printed Material).

The following pages are simply restricted to reproducing an estimate of the number of AIDS patients (as well as the asymptomatic infected) and the cost of their treatment through August, 1990. This at least provides some hint as to the potential problems faced by Illinois.

# Sept. 22, 1987

# New AIDS Laws in Illinois

United Press International

Chicago

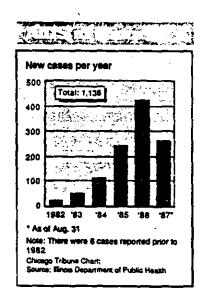
Governor James Thompson signed into law yesterday a comprehensive package of AIDS bills.

The legislation signed by the governor:

- Permits individuals with AIDS to be isolated from the rest of the population only if they are deemed a danger to the public and a court order is obtained. Previously, the health department could confine a person to hospital or home without court approval.
- Directs state health authorities to try to trace the sexual partners of people diagnosed as having AIDS, using information volun-

teered by the infected person.

- Requires schools to teach children about the dangers of AIDS and to urge them to abstain from sex before marrying.
- Requires couples to submit to an AIDS test before marriage.
- Requires the testing of persons convicted of sex offenses.
- Requires that state agencies keep information on AIDS sufferers strictly confidential.
- Requires doctors and laboratories to report AIDS cases to the state Public Health Department.
- Requires the testing of all donated blood, semen and tissue.



# Broad Laws on AIDS Signed in Illinois

# By DIRK JOHNSON

Special to The New York Times

CHICAGO, Sept. 21 - Gov. James R. Thompson today signed a broad package of bills aimed at fighting AIDS, including one that requires marriage license applicants to show proof they have been tested for infection with the AIDS virus, but does not ask for the re-

Under the legislation, Illinois becomes the second state, along with Louisiana, to make AIDS virus testing a requirement for couples who want to

таггу.

The Governor also approved bills calling for automatic AIDS virus testing for sex crime offenders, mandatory education about AIDS in the public schools for grades six through 12, financial incentives for nursing homes to accept AIDS patients and strict confidentiality measures for testing for the virus. The package brought mixed reactions from partisans on both sides; indeed, the Legislature's debate on the AIDS bills was sort of a microcosm of the national debate on the issues posed by the deadly disease.

# Thompson Speaks to Dilemma

Mr. Thompson described the di-lemma today when he said, "Until a time when medical science can tell us more precisely the roots of this epi-demic, we must be firm in our stand to balance the strong issues of protecting the public health and preserving the individual rights of our citizens."

Mr. Thompson vetoed bills passed by the Legislature that would have required AIDS virus tests for all prison inmates and for hospital patients from 13 to 55 years old. He also rejected a bill that would have required the state Public Health Department to seek out the sexual partners that AIDS victims have had for the last seven years.

State Senator Penney Pullen, who sponsored the hospital testing and mandatory tracing measures, said she would seek to override the vetoes of



Gov. James R. Thompson Jr. of

Illinois as he signed AIDS legislation yesterday in Chicago.

those bills. Senator Pullen is a member of the President's commission on AIDS.

AIDS experts and gay rights activists criticized the marriage test requirement as political grandstanding diverting attention from the groups at high risk of getting the AIDS virus, homosexual men and intravenous drug users. But the AIDS experts and rights groups lauded the balance of the package for its focus on counseling, education and confidentiality.

"It's a whole lot more reasonable package than he was presented with," said Jeffrey Levi, executive director of the National Gay and Lesbian Task Force in Washington.

Dr. Renslow Sherer, chairman of the Governor's AIDS InterDisciplinary Council, had urged the rejection of the marriage license test. But he said the package "includes some of the most positive legislation in the country today," including the bill to encourage nursing homes to accept AIDS patients and measures aimed at expediting Medicaid funds for treatment outside hospitals.

But Dr. Sherer said he feared "widespread and unnecessary anxiety and fear" among marriage license applicants who might be mistakenly diag-nosed as having been infected. Such mistakes will be corrected in later tests, he said, but marrying couples will endure needless suffering in the

Acquired immune deficiency syndrome cripples the body's immune system, leaving victims susceptible to serious infections and cancers; there is no cure. The virus spreads chiefly through sexual intercourse with an infected partner or exchanges of blood. such as in shared hypodermic syringes; many studies indicate that it does not spread through casual social or household contact.

## Protecting the Unwitting Partner

Under the marriage license bill, couples will need proof from a private doctor that they have been tested for infection with the AIDS virus. The couples need not divulge the results to anyone other than each other. People infected will thus not be prevented from marry ing; the authors of the measure say the aim is to protect an unwitting partner.

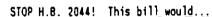
The Louisiana law on marriage license testing requires disclosure of the results. Couples who test positive must agree to counseling, but will not be for-bidden to marry. The laws in both states go into effect on Jan. 1.

In addition, the Texas Legislature has passed a bill that would require AIDS testing for marriage licensing when the percentage of AIDS victims in that state reaches a certain percentage, far higher than its present level.

# VETO: VETO:: VETO:::

# ALL & WRITE GOVERNOR THOMPSON TODAY! THE GOVERNOR MAYBE ACTING ANY DAY.

Governor James R. Thompson — State Capitol, Springfield, IL 62706 Phones: (217) 782-6830 or (312) 917-2121



- ... require couples seeking marriage licenses to obtain a certificate stating that they have taken the HIV antibody test. The certificate would not state the results, but the physician would be required to report positive results to Public Health officials. Positive results would not prevent the issuance of the marriage license.
- ... require health care workers, testing positive for the HIV antibody, to notify their employer of that fact. The employer is authorized to remove the employee from direct patient contact.
- ... require anyone convicted of a sexual or drug related offense to be tested for the HIV antibody; the presiding judge decides who is entitled to the test results.
- ... require that identity of AIDS, ARC or HIV antibody positive school age children be reported to the principal, school nurse and teachers.

# STOP H.B. 2682! This bill would...

- ... mandate Public Health officials to collect the names and addresses of all individuals who are HIV antibody positive, have AIDS or ARC. Private doctors, laboratories, and clinics could be required to report this information.
- ... require Public Health Officials to:
  - \* ask the above individuals to identify sexual partners for the last 7 years, and
  - \* contact those so identified to warn them of potential exposure to AIDS, and
  - \* seek records from the armed forces, federal agencies, other states and jurisdictions on Illinois residents found to be HIV antibody positive for contact tracing.

# STOP S.B. 85! This bill would...

- ... require couples seeking marriage licenses to obtain a certificate stating that they have taken the HIV antibody test. The certificate would not state the results, but the physician would be required to report positive results to Public Health officials. Positive results would not prevent the issuance of the marriage license.
- ... require that everyone convicted of a crime and being incarcerated in an Illinois state prison or county jail be tested for the HIV antibody. (However, the bill does not outline any actions in the case of positive test results.) Prior to release, inmates must be tested and, if necessary, counseled
- ... require those between ages 13-55 being admitted to a hospital to take HIV antibody test.
- ... allow anonymous testing and written informed consent at designated alternative testing sites only.

# STOP S.8. 651! This bill would...

- ... authorize Public Health officials to collect the names and addresses of all individuals who are HIV antibody positive, have AIOS or ARC. Private doctors, laboratories, and clinics could be required to report this informacion.
- ... require Public Health officials to:
  - \* ask the above individuals to identify their past sexual partners
  - \* attempt to contact those so identified to warn them of potential exposure to AIDS.
- ... allow the quarantining of individuals 'deemed' dangerous to the public health.











DATE: July 31, 1987

TOTAL CASES - 1077

MALES - 1041

FEMALES - 36

JNKNOWN JOUNTY

DATE OF I	DIAGNOS	IS AND NUMBER	DEAD
		DIAGNOSED	DEAD
PRIOR TO		6	6
	1982	18	16
	1983	51	41
	1984	123	101
	1985	252	193
	1986	419	208
	1987	208	51
		1077	616

TOTAL & DEAD -

689

301

80 7

78

5 5 64

28

1

CHICAGO RESIDENTS - 794

CHICAGO METROPOLITAN - 171

DOWNSTATE ILLINOIS - 112

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	30 - 39	464	4 43	OT	BER
1 1 7	40 - 49	24:	3 22		
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	BETEROSEXUAL	•	34		_		
	TRANSPUSIONS		45		4		
	PARENT WITH . AT RISK	AIDS/	7		1		
	NONE OF THE	ABOVE	27	÷	3		
•	INCLUDED 23 HETEROSEXUAL WITH AIDS OR 11 PERSONS HETEROSEXUAL TO BE THE MA	CONTA AT RI BORN TRANS	CT ISK IN SMIS ODE	WITH FOR COUN SION OF T	A PER AIDS A TRIES IS BI	ison and where Elieved	
25	CASTRON SERVER	1		4			

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DEPARTMENT OF PUBLIC HEALTH Bernard J. Turnock, M.D., M.P.H Director

# **ABSTRACT**

The In-patient Cost of Hospitalization and Future Economic Impact for Patients with AIDS.

Phillip P. Sitter
Office of Health Policy and Planning
Illinois Department of Public Health
Springfield, Illinois

In-patient hospital utilization for 182 persons with AIDS (PWAs) from April, 1982 to March, 1986 at four major hospitals in Cook County and Chicago, Illinois was reviewed. The overall cost of hospitalization was 7.1 million dollars. There were 363 hospitalizations for 182 PWAs, an average of 1.98 hospital visits with an average total hospitalization of 31.5 days per patient. PWAs spent an average of \$19,435 per admission. Overall mortality was 48%. There were 108 hospitalizations for 49 deceased PWAs, an average of 2.2 hospital visits with an average total hospitalization of 40.0 days per PWA. Total in-patient cost was \$64,532 per patient, with the PWAs spending an average of 18.2 days per hospitalization at a cost of \$29,342. Cost techniques were applied to care statistics for Illinois PWAs. The in-patient cost of hospitalization for PWAs as of August, 1985 is projected at 19.3 million dollars. Five (5) year projections based on a 10 month doubling time yields 19,136 cases of AIDS, 750,131 hospital days, and an adjusted, cumulative cost of \$1,574,484,868.

DEAFT
For Discussion Purposes Only

# Estimated Population In Need of AIDS-Related Services

			Po	Population In Need of Service					
Date	New AIDS Cases	Total AIDS Cases	AIDS -50% Patality	ARC	Other HTLV III Positive	Total In Need Of Service	Total HTLV III Positive		
8/85	150	299	150	1,495	5,681	7,326	7,475		
6/86	299	598	299	2,990	11,362	14,651	14,950		
4/87	598	1,196	598	5,980	22,724	29,302	29,900		
2/88	1,196	2,392	1,196	11,960	45,448	58,604	59,800		
12/88	2,392	4,784	2,392	23,920	90,896	117,208	119,600		
10/89	4,784	9,568	4,784	47,840	181,792	234,416	239,200		
8/90	9,568	19,136	9,568	95,680	363,584	468,832	478,400		

Estimates from Illinois Department of Public Health,
Office of Health Policy and Planning/Office of Health Services

# THE CITY OF CHICAGO

For the cumulative number to date of AIDS cases in Chicago see chapter III Epidemiology (CDC Weekly Surveillence Report of September 28, p. 3). The following pages simply offer a breakdown of Chicago AIDS cases in 1987 as well as a projection of cases until 1991.

The City of Chicago, in June 1986, received a report on AIDS from a broadly based special advisory panel. This AIDS Advisory Panel paralleled, on the local level, the Illinois AIDS Interdisciplinary Council which advised the State. Because of its importance, and in order to allow for a detailed comparison, this document is also attached in full to the present report (see Sources: Printed Material).

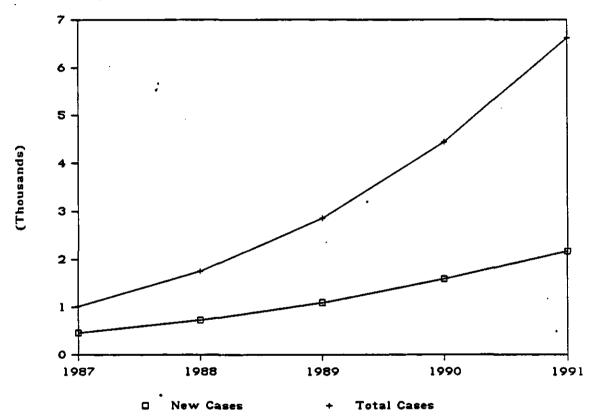
In addition, the City received advice from The Center for Urban Research and Policy Studies of the University of Chicago. The Table of Contents and Executive Summary of this planning paper, "Policy Making for AIDS Care in Chicago," are reproduced on the pages following the Chicago epidemiological data.

	Jan	Feb	Mar	Apr	May	Jun	Ju1	Aug	Total
GRAND TOT/LS (adolercent/ adult, children)	22	25 	28	36	42	46	37	. 33	269
ADOLESCENT/ADULTS									
TOTAL CASES	21	23	28	36	42	46	37	33	266
MALES PEMALES	20 1	22 1	27 1	3 <b>6</b>	40 2	46 0	35 2	29 4	ι 255 11
White Black Hispanic Other	12 8 1 0	15 6 2 0	15 9 4 0	17 16 3 0	20 19 3 0	27 <sup>.</sup> 17 2 0	21 13 2 1	14 11 8 0	141 99 25
Homosexual/Bisexual IV Drug user, Heterosexual IV Drug user, Homosexual/Bisexual Hemophiliac Heterosexual Contact Transfusion Recipient None of the above/Others	17 2 1 0 0	19 3 0 0 0	19 2 2 0 0	28 2 3 0 0	35 2 1 0 2 1	41 2 2 0 0	30 2 1 0 1 2	24 2 1 1 1 3	213 17 11 1 4 11
CHILDREN (under 13 yr.) TOTAL CASES	1	2	0	0	0	0	0	0	3
Males Pemales	1 0	2 0	0	<b>0</b> 0	0	0	0	0	3
White . Black Hispanic Other	0 1 0	0 1 1 0	. 0 0 0	0 0 0	0 0 0	0 0 0	0 0 0	0 0 0	0 2 1 0
Born of Parent(s) with HIV Infection/at risk	1	2	0	0	0	0	0	0	3
Hemophilia Transfusion/Blood Product Recipient None of the above/Others	0 0 0	0 0 0	0 0	0 . 0	0 0	0 0 0	0 0 0	0 0 0	0 0
DEATHS									
Total Cases Newly reported Previously reported Adults/Adolescent Children	13 4 9 13 0	8 3 5 8 0	18 8 10 18 0	21 9 12 21 0	22 11 11 22 0	17 8 9 17	18 6 12 17	15 5 10 15 0	132 54 78 131 1

<sup>\*</sup> Case deletions have occured one each for April & June requiring a slight adjustment in the previously reported data.

# **Projections**

# Projections of AIDS Cases in Chicago



# POLICYMAKING FOR AIDS CARE IN CHICAGO

Edward F. Lawlor, Elaine D. Blatt, Hilarie A. Koplow, Karyn A. Reif, Jeanette C. Wilson

The Center for Urban Research and Policy Studies

Working Paper Series

The University of Chicago

August 1987

# Policymaking for AIDS Care

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# **Executive Summary**

The recent controversy about public policy for preventing the spread of AIDS has obscured an equally important public policy issue: the development of a system of care for individuals who already have contracted AIDS. In Chicago, approximately 320 individuals currently are HIV infected and have expressed symptoms that meet the defintion of AIDS; we project that by the end of 1991 nearly 7,000 individuals in the City will have contracted the disease and require care. We expect that roughly 3,000 individuals with AIDS will be alive in Chicago at the end of 1991. By 1991, AIDS will become the leading cause of death for young adults in Chicago, roughly doubling the total deaths currently experienced by that population.

Based on our projections, inpatient costs will be \$50-265 million for that year alone. Outpatient care could cost in excess of \$3 million a year. On the public ledger, between 25 and 40 percent of these patients will be eligible for Medicaid and, if current patterns continue, roughly 15 percent will receive their care at Cook County Hospital.

Perhaps the single biggest unknown factor in the AIDS epidemic is the extent and consequences of AIDS Related Complex (ARC). Estimates of ARC incidence range from two to ten times the number of AIDS cases; however, these estimates are at best rough guesses. At present, very little is being done to address the issues of the ARC patient. It is clear, however, that ARC will by itself present difficult policy problems and demands for intervention over and above those generated AIDS cases as defined by the CDC.

In order to provide access and quality care for AIDS patients, attention must be paid to a number of dimensions of the delivery system not typically considered part of the health care system. Although housing, social services, counseling, and hospice care are at the margins of the debate about the overall health care delivery system, these programs take on great significance for individuals with AIDS. Inpatient care for AIDS patients is expensive, yet many patients will have no insurance, inadequate insurance, or Medicaid. Difficult choices with economic, political, and ethical content will have to be made about the locus of inpatient care, the appropriate standards of inpatient care for AIDS patients, and who will bear the costs of that care.

The formulation of AIDS policy for the City of Chicago can benefit from a survey of programs in New York and San Francisco, the two cities that have been hit hardest by AIDS. By examining the programs of other cities and states, policy recommendations can begin to emulate the more innovative and effective approaches while avoiding some of the mistakes. In many respects, the experience being gained in San Francisco and New York is an important foreshadowing of the problems and prospects of delivering AIDS care in Chicago. In 1991, the numbers and concentration of AIDS cases in Chicago will fall between the current numbers in New York and San Francisco.

To the degree possible, Chicago should attempt to emulate San Francisco's utilization of community resources and minimization of inpatient hospital care. Partly as a result of the availability and utilization of community resources, San Francisco exhibits hospital lengths of stay for AIDS patients that are one half the duration of those in New York City. To be sure, San Francisco has in place a highly developed set of community resources, but the city and state accomment have been effective in structuring flexible arrangements with these providers, as illustrated by the Shanti project.

# THE AIDS FOUNDATION OF CHICAGO

In spite of its title, which is similar to that of the San Francisco AIDS Foundation, the AIDS Foundation of Chicago can in no way be compared to it. Housed in two rooms provided free of charge by a local hospital, the AIDS Foundation of Chicago has a staff of three. Their main function to date is coordination and referral among the various Chicago groups and organizations dealing with AIDS. There is undoubtedly potential for future growth, but at this time the AIDS Foundation of Chicago does not seem a major force in the prevention struggle. The various elements engaged in this struggle in Chicago form a Service Providers Council. The membership list is reprinted on the following pages.

# AIDS FOUNDATION OF CHICAGO Service Providers Council

AIDS Assistance Association Emergency provisions/grants 787-6410

AIDS Pastoral Care Network
Multi-denominational spiritual
services
942-5571

American Civil Liberties Union Legal counsel 427-7330

Chicago Area AIDS Task Force Forum for care and prevention strategies 467-6370

Children's Memorial Hospital
Full pediatric medical services
for patients
880-6319

COMPRAND (Comprehensive Research and Development) Health education 375-8200

Cook County Hospital
Full medical services
633-7810

Genesis House Counseling and risk reduction for prostitutes 324-0494

Hispanic AIDS Network
Forum for providers in the
Hispanic community
472-3939

Horizons Community Services Psycho-social counseling 472-6469

Human Resources Dvlpmt. Inst. Education and prevention for inner city residents 939-0888 AIDS Home Nursing Home care/case management 288-2253

Alexian Brothers Assisted Living Center Group residence and care 640-7550

<u>Catholic Charities</u>
Counseling/emergency services
236-5172

Chicago House and Social Service Agency Residences 248-5200

City of Chicago -Department of Health Prevention activities/ HIV testing 744-4372

Cook County Department
of Health
Prevention activities/HIV
testing
865-6418

Gateway Foundation Counseling and education for IV drug abusers 324-0494

Hemophilia Foundation Education and case management for hemophiliacs 427-1495

<u>Horizon Hospice</u> Services for the terminally ill 871-3658

Howard Brown Memorial Clinic Testing and prevention services; living assistance programs 871-5777 Illinois Alcoholism and Drug Dependence Association Education and support services to recovering addicts and drug abusers 472-0731

Interventions
Education and referral for drug abusers
663-0817

Michael Reese Hospital Full medical services 791-2750

Substance Abuse & Alcoholism Treatment Center Counseling and referral 829-3002

Travelers & Immigrants Aid Prevention and education programs for Hispanics, youth, and the homeless 435-4555

University of Illinois Hospital
Dept. of Medical Social Work
Full medical service
996-6916

Illinois Dept. of Public Health AIDS Activity Office Coordination of state AIDS programs 917-4846

Illinois Masonic Medical Ctr. Full medical care 883-7048

Kupona Network
Education and counseling to the Black community
235-6123

Pilsen-Little Village Community Mental Health Center
Bilingual, bicultural prevention and treatment
523-6860

Treatment Alternatives to to Street Crimes Education programs for drug abusers 787-0208

Women Organized for Reproductive Choice/Chicago Women's AIDS Project Counseling for women at risk 786-0036

For General Information Call 1-800-AID-AIDS

# THE HOWARD BROWN MEMORIAL CLINIC

The Howard Brown Memorial Clinic was named in honor of Howard J. Brown, M.D., a native of Peoria IL, who was New York City's first Public Health Administrator. In this position he publicly revealed his homosexuality, attracting national attention and becoming a model for many "closeted" physicians all over the country. In 1974, a number of medical students and community volunteers in Chicago began a low-cost confidential STD clinic, naming it after Dr. Brown. In 1978 the clinic was chosen by the Centers for Disease Control to participate in a nationwide Hepatitis-B Prevalence Study. This study, in turn, prepared the clinic to deal with the challenge of AIDS.

Today, Howard Brown Memorial Clinic still offers the full range of STD treatment and counseling, providing services for more than 700 patients per month. The clinic also offers confidential HIV antibody testing and counceling, AIDS clinical screening and referral and support services for people with ARC and AIDS. The clinic also offers extensive AIDS education programs through a speakers bureau, seminars and the production and distribution of publications. It also operates a state-wide hotline under a grant from the Illinois Department of Public Health. Finally, Howard Brown Memorial Clinic, in conjunction with the Northwestern University Medical School, also conducts a number of AIDS research projects.

Howard Brown Memorial Clinic is a non-profit, tax-exempt organization which, apart from its research, counseling and education grants, needs private donations in order to remain active.

In the city of Chicago, the Howard Brown Memorial Clinic is undoubtedly the major positive factor in fighting AIDS.

# THE ILLINOIS ALCOHOLISM AND DRUG DEPENDENCE ASSOCIATION

The Illinois Alcoholism and Drug Dependence Association (IADDA) is trying to carry the concept of AIDS prevention into the IV drug-using population of Chicago. That is to say, the drug users are visited "on location" in the streets and "shooting galleries" by trained councelors and "street workers", some of whom are ex-drug users themselves. Bella H. Selan, the AIDS project director of IADDA in Chicago, has, together with two equally recognized experts in the field, described the special problem of AIDS prevention in the IV drug scene. This very recent article is reproduced on the following pages. Following it is an IADDA information handout.



# The Special Problems of Intravenous Drug Users as Persons at Risk for AIDS

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Bella H. Selan, M.S., AIDS Project Director, Illinois Alcoholism and Drug Dependence Association, Chicago

Don C. Des Jarlais, Ph.D., AIDS Research Coordinator, New York State Division of Substance Abuse Services

## KEY POINTS

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- 1. In the U.S., intravenous drug users are the major source of heterosexual and *in utero* transmission of HIV.
- 2. Intravenous drug users know much more about AIDS than commonly is assumed. Furthermore, many of them try to reduce their risk of becoming infected and try to protect others as well.
- 3. On a small scale, drug users have begun to organize their re-

sponse to the AIDS epidemic. Where feasible, public health encouragement of such efforts can be valuable.

4. AIDS prevention efforts should include expansion of drug treatment facilities, outreach projects to inform IV drug users and their sex partners about their risks and options, voluntary antibody testing, and experimentation with methods to make sterile injection equipment available to IV drug users.

IV drug users are the second largest group of persons in the U.S. at risk for AIDS. Fully 16% of U.S. AIDS cases have been IV drug users, and another 8% have been men who have both used IV drugs and had sexual relations with other men. Although the great majority of AIDS cases resulting from IV drug use have been in the New York metropolitan area, seroprevalence data on human immunodeficiency virus (HIV) infection among IV drug users indicate that the case totals soon will begin ris-

ing in many other cities. Once HIV infection becomes established among IV drug users in a city, the great majority of heterosexual and in utero transmission cases are due to transmission by IV drug users. In New York City, IV drug users have been the probable source of infection in 93% of heterosexual transmission cases and in 80% of in utero transmission cases. Infection rates among IV drug users seem to vary considerably from city to city. While over half of them have been infected in New York City,

Edinburgh, Scotland, and Milan, Italy, less than 5% of them have been infected in New Orleans, Los Angeles, and Glasgow, Scotland. IV drug users in San Francisco, Chicago, and Amsterdam have intermediate levels of infection.2-9 While we do not fully understand why cities differ in seroprevalence, we believe it is largely due to differences in the times HIV first was introduced among IV drug users in a given city. Social factors that affect patterns of sharing injection equipment also may influence the spread of the virus among users.

Epidemiologic studies of the risk factors for infection have been conducted for a number of cities. 2.5.10 Drug injection frequency seems to be the most important determinant of who gets infected. This reflects the fact that before AIDS becomes known to IV drug users as an injection-related risk in a given area, the sharing of syringes is a routine and valued activity. 11.12 A second determinant of exposure is the extent to which injection occurs

either in "shooting galleries" (places where users go to take drugs out of the streets, and where they typically rent syringes and then return them to the shooting gallery owner for reuse by others) or "dealers' houses" (where the drug seller either lends or rents syringes for customers to use). Shooting galleries and dealers' houses seem to provide a pathway for HIV to travel between otherwise isolated friendship groups. 2.10

# A Comparison of the Responses of IV Drug Users and Gays

Most American persons with AIDS have been gay males. The gay response to AIDS has involved a remarkable degree of organizational and educational activity, major disagreements among gays about how to respond to the epidemic, and a considerable change in individual behavior that has led to a drastic slowing of the new infection rate among gay males in San Francisco. 13,14 IV drug users are much less organized and have not been able to change individual behaviors as much, although both organizational efforts and individual behavior change have occurred.

In a small 1984 survey, in which we interviewed 22 gay men in the streets of New York City and 59 current and recent IV drug users who were patients at a Manhattan methadone clinic, we found substantial differences between gays and IV drug users in terms of what they knew about AIDS and the extent to which they had attempted to protect themselves. Nevertheless, in spite of these differences, we were impressed by the extent to

which the drug users knew that drug injection and sharing syringes put them at risk, and by the fact that a majority of the drug users reported that they had attempted to protect themselves by risk-reducing changes in behavior. 18 Serologic evidence indicated that these reported behavioral changes actually were occurring;15 and field observations of and interviews with sellers of illicit syringes supported the evidence of a considerable attempt by IV drug users to protect themselves by buying and using sterile syringes. 16,17 In lectures given by one of the authors at seven Chicago drug treatment programs, it was found that users who had previously attended other AIDS lectures actively recruited other users to attend the talk. They were adamant that attention be paid to the fact that infected drug users can spread HIV to children. As one woman ex-user put it, "You junkies want to kill yourselves, OK, that's your business. But don't give me a baby with AIDS; I couldn't handle it."

IV drug users have tried to organize against AIDS, too. This has been most visible in Holland, where preexisting drug users' unions have become involved in efforts to prevent AIDS. In the U.S., such efforts have involved persons who used to inject drugs to a greater extent than they have involved current users. Most notably, exusers in New York have formed ADAPT. ADAPT enlists the energies of ex-users, current users, health professionals, and other volunteers for efforts on AIDS prevention, AIDS policy, and support to the ill. Its activities include outreach work among drug users in the streets of New York; negotiating with shooting gallery owners to make sure they have sterile works, bleach to clean used works, sterile cookers, sterile cotton, and trash cans (in which to deposit used materials) for IV drug users to use; visits to drug users with AIDS or other HIV-related diseases who are in jail, in order to provide them with a support system while they are incarcerated and with assistance when they get out; and making their views known on public issues such as experimental proposals to make sterile syringes available to IV drug users to reduce infection.

Thus, IV drug users cannot be thought of as persons with no ability to protect themselves and others. They have attempted individual risk reduction, and there has even been some attempt to set up formal organizations of IV drug users to deal with their problems. Indeed, one of the authors of this paper has attended meetings of a Dutch IV drug users' organization. At this meeting, they were quite able to discuss organizational policy and strategy, in spite of the fact that many of them injected heroin just before the meeting and that a few of them were smoking high-purity heroin during the meeting.

# Factors Affecting Risk-Reduction Efforts

Although the stereotypes of the IV drug user overstate the incapacitating effects of drug use, it is nonetheless true that consistent risk reduction and transmission reduction are extremely hard for IV

drug users. Their addictions often consume most of their time, energy, and attention, since they need to get the money, then get the drugs, and then take the drugs. This adds up to a lot of time and effort, so they have little to spare for risk reduction. If their access to drugs is delayed past the point where they start feeling withdrawal pains, they are impelled physically and psychologically to get and take the drugs as quickly as possible. Almost every drug user we have talked to tells us that, under these conditions, they will use any syringe that is available. This is worsened by the fact that acquiring the drug can sometimes provoke the beginning of withdrawal. 18,11 Thus, in a series of focus groups with Chicago users, one of the authors of this paper asked the users if they followed the recommendation to soak the syringe and needle in a bleach solution for 15 to 20 minutes prior to rinsing them and using them to inject the drugs. The users gave this a good laugh, and said that if you had the drugs to get high, you wouldn't wait this long. One man said that he had a diabetic sister who lives five minutes from his shooting gallery, but reported: "She gets needles and works by the carton, but I would never take the time to go there and pick up a new needle. I'd rather share or buy one from the dealer." Similar sentiments have been widely reported to us in New York, too, but with one difference; in Chicago, the epidemic is relatively new. As increasing numbers of New York drug users have gotten AIDS, IV users in the city are increasingly trying to avoid using infected

Furthermore, many (but not all) IV drug users have few friends and live by manipulating their environments and the people around them. Some of them use needles together as an expression of nonmanipulative friendship in which their greatest value (using drugs) is shared. One IV user expressed it this way: "When I am high, I want my old lady to feel the same way. I want to be the one who gives her the high. I want her to use my needle." Of course, there are many IV drug users who never share works because they are the only thing they own, and who never borrow anyone else's needle. Most of these "clean" users, however, admit that they were initiated into IV use with someone else's needle.

On top of these inherent difficulties in protecting themselves, IV drug users also have to face socially created difficulties. For example, every AIDS education program that we know of gives users the following advice: "Don't shoot up. But if you do shoot up, make sure that you always use sterile works and that you never share works." Users who seek to follow the advice about sterile works immediately come up against a legal problem. In many states, including New York, New Jersey, Connecticut, California, and Illinois, it is illegal to sell syringes without a prescription; prescribing syringes for IV drug use is forbidden; and possession of syringes and other drug paraphernalia is outlawed. In practice, this means that syringes are relatively expensive (\$3 on the streets of New York, which is a lot of money that could be spent on drugs), so users try to save this money by re-using them or sharing them. Furthermore, the laws against possession of paraphernalia mean that users who are on probation or parole often prefer renting works in shooting galleries or borrowing them from friends, rather than risk being searched (and thus, being sent back to prison for parole violation).

Even IV drug users who violate the law every day by buying and injecting drugs, as well as by illegally obtaining money to buy their drugs, have a curious fear of being caught by the police with works in their possession. In interviews in Chicago, several users said that this is because the police are particularly rough on them for this offense and often accuse them of crimes they didn't even commit.

IV drug users often have to face social pressure from other users to let them use their works. In current IV user subculture, such requests are considered legitimate, and refusing to let a friend use your works is seen as an irresponsible. unfriendly act. Indeed, such refusals can lead to other users seeing you as unreliable and thus, to their breaking what may be your last friendships.

As a result of these legal, psychochemical, and social pressures, consistent risk reduction is difficult for IV drug users. It seems likely that it requires social support from other drug users. Indeed, in the study of 59 methadone patients referred to above, we found that the users who were most likely to

# XANAX\* Tablets

#### CONTRAINDICATIONS

Patients with sensitivity to this drug or other benzodiazepines and in acute narrow angle glaucoma.

### WARNINGS

Not of value in psychotic patients. Caution patients against hazardous occupations requiring complete mental alertness and about the simultaneous ingestion of alcohol and other CNS depressant drugs.

Benzodiazepines can cause fetal harm in pregnant women. Warn patients of the potential hazard to the fetus. Avoid during the first trimester.

#### PRECAUTIONS

General: The dosage of XANAX Tablets should be reduced or withdrawn gradually, since withdrawal seizures have been reported upon abrupt withdrawal. If XANAX is combined with other psychotropics or anticonvulsant drugs, consider drug potentiation (see Drug interaction section). Exercise the usual precautions regarding size of the prescription for depressed or suicidal patients. In elderly and debilitated patients, use the lowest possible dosage (see Dosage and Administration). Observe the usual precautions in treating patients with impaired renal or hepatic function.

Information for Patients: Alert patients about: (a) consumption of alcohol and drugs. (b) possible fetal abnormalities. (c) operating machinery or driving. (d) not increasing dose of the drug due to risk of dependence, (e) not stopping the drug abruptly. Laboratory Tests: Not ordinarily required in otherwise healthy patients. Drug Interactions: Additive CNS depressant effects with other psychotropics, anticonvulsants, antihistamines, ethanol and other CNS depressants. Pharmacokinetic interactions with other drugs, e.g., cimetidine, have been reported. Drug/Luboratory Test Interactions: No consistent pattern for a drug or test. Carcinogenesis, Mutagenesis, Impairment of Fertility: No carcinogenic potential or impairment of fertility in rats. Pregnancy: See Warmings. Nonteratogenic Effects: The child born of a mother on benzodiazepines may be at some risk for withdrawal symptoms and neonatal flaccidity. Labor and Delivery: No established use. Nursing Mathers: Benzodiazepines are excreted in human milk. Women on XANAX should not nurse. Pediatric Use: Safety and effectiveness in children below the age of 18 have not been established.

### ADVERSE REACTIONS

Side effects are generally observed at the beginning of therapy and usually disappear with continued medication. In the usual patient, the most frequent side effects are likely to be an extension of the pharmacologic activity of XANAX, e.g., drowsiness or lightheadedness.

Central nervous system: Drowsiness, lightheadedness, depression, headache, confusion, insomnia, nervousness, syncope, dizziness, akathisia, and tiredness/ sleepiness. Gestrointestinel: Dry mouth, constipation, diarrhea, nausea/vomiting, and increased salivation. Cardiovascular: Tachycardia/palpitations, and hypotension. Sensery: Blurred vision. Musculoskeletal: Rigidity and tremor. Cutaneous: Dermatitis/allergy. Other side effects: Nasal congestion, weight gain, and weight loss. Withdrawal seizures have been reported upon rapid decrease or abrupt discontinuation of XANAX. (See Precautions.)

in addition, the following adverse events have been reported with the use of benzodiazepines: dystonia, irritability, concentration difficulties, anorexia, transient amnesia or memory impairment, loss of coordination, fatigue, sedation, slurred speech, jaundice, musculoskeletal weakness, pruritus, dipiopia, dysarthria, changes in libido, menstrual irregularities, incontinence and urinary retention.

Paradoxical reactions such as stimulation, agitation, increased muscle spasticity, sleep disturbances, and hallucinations may occur. Should these occur, discontinue the drug.

During prolonged treatment, periodic blood counts, urinalysis, and blood chemistry analysis are advisable. Minor EEG changes, of unknown significance, have been observed.

## DRUG ABUSE AND DEPENDENCE

Physical and Psychological Dependence: Withdrawal symptoms have occurred following abrupt discontinuance of benzodiazepines. Withdrawal seizures have occurred upon rapid decrease or abrupt discontinuation of therapy. In all patients, dosage should be gradually tapered under close supervision. Patients with a history of seizures or epilepsy should not be abruptly withdrawn from XANAX. Addiction-prone individuals should be under careful surveillance. Controlled Substance Class: XANAX is a controlled substance and has been assigned to schedule IV.

## OVERDOSAGE

Manifestations include somnolence, confusion, impaired coordination, diminished reflexes and come. No delayed reactions have been reported.

# DOSAGE AND ADMINISTRATION

Dosage should be individualized.

The usual starting dose is 0.25 to 0.5 mg, t.i.d. Maximum total daily dose is 4 mg. In the elderly or debilitated, the usual starting dose is 0.25 mg, two or three times daily. Reduce dosage gradually when terminating therapy, by no more than 0.5 milligram every three days.

## HOW SUPPLIED

XANAX Tablets are available as 0.25 mg, 0.5 mg, and 1 mg tablets.

Caution: Federal law prohibits dispensing without prescription.

Upjohn THE UPIOHN COMPANY
Kalamazoo, Michigan 49001 USA

**B**-5-S

3-7364 February 1987 have attempted to protect themselves against AIDS were those who told us that their friends were also trying to protect themselves. Thus, support from friends seems to be important. A more general change in the subculture of IV drug users, to legitimate the refusal to share works and to discredit asking to share, may well be needed to make risk reduction more frequent. Changing the legal environment of drug use might also enable more consistent risk reduction.

## **Prevention Programs**

Prevention programs for IV drug users should aim to prevent infection of participants via intravenous injection, prevent intravenous transmission of HIV by infected users, and protect IV users from heterosexual infection or transmission. (See 19 for a fuller discussion of prevention programs.) Drug treatment programs attempt to get participants to stop using drugs. To the extent that they are successful, this prevents new infections; it also prevents infected clients from intravenously transmitting HIV to others. Many programs in the New York area also have been teaching clients about safer ways to inject drugs as well as about safer sex and the need to practice it if they might be infected with HIV. Our studies indicate that, although many clients drop out of treatment, those who remain in treatment considerably reduce the extent to which they may intravenously transmit HIV.20

Outreach programs have been instituted in a number of areas to try to educate IV drug users and their sexual partners about the risk

of AIDS and about how to protect themselves. Typically, these projects employ ex-users, in order to maximize communication between outreach workers and persons on the street. In their efforts to get drug users to protect themselves, they often use an approach that presents a hierarchy of options about how such protection can be obtained. In this hierarchy, quitting drug injection through entry into drug treatment is presented as the option most likely to be effective. If this is not chosen, never sharing works is suggested as the next most effective approach. Finally, if works must be shared, decontaminating them with bleach is the suggested option.

- Testing for antibodies to HIV has been the subject of considerable controversy. In the case of IV drug users, little information is yet available about the effects of testing. What evidence there is suggests that voluntary antibody test-, ing, with careful and well-thoughtout pre-test and post-test counseling, may lead to responsible risk and transmission reduction efforts on the part of the tested drug users. 21,22 These studies, however, examined the effects of testing on users in treatment programs, so it is difficult to use them to predict the effects of testing on street drug users. We also would suggest that attempts to force users to be tested are likely to backfire. Such attempts would cause users to avoid treatment programs (and thus, lead to an increase in the amount of IV drug injection taking place) and also would drive them further underground (and thus,

make it harder for people to know whether a potential sex partner is a current or former IV drug user).

Ex-users (together with health professionals and, to a limited degree, current users) in New York have set up an organization (ADAPT) to provide information, to encourage behavioral change and subcultural adaptation, to assist the ill, and to provide a voice for drug users during this crisis. In the Netherlands, previously existing drug users' "unions" have begun to conduct AIDS education and, in some cities, have set up "needle exchanges" to provide users with sterile syringes. Official needle exchanges have been suggested in several states in the U.S. in order to make it more feasible for IV drug users to avoid injecting with infected equipment. To date, such programs have not been accepted, the major reason for rejection being a fear of encouraging drug use by seeming to legitimize it. However, official needle exchanges have been established in the Netherlands, Great Britain, and Australia. So far, there is no evidence that any harmful effects have resulted, and the program in Amsterdam seems to have reduced the sharing of injection equipment by drug users who take part in it.23

Finally, concern has sometimes been expressed that prevention efforts might contradict each other. Most often, this has taken the form of a fear that outreach efforts or other projects that teach drug users how to inject more safely might reduce their motivation to seek treatment. This has not occurred. The various projects seem to mesh

well. In New Jersey and Chicago, for example, the outreach projects led to a considerable increase in the demand for drug treatment.24 The one area where a serious problem has been encountered is the reverse of what had been feared. Outreach programs encourage applications for treatment, but in many areas (including New York City and Chicago), there is a critical shortage of available space in treatment programs. Applicants are told that they have to wait several months before admission, and this is something that IV drug users find unacceptable. One of the most pressing public policy needs in fighting AIDS, then, is the provision of additional funding for drug treatment programs. Finding ways to keep local opposition to programs from preventing a desperately needed expansion of facilities is equally important.

# The Role of Physicians

Physicians who give medical care to IV drug users can help in AIDS prevention efforts. First, though, it is important to realize that there are many IV drug users who do not fit the stereotype of IV drug users as lower class and as minorities. In New York State, for instance, we estimate that there are at least 22,000 persons with annual incomes of \$25,000 or more who may have been at risk for HIV infection through injecting drugs.<sup>25</sup>

Doctors should make sure that all patients are aware of the risks of AIDS and how the disease is transmitted. Patients who shoot drugs should be counseled to seek treatment and should be aware of the

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different treatment approaches that exist. Methadone maintenance treatment is the largest treatment modality. It provides opiate users with methadone, which can both block the craving for heroin and prevent heroin from producing its effects. Methadone treatment also involves counseling and other services that can help a user avoid drug use. Even among those clients who continue drug use (typically cocaine), methadone reduces drug injection frequency and, by reducing their drive to get money and heroin, may give them more time

for risk-reduction efforts. Drugfree therapeutic communities provide residential care involving strict adherence to rules that emphasize "no drugs; our lives need new directions; we are a family and thus, look out for each other." This approach, though expensive and time consuming, can be successful for drug users who are really committed to changing their lives.

All patients who may use drugs should be counseled about the risks involved and about how to minimize them. This should include the dangers of sharing drug injection equipment, and ways of negotiating situations so as to avoid social pressures to share; methods of decontaminating such equipment; sexual transmission; and safer sex. Patients who may have sex with drug injectors should be warned about the dangers of viral transmis-

Finally, since these may be difficult subjects for doctors to raise with their patients, the American Medical Association has a number of AIDS-related programs that may offer useful advice about how it can be done. 4

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21. Casadonte PP. Des Jariais DC, et al: Psychological and behavioral impact of learning HTLV-III:LAV antibody test results. Presented at the International Conference on AIDS, Paris. June 1986.

22. Cox CP. Selwyn PA, et al: Psychological and behavioral consequences of HTLV-III:LAV antibody serving and conference approximately approxim

testing and notification among intravenous drug abusers in a methadone program in New York City. Presented at the International Conference on AIDS, Paris, June

23. Buning EC, van Brussel GHA, et al: Amsterdam's drug policy and its implications for controlling needle sharing. In: National Institute on Drug Abuse

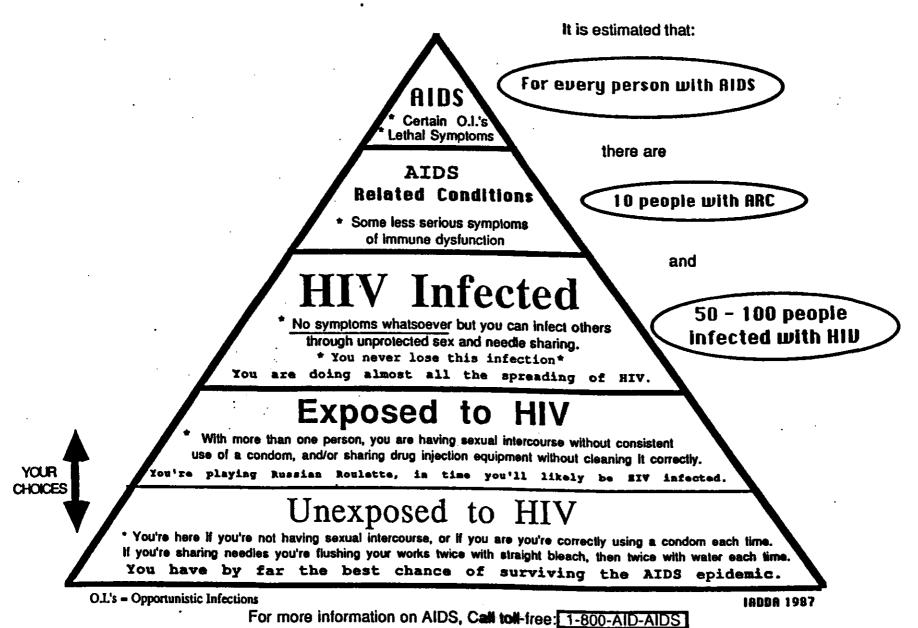
Research Monograph. R Batties (Ed), in press.

24. Jackson J, Rotkiewicz L: A coupon program:
AIDS education and drug treatment (abstract no.
TH.5.2). Presented at the Third International Conference on AIDS, Washington, DC, June 1987.

25. Friedman SR, Des Jartais DC: AIDS and the

intravenous drug user: common misconceptions. Medi-cal Aspects of Human Sexuality, in press.

# The AIDS Pyramid: Where do YOU fit in?



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# THE AIDS PASTORAL CARE NETWORK

The AIDS Pastoral Care Network is a new effort in Chicago to offer spiritual and religious support to AIDS patients and those who care for them. The program admission statements are reprinted on the following pages.

Pastoral volunteers bring faith and understanding to clients, families and friends.



The AIDS Pastoral Care Network consists of men and women professionals from different faith traditions, who are trained to offer pastoral care to their sisters and brothers who are affected directly and indirectly by AIDS. They will assist them in an open and nonjudgmental way, respecting each person's background and faith tradition.

Since September 1985 more than 30 pastoral volunteers have cared for over 50 PWAs in addition to their families and friends.

APCN volunteers minister to PWAs, PWARCs and their loved ones by providing pastoral services, counseling and liturgical services as appropriate.

In particular APCN ministers to:

- ▶ the gay and lesbian community and other groups affected by the disease:
- ▶ those who provide medical, psychosocial and other forms of care;
- those who fear not only the disease but even fear members of the affected communities.

Pastoral volunteers are committed to minister both within the affected communities and within the faith community in order to provide a pastoral bridge between the faith community and groups marginalized by the disease or other factors.

In the midst of suffering volunteers affirm the presence of hope and meaning by empowering those affected by the disease to locate hope and meaning in places appropriate to their spirituality.

Volunteers are convinced that authentic pastoral care proceeds from a wholeness that addresses political and religious issues, avoidable and unavoidable suffering, social justice and pastoral care.

Finally, volunteers affirm that their connections to and influence with religious leaders and institutions require them to play an assertive role in opposing actions of those leaders or institutions which adversely affect the people with whom and for whom they minister.

# MISSION STATMENT OF AIDS PASTORAL CARE NETWORK (APCN)

The AIDS Pastoral Care Network ministers to those affected by the AIDS epidemic in the greater Chicago area: 1) those most directly affected by AIDS, people with AIDS (PWAs) and people with an AIDS-related condition (PWARCs); and 2) others affected by AIDS, especially the loved ones—families of origin and election—as well as friends of PWAs and PWARCs.

Our ministry to PWAs, PWARCs and their loved ones is to provide pastoral services, including counseling and liturgical actions, to them.

In particular we minister to:

- --members of communities affected by AIDS, and in a special way to the gay community which has been hit so terribly hard by AIDS and which has provided the backbone of the psychosocial response to AIDS;
- -- those who provide medical, psychosocial and other care to persons affected directly by the epidemic;
- -- those who fear not only the disease but even fear members of the affected communities.

Our ministry to affected communities, caregivers and society stems from our commitment to educate them about the pastoral, spiritual and religious implications of AIDS and to provide direct pastoral services to them when these are needed.

We commit ourselves to minister both within the gay and lesbian community as well as within the religious community because we believe this is the only way to provide effective pastoral care in the present situation, and because we are fully cognizant of the deep divisions and tensions which exist between members of the gay and lesbian community and their faith traditions as a result of leaders and institutions within those traditions. We further commit ourselves to provide this pastoral bridge between the religious community and any marginalized group affected by the AIDS epidemic.

We understand that, although much of the suffering connected with AIDS is unavoidable and that we are nearly powerless to combat the biological processes which take over after the HIV infection has entered a person's body, nevertheless we affirm the presence of hope and meaning in such situations by seeking to empower those we serve pastorally to locate that hope and meaning in places appropriate to their spirituality.

As pastoral ministers we are committed to work for social justice because we are aware that prejudice, discrimination and alienation have increased in unconscionable ways the already heavy burden of suffering of people affected by AIDS. We have done this in the past through our educational efforts. We are willing in the future to seek other ways, including playing a

"political" as well as "religious" role, for we believe authentic pastoral care proceeds from a wholeness that addresses political and religious issues, avoidable and unavoidable suffering, social justice and pastoral care.

We further believe that our connections to and influence with religious leaders and institutions require us to play an assertive role in opposing any actions of these leaders or institutions which adversely affect those with whom and for whom we minister.

For more intermation contact:

REV. CARL E. MEIROSE, S.J. EXECUTIVE DIRECTOR AIDS PASTORAL CARE NETWORK c/o AUGUSTANA HOSPITAL 2035 NORTH LINCOLN AVENUE CHICAGO, ILLINOIS 60614 312/975-5180

October 7, 1986

# VIII. AIDS PREVENTION IN MINNEAPOLIS

The State of Minnesota, with a mostly white population of Scandinavian origin, is, at the present time, a "low incidence state" with regard to HIV-infection and AIDS. Nevertheless, the state has made extraordinary efforts to prepare itself for the expected growth of the epidemic. For this reason, it seems appropriate to take a closer look at Minnesota AIDS prevention programs.

In the present context the state is also interesting for another reason: State law requires the reporting and registration of all persons testing positive for HIV antibodies (also of ARC and AIDS patients, of course). Thus, Minnesota is the only state among those covered in this report that has a mandatory reporting system ("Meldepflicht") for infected individuals.

# THE STATE OF MINNESOTA

The present epidemiological situation in Minnesota is summarized in a recent surveillance report reproduced on the next page. This is followed by a summary of past, present and projected state AIDS budget figures. Finally, a longer term projection prepared by researchers at the Minnesota Department of Health completes the epidemiological picture.

Following the epidemiological reports are documents relating to a Minnesota AIDS Physician Survey and the mandatory reporting of HIV-infection.

The Minnesota Department of Health has also issued an information packet for the general public providing an outline of its activities together with some informational material. This instructive packet is attached in full to the present report (see Printed Material, II, 2).

# MINNESOTA DEPARTMENT OF HEALTH ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) WEEKLY SURVEILLANCE REPORT September 28. 1987

1. NUMBER OF CASES 237 (Meeting Old Case Definition) (Meeting Revised Case Definition) TOTAL DEATHS 146 NUMBER OF CASES <u>22</u> TOTAL CASES 2. AGE CASES (%) Under 13 **(<1)** City of Minneapolis 138 (53) (0) 13-19 City of St. Paul 35 (14) (24) 20-29 62 7 County metro 51 (20) 30-39 128 (50) (other than M/SP) (19)40-49 Greater Minnesota 35 (14) 49 (7) Over:49 **259** (100) 259 (100)Total TRANSMISSION CATEGORIES ADULT/ADOLESCENT **CASES** (%) (82) Homosexual/Bisexual Male 213  $(\cdot 4)$ Intravenous Drug Abuser (IVDA) Homosexual/Bisexual/and IVDA (5) (3) Hemophilia/Coagulation Disorder Transfusion, Blood/Components Heterosexual Cases (2) (2)

259

(2)

(100)

Undetermined

TOTAL

DATES		NUMBER _OF_CASES	NUMBER OF KNOWN DEATHS	CASE-FATALITY RATE (%)
1982	JanJune July-Dec.		$\frac{1}{3}$	(100) (100)
1983	JanJune July-Dec.	<u>3</u>	3	(100) (100)
1984	JanJune July-Dec.	11 10	108	(91) (80)
1985	JanJune July-Dec.	<u>15</u> <u>38</u>	<u>14</u> 31	(93) (82)
1986	JanJune July-Dec.	48	30 24	(63) (57)
1987	JanJune July	63 23	<u>15</u> 	(24) (22)
[otal		259	146	<u>(56)</u>

TATE Minnesota	FISCAL YEAR 1985 - 86  FISCAL YEAR 1986 - 87		FISCAI 1987 (Proje	
			BUDGET REQUEST	AMOUN1 FUNDED
o EDUCATION/INFORMATION o General Public o High Risk Groups o Health Care Providers	\$126,894	\$347,571	\$866,500	To be determined May 18, 19
o RESEARCII				end of legislativ session
o SURVEILLANCE	61,000	134,612	106,911	•
o TESTING/COUNSELING	166,111	218,440	128,000	
o PATIENT CARE/TREATMENT				
o SUPPORT SERVICES (c.g. housing, transportation, case management)				i
o STAFF and SUPPORT ACTIVITIES	12,995	50,663	121,000	
o OTHER (please specify)				
Legal Assistance Contact Notification Economic Analysis	30,000 - -	34,452 84,262 30,000	31,814 95,775 -	1
N Totals	\$397,000	\$900,000	\$1,350,000	



## AIDS IN MINNESOTA

-- Number of Cases Reported (as of 4/13/87)

189\*

-- Number of Deaths

105\*

-- It is currently estimated that 15,000 - 25,000 Minnesotans are already infected with the AIDS virus (HIV). 1,500-2,000 will develop full-blown AIDS by 1990.\*

Patient Groups (Adults/Adolescent Cases) \*

- 87% Homosexual/Bisexual Men
  - 3% Intravenous Drug Users
  - 5% Homosexual/Bisexual/I.V. Drug Users
  - 2% Hemophilia
  - 1% Transfusions
  - 2% Heterosexual
  - 1% None of the above; other
- -- For every case of AIDS, it is estimated that there are 5-10 cases of AIDS-Related Complex (ARC). People with ARC can experience a variety of chronic symptoms including swollen lymph glands, diarrhea, weight loss, fatigue, night sweats and dementia.

# THE COST OF AIDS

- -- by 1990, estimates predict 20% of the hospitalized patient population will be AIDS cases or AIDS related illnesses.
- -- Health care costs per patient will range from \$30,000 to \$150,000, depending upon the availability of less expensive community based services and home/hospice care, which can reduce average medical care costs from \$773/day for hospital care to \$94/day.
- -- Direct health care costs in Minnesota for 1986-1990 are estimated at 65 to 128 million dollars.\*
- -- Total economic imp[act of AIDs in Minnesota by 1990 is projected at 436 to 840 million dollars. Total costs include direct health care costs, lost income and productivity from both illness and death.\*
- Minnesota Department of Health statistics and projections.

# contributions

The predicted disease impact of acquired immunodeficiency syndrome in Minnesota: five-year projection models for a low-incidence state\*

James M. Shultz, M.S.†, Richard N. Danila, M.P.H.†, Kristine L. MacDonald, M.D.†, Michael T. Osterholm, Ph.D., M.P.H.†

As of January 1, 1987, 155 Minnesota resident cases of acquired immunodeficiency syndrome (AIDS) had been reported (37 cases per 1 million residents). Minnesota ranks 25th among states and territories in incidence rate, and has a 3- to 14-fold lower incidence than the five states (New York, California, Florida, New Jersey, and Texas) that currently account for 72% of cases nationally. To formulate public health prevention strategies and health care service policies for human immunodeficiency virus (HIV) infection, the Minnesota Department of Health (MDH) has developed five-year projection models for future numbers of AIDS cases in Minnesota. Based on three case-number doubling models presented, we predict that between 1986 and 1990, 1,246 to 1,860 new cases of AIDS will occur with 840 to 1,209 deaths. From 23,510 to 33,847 person-years of potential life lost (YPLL) prior to age 65 will be attributable to AIDS. By 1990, YPLL for AIDS will exceed all other causes of YPLL for single, never-married men, ages 25 to 44 in Minnesota. Estimates of cumulative direct health care costs for the five-year period range from \$30 million to \$43 million (1984 dollars). Estimates of indirect morbidity costs, a disability measure, range from \$18 million to \$27 million, and indirect mortality cost estimates add another \$480 million to \$691 million. Our projection models indicate that morbidity and mortality from AIDS will lead to substantial health care burdens and economic costs for Minnesota in the very near future. The projection models presented here may be applicable to similar calculations for other low-incidence states. Thus, the medical and public health communities in such states need to begin now to develop programs and policies to accommodate this disease impact. In addition, for lowincidence states, future economic burdens need to be considered when allocating current limited funds for disease prevention efforts.

s of January 1, 1987, more than 29,000 cases of acquired immunodeficiency syndrome (AIDS) had been reported to the Atlanta-based Centers for Disease Control (CDC) and over 16,000 case-fatalities (56%) had been confirmed. The number of AIDS cases that will occur in this country through 1991 has been esti-

mated to exceed 270,000 with 179,000 deaths (66%).<sup>2</sup> In addition, experts predict that increasing numbers of cases will be reported from currently low-incidence areas of the United States, with progressively diminishing proportions of new cases identified from currently high-incidence areas.<sup>2</sup>

Minnesota is currently a "low-incidence" state for AIDS. As of January 1, 1987, 155 Minnesota resident cases of AIDS had been reported with a cumulative incidence rate of 37 cases per 1 million population. Minnesota ranks 23rd among states and territories in numbers of reported cases and 25th in

incidence rate. Our incidence rate is 3- to 14-fold lower than that for the five states (New York, California, Florida, New Jersey, and Texas) that currently account for 72% of cases nationally. Ninety-one percent (141) of cases have occurred in the seven counties comprising the Twin Cities SMSA.

The primary risk group for infection with human immunodeficiency virus (HIV) in Minnesota is homosexual and bisexual men (Table 1). We estimate that at least 100,000 men in our state are homosexual or bisexual and are at risk for acquiring HIV infection (using either the proxy measure of 104,000 single, never-married males, ages 25 to 44 or the conservative Kinsey report figure of 5% of the Minnesota male population of 2.1 million). In addition, we estimate that 1.000 to 1.500 addicted intravenous drug users reside in the state (C. Falkowski, personal communication, April 1986). Finally, based on HIV antibody seroprevalence surveys among male homosexuals and the rates of HIV antibody seropositivity among persons tested at MDH-sponsored counseling and testing sites, we estimate that at least 20,000 Minnesota residents are currently infected with HIV.

To provide a data base for future policy decisions regarding prioritization of prevention efforts, use of medical resources, payment for medical care of AIDS patients, and development of funding sources for AIDS-related public health activities, we have developed projection models to provide five-year estimates of the health and economic impact of AIDS on the residents of Minnesota. To estimate the

<sup>\*</sup>Presented at the American Public Health Association 114th Annual Meeting, Las Vegas, NV, Suptember 28-October 2, 1986.

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Reprints: James M. Shultz, M.S., Acute Disease Epidemiology Section, Minnesota Department of Health, 717 Delaware Street SE, PO Box 9441, Minnespolis, Minnesota 55440.

TABLE 1 Acquired immunodeficiency syndrome (AIDS) cases by risk group: Minnesota\* and United States\*

	Min	resota	United States		
Risk Group	Casee	Percent	Cases	Percent	
Homosexual/bisexual	132	85%	18,750	66%	
Intravenous drug	4	3	4,846	17	
Homosexual/bisexual					
and intravenous drug	10	7	2,230	8	
Hemophilia	3	2	246	1	
Transfusion	1	1	524	2	
Heterosexual contact	3	2	1.524	4	
None of the above	2	1	905	3	
TOTAL	155	100	28,593	100	

\*Jan. 1, 1987 \*\*Dec. 29, 1986, (excludes 410 pediatric cases)

disease impact, we used epidemiologic models to predict future numbers of AIDS cases through 1990 and used health economics methods to predict the costs associated with these expected AIDS cases. Based on the latency period from HIV infection to the onset of AIDS as defined by the CDC, the models presented in this report provide estimates of the numbers of AIDS cases that will occur predominantly among persons who are currently infected.3 We intentionally did not estimate the disease impact of non-AIDS HIV-associated disease because of lack of data, but we anticipate substantial additional costs beyond those estimated for AIDS. The results presented here will likely be applicable to other low-incidence states and emphasize the magnitude of the AIDS problem in this country.

# Methods

Definitions: The following definitions describe measures used in the prediction models.

- New cases Reported (predicted) AIDS cases meeting the CDC surveillance case definition by month of diagnosis.
- Cumulative cases Running total of AIDS cases.
- Deaths Reported (predicted) case-fatalities among reported AIDS
- Cumulative deaths Running total of deaths.
- Live cases Cumulative cases minus the cumulative deaths.

- Years of potential life lost (YPLL) - Two variations of the YPLL measure are used to quantify the premature mortality associated with AIDS; first, YPLL prior to age 65 (YPLL-65), which measures the loss of income-earning years due to early death from AIDS, and second, YPLL relative to years of life remaining at age of death (YPLLall), which measures the magnitude of foreshortened life expectancy.
- Direct health care costs Direct health care costs estimated in this study are personal health expenditures for hospital care, physicians' services, medications, nursing home care, and other professional services. Additional "non-personal" direct costs for public health activities and research were not projected.
- Indirect morbidity costs The costs of lost income and productivity for persons who are disabled by AIDS illness. Productivity losses are measured as wages, salaries, and supplements from days lost from work among currently employed persons, long-term disability days, and hospitalization days for AIDS patients.
- Indirect mortality costs The estimated costs of lost income and productivity resulting from AIDSassociated premature death. Discounting was used to estimate this forfeiture of expected future earnings in present-valued dollars.
- Estimation models The MDH currently employs a combination of active and passive surveillance for

reporting of all HIV infections. The mean lag time from diagnosis to report is less than one month. Recent review of all statewide death certificates coupled with interviews with all physicians who have diagnosed or reported cases of HIV infection uncovered no instances of unreported AIDS cases.

The cumulative number of Minnesota resident AIDS cases doubled from 30 cases to 60 cases between April and October 1985, a seven-month doubling period that directly preceded the prediction period. Future case-number doubling cycles were modeled for 1986 through 1990. A power of two equation was used to simulate doubling for all models: Cumulative cases (.9375 X 2<sup>--</sup> + 10). To obtain the original base for doubling (60 cases), the first exponent inserted was 6  $(2^6 = 64; .9375 \times 2^6 = 60)$ . Actual cases at the beginning of the prediction period (70 cases as of January 1, 1986) were obtained by adding 10 (.9375  $\times$  2\* + 10 = 70); estimates of cumulative cases included these pre-existing cases. Each doubling of cases is represented by a unit increase in the power of the exponent. Fractional exponents (equal to 1/number of months in current doubling cycle) were added to the exponent to produce monthly estimates of cumulative cases.

The first model assumes a constant doubling cycle of 12 months, comparable to the length of the national doubling cycle at the time the models were developed. The other two models incorporated a sequence of expanding doubling cycles based on observation of progressively increasing case-doubling cycles nationally (Table 2).4

Calculation procedures: Cumulative cases of AIDS in Minnesota are generated directly from the model equations. Using the predictive equations described above, the monthly cumulative cases were calculated for each of the 60 months

TABLE 2

Doubling cycles for Minnesota models for AIDS cases

Doubling Cycle	<del>-</del>	Months Required for Doubling of Cases				
	Cases/ Cycle	Model A	Model &	Medei C		
Cycle 1	60	12	8	10		
Cycle 2	120	12	10 .	12		
Cycle 3	240	12	12	14		
Cycle 4	480	12	14	16		
Cycle 5	960	12	16	8*		
Total months,						
1986-1990		60	60	60		

\*8 months of an 18-month cycle will be completed by 12/31/90

from January 1986, through December 1990. The fractional increment added to the exponent for each month corresponds to the length of the cycle in months. For 8, 10, 12, 14, 16, and 18 month cycles, the increments are .1250, .1000, .0833, .0714, .0625, and .0556, respectively. Monthly new cases of AIDS were calculated as the difference between cumulative cases for successive months.

Calculation of AIDS deaths by month relied on previous estimation of new cases of AIDS per month, distribution of cases into disease groups, and application of differential survival rates by disease group. We used the U.S. distribution of cases by diagnosis for over 16,000 cases for our analyses because it was regarded as more stable and representative than the data available for 70 Minnesota cases at the time the models were constructed. Accordingly, estimated monthly new cases in Minnesota were subdivided into disease groups according to the percentage distribution of national AIDS cases as of January 6, 1986 (18.52% Kaposi's sarcoma (KS), 57,40% Pneumocystis carinii pneumonia [PCP], 5.65% KS plus PCP, and 18.43% No KS/ No PCP).

Survival rates by disease group were used to calculate monthly mortality from KS, PCP, KS plus PCP, and No KS/No PCP based on detailed California data for over 3,000 AIDS cases.<sup>5</sup> Cumulative deaths were obtained by sequential summation of monthly AIDS deaths. Live cases by month

by disease group were calculated as the difference between monthly cumulative cases and monthly cumulative deaths.

YPLL-65 were computed as the sum of the differences between age 65 and age at death. Predicted Minnesota AIDS deaths were subdivided by age (in five-year age intervals) and gender (92.0% males. 8.0% females) in proportion to the distribution of 8,220 U.S. case-fatalities reported to the CDC by January 6, 1986. For YPLL-all, U.S. Life Tables were used to provide expected years of life remaining at age of death by birth cohort and gender; YPLL-all were computed as the sum of the differences between life expectancy and age at death.\*

Direct health care costs for AIDS are based on an estimate of \$33,500 for annual costs per cases obtained from a recent study performed for the CDC (A. Scitovsky, personal communication, June 1986). The \$33,500 annual cost figure was selected as most applicable to Minnesota after review of available data on AIDS hospitalization costs in Minnesota and review of previous per-case direct cost estimates ranging from about \$30,000 at San Francisco General Hospital,7 to \$91,000 in billed commercial costs (\$59,000 in paid Medicaid costs) for California AIDS patients with Medi-Cal claims,5 to \$147,000 for a national estimate of per-case direct costs for the first 10,000 patients.\* Estimated monthly direct health care costs were calculated as the products of the numbers of Minnesota live cases times the average monthly costs summed across disease groups.

Estimated AIDS live cases per month and estimated average monthly income for the age and gender distribution of AIDS cases were used to estimate indirect morbidity costs. Entered into the calculation were Minnesota-specific male and female median full-time income data by age, labor force participation rates (full-time and part-time), population estimates by age group, the age and gender distribution of current U.S. live cases, and an estimate of percentage disability from AIDS (86%).\*

The economic analog of the YPLL measure, indirect mortality costs, incorporates both the number of AIDS deaths and age at death. National estimates of the present values of future earnings by gender and five-year age group for 1980, using a discount rate of 4% (routinely used in national costs of illness calculations, including costs specific to AIDS), were inserted into the calculations. 10 Future Minnesota AIDS deaths were assumed to follow the age and gender distribution of the U.S. AIDS deaths. Indirect mortality costs were estimated as the sum of the products of numbers of deaths times the present value of future earnings for each age group. Final values were inflated to 1984 dollars.

# Results

Our models predict that 1,246 to 1,860 new cases of AIDS will be diagnosed and reported in Minnesota from 1986 through 1990 (Table 3). From 840 to 1,209 deaths will occur among these cases (including deaths among the cases diagnosed before 1986 and known to be living at year-end 1985). The prevalence burden of AIDS cases will range from 443 to 805 live cases of AIDS under medical treatment at year-end 1990.

Estimated YPLL-65 will range from 23,510 to 33,847 person-years

TABLE 3
Summary of basic prediction measures for AIDS in Minnesota

Yeer	Cumulative Cases*	New Cases	Deaths	Cumulative Deaths**	i.Jve Çase:
		Mo	del A		
1986	130	60	42	76	54
1987	250	1.20	72	148	102
1968	490	240	140	288	202
1989	970	480	279	567	403
1990	1,930	960	557	1,125	805
		Мо	dei B		
1986	168	98	54	88	80
1987	349	181	110	198	151
1988	656	307	196	394	262
1989	1,152	496	328	722	429
1990	1,930	778	521	1,243	687
	·	Mo	del C	,	
1986	145	<i>7</i> 5	47	81	64
1987	275	130	83	164	111
1988	490	215	139	303	187
1989	817	327	223	526	291
1990	1,316	499	348	874	443

<sup>\*</sup>Cumulative cases include 70 cases reported by 12/31/85

TABLE 4
Predicted disease impact of AIDS in Minnesota: Epidemiologic measures

Mossure	Model A	Model B	Model C
	1986 Estimates		
New AIDS cases	60	98	<i>7</i> 5
Deaths	42	54	47
Live cases (year-end)	54	80	64
YPLL-65 (person-years)	1.170	1.519	1,308
YPLL-all (person-years)	1,531	1,987	1,712
1986-	1990 Cumulative Estin	nates	
New AIDS cases	1,860	1.860	1,246
Deaths	1.090	1,209	840
Live cases (year-end, 1990)	805	687	443
YPLL-65 (person-years)	30,530	33,847	23,510
YPLL-all (person-years)	39,956	44,295	30,767

(Table 4). Estimated YPLL-all will range from 30,767 to 44,295 person-years. For all men ages 25 to 44, the range of estimates for AIDS-associated YPLL-65 and YPLL-all progressively increases and ultimately exceeds the all-causes YPLL for this group in years before AIDS entered the community (Figure).

For direct health care costs, using annual medical costs per case of \$33,500, Minnesota will experience between \$1.4 million and \$1.9 million in health care costs for AIDS patients in 1986; and between \$29.8 million and \$43.0 million for the period 1986 through 1990. Estimates of indirect morbidity costs for 1986 range from \$0.9 million to \$1.2

million in lost income and productivity. For the five-year interval 1986 through 1990, disability cost estimates range from \$18.4 million to \$26.5 million.

Indirect mortality costs are the greatest contributor to AIDS-associated costs. Estimates of this measure range from \$23.9 million to \$31.0 million for 1986. For the five-year interval, the estimated indirect mortality costs range from \$480.3 million to \$691.5 million.

Summing the three cost measures, the estimates for 1986 range from \$26.2 million to \$34.1 million in AIDS-associated costs. For the five-year interval, 1986 through 1990, estimates range from \$528.5

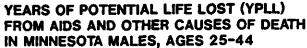
million to \$761.1 million (Table 5).

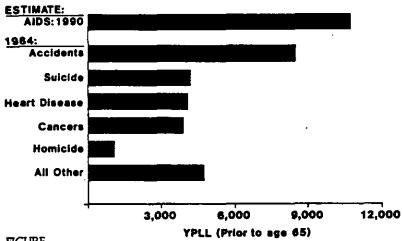
### Discussion

Modeling trends: We believe that the data presented from our models provide a realistic but discouraging projection for the impact of AIDS in a state currently classified as "low-incidence" for AIDS. Two diametral methods may be applicable for modeling trends in AIDS cases. First, models may be produced by starting from the numbers of persons at risk for HIV infection and telescoping downward to define the numbers of HIV-infected persons, the probable numbers of AIDSrelated complex (ARC) cases, and finally, the probable numbers of AIDS cases. However, this approach is seriously limited by the unavailability of reliable information on numbers of high-risk persons, epidemiology of risk-related behaviors among risk group members, infection rates in relation to risk behaviors, seroprevalence rates by risk group, and projections of the proportions of HIV-infected persons who will develop AIDS. The alternative approach selected for the Minnesota calculations, is to begin with the baseline number of confirmed AIDS cases locally over time. The models used are mathematically simple and preclude the need for precise estimation of the size of the risk groups.

In assessing the efficacy of our models in predicting future numbers of AIDS cases in Minnesota, several assumptions and limitations of the modeling were considered. First, we assumed that a high-risk population exists of sufficient numbers to sustain the predicted numbers of cases and that a sufficient number of those persons are infected with HIV to generate the predicted numbers of AIDS cases. Estimates of numbers of homosexual and bisexual men for Minnesota and current HIV seroprevalence data support this assumption.

<sup>\*\*</sup>Cumulative deaths include 34 deaths reported by 12/31/85





FIGURE

Second, due to the long incubation period from initial HIV infection to onset of AIDS symptoms. most cases diagnosed during 1986 through 1990 will be from the pool of persons currently infected with HIV. Also, no vaccine will be available before the end of 1988. Based on the incubation period, a vaccine available after that date would not substantially alter the numbers of incident cases developing before 1991.

Third, no treatment for AIDS patients will significantly alter the case-fatality rate or the life expectancy from diagnosis during the interval 1986 through 1990. Results of the recently conducted azidothymidine (AZT) clinical trial (M. Fischel, Interscience Conference on Antimicrobial Agents and Chemotherapy, New Orleans, LA, 1986) suggest the possibility of prolongation of patient survival at least in the short term. If AZT is widely used in Minnesota, such use may lead to an overestimate of mortality measures presented here (deaths, YPLL, indirect mortality costs). However, in the trial, no significant decrease in the incidence of opportunistic infections among AZTtreated patients was noted and 30% of the treatment patients required

multiple transfusions for AZTinduced reversible anemia. Thus, direct health care costs and disability costs for patients receiving AZT may have been underestimated.

Fourth, the use of the U.S. distribution of AIDS cases by age, gender, and disease group was intentional. When the prediction models were developed, a baseline of 70 cases was not regarded as sufficiently stable or representative provide parameters for estimation.

Fifth, the models assume a static distribution of cases into disease groups. National surveillance data suggest that the proportion of PCP cases is increasing with a corresponding decrease in cases presenting with KS. Therefore, this distribution may change over time, and we did not include this in our modeling.

Finally, the choice of the doubling periods is hypothetical; future Minnesota experience may not reproduce previous national experience because of differences in risk dynamics. Therefore, we chose multiple prediction models to provide a range of possible future scenarios. Model B is regarded as most realistic. Cases reported during 1986 have followed estimates predicted by this model.

The models presented here are based on the assumption that the future experience in Minnesota can be generally predicted from the experience of currently high-incidence locations. We believe this approach is supported by several points. First, it has been previously suggested that hepatitis B virus (HBV) transmission is similar to HIV transmission. Minnesota hepatitis B surveillance and selected ser-

TABLE 5 Predicted disease impact of AIDS in Minnesota: Health economics

measures*			
Messure	Model A	Model B	Model C
19	286 Estimated AIDS Co (in thousands)	ets	
Direct health care costs** Indirect morbidity costs	\$ 1,446 891	\$ 1,919 1,183	\$ 1,631 1,005
Subtotal: Indirect mortality costs	\$ 2,337 23,900	\$ 3,102 31,000	\$ 2,636 26,700
Total costs:	\$26,237	\$34,102	\$29,336
1986-1990	Estimated Cumulative .	AIDS Costs	
Direct health care costs** Indirect morbidity costs	\$38,963 24,015	\$43,048 26,533	\$29,816 18,377
Subtotal: Indirect mortality costs	\$62, <i>978</i> 623,700	\$69,581 691,500	\$48,193 480,300
Total costs:	\$686,678	\$761.081	\$528,493

<sup>\*</sup>All values in 1984 dollars

<sup>\*\*</sup>Based on annual medical care costs per case of \$33,500

FIGURE-Years of potential life lost (YPLL) from acquired immunodeficiency syndrome (AIDS) and other causes of death in Minnesota for single, never-married males, ages 25-44.

oprevalence data suggest that sexual practices among homosexual/bisexual men are similar in Minnesota to those documented in other areas of the country, including regions considered to be "high-incidence" areas for AIDS. Seroprevalence of hepatitis B markers among homosexual/ bisexual men who attended sexually transmitted disease clinics in Minnesota (58%) is similar to that seen in San Francisco (61.5%) and New York (68.1%) (M.T. Osterholm, personal communication).11,12 Also, a decline in incidence of acute HBV infection among Minnesota homosexual/bisexual men between 1980 and 1985 has not been noted through our active laboratory-based HBV surveillance system. Since HBV cases continue to occur among homosexual/bisexual men, these data suggest that sexual practices that may affect HIV transmission have not changed substantially over the past several years in Minnesota.

Second, Minnesota five-year estimates are based on the development of AIDS among currently HIV-infected persons. The CDC originally estimated that 5% to 20% of HIV-infected persons will develop AIDS within two to five years of initial infection3 based on the results of several cohort studies.13,15 Goedert and colleagues summarized three-year incidence of AIDS among five cohorts of HIVinfected persons ranging from 8% to 34%.16 The recent Coolfont Report indicated a five-year incidence of AIDS among HIV-infected persons at 20% to 30%.2 Assuming that this range of incidence rates is applicable to the Minnesota experience, the estimated 20,000 currently HIV-infected Minnesota residents provide sufficient numbers to generate predicted future AIDS cases. Thus, case-incidence modeling for the interval of 1986 through 1990, a time period for which future cases have largely been determined by existing HIV infection in the population, will be minimally affected by

current risk reduction programs.

Cost predictions: When examining predictions of the economic costs of AIDS to the state of Minnesota as determined by the models, several points deserve mention. First, all assumptions noted in the discussion of estimation models are applicable to the economic estimates that are derived from the models. Second. the methods of computing economic costs of illness possess intrinsic limitations, and the compounding of error in economic calculations with error in the epidemiologic modeling limits the precision of the AIDS cost estimates. 17.20 Third, in calculating direct costs, available national estimates of per-case costs ranged from \$30,000 to \$147,000.7.8 Differences in methodology, case-mix, risk groups, treatment protocol, availability of non-hospital care facilities, and community-based voluntary support partially accounted for the wide disparity in estimates. For Minnesota, multiple initial calculations were performed using the low and high figures plus a mid-range estimate of \$91,000.5 Revised direct cost estimates presented here are based on an estimate of \$33,500 in "annual medical care costs per case" developed in a subsequent consultant report to the CDC using assumptions of 1.7 hospital admissions per year with an average length of stay of 20 days billed at \$900 per day for inpatient costs plus \$3,000 in outpatient costs (A. Scitovsky, personal communication, June 1986). The direct cost figure estimated at \$1.9 million in 1986 and at \$18.6 million for 1990 represents only 0.03% and 0.30% of total state personal health expenditures, respectively. Nevertheless, these are new costs for a new disease-an overlay to the costs of prevalent chronic diseases. Furthermore, the expected costs in 1990 are not regarded as peak costs of AIDS, which will continue to increase beyond the end of the prediction period. Fourth, in calculating indirect morbidity costs, the estimation of percent disability during AIDS illness was derived from the single estimate appearing in the literature.9 More accurate assessment of the degree and duration of disability is needed for upgrading future estimates.

The economic cost estimates are conservative because they are limited to AIDS cases. HIV infection may lead to a clinical spectrum of illness including various levels of immunodeficiency and neurologic impairment.21 Cost estimates included here are restricted to CDCdefined AIDS cases and do not include the costs for treatment of HIV-antibody seropositive persons with or without ARC symptoms. No costs for the treatment of persons infected with HIV who exhibit neurologic symptoms are included unless the patient concurrently has a diagnosis of AIDS. The costs of non-AIDS HIV-associated diseases will likely add significantly to the economic burden. Furthermore, the costs for Minnesota AIDS public health activities are substantial but not predictable for five years.

#### Summary

It is apparent that AIDS will have a dramatic nationwide impact on the health care delivery system and health care financing by 1990. Therefore, it is critical that the public health and medical communities here and in other low-incidence areas begin now to develop programs aimed at dealing with the AIDS epidemic. Other low-incidence states may be able to use the disease and economic impact models we have developed so that similar predictions can be made for other areas of the country.

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### The Minnesota AIDS Physician Survey

The Minnesota Department of Health, in an attempt to gain a correct estimate of the need for continuing medical education, has devised a questionnaire to be sent to physicians in the state.

The survey questionnaire is highly detailed and meant to be answered anonymously by the physician. The anonymity is necessary because the survey tries to obtain, among other things, information as to personal feelings toward homosexuality. Indeed, it contains an explicit question as to the respondent's sexual orientation (heterosexual, homosexual or bisexual). Such questions are obviously not frivolous. The Minnesota Department of Health simply realizes that, at least at the beginning of the epidemic, most AIDS patients will be homosexual and bisexual men, and that it will be necessary for the state to gauge the extent of antihomosexual prejudice in the medical profession. After all, such prejudice might have a negative influence on the treatment.

Because of its importance as a possible model for similar European surveys, the entire questionnaire is reproduced on the following pages.



### MINNESOTA DEPARTMENT OF HEALTH

### **MINNESOTA AIDS PHYSICIAN SURVEY:**

KNOWLEDGE AND CLINICAL PRACTICE FOR ACQUIRED IMMUNODEFICIENCY SYNDROME AND HUMAN IMMUNODEFICIENCY VIRUS INFECTION

ABBREVIATIONS AND DEFINITION MDH: Minnesota Department of Health HIV: Human Immunodeficiency Virus The consensus name for the reauses AIDS (Also known as LAV, AIDS: Acquired Immunodeficiency Syndasyndrome of diseases at least dicative of underlying cellular ciency. The complete list of disease the definition and the exclusion of tained in the Centers for Disease lance case definition.  ARC: AIDS-Related Complex Early signs of immunodeficien with HIV infection including general denopathy, chronic diarrhea with persistent fever, drenching night	retrovirus that (,HTLV-III, ARV) drome moderately ingrises included incriteria are con-Control surveil- acy associated eralized lymphath weight loss,	HI Ri	RISK: A person is defined as being at high risk quiring HIV infection if that person:  1. is a man and has had sex with another any time since 1977  2. has used intravenous drugs at any time 1977  3. received clotting-factor products be 1977 and 1985  4. was born in a country where hetero transmission is thought to play a major the spread of HIV (particularly count Central Africa and the Caribbean)  5. has had sex with male or female prost 6. has had sex with a person who is in with HIV or is in a high-risk group for ing HIV infection  7. is an infant born to a mother at high ris fected with HIV					
INSTRUCTIONS: Please answer a Please place an "X" in the approp dicating your response for each of question should be marked with a the "YES" or "NO" category.  1. When performing routine comprehe physical examinations, do you rour ask patients about risk factors for acq HIV infection? (CHECK "YES" or "N 2. If yes, check the risk factors that you tinely assess: (CHECK "YES" or " FOR EACH RISK FACTOR.) a. Homosexuality/bisexuality b. Use of intravenous drugs c. History of blood and blood pre transfusion from 1977 through Ap 1985 d. Hemophilia e. Heterosexual contact with a mem a high-risk group f. Heterosexual contact with mu partners (at least 10 since 1977) g. Pregnancy/family planning for for patients in high-risk groups	criate box inchoice. Each a response in (1) (2) YES NO ensive tinely juiring (O'') (1) (1) (2) (3) (3) (4) (5) (ber of (6) (4) (7)	<b>4</b> .	In your practice have you seen any patients that you know are or were infected with HIV? (CHECK "YES" or "NO")  If yes, please estimate the total number:  About how many times in the past year have you ordered an HIV antibody test? (IF YOU HAVE NOT ORDERED ANY TESTS, PLEASE SPECIFY "O"):  If yes: Please address why you ordered the test: (CHECK "YES" or "NO" FOR EACH CATEGORY)  a. Symptoms compatible with AIDS or ARC  b. History of previous HIV antibody test c. History of high-risk activity(ies)  d. Other: Specify:  As part of primary care for asymptomatic high-risk patients would you: (CHECK "YES" or "NO")  a. Discuss with the patient the risk of HIV infection  b. Suggest HIV antibody screening and help the patient decide whether to take the test  c. Order HIV antibody screening  d. Refer the patient for counseling	(1) (2) YES NO				

6.	Who among your office staff of AIDS prevention information/coun high-risk patients? (CHECK "YES" "NO" FOR EACH CATEGORY)  a. No counseling is currently prov	seli ' or	ng t			·(2) 5 NO	10.	Please indicate your level of interest NUMBER ON THE SCALE INDI LEVEL OF INTEREST WITH "1" ! INTEREST AND "5" INDICATING SEST)	CAT NDI	ING CATI	YO NG	UR NO	
	b. Physician		_			(25)			)		Street	•	
	c. Staff nurse					(26)			erest		later	<b>K</b> t	
	d. Public health nurse					(27)		<ul> <li>Information packet on treat-</li> <li>ing persons with AIDS</li> </ul>	2	3	A	5	(49)
	e. Other (specify)					(28)		b. Informational meetings on	_	•	•	5	1407
7.	What topics are addressed du health education/counseling pr (CHECK "YES" or "NO" FOR EAC	ovi	ded	?			i	AIDS conducted by MDH staff in your hospital or community 1  c. Training session(s) on coun-	2	3	4	5	(50)
	GORY)				YE			seling the AIDS patient and					
	a. No counseling is currently prov	ride	d			(29)		high-risk patient regarding HIV				_	
	b. HIV antibody test information				느	(30)		antibody testing, risk reduction 1	2	3	4	5	(51)
	c. Recommend condom use				Ш	(31)		d. Information packet with sample chart insert for taking					
	d. Recommend reducing the nu	ımb	er c	of		l <b>□</b>		sexual histories 1	2	3	4	5	(52)
	sex partners				<u> </u>	(32)		e. CME courses on AIDS topics					
	e. Recommend avoiding exchapody fluids	ang	e c	)Ť		(33)	•	and medical practice issues 1	2	3	4	5	(53)
	f. Recommend not sharing needle	6	i-		_	<u> </u>	11.	In the past 12 months, from which	h of	the			
	jection of illicit drugs	69 I	01 11	,-		(34)		following information sources ha		you			
	g. Explain needle cleaning and ste	erilia	zina			(35)		obtained AIDS information? (CHEC "YES" or "NO" FOR EACH INF		.AΔ_	(1)	(2)	
	h. Recommend obtaining new ste		_					TION SOURCE).	Ų MI	·· —		NO	
	dies		-	-		(36)		a. Minnesota newspapers					(54)
	i. Recommend that HIV-infected persons		S				b. National newspapers					(55)	
	refer sex/drug partners for con	fide	entia	al		(37)		c. Minnesota Medicine series on A	IDS				(56)
	HIV-antibody testing	•	L: 1	_	_	<u>       </u> (37)		d. MDH Disease Control Newslett	e <i>r</i>				(57)
0.	Have you referred or would you re risk or HIV-infected persons to the							e. Major national medical journals					(58)
	ing services? (CHECK "YES" or "NO" FOR EACH CATEGORY)						f. Colleagues					(59)	
							g. General media					(60)	
	a. Counseling and testing sites tive test sites) for HIV-antibody te			9-	YE	(38)		Are there other physicians you wo sult if one of your patients is HIV-in	fect	ed?	YES	NO.	) ](61)
	b. Minnesota AIDS Project				Ц	(39)	13.	Would you be interested in the d					
	c. State or local health departr AIDS information	ner	nt fo	or		(40)		ment of multidisciplinary care te HIV-infected patients? Such a tear include the physician, nurse prac-	n mi	ight			
	d. Mental health professionals		_		Ш	(41)-		health educator, and counseling					,
	<ul> <li>e. Chemical dependency treatme venous drug abusers)</li> </ul>	nt (	intra	<b>)</b> -	_	(42)		sional.			Ш	_	(62)
	f. AIDS hotline (telephone number	e)			┢	(43)	14.	Do you believe that a homosexual of					
9.	Please indicate your support for the cies: (CIRCLE THE NUMBER ON T	ne f HE	SC	ALE	INI	oli- DI-		able to manage the special health p of homosexual patients: (CHECK ( TION).					
	CATING YOUR LEVEL OF SUPPOF							Better than a heterosexual doctor?					(63)
	DICATING STRONG OPPOSITION OF THE STRONG SUPPORTS.		IA	NU	•	<b>o</b>		The same as a heterosexual doctor			_	(2)	
		_	ngiy		Stre			Worse than a heterosexual doctor?			Ш	(3)	
	a. Reportability to the MDH of	Opp	•••		Sup		15.	Do you believe that having homose tients in your practice cause you: ONE OPTION).					
	AIDS patients	1	2	3	4	5 (44)		A great deal of discomfort?				(1)	<b>(64)</b>
	b. Reportability to the MDH of	_	_	_				A moderate amount of discomfort	,			(2)	
	ARC patients	1	2	3	4	5 (45)		Very little discomfort?				(3)	
	c. Reportability to the MDH of asymptomatic HIV antibody positive patients	1	2	3	4	5 (46)		No discomfort at all?			$\overline{}$	(4)	
	d. Notification of contacts by												
	patients	1	2	3	4	5 (47)							
	e. Notification of contacts by MDH	1	2	3	4	5 (48)						3/	0

•

6.	Please indicate your leve (CIRCLE THE NUMBER ON DICATING YOUR LEVEL ( WITH "1" INDICATING ! AGREE AND "5" INDICAT AGREE).	NTHE S OF AGR STRON	CALE IN EEMEN' GLY DIS	-    -			Health care workers caring for AIDS patients  Morticians in contact with AIDS patients    Iligh   Motorate   Nich   Nich   Nich	(85)
	a. Homosexuality should be a cause for job discriminal in any situation		Strongly Disagree 1 2	Stre Agr	ingly 10 5 (65)	19.	What AIDS-related programs/services would you like the MDH to provide in order to assist you in your practice?	
	b. Homosexual behavior acceptable for our society		1 2	3 4	5 (66)			•
	c. To some extent, people contract AIDS through a behavior or IV drug use de their disease	e who	1 2	3 4	5 (67)			•
	d. Homosexuality is me different kind of lifestyle should not be condemned	e that	1 2	3 4	5 (68)			-
	e. Homosexuality is a thr many of our basic social in							-
	tions f. If a person has homos feelings, he/she should de		1 2	3 4	5 (69)		Answer code	(87-88)
	rything he/she can to over them	rcome	1 2	3 4	5 (70)		Your age:	(89-90)
17.	Regarding your HIV or AID you experienced any of the			e			Sex: Male (1) Female (2) Medical subspecialty:	(91)
	(CHECK "YES" or "NO" F			, ,			Family Practice (1)	
	a. Staff discomfort/refus	sai to w	ork wit	h _	_		Internal Medicine (2) Other (3)	
	patient b. Difficulty with nursing	borne o	lacemen	, H	(71)		If Other, please specify	(92)
	c. Patient's loss of job due	-		_	<b>173</b> 1	23.		
	d. Problems with third pa	ırty insu	rance re	· _	[] <sub>(74)</sub>		Private (1)	
18.	Please rank your underst	tanding	of the	ات followi			Academic (3)	
	with regard to the degree AIDS. (PLEASE INDICATE RISK, OR NO RISK):	e of rist	k for co	ntracti	ng		Industrial (4) Other (5)	(93)
		High Rink	Mederata Rick	No Riek		24.	If Other, please specify Do you practice in:	(94)
	Persons with hemo- philia	□ m	(2)	<b>(3</b>	3) (75)		The 7-county metro area (1)	
	Family members of persons with AIDS Dentists				(76) (77)		Duluth/Rochester/ St. Cloud (2) Other (3)	
	Female sex partners of active bisexuals Intravenous drug users				(78) (79)	25	If Other, give size of community	(95-99)
	Female sex partners of intravenous drug users				(80)	25.	Sexual preference Exclusively hetero-	
	Homosexual men with multiple sex partners				(81)		Sexual (1)  Exclusively homo- sexual (2)	
	Homosexual men prac- ticing receptive anal in- tercourse				(82)		Bisexual (3)	(100)
	Homosexual men prac- ticing insertive anal in- tercourse				(83)	sum	n in answering these questions. Results will be marized and we will send them to you once the ysis is complete.	٠ .
	Surgeons				(84)	Data	analysis code	(101-104
						3		311

### Mandatory Reporting of HIV-Infection

The state of Minnesota, without much public notice or controversy, decided last year to subsume AIDS under the general list of communicable diseases. As a result of this decision, not only AIDS itself but also the "carrier status," i.e. the state of being infected with HIV, became reportable to the Minnesota Department of Health. Every Minnesota physician is required to report the name and address of an HIV-infected patient. Theoretically it is still possible in Minnesota to be tested "anonymously," i.e. by giving a false name, at a state testing center. However, those who test positive are advised in a post-test counseling session to consult a physician in order to be monitored and to protect their own health. Once the individuals appear in their doctor's offices, of course, they will have to give up their anonymity and at that point they will be reported.

The Minnesota Department of Health does have an excellent record of maintaining the confidentiality of its files. Furthermore, it claims that its register of infected men and women provides a useful basis for "contact tracing," i.e. for finding and counseling the sexual partners of the infected. This contact tracing is conducted by highly trained and experienced personnel in a discreet and efficient manner. The Department maintains that the entire program is sufficiently effective to warrant its continuation.

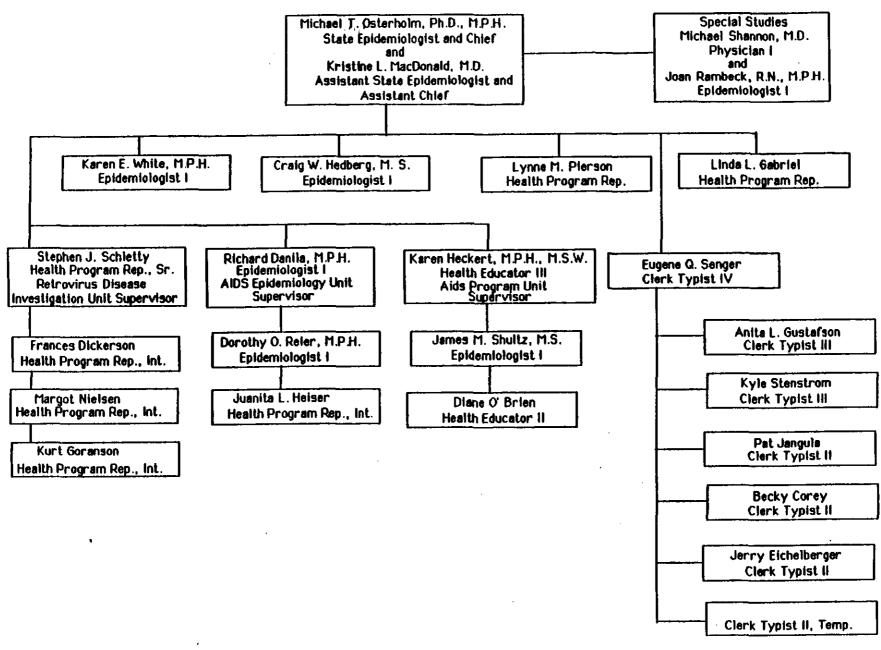
Since, at the present time, the number of AIDS cases (and with it the number of infected individuals) is relatively low in Minnesota, it is understandable that no serious problems with mandatory reporting have arisen so far. However, there are some professionals, especially those active in the gay community, who are worried about potential future violations of confidentiality and subsequent discrimination. It has to be remembered that Minnesota is among the 22 states in the U.S. still retaining a "sodomy" law (i.e. a law against oral and anal intercourse). This may eventually turn out to be a serious stumbling block in contact tracing efforts because those who are asked to name their sexual partners very often, at the same time, would have to admit having committed the crime of sodomy. Even the accidental disclosure of this information could lead to criminal prosecution. At the present time this problem is not taken seriously by the Department of Health, which prides itself on its unblemished record and nonjudgemental professionalism.

Ultimately, only the future will decide whether the Department's optimism is justified or whether, by design or accident, some breach of confidentiality will occur. It is understood by all concerned that one such breach will be sufficient to undermine the entire program and to cast its further success in serious doubt.

The following pages illustrate some facets of the present practice:

- 1. An organizational chart of the relevant division in the Minnesota Health Department.
- 2. A handout for individuals who test positive for HIV antibodies describing Partner Outreach and Partner Notification Services ("contact tracing").
- 3. A more detailed information sheet for the same group of individuals.
- 4. A procedural flow chart describing the process of dealing with infected persons persisting in infectious behavior.
- 5. A form letter used by a physician to inform seropositive patients of his intent to report their names to the Minnesota Department of Health.

### Division of Disease Prevention and Health Promotion



# YOU CAN HELP STOP THE AIDS EPIDEMIC IN MINNESOTA BY NOTIFYING YOUR SEXUAL AND NEEDLESHARING PARTNERS

Tell them that they may have been exposed to the AIDS virus and refer them to their physicians or to an AIDS Counseling and Testing Site.

### How Can You Tell Your Partners?

There are two programs designed to help you:

Partner Outreach Services -> to help you inform some or all of your partners

Partner Notification Services -> to have someone else notify your partners without revealing your identity

Both programs are free and voluntary. You can use one or both services.

### Partner Outreach Services

When you want to be the person to tell some (or all) of your partners about your antibody test results you can get emotional support and practical help from the counselors at Partner Outreach Services (POS). Your POS counselor will not ask for your name or your partners' names. He will help you plan your approach to notify each of your partners and he will provide support and information as you carry out your plan. For more information about Partner Outreach Services call (612) 347-3302 in Minneapolis; (612) 292-7752 in St Paul; and either number from greater Minnesota.

### Partner Notification Services

When you want your partners to know that they may have been exposed to the AIDS virus, but prefer not to notify some or all of them personally, you can get confidential help from Partner Notification Services (PNS). The professional Partner Notification Services staff will contact some or all of your partners for you and protect your privacy during the notification process. Partner Notification Services are confidential. Partner notifiers will not reveal your identity to any of the people they notify. Any information you give to the Partner Notification Services staff is voluntary and will be kept confidential. The Minnesota Data Practices Act assures the confidentiality of the information you give. No information about you will be given out to others. For more information about Partner Notification Services please call (612) 623-5414.

POS and PNS are funded by the Minnesota Department of Health.

## IF YOU ARE POSITIVE FOR ANTIBODY TO THE AIDS VIRUS PLEASE CONSIDER TELLING YOUR PARTNERS

There are many tools available to fight the battle against AIDS. Risk reduction education is one tool which is important for everyone. For some individuals who are at especially high risk for acquiring the AIDS virus, other tools are also available. Persons who are sexual or needlesharing partners of individuals who are positive for antibody to the AIDS virus (seropositive) are one such very high-risk group. These people may become infected and spread the virus without knowing it. Informing partners of their risk and directing them to educational, medical, psychosocial, screening and other resources can be a powerful way to help stop the spread of AIDS. Any person who is seropositive should seriously consider informing their sexual and/or needlesharing partners of their risk, if he or she has not already done so.

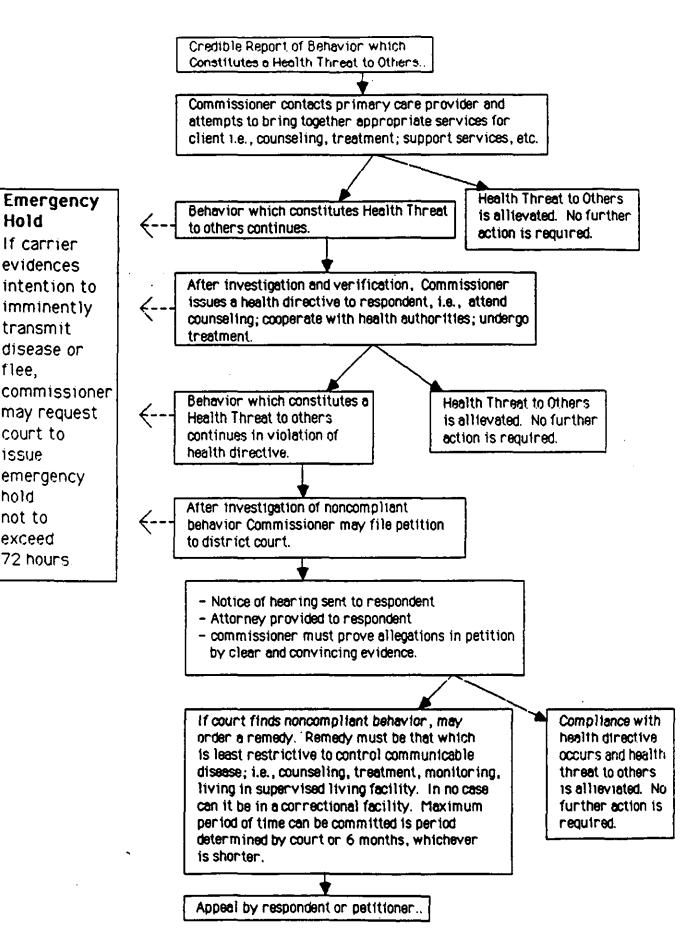
This sheet contains ideas on how a seropositive person can inform his or her sexual or needlesharing partners of their risk. These suggestions are derived from a handout used in the Partner Outreach Services (POS) Pilot Program. This Pilot Program recently started at the Red Door Clinic in Minneapolis, and provides assistance for seropositive individuals who wish to notify their partners of their risk. The Program is free, confidential and anonymous for both the seropositive person and his or her partners.

Any seropositive person, whether tested recently, or a while ago; whether tested at the Red Door, other public test sites or by a private physician, is welcome to make use of the POS Progam. (Call The Red Door Clinic for information and an appointment.) This handout is an outline of how a POS counselor would help you to proceed. Whether you use the POS program or do it on your own with these suggestions, please seriously consider notifying your sexual or needlesharing partners of their risk if you are seropositive. By doing this, you personally have the ability to help stop the spread of AIDS. You owe it to yourself, your partners, and your community. Suggestions for notifying partners include:

- 1) Make a list of all your sexual and needlesharing partners during the time period that you think you may have been infected. People generally include at least the 12 months prior to being tested. Include no last names or identifying information on this list, and keep it confidential.
- Take a few days and imagine what it might be like to notify each person on the list about their risk of exposure. Imagine what their reaction might be and what your reaction might be. Run it through your head a few times, without forcing yourself to come to a quick decision about who you might notify easily and who you might have trouble notifying. Instead, let your imagination give you the most possible information about what it might be like in each case.
- 3) Figure out who your closest and most trustworthy friends are. If you have not already done so, consider telling them that you are seropositive for the AIDS virus antibody and ask for their support in helping you deal with this and their assistance in helping you work on a partner outreach plan. If there is no one you really trust to do this, we would recommend that you seek assistance from a partner outreach counselor (available at the Red Door Clinic), if you have not already done so.
- 4) After you and your support person have had some time to discuss this together, ask for that person's assistance in helping you make a partner outreach plan for each person on your list. Telling your support person the identities of the partners is certainly not necessary, and we strongly suggest that you keep that information confidential.
- 5) Using whatever amount of input you feel most comfortable with from your support person, classify your list of partners into three groups: those who will be easiest to notify, those who will be somewhat difficult to notify, and those who will be very difficult to notify.

- 6) Start with the partners who will be easiest to notify and make a plan using your support person to help you as you wish. It might be a good idea to use your support person to role play what this outreach might be like.
- 7) This plan should also include how you think it might be for you and how it might be for the partner. In addition, be prepared to direct your partner to medical support, educational, and AIDS virus antibody screening resources. (You can obtain this information through the Counseling and Testing Sites or the Minnesota AIDS Project.)
- At a time and in a private place that you think is the best suited, tell the first partner you have chosen. Keep in mind that they may be upset or deny this information. You may have to repeat it a few times to them and may have to have other talks with them to fully discuss it. Do not pressure yourself to do it quickly or to do it right. Simply do the best you can, and use your judgement. Also keep in mind that there is a limit to how much you can do for your partner, because you may have your own distress to deal with. Remind the partner of the medical, support, educational, antibody screening resources available and encourage the partner to seek them out. You do not have to provide all these resources for your partner yourself, but merely direct the partner to these resources.
- 9) After you have completed the first outreach, review it for awhile, perhaps with your support person, and figure out what you have learned from this. Then, go to your list and look at the other partners whom you have decided definitely to tell, and consider if you wish to change any of your strategies for these other partners based on your first experience. Make plans, using your support person if necessary, to contact these other partners on your list who were classified as "easiest to tell" and proceed to tell them as outlined above, reviewing with yourself after every outreach how it went and what you might like to do differently. We also recommend that you check in with your support person about your own stress level and whether the pacing of telling the various partners is such that you are capable of doing your best.
- 10) After you have completed going through your "easiest to tell" list, take another look at your "somewhat difficult" list and make another decision about which of these people you are ready to tell. If you do decide to tell people on the "somewhat difficult" list, proceed as above. After you have completed doing outreach to all those in this category that you intend to, review again what you have learned, and how you feel about it.
- 11) Finally, when you have gone through the first two lists, reconsider whether there are any people on the "very difficult" list whom you might now be ready to tell. If you have a strong feeling that one or more of the people on the "very difficult" list might act in a malicious or harmful manner towards you, or may react with such upset that you fear for their safety, these may well be good reasons for you not to tell that person. Also keep in mind that the Counseling and Testing Sites can direct you to third party notification resources which may provide a method for notifying the most difficult people on your list to tell, should you deem that necessary.
- 12) If there are some people on the "somewhat difficult" and "very difficult to tell" lists that you have not contacted, we would ask you to again consider contacting them after some time has passed. Remember, it may not be in your best interest to contact all of your partners yourself. Some people feel differently about contacting their partners themselves or having others do it after their own reactions have settled down and after some of their outreach has been completed. Again, remember that there are resources available to help you with either option.

Prepared by Dr. John Gonsiorek in conjunction with the Acute Disease Epidemiology Section Minnesota Department of Health





UNIVERSITY OF MINNESOTA

Infection Control Department Box 421 UMHC University Hospital and Clinic Harvard Street at East River Road Minneapolis, Minnesota 55455

(612) 626-5036

August 19, 1987

Dear

This is to let you know directly that I plan to file a "confidential HIV case report" form with the Minnesota Department of Health reporting that you have been infected by the AIDS virus. I realize this will cause anxiety among some recipients of this letter. But I have an extremely high degree of confidence that the Acute Disease Epidemiology Section of the Minnesota Department of Health will maintain its unviolated tradition of absolute confidentiality. I believe the information will not leave the Acute Disease Epidemiology Section even to other sections of the state government.

In my opinion, these reporting requirements are, on balance, a good thing. Within the past several months the Minnesota Department of Health has begun to call most reported patients to be sure that they understand how to avoid passing on the virus. They also encourage notification of contacts and, for those who desire it, provide direct assistance in contact notification. If you would like me to ask the state health department to not call you up please leave word at 625-1462.

I also realize that some persons will feel that I have betrayed a confidence. But, even if I didn't feel the Department of Health program was desirable, I do not have a choice about whether or not to file these reports. If you would like to discuss this matter please call me at 626-5036.

Sincerely yours,

Frank S. Rhame, M.D.
Asst Prof Dept of Medicine
Infectious Diseases
Section
U Minn Medical School

### THE MINNESOTA HEMOPHILIA SOCIETY

The Minnesota Hemophilia Society is a chapter of the National Hemophilia Foundation. Since a number of hemophiliacs have been infected through blood products before the virus was discovered and the blood products were made safe, the various hemophilia organizations had to deal with a number of problems associated with AIDS early on. Prominent among these are discrimination, especially in schools, and "safe sex" practices. The Minnesota Hemophilia Society, as well as its national umbrella organization, have risen to the challenge and provided their members with continuous and adequate information.

By way of illustration, the following pages offer excerpts from the Minnesota hemophilia newsletter and a report of the national hemophilia information exchange. This report, although dated, is remarkable for the frankness and good sense with which it discusses sexual issues, including those confronting hemophilic teenagers.



# TEINE INE

minnesota chapter NSTIONAL HEMSPHILIA FOTN. 2304 Park Svenae Minneapolia, Mn 55404 (612)871-3340

## NEWSLETTER OF THE MINNESOTA HEMOPHILIA SOCIETY

Mark Faitek, President and Editor No. 87-4

Harold Naiditch Associate Editor

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### I. NHF AND NIAID DEVELOPING AIDS TREAT-MENT AND EVALUATION NETWORK "WITHOUT WALLS"

The National Hemophilia Foundation, in cooperation with The National Institute of Allergy and Infectious Diseases (NIAID) of The National Institute of Health, is developing a proposal to conduct clinical trials of Azidothymidine (AZT) on hemophilic patients who test positive for HIV but are without symptoms of AIDS. The study involving 500 patients, which is expected to begin in late November, will be conducted through the existing regional network of 80-100 hemophilia treatment centers, in cooperation with NIAID's AIDS Treatment and Evaluation Units (ATEUs).

Unlike the usual way in which AIDS treatment and evaluation activity is being conducted at 19 NIAID designated centers, this study will utilize an AIDS treatment and evaluation "without walls" concept for the hemophilia population. This innovative approach will involve the establishment of regional hemophilia centers that will be affiliated with the NIAID funded ATEUs. The regional hemophilia centers will in turn supervise the enrollment of patients at other hemophilia centers within their respective regions.

Thomas C. Merigan, MD, NIAID liaison on hemophilia and AIDS and a member of the Medical and Scientific Advisory Council (MASAC) of NHF, designed the protocol for this study, \*A Placebo-Controlled Trial to Evaluate Azidothymidine (AZT) in the Treatment of Human Immunodeficiency Virus (HIV) Infection in Hemophilia Patients.\* Dr.

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### AIDS UPDATE

CHAPTER ADVISORY # .57

### IX. AIDS IN THE SCHOOLS - A MODEL

This is a report of how the small town of Granby, Connecticut dealt with the AIDS in the schools issue in a most sensitive and appropriate manner. The attached reprint of a story published in The New York Times is being shared to illustrate how school officials, parents and classmates can function during and after such a crisis with calm and compassion. This article may be selectively used by chapters and treatment centers when there is potential of people becoming inappropriately alarmed with students in school who have been exposed to HIV or contracted AIDS. For parents in a PTA or sitting on a school board, such an article may give cause for reflection before rash discriminatory acts are performed. It should not be used where the issue does not exist, lest it cause an issue to arise. WE ARE NOT RECOMMENDING GENERAL DISTRIBUTION TO SCHOOL OFFICIALS, BUT WITH POTENTIAL DISCRIMINATION BEING A REALITY AT THE LOCAL LEVEL, YOU MAY FIND THIS USEFUL FOR LIMITED CIRCULATION UNDER CERTAIN CONDITIONS. THE APPROPRIATE USE OF THIS MATERIAL DEPENDS ENTIRELY UPON YOUR ASSESSMENT OF LOCAL CIRCUMSTANCES, AND YOUR BEST JUDGMENT AS TO HOW TO ABATE UNWARRANTED FEARS.

The National Hemophilia Foundation (NHF) stated its position in Chapter Advisory # 35 (November 18, 1985) that "school attendance by children with AIDS presents no risks." Medical Bulletin # 31/Chapter Advisory # 36 (November 25, 1985) suggested that while such a policy concurs with recommendations of the Centers for Disease Control (August 30, 1985 Morbidity and Mortality Weekly Report) and the American Academy of Pediatrics, there can be an expectation of "inappropriate school exclusion and isolation in some areas of the country." While such incidents have not been widespread, they have and continue to occur. These local developments usually capture media attention and often result in hysteria and fear that exascerbate the situation. THERE HAS BEEN NO MEDICAL EVIDENCE OR SCIENTIFIC INFORMATION TO WARRANT A CHANGE IN THE NHF POSITION ON SCHOOL ATTENDANCE. It is important that you share local developments with Christopher Whitney, Coordinator of Education and Preventive Services of the National Resource and Consultation Center for AIDS and HIV Infection (NRCC) so that the NRCC can continually monitor the AIDS in the schools issue.

The Granby, Connecticut story illustrates that while school authorities must contend with an outspoken few who promote exclusion of AIDS patients, strategies can be enacted to support school officials in responsible decision making. This reprint of Michael Winerip's column ("Our Towns" The New York Times, February 27, 1987) further informs on the positive experiences that took place at Kelly Lane Elementary School.

The NHF appreciates the cooperation of Mr. and Mrs. Barnoski, Mr. Winerip and The New York Times in allowing us to share this story.



### AIDS UPDATE/September 1985

## HEMOPHILIA AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS): INTIMACY AND SEXUAL BEHAVIOR

This report is based on the most current information available.

The NHF will keep you advised of new developments through updates of this report.

Stephen B. Levine, M.D. Case Western Reserve University Cleveland, Ohio

The appearance of AIDS in the hemophilia population has caused considerable emotional distress. A major focus of the AIDS concern has been the sexual activity of men and adolescents with hemophilia. The following questions and answers address the concerns of patients, parents, and sexual partners. Because of the rapid development of medical knowledge in this area the current, most reasonable recommendations to prevent the transmission of the AIDS virus are considered tentative. The National Hemophilia Foundation (NHF) is concerned with preventing the transmission and development of AIDS while at the same time maintaining a psychologically comfortable intimacy between men with hemophilia and their loved ones. Some of these issues may raise further questions and concerns. It is strongly encouraged that further dialogue about these matters take place with your physician and other health care providers.

### SECTIONS

- A. Sexual Intimacy and AIDS: Who is at Risk?
- B. Sexual Intimacy and Risk of AIDS: Advice for Prevention.
- C. AIDS and Pregnancy
- D. Sexual Intimacy and the Risk of AIDS: Additional Advice for Teenagers and Their Parents.
- E. Sexual Intimacy and the Risk of AIDS: Other Considerations.

## A. SEXUAL INTIMACY AND AIDS: WHO IS AT RISK?

1. Are all persons with hemophilia and von Willebrand's Disease at risk?

During the past year it has become clear that heterosexual transmission of HTLV-III virus is possible.

Until we know more about the possibility of AIDS occurring in sexual partners of persons with hemophilia, the recommendations included in this document are intended for all persons with hemophilia and von Willebrand's Disease regardless of their antibody status or antigen (virus) status.

### 2. Exactly how is the HTLV-III virus transmitted during sexual behavior?

The HTLV-III virus is in certain body fluids including the male ejaculate or semen. It is possible that the virus may be absorbed through the sexual partner's mucous membranes, the tissues which line the vagina, the anus or the rectum. This may occur directly or through small injuries of the mucous membranes, or through raw or bleeding areas such as may develop during rectal intercourse.

3. If I don't have evidence of AIDS, do I still have to be concerned about transmitting the AIDS risk to my sexual partner?

Yes. Even though the chance of disease transmission in men with hemophilia to their sexual partners is rare, approximately 90% of the persons with hemophilia have HTLV-III antibodies. It has been suggested by some treaters that repeated exposure to antibody positive semen increases the risk of female partners developing HTLV-III antibodies. NHF recommends the use of condoms because they provide the most effective barrier for semen.

4. If I don't have evidence of antibody to the HTLV-III virus, do I still have to worry about transmitting the AIDS risk to my sexual partner?

It is uncertain. In only rare instances have men with hemophilia had the virus without the antibody to it being present, but a recent exposure to the virus through a blood product could have occurred without the antibody having yet developed, due to the long incubation period of the virus. For this reason, the use of condoms is recommended until more information is available

# 5. If I am the sexual partner of a person with hemophilia who has a positive HTLV-III antibody test, what should I do?

Until more information is available, NHF is recommending the use of condoms. Many persons with hemophilia have been exposed to this virus without developing any evidence of AIDS. Having antibodies simply indicates the individual has had an immune response. Recent research, however, has shown that in some instances the virus has been transmitted to sexual partners of otherwise healthy persons with hemophilia, and only in extremely rare instances, has the disease been transmitted. But it is important to remember that preventive measures should be taken (see section B, below).

### 6. I am a sexually active man with hemophilia who is worried about contracting AIDS through sexual behavior. What do I need to know?

Heterosexually active men do not generally have to be concerned about contracting AIDS through sexual behavior. Men with hemophilia, however, who have had sexual contact with women who are antibody positive to the HTLV-III virus may be at an increased risk of contracting AIDS. Women who may be antibody positive to the HTLV-III virus include women who have had sexual contact with IV drug users, bisexual men or antibody positive men. There is some speculation that a high percentage of prostitutes have also been found to be antibody positive.

For the vast majority of men with hemophilia, the major concern is that they might transmit the virus through sexual behavior to their sexual partner. Men with hemophilia typically acquire the virus through blood products, not sexual behavior.

### B. SEXUAL INTIMACY AND THE RISK OF AIDS: ADVICE FOR PREVENTION.

### 7. What can be done to minimize the

### transmission of HTLV-III virus to a partner?

It seems likely that condoms will prevent the transmission of the virus to the muccous membranes of the partner's vagina, anus or rectum. It also seems wise to avoid rectal intercourse and ejaculation into the partner's mouth even though oral spread of virus seems a remote possibility. It is vital to remember that other things can be done to enhance sexual pleasure. The hand is often overlooked as a means of generating your own and your partner's orgasm. Men and women are capable of giving and receiving sexual pleasure with combinations of caresses, massages, lotions, body rubbing and vibrators. Sex manuals from all parts of the world depict the skillful innovative use of the hands in producing male and female orgasms.

Orgasm in the vagina is the most efficient means of achieving the male's orgasm, but not the only one. Hand stimulation, not intercourse, is the way most women achieve orgasm.

# 8. Rather than using a condom, why not just have intercourse until I am ready to achieve orgasm and withdraw the penis from the vagina?

Commonly there is a little seepage of semen or sperm prior to the actual orgasm. This has led to pregnancies even when couples disciplined themselves to withdraw prior to orgasm. HTLV-III virus could be in the few drops of seepage. In addition, knowing that the man must withdraw keeps him and his partner preoccupied with withdrawing rather than with getting lost in the sensations of sexual arousal. This tends to ruin the experience for both of them and makes male and female orgasm more difficult to achieve. The results may be often a gradual cessation of sexual intercourse.

### 9. If I have not used condoms with my spouse of ten years why should I start now if I am using heat treated product?

A high percentage (90%) of persons with hemophilia have developed and continue to have HTLV-III antibodies as a result of blood product usage previous to the use of heat treated products. The use of condoms is recommended to prevent the repeated exposure of the sexual partner to antibody positive semen. This is recognized as an extremely difficult and very personal area. Talking through your concerns with each other is the healthiest approach. Consult your treatment center staff if you feel the need of professional support.

### 10. Is AIDS passed by kissing?

While it cannot be absolutely guaranteed that it is not, the chances of transmission by kissing is remote. If AIDS were transmitted by saliva, it would be found that many family members of persons with HTLV-III infection would also develop HTLV-III infections. This has not occurred. A total of several hundred family members of persons with hemophilia have now been surveyed for HTLV-III infections at various centers; only a few sexually active partners of hemophiliacs were positive for antibody. The spread of AIDS is thus believed to occur very infrequently, and to happen by intimate sexual activity, rather than by kissing, touching, coughing or sneezing, etc.

### 11. How am I and my partner to cope with the AIDS risk?

AIDS is not an invariable consequence of multiple transfusions. Even though a person is exposed to the virus the chances of him or her developing AIDS are low. Some people exposed to the virus: will develop AIDS (less than 1%); some may develop symptoms of mild immune deficiency which does not progress to AIDS; others may carry the virus without any symptoms of illness; some may develop antibodies to the virus and others will not carry the virus. It is the uncertainty of outcome that creates emotional discomfort.

The answer to "how am I to cope?" is, "in the same way you have successfully dealt with other trouble-some life circumstances that you have had to master." NHF and the medical community are hard at work on the problem; the rate of new useful knowledge generated is impressively high. After a brief period of alarm and taking prudent precautions, one simply has to lead one's life—dating, forming new attachments, experiencing safe sexual behavior with one's partner when the relationship is ready. If married, after discussing fears and risks and understanding the need for temporary condom usage, behave sexually within the limits.

Sexually, the current uncertainties about AIDS have at least one "silver lining", that is, the opportunity to increase one's sexual behavioral repertoire, to go beyond the standard intercourse and discover the many means of giving sexual pleasure without depending solely upon intercourse.

## 12. Do "normal" people really make love without having intercourse?

Yes. Here are some reasons: variety; menstruation; vaginal infection; recent vaginal delivery; spontaneous discovery during foreplay leading to orgasm; intimacy before marriage or prior to having effective contraception. There are a number of alternatives to having intercourse. However, there seems to be no

reason to stop having intercourse at this point; just use a condom.

# 13. Specifically, what can I do to bring my partner to orgasm besides manual clitoral stimulation?

The woman or the man can use the penis, with a condom, to stimulate the clitoris. The opening to the vagina and the vaginal walls are very sensitive to a slight lateral distention. Depending on the exact location of the vaginal stimulation a slightly different but intensely voluptuous sensation leading to female orgasm can result.

### 14. What about oral stimulation of the penis?

There seems to be no risk in the behavior as long as the pre-ejaculatory seepage of the semen and sperm do not contact the inside of the mouth during oral stimulation. The penis does not need to be taken fully into the mouth. The shaft of the penis or the testicles can be caressed with the lips or tongue.

# 15. Can AIDS be transmitted through oral stimulation of the female genitals in order to arouse the partner or bring her to orgasm?

As with kissing (see Question #10), it cannot be absolutely guaranteed that it is not, but the chances are remote, as the transmission of AIDS through saliva appears to be quite unlikely.

### C. AIDS AND PREGNANCY

### 16. My wife and I are hoping to conceive a child in the next few months. Since I have hemophilia, is the pregnancy or the child at risk?

A baby recently born to a couple with a hemophilic father, who later developed AIDS, was diagnosed with AIDS shortly after birth. Although this is the only such case, it suggests the heterosexual transmission of the HTLV-III virus to the mother, who then transmitted the virus to her newborn child. As a new precaution, we are urging that serious consideration be given to deferring pregnancy until better data is available. The potential risk of intra-uterine passage of HTLV-III from a mother to the fetus is

real, and infants so infected appear to run a relatively high risk of AIDS. Discuss this matter with your treatment center staff. We recognize this to be an extremely anguishing personal dilemma, which will again raise the level of concern for persons with hemophilia and their sexual partners. We hope to have more medical knowledge soon on the risk to the child. In the meantime, discussing the risk of pregnancy with your partner and treatment center staff is recommended.

### D. SEXUAL INTIMACY AND THE RISK OF AIDS: ADDITIONAL ADVICE FOR TEENAGERS AND THEIR PARENTS.

17. What should a parent of a teenager with hemophilia do about the AIDS risk?

You may be concerned about the impact of AIDS on the development of your teenage son's social interactions and relationships. Social interactions that often lead to intimate physical contact up to (and sometimes including) intercourse between teenagers are an important step in the emotional development of young people. On the other hand, there are many medical uncertainties about the transmission of the AIDS virus. The conflict between the need to encourage teenage social interactions and the medical anxiety of genital viral transmission causes serious dilemmas. At this point (September 1985) it is reasonable to assure teenagers and their parents that the hand-holding, hugging, kissing, and petting that usually appears as teenagers become more psychologically intimate with one another, should not be discouraged.

It is a concern that as teenagers get older and feel ready for sexual intercourse they pay careful attention to three things: 1) contraception, 2) the prevention of transmission of the AIDS virus through semen and sperm, and 3) sharing information about the AIDS risk with the prospective sexual partner. The recommended solution for the first two of these problems among teenagers is the use of a condom, prophylactic or "rubber." The teenager who already is having intercourse, or those who are contemplating it, are strongly encouraged to obtain prophylactics and use them.

Commonly, parents and their teenagers find they are unable and uncomfortable with discussing sexual intimacy. Most teenagers have a natural need to separate their sexual experiences from the perspective of their parents. But hemophilia and AIDS require some exception to this general pattern. If the parent or the teenager feels uncomfortable, parents may want to indicate their concern about this and urge the health care provider and the teenager to

discuss this in a medical setting. This topic should not be swept under the rug. Even if AIDS were not the issue, it is important for parents to articulate that if a teenager is mature enough to have sexual intercourse, he has to be mature enough to do so responsibly.

In essence recommendations concerning AIDS for teenagers with hemophilia, are quite similar to recommendations that have existed before AIDS became a problem.

# 18. What can the teenager with hemophilia do about being teased about becoming homosexual?

Because of the widespread publicity about AIDS in the media, the public associates AIDS with homosexuality. A number of teenage boys with hemophilia have been teased by their friends about getting transfusions. For example, one young man was teased: "I don't know if I would get a transfusion. You might go from hemo- to homo-!" Obviously such a remark about the relationship between hemophilia and homosexuality is based upon ignorance and misunderstanding — hemophilia and homosexuality are quite separate. The vast majority of hemophilic men are not, nor will ever become homosexual or interested in a homosexual experience. There is no way a transfusion can have anything to do with the development of homosexuality. The issue becomes how to handle the misunderstanding and ignorance of one's friends and acquaintances. In general, hemophilic teenagers are probably quite used to jokes about hemophilia that disguise other people's lack of understanding and knowledge. These things are best dealt with simply and directly. "The joke may be funny, but it isn't true." The person who made the joke must simply be educated in a direct, simple fashion. "If that were true I'd have a lot to worry about, but I've had hundreds of transfusions and not once have I become gay." You may want to discuss some of your thoughts further with your parents, friends, or a health care provider at your hemophilia treatment

# E. SEXUAL INTIMACY AND THE RISK OF AIDS: OTHER CONSIDERATIONS.

# 19. How can I feel comfortable and open about starting a new relationship at this time?

Some single men with hemophilia are hesitant to become involved intimately with another person. There are many reasons for this pattern. Fear of rejection, unwillingness to burden another person with the illness that goes along with the loving relationship, and fear of sexual inadequacy are common reasons for hesitation. The concern about transmitting the AIDS virus through sexual behavior can further discourage some men from starting psychologically intimate relationships. This is quite unfortunate; a great deal of life's richness comes from being able to share intimacy with another person.

The burden of the AIDS risk may be much greater in the man's mind than in the mind of the informed partner. Many women when fully informed of the consequences and the meaning of hemophilia, still find that the human relationship transcends the fact that the particular man has an illness. The AIDS risk then is an added dilemma for both the already hesitant man and the interested woman. Close relationships which might otherwise have formed may remain undeveloped.

### 20. How are we to understand the withdrawal from sexual behavior when a person discovers he is antibody positive for the AIDS virus?

Stopping sexual behavior when one discovers the risk of being an AIDS carrier is a perfectly understandable reaction.

The antibody positive individual feels, for a while at least, that he has become infectious and may withdraw from intimate relationships. The greater worry is that "Oh, no, I could be giving this thing to my partner. I don't want to do that! It is better not to have sex at all or to simply return to masturbation!: As in other stresses in life, the way a person feels about a problem one day is often quite different than a week, two weeks, and a month later. It is important to respect one's emotions — one's natural reactions — to understand the array of feelings and thoughts that come with any particular new life circumstance. There is a tension between the sense that "I am contagious," and "I need another person."

# 21. Why not just give up all partner sexual contact and content oneself with masturbation?

Masturbation certainly is safe but withdrawal from partner sexual behavior is not psychologically risk free. Sexual contacts, for those who emotionally want it, is usually a rewarding experience that helps to form and maintain emotional closeness to others.

Sexual intimacy tends to enhance self-esteem and the sense of masculinity and your partner's femininity. It is widely regarded as generating emotional health. These important psychological uses of sex may be a lot for you and your partner to give up. Very likely a compromise (using a condom) is a more prudent temporary approach until more is learned about the virus.

### 22. What about homosexually active men with hemophilia?

The same principles apply, that is, steps should be taken to avoid the discharge of body fluids, rectal intercourse and fellatio with ejaculation in the mouth should be avoided, or if practiced, a condom should be used. Manual stimulation outside body cavities is medically safest.

SUMMARY: The AIDS risk has caused distress concerning sexual activity for many hemophilic men, teenagers, and their partners. The danger is that this distress will cripple the sexual development and sexual behavior of many young and adult men with hemophilia, or cause undue alarm for their sexual partners. While it is not denied that there are reasons for concern, it is important to realize that people with hemophilia are used to dealing with many medical and social problems that others do not have to confront, and have a long tradition of overcoming seemingly overwhelming obstacles. In fact, this hopefully temporary dilemma may be used to broaden a couple's sexual repertoire.

The National Hemophilia Foundation will continue to provide new information and recommendations as they are developed.

### **ACKNOWLEDGMENTS**

"Intimacy and Sexual Behavior" was produced under the aegis of the NHF AIDS Task Force and Mental Health Committee. The NHF AIDS Task Force wishes to express its appreciation to Stephen B. Levine, M.D., for his leadership in authoring this document. The contributions of the Centers for Disease Control and NHF's Mental Health Committee were significant in assisting Dr. Stephen B. Levine in his efforts.

We wish to thank Armour Pharmaceutical Company. Their support of NHF's Mental Health Committee helped make the preparation of this document possible.

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### THE MINNESOTA AIDS PROJECT

One of the most important elements in the fight against AIDS in Minnesota is, and undoubtedly will remain, the Minnesota AIDS Project. Its multiple activities, as well as its budget, are clearly and exhaustively described in its report to the community in June 1987. This report is reproduced in full on the following pages.

### MINNESOTA AIDS PROJECT

The Minnesota AIDS Project is dedicated to stopping the spread of the AIDS virus in Minnesota and providing education and support services for persons with AIDS illnesses. The work of the Minnesota AIDS Project is directed by a professional staff and carried out by a volunteer work force of over 350 people.

### EDUCATION

The Minnesota AIDS Project believes that a full range of educational programs which work to increase awareness, provide safe alternatives and provide positive reinforcement for healthy behavior choices are necessary for an overall AIDS risk reduction effort. To this end the Minnesota AIDS Project provides the following:

- The AIDSline.
  Hours are Monday thru Thursday, 10:00 AM to 10:00 PM, Friday 10:00 AM to 5:00 PM. We averaged nearly 1,000 calls per month in 1987. 7 County Metro AIDSline (612)870-0700; Statewide Tollfree AIDSline 1+800-248-AIDS
- 2. Speakers' Bureau.
  Our Speakers' Bureau provides individually-tailored professional presentations and in-service training sessions to help social service workers, community groups, church groups and others better understand AIDS-related issues.
- 3. <u>Materials Production and Distribution</u>.

  We distribute an average of 15,000 brochures, posters and flyers throughout Minnesota each month. We also distribute a quarterly informational newsletter.
- 4. <u>Safe Sex Seminars and Workshops</u>
  The Minnesota AIDS Project provides experientially-based workshops which provide motivation and peer support for positive behavior changes.
- 5. Media Campaigns.
  The Minnesota AIDS Project has developed several media campaigns for targeted audiences.M.A.P. is also a member of the Minnesota AIDS Mass Media Consortium which is developing a large-scale mass media campaign for all of Minnesota.
- 6. Statewide Program.
  Over 80 Minnesota AIDS Project representatives provide educational materials, arrange for speakers, and respond to concerns about AIDS in more than 40 communities throughout the state.
- 7. <u>Training/Consultation</u>.
  Technical assistance and training are provided to private and public organizations regarding a wide range of AIDS-related issues including legal issues, testing, confidentiality, psychosocial and family concerns.
  - 8. Youth Education
    Workshops, materials and videos targeted to adolescent, and young adults are presented to 500-1,000 youth each month.

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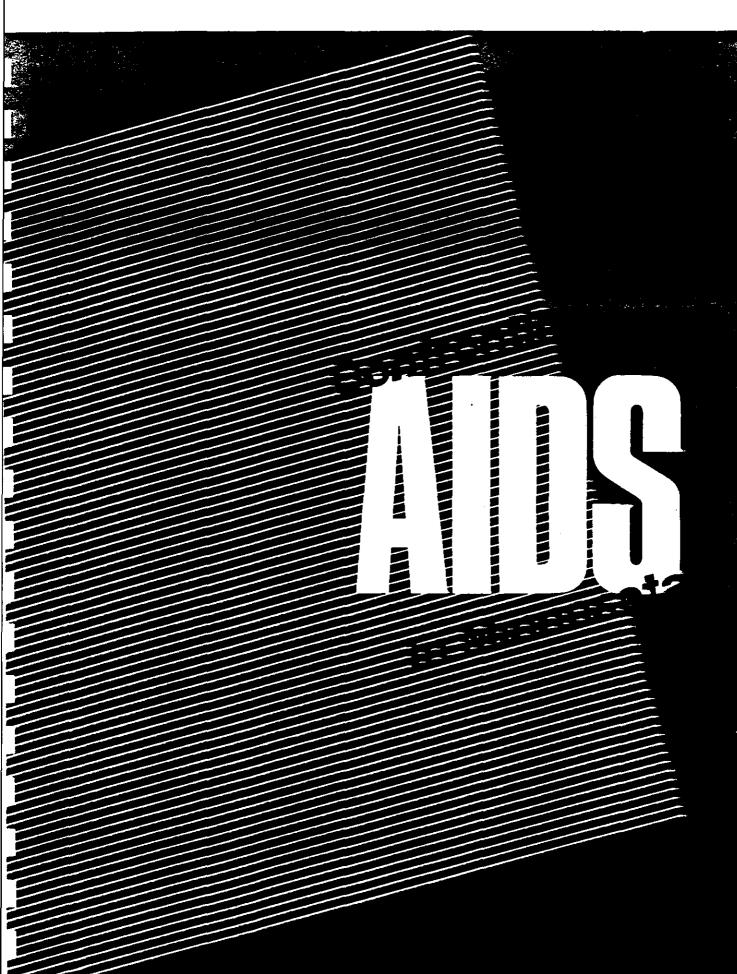
SUPPORT SERVICES

The Minnesota AIDS Project has consistently been providing support services to 75% of the diagnosed cases in the state of Minnesota. Volunteers of these programs have received awards from the McKnight Foundation and the United Way

### CURRENT SUPPORT SERVICES

- 1. <u>Emergency Financial Assistance</u>
  For housing, food, transportation and insurance are available to persons with AIDS/ARC.
- Long Term Housing
   Housing is provided to persons with AIDS/ARC who have low incomes, and need a structured yet supportive environment.
- 3. Emergency Housing This housing is available to persons with AIDS/ARC in a short term basis
- 4. AIDS Crisis Team
  A home and hospital visitation program for newly-diagnosed AIDS patients
  This team can also provide crisis intervention.
- 5. <u>Emotional Support Buddies</u>
  Volunteers are trained to provide emotional support through an ongoing personal relationship with AIDS/ARC patients.
- 6. <u>Practical Support Buddies</u>
  Trained volunteers provide practical support to persons with AIDS/ARC including: meal preparation, housecleaning, transportation, grocery shopping, etc.
- 7. Support to Caregivers Program
  Phone counselors call caregivers on a pre-arranged weekly or monthly bassis to provide emotional support and referrals to family members, friends or lovers who care for a loved one with AIDS.
- Service Coordinators & Case Management
  Facilitated by caseworkers who coordinate support services provided through M.A.P. such as client advocacy, referrals to hospitals, nursing homes, hospice agencies, medical assistance, General Assistance, Social Security, etc.
- 9. Professionally facilitated and Peer Support Groups
  A number of support groups meet weekly to provide educational and
  emotional support for people who are HIV antibody positive, have
  AIDS/ARC, women with AIDS-related concerns; family, friends, and lovers.
- 10. Referrals
  we provide referrals to meet needs such as chemical dependency
  evaluation and treatment, spiritual counseling, legal and civil rights,
  massage therapy and others.

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### "Growth has strengthened our accountability"

s the executive director of the Minnesota AIDS Project. I have been involved with this organization during a period of phenomenal growth. In services and education, the Project is on the front lines in the fight against AIDS in Minnesota.

In the past year alone, the Project has tripled its operating budget, quadrupled its staff, and increased its volunteer work force to over 300 individuals.

This growth has not been for its own sake: our evolution is in direct response to the massive, escalating challenge of AIDS.

The Minnesota AIDS Project began as a truly grass roots, community-based organization. I'm proud to say that our

growth has strengthened our ties to the community. The membership of our governing board of directors is diverse and representative, and includes persons with AIDS. Working committees composed of board members and other volunteers direct the efforts of paid staff, further ensuring accountability to the community.

Our growth has been made possible because the Minnesota AIDS Project has sought financial support from both the public and private sector. Maintenance of this partnership is crucial to the future of the Project. Of special importance is the establishment of a funding base for provision of basic social services for people affected by AIDS.

I have watched our compe-

tent, professional staff develop innovative educational and service programs. I have seen the caring and compassion of hundreds of our hard-working volunteers. These efforts are documented in this Report to the Community.

The true test of any nonprofit organization is whether it gives back to the community more than it takes. I am sure that once you have read our report you will find that the Minnesota AIDS Project more than meets the test.

Lie Gergeten

Eric Engstrom

Executive Director

### "We must continue to be a forceful advocate"

he Minnesota AIDS Project serves as an advocate for people affected by AIDS in Minnesota. Working with a crisis like AIDS has led to a number of controversies in which the Project has been involved. We have struggled with government officials over contact tracing, mandatory testing, non-compliant carriers, and risk reduction advertising, to mention just a few.

Trying to work as a bridge between people affected by the virus and the government is not a simple balancing act. The challenge we face is to continue to be a forceful, independent advocate for an effective response to AIDS. Our success will depend on a willingness among all of us to keep communication open: to be candid with problems and concerns as well as with praise and support.

The Minnesota AIDS Project faces many demands, sometimes conflicting; we will not always be able to solve these dilemmas. Our hope is that people will work with us, bringing their ideas and suggestions in finding better solutions.

Irrespective of what the Project or any other organization does right now, the AIDS crisis is going to get much worse before it gets better. We are confident, however, the Project is on solid ground as we move for-

ward. With the continuing support of the hundreds of volunteers, contributors, community activists, and government officials who have made our efforts possible, we will continue to do our best to stop new infections while providing services to those already infected.

Jim St. George Chair. 1986

Kris Wayne

Kris Wayne Chair, 1987

## THE MINNESOTA AIDS PROJECT: CONFRONTING THE CRISIS

Dedicated to stemming the spread of AIDS in Minnesota, the Minnesota AIDS Project is a private non-profit community organization. The Project provides prevention education to all Minnesotans, and support services to those affected by AIDS.

he first case of Acquired Immune Deficiency Syndrome (AIDS) in Minnesota was reported in fall of 1982, a year after the disease was first recognized in the United States. Bruce Brockway, a Minneapolis community activist and concert pianist, suffered unexplained weight loss, numbing fatigue, and susceptibility to a variety of crippling infections. His doctors recognized the symptoms of AIDS, the puzzling new "gay epidemic." Brockway did not remain Minnesota's only AIDS patient for long. Within weeks, other men were discovering that they, too, had been exposed to the deadly virus. In Minnesota, the AIDS crisis had begun.

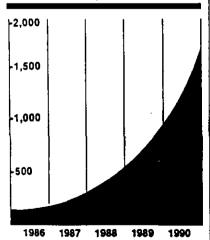
...

The first to confront the crisis were members of the Twin Cities' gay community. In January, 1983, a group of concerned volunteers held the first meeting of what would become the Minnesota AIDS Project. Their goal was twofold: to care for those affected by AIDS, and to prevent its spread through education. They were soon joined by concerned public officials and medical professionals, who recognized the threat of a potential epidemic.

As the effects of the virus spread, the Project's efforts grew. Volunteer "Buddies" were trained to assist people with AIDS who, because of the disease's stigma, lacked the support traditionally extended to the ill: comfort, financial security, a place to live and a place to die. Meanwhile, Project volunteers redoubled their efforts to reach and teach those not yet infected. Flyers were passed out, community forums held. Rumors were counteracted with accurate information: AIDS was not spread by toilet seats, mosquitos, doorknobs. It is a blood-borne viral disease, spread by intimate sexual contact or through intravenous needle use.

In fall, 1985, with a grant from the U.S. Conference of Mayors, the Project took on its first paid staff: a health educator and a director. Working from a tiny office, on a shoestring budget, volunteers and staff developed educational media: a poster campaign, a videotape, a speakers' bureau. By January of 1986, the Project's effectiveness was recognized with much needed funding from city, county and state health departments. Private sector support from individual and corporate donors grew. Today, thanks to these increased resources, the Minnesota AIDS Project carries out its mission with a volunteer force of over 300 and a staff of 20 serving the entire state.

### PROJECTED AIDS CASES



Health officials estimate 2,000 Minnesotans will have developed AIDS by 1990.

People with AIDS are not the only ones the Minnesota AIDS Project serves. Those who are infected with the virus but show no symptoms, or who have initial symptoms of immune deficiency are also among the Project's clients. Families, friends and loved ones of those infected by the virus are offered counseling and support as well. The general public's questions about AIDS get answers through the Project's AIDSLine. In the workplace, Project speakers help employees and management to respond appropriately to the needs of coworkers with AIDS. Trained Speakers' Bureau members also provide AIDS education to church, school and community groups.

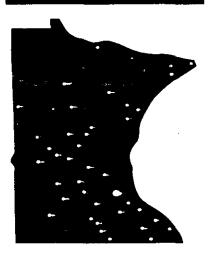
Professionals direct these prevention and care efforts, but the hard and essential work is still carried out by a legion of men and women who volunteer their time and energy. The diversity of ages, lifestyles and backgrounds of these volunteers is evidence that, in Minnesota, AIDS affects us all.

. . . .

On March 25, 1987, AIDS claimed its 100th death in Minnesota. Don Gillis, a public affairs consultant and board member of the Minnesota AIDS Project, died suddenly, of pneumonia. In the weeks before he died, Gillis had worked with characteristic zeal on a myriad of Project priorities—including this annual report. His death was another very personal reminder to all of us at the Project of the work to be done.

With projections of the number of diagnosed cases in Minnesota as high as 2,000 by the year 1990 and with an estimated 15,000 men and women already infected, the challenge the Project faces is enormous. The Minnesota AIDS Project is committed to successfully confronting the AIDS epidemic in this state. Working together, Project volunteers, staff and board members have developed confidence in our ability to fight AIDS on every front, despite our sorrow and loss. By drawing on our experience and by responding when the call comes, the Minnesota AIDS Project will be able to help those among us who confront the prospect of living with AIDS.

### PROJECT COMMUNITIES



Minnesota AIDS Project representatives are active in over 40 communities of all sizes across the state.

### PREVENTION



"Play It Safe"—practice safe sex and avoid IV drugs— is the Project's message to high-risk audiences.



A comic book directed at sexually active teens is one of the Project's educational publications.

ducating the public about AIDS and how to prevent it has been a major focus of the Minnesota AIDS Project program since its early days. In three short years, the Project's prevention education program has evolved from a word-of-mouth campaign into a large, organized effort of paid and volunteer staff, bringing up-to-date information on AIDS to Minnesotans throughout the state. The range of education services has grown from a few brochures distributed among persons at high risk, to a well-organized program of media information, peer counseling, and training seminars.

By June 1987, the Project had distributed over 125,000 pieces of information, including brochures, pamphlets, educational posters and fact sheets. The Speaker's Bureau made 125 presentations reaching more than 10,000 people, from nurses to politicians to school children. Minnesota AIDS Project staff appeared on several TV shows and at numerous public forums, and several thousand people learned more about the epidemic at the Project's booth at the Minnesota State Fair.

The Project's AIDSLine, an information and counseling hotline, now handles over 1,000 calls a month. Seminars on safer sex methods have been developed by the Project to teach people how to lessen their risk of exposure to the AIDS virus. Counselors also work with intravenous drug users and prostitutes to explain the serious risks AIDS poses for them.

The Project's Statewide Outreach program brings information about AIDS to communities in every corner of Minnesota. Over 75 Project outreach representatives have been trained to evaluate AIDS resources in areas throughout the state and to make referrals to local agencies and organizations.

While risk-related behavior is especially difficult to change, our educational efforts have paid off: surveys conducted at the 1985 and 1986 Gay Pride Festivals indicate that gay men—those most at risk for AIDS—have substantially reduced involvement in sexual activities that put them at highest risk. In 1986, for example, 71% of those responding said they suggested using safe sex practices to their partners, compared with 46% the previous year. Reported unsafe practices also dropped significantly.

Communication is the essence of education. In the coming year, the Project's educational efforts will include participation in a statewide mass media advertising campaign, increased outreach to people of color and to youth at risk, and development of innovative educational materials. As always, the focus will be on communicating the facts about AIDS and its prevention in the most effective way possible.

### CARE AND SUPPORT

he Minnesota AIDS Project's support services program grew out of a small group of volunteers who offered their help to people with AIDS. Today, dozens of volunteers enable the Project to offer assistance wherever it is needed. The Project currently serves over 85% of those diagnosed with AIDS in Minnesota.

People with AIDS come to the Project for help with a wide range of problems. The Project helps its clients apply for public financial assistance, including Medicaid, General Assistance, and Social Security. The Project also provides direct assistance from its emergency fund in cases of immediate need. The Project staff and volunteers follow up cases for clients, spelling out what they can expect from employers and insurers. People with legal problems receive referrals to attorneys. This system of advocacy on behalf of clients has helped provide adequate housing, medical attention, and fair treatment in the workplace for people with AIDS.

Several of the Project's support services programs are aimed directly at helping people with AIDS confront their illness. In the Project's support groups, individuals can confidentially discuss their concerns about living with AIDS, caring for family members, and minimizing the risk of exposure to the virus. An extensive referral manual on services available statewide helps clients find adequate treatment

and emotional support.

The Buddies Program is one of the best known and most successful services of the Minnesota AIDS Project. Currently, over 50 trained volunteers serve as buddies to persons with AIDS and to those who care for them. A growing number of buddies are active in communities outside the Twin Cities. Each buddy volunteer attends training workshops on AIDS issues and learns how AIDS affects the personal lives of those it has infected. Buddies serve as a special kind of support person in the lives of people with AIDS. Often they are the only human being who takes a deep personal interest in someone who has few friends and no family to care for him or her.

In 1986 the Minnesota AIDS Project designed a program of care coordination, which would assure complete continuity in the delivery of medical treatment, personal care, and support services to each individual. During 1987 the Project anticipates the start-up of this innovative program, the first of its kind in Minnesota. 1987 will also see the inception of the AIDS Housing Program which offers shelter to up to forty people with AIDS-related illnesses. In all of these programs, the Project's goal is to respect each individual's lifestyle, and to support the choices they make in coping with AIDS.

When I had nowhere to go and no one to talk to, when I had just been devastated by the news of this disease, and when even close, trusted friends weren't there for me, you were.

You offered me this apartment, so lovely and homey, so safe and welcoming. No hassies, no strings attached, only a free haven to feel less atraid in.

My children and I can never thank you enough. During our two months here, I was able to recover my health, learn to live with my disease and create a happy "in between" home for my family.

Now we are moving to our new home. Friends have gotten over the shock and are by my side once again. I am determined to live the rest of my life as fully and generously as I can.

But never will I be able to thank you all enough for lighting the way during my darkest hour. And never will I forget the kindness you have extended me.

Love,

Karen



Housing for people with AIDS is a Project priority for 1987.

### **VOLUNTEERS**



AIDSLine counselor Jennifer Reinhart is a volunteer veteran.

olunteers have been—and will always be—the lifeblood of the Minnesota AIDS Project. Volunteer contributions of time, effort and caring ensure the Project's connectedness to the people it serves. We were pleased to have these contributions recognized when the McKnight Foundation gave Bob Russell, a long-time volunteer, one of its 1986 Human Service Awards. In addition, our Buddies program was named United Way's 1987 "Volunteer Project of the Year".

In 1986, volunteers from all over Minnesota contributed over 34,000 hours of time to the Project, doing the work of 16 and one-half full-time staffers, and literally doubling the Projects capabilities. Below, an accounting of what the Project volunteers do, and what that's worth:

#### **VOLUNTEER STAFF: ESTIMATED ANNUAL VALUE**

TOTALS	305	\$318,000
Special Projects Workers: Carry out office chores and special assignments.	50	\$26,000 
Statewide Representatives: Carry out MAP educational and service programs outside the Twin Cities.	65	\$18,700
Home Helpers: Help with household chores, errands and other temporary needs.	10	\$3,800
Service Coordinators: Intake new clients and oversee their service needs.	12	\$57,000
Support Team Leaders: Provide support and supervision to Buddies.	6	\$5,200
Buddles: Provide one-on-one emotional support and companionship to persons with AIDS.	65	\$78,000
Support Group Facilitators: Coordinate meetings and provide guidelines for a variety of support groups.	9	\$11,700
Seminar Facilitators: Lead safe sex discussions with groups of gay men.	10	\$2,200
Information Booth Attendants: Answer questions and hand out literature at special events.	20	\$5,800
Speakers Bureau: Present talks on AIDS to outside groups.	30	\$72,000
Hotline Counselors: Answer our AIDSLine to provide information, referral and counseling.	28	\$37,600



In early 1987, the Project's Buddies won recognition from the United Way and the McKnight Foundation.

### CONTRIBUTORS

s understanding of the implications of the AIDS epidemic for all of Minnesota has broadened, so has funding for the activities of the Minnesota AIDS Project. First to respond were members of the Twin Cities' gay community, followed by agencies which safeguard the public health of the state. Corporations and foundations are now adding their support, as is an ever-widening group of individual donors.

Prevention activities have received strong support from the Minnesota Department of Health, the U.S. Conference of Mayors, the Hennepin County Health Department, the Minneapolis Health Department and the United Way.

The Project's major funding task for 1986-87 has been to find desperately needed support for services for those with AIDS, and we are deeply pleased to report success in that area. In November 1986, joint support for a major program of housing and services for Hennepin County residents was authorized by the Hennepin County Board, the Minneapolis City Council, and the Minneapolis/St. Paul Family Housing Fund. In addition, the Minnesota Department of Human Services awarded the Project the contract to coordinate medical case management for Medical Assistance recipients throughout the state. Most recently, the McKnight Foundation allocated significant support for advocacy and social services.

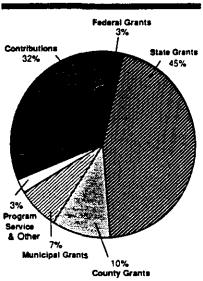
We are also looking to ensure the long-term financial health and stability of our AIDS efforts. To that end, we have established designated "endowment" funds at both the Minneapolis Foundation and the St. Paul Foundation. These funds are capable of receiving both current and planned gifts of income, securities or property.

Individual donations provide the Project with critical flexibility to respond quickly to the demands of the epidemic, and to needs outside the guidelines of major funders. For example, until recently, such contributions were the sole support of our services and financial assistance for people with AIDS. Information about making a donation can be obtained from the Development Director.

### MAJOR ORGANIZATIONAL DONORS:

- -Minnesota Department of Health -Hennepin County Health Dept and Community Services Dept
- -Minneapolis Health Dept
- Ramsey County
- ·City of St. Paul
- ·Headwaters Fund
- -United Way (Risk Fund)
- ·Western Ntnl Life insurance Co.
- Andersen Foundation
- McKnight Foundation
- -Mpis/St. Paul Family Housing Fund
- Whitney Foundation
- ·Blue Cross/Blue Shield (goods)
- •Wheeler Hildebrandt, Inc. (goods)
- •Office Interiors, Inc. (goods)
- ·Target Stores (goods)

#### 1986 SUPPORT AND REVENUE



#### INDIVIDUAL DONORS:



92 Donors of \$50-\$200 \*\*\*\*\*\*\*\*

25 Donors of more than \$200 **†**‡1

### FINANCIAL STATEMENTS

January 1, 1986 — December 31, 1986

### NOTES TO FINANCIAL STATEMENTS

Note 1: The Minnesota Acquired Immune Deficiency Syndrome (AIDS) Project (The Project) is a not-for-profit corporation organized under the laws of the State of Minnesota. A summary of The Project's significant accounting policies follows:

Income taxes: The Project is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code.

Contributed Assets and Services: Furniture and equipment received as contributions are recorded and reflected in the financial statements at their fair market value at the date they are received. The value of contributed services is not reflected in the accompanying financial statements because no objective basis is available to value such services.

Property and Equipment: Expenditures for the acquisition of property and equipment are capitalized at cost and the fair market value of donated furniture and equipment is similarly capitalized. Depreciation is calculated on the straight-line method over estimated useful lives of five years

Deferred Revenues: Grants and contributions are recognized as income in the period in which they are received unless they are specifically designated as being for a future period or specific use. In the latter case, they are initially recorded as deferred revenue and then taken into income in the period for which they are designated.

Note 2. Grant revenues. The Project receives a substantial amount of support from federal, state, county, and local municipal governmental agencies in the form of grants.

Note 3. Restricted contributions. During the year, the Project received a number of restricted contributions to be used for support services for persons with AIDS. All these contributions were expended for these services during the year.

Note 4. Lease arrangements. The Project leases office furniture, and housing for persons with AIDS on a semi-annual or annual basis. Total rental expense for 1986 was approximately \$14,760 for this space. The Project also leases office equipment under operating leases. The total rental expense for 1986 was approximately \$2,280. The future minimum lease payments for the next five years are approximately: \$3,200 in 1987; \$2,400 in 1988; \$1,500 in 1989; \$1,500 in 1990; and \$250 in 1991.

e have examined the balance sheet of The Minnesota AIDS Project as of December 31, 1986, and the related statement of support, revenue, expense, and changes in fund balance for the year then ended. Our examination was made in accordance with generally accepted auditing standards, and, accordingly, included such tests of the acounting records and such other auditing procedures as we considered necessary in the circumstance.

In our opinion, the financial statements referred to above present fairly the financial position of The Minnesota AIDS Project as of December 31, 1886, and the results of its activities and changes in fund balance for the year then ended, in conformity with generally accepted accounting principles applied on a basis consistent with that of the preceding year.

McClodrey Hendrichson & Pullen

Bloomington, Minnesota

March 18, 1987

BALANCE SHEET As of December 31, 1985		STATEMENT OF SUPPORT, RE PENSES AND CHANGES IN FUN For the Year Ended December 3	D BALANCE
ASSETS		SUPPORT AND REVENUE	
Cash & Investments	\$ 38,527	Federal grants	\$ 11,355
Grants receivable	40,643	State grants	165,650
Deposits	350	County grants	38,000
		Municipal grants	27,000
Total current assets	79,520		
Office furniture, substantially		Total grants	242,005
donated, net of accumulated		Contributions and fund raising	117,177
depreciation of \$2,312	36,534	Program services	9,046
		Interest and other income	3,062
	\$116,054	Total support and revenues	371,290
LIABILITIES		EXPENSES	
Accounts payable	\$10,872	Prevention	207,519
Accrued expenses	10,060	Social services	53,228
Deferred revenue	41,523	Fundraising	21,580
Total aureant habilities	62.455	Total manage agains	282.327
Total current liabilities FUND BALANCE	52,455 53,599	Total program services Administration	57.844
PUNU BALANCE	53,399	Administration	
	\$116,054	<b>.</b> .	350,171
		Total expenses	350,171
		EXCESS OF SUPPORT AND	
		REVENUES	
		OVER EXPENSES	\$ 21,119
		FUND BALANCE, BEGINNING	32,480
		FUND BALANCE, ENDING	\$ 53,599

### THE UNIVERSITY OF MINNESOTA

The University of Minnesota has begun to educate its students on AIDS. For example, at the beginning of the fall semester in 1987, free condoms were distributed to all incoming students. In February of this year students participated in the events of National Condom Week. These events were also supported by a religious organization, the Lutheran Episcopal Center. Some relevant documents are reprinted on the following pages.

Still, the University Health Service feels that, in the future, its efforts have to be stepped up considerably. A preliminary "University Statement on AIDS" is also included.

AIDS-It's not who you are, it's what you do

Learn more about safer sex at the Minnesota Unions. ... an Issues, Ideas and Values Program

February 16

"Men's Sexual Responsibility"
A slide-tape show on sexual anatomy, contraception options,

and responsible sexual communication.

Discussion leader: David Selzer, Chaptain at the University

**Episcopal Center** 

12:15 SPSC Global Perspectives Room

February 17

"Condom Sense"

An original, funny informative film that urges men to take a

more active role in contraception.

Discussion leader: Candy Gray, Community Educator for

Planned Parenthood 12:15 WBU Auditorium

February 18

"Sex, Drugs and AIDS"

A film promoting AIDS Education and Safer Sex

Discussion leader: Mark Hochhauser, PHD, Boynton Health

Service

12:15 pm CMU 320

Information available at the Minnesota Union restrooms at Coffman Memorial Union, West Bank Union, and St. Paul Student Center, and at Boyton Health Service and the Lutheran Episcopal Center.

#### HOW TO USE A CONDOM

- Either partner unrolls the condom over the man's erect penis, making sure the condom is unrolled as far as possible.
- Always put it on before beginning intercourse because sperm often leaks out of the penis even before orgasm!!
- Leave about half an inch of space at the tip to allow room for the sperm.
   Some condoms have a receptacte tip to hold the fluid when the man reaches his climax. Before the penis retaxes after orgasm, remove it. Hold onto the top of the condom while removing the penis to keep sperm from spilling or allowing the condom to slip off.
- Put on a fresh condom before having intercourse again. This prevents sperm from leaking out.
- If necessary, lubricate the condom with contraceptive foam, cream or jelly or a special lubricating jelly (brand names are H-R or KY Jelly). Do not use vaseline or petroleum based jellies they will damage the rubber! Using a contraceptive foam, cream or jelly along with the condom will provide lubrication and increase the effectiveness of the condom. If you have a tendency to tear the condom during intercourse, definitely use an additional form of lubrication, preferably a spermicide.
- Check the condom after use. If it is torn or comes off and you have not inserted a spermicide prior to intercourse, do so immediately after.
- A condom must be worn each time you have intercourse if you want to be protected against pregnancy, regardless of the time of the month.
- To help prevent AIDS, condom use is recommended for anal, oral or vaginal sex.

#### **ADVANTAGES**

#### Condoms . . .

- are available without prescription at drugstores (and elsewhere in some states).
- · are inexpensive and effective contraception.
- help prevent AIDS
- help prevent veneral (sexually transmitted) diseases.
- help some men avoid ejaculating too early.
- · add to the effectiveness of other methods of contraception.
- don't have harmful side effects.
- can be part of love play.

#### DISADVANTAGES

#### Condoms . . .

- Have a little higher failure rate than pills or IUD's, perhaps because they aren't always used properly.
- · may reduce penis sensitivity a little (not always a disadvantage!).
- interrupt love making for a moment (unless using them is made a part of love play!).

#### PROTECT YOURSELF, PRACTICE SAFER SEX

Printed with permission of The Rubber Tree, a project of Zero Population Growth, 4426 Burke Avenue North, Seattle, Washington 98103, 208/633-4750

Presented by ISSUES, IDEAS AND VALUES A program of THE MINNESOTA UNION Boynton Health Service Lutheran Episcopal Center

#### UNIVERSITY STATEMENT ON AIDS

The Acquired Immune Deficiency Syndrome (AIDS) is one of the most perplexing diseases confronting the medical community today. Despite the relatively low incidence of AIDS in the general population, this disease presents a serious public health issue because there is no effective vaccine or known cure.

Given the size of the University of Minnesota community, we know that cases of AIDS have and will occur here. University responses to such occurrences are guided both by the University's commitment to the protection of individual rights (including confidentiality) and by due regard for community public health interests.

Studies and guidelines from the Centers for Disease Control and the Public Health Service indicate that individuals with AIDS or AIDS-related conditions do not pose a health risk to others while carrying out their regular activities as students or employees. Available evidence strongly indicates that AIDS is transmitted only by intimate sexual contact or by injection of contaminated blood. The overwhelming consensus of authoritative medical opinion is that AIDS is not readily communicable and that it does not spread through casual contact.

Should administrative decisions with respect to participation by any student, faculty, or staff member with AIDS

or an AIDS-related condition in University activities and programs become necessary, they will be made on a case-by-case basis by appropriate administrative officers in consultation with medical experts.

At the present time, the most effective means to prevent the spread of AIDS is health education. The University will continue to review and revise its health education program and relevant administrative guidelines as new information about AIDS becomes known.

#### THE SPRING HILL AIDS CONFERENCE, JULY 1987

In July of this year, Spring Hill, a conference center outside of Minneapolis, organized a special 2 1/2 day conference under the title "AIDS: Confronting the Crisis in Minnesota."

This very successful conference, which will be followed by a second one in November of this year, was carefully planned with four objectives in mind:

- 1. To address the AIDS crisis in Minnesota early enough, before it becomes unmanageable.
- 2. To invite community leaders from all over the state as participants.
- 3. To keep the participants in one location together for a long weekend and to expose them to a well-designed process of personal experiences leading to a heightened awareness of AIDS as a socio-political problem.
- 4. To prompt the participants to become active in the fight against AIDS in their respective communities.

In the author's opinion, this innovative conference is one of the most promising projects he encountered while preparing this report. He also believes that it should be copied immediately in all states of the German Federal Republic and in other European countries.

In order to give some impression of the enterprise, the following pages offer a brief description, the conference program and an invitation for the November follow-up conference. The complete conference material, which documents the enormous organizational effort involved, remains in the author's possession in San Francisco. It can also be ordered directly from the Spring Hill Center.

October 2, 1987

SpringHill

Dr. Erwin J. Raeberle 1100 Gough Street, #7-C San Francisco, CA 94109

Dear Dr. Haeberle:

Enclosed is a copy of Spring Hill Center's conference notebook for "AIDS: Confronting the Crisis in Minnesota." It contains the July agenda, list of speakers, participant list (from which you can get some idea of the type of participant), and background readings. It also includes a set of clippings from press coverage of the event (in the "clippings" section).

Spring Hill Center is an independent not-for-profit organization whose mission is to convene discussions of important public issues. We were asked to work on this by Dr. Michael Osterholm, the Minnesota State Epidemiologist, in part because we are independent and neutral, and have a reputation for good work. The project was funded by grants from a variety of foundations and corporations.

The basic concept was to convene teams of community leaders from 14 Minnesota communities and leaders of statewide associations and the Legislature. We worked hard to make sure these were people who could go back to their communities and act as opinion leaders and initiators of community actions to deal with AIDS. It was also critical to our strategy that they not be merely health professionals already knowledgeable about AIDS.

The same group plus additional individuals will reconvene in November. The July conference focused on providing information about AIDS and key issues in ways that would mobilize communities to take action. The November conference is geared to a discussion of community level strategies for combatting AIDS. We have not spent much time on medical research because, for the most part, it is not something communities can affect.

Our success in July was outstanding. It was attributable to the combination or blending of several factors in the one program:

 Information Delivery — We had several very well informed presentors on the facts about AIDS and on what issues were important in education, the workplace, health care, and financing. While perhaps not critical to our success these presentations, coupled with reading, laid a solid foundation.

> SPRING HILL CENTER P.O.BOX 288 WAYZATA, MINNESOTA 55391

> > 612-473-0221

Dr. Erwin J. Haeberle October 2, 1987 Page 2

2) Emotional Content — We developed, using a consultant, a series of discussions among small groups of participants that got them thinking about AIDS on a personal level. This included an ice breaker called the Wagon Train Exercise designed to get people talking and talking about values. Second, it included a small group discussion on the next day in which each group met and talked with a person with AIDS.

Third, a discussion on the final day of the conference in which the same small groups met to talk about what they could do in their communities. In addition, on each day, each participant receive a personal letter from a person with AIDS (there were about 15 different letters so some conferees got the same letter). On the final day, participants were asked to write back and most did. These letters were handled with utmost confidentiality and were passed back and forth through the consultant using only first names. This series of events had tremendous impact on all concerned in getting them to see AIDS and homosexuality at a personal level.

- 3) Televised Roundtable —— Public television produced a roundtable discussion about the impact of AIDS on a hypothetical Minnesota community. It was done live during the conference, video taped and aired statewide two weeks later. Participants in the roundtable included a conservative state legislator, a liberal city council woman, a minister, a businessman whose place of business was next door to an AIDS research lab, the head of the AFL-CIO in Minnesota, a gay activist, a school superintendent, an editor and others. The discussion was set up using a special video tape of a mock news report on the discovery of AIDS in "Flagstone" and the diverse reactions of the citizens. There were three video segments designed to move the discussion along to new issues. It was moderated by the Dean of Hamline Law School, and we followed up the discussion by throwing it open to our entire group of participants.
- 4) Press Coverage -- We worked closely with a wide variety of large and small press organizations to ensure coverage of the conference especially by papers in smaller Minnesota which participated as well as Minneapolis and St. Paul.

The project is run by Spring Hill with the advice and guidance of a steering committee. As with the conference itself, the composition of the steering committee reflects Spring Hill's and Minnesota's commitment to using coalitions of public and private leaders in dialogues about public policy issues. In the case of AIDS, this is particularly important because much of the "action" that is needed must come from the private sector: policies and educational programs in the workplace are one example; setting the tone for policy discussions whether for the state or for a local school is another area in which private sector leaders have an important role to play; and the religious community also will impact the tone and character of public debate and indeed have a role to play in educating their members about AIDS.

Dr. Erwin J. Haeberle October 2, 1987 Page 3

I am sure there is more I could tell you. The model has been very successful, and you will see enclosed a list of activities going on around the state, some of which are directly attributable to the Spring Hill project (at the back of the notebook).

Sincerely,

David H. Rodbourne Director of Programs AIDS: Confronting the Crisis in Minnesota

#### Program Outline

Concept:

Two stage conference program sponsored by Spring Hill Center to identify issues and develop strategies responding to AIDS.

Conference One - Increase knowledge and sensitivity about the disease; human sexuality and prevention; social conflict, and ethical, workplace, health care, social service, and financing issues. (July 1987)

Conference Two - Identify and elaborate on strategies that can be used by Minnesota communities and by the state to help those with AIDS, resolve issues, and prevent the spread of AIDS. (Fall 1987)

Steering Committee: Program leadership will be provided by a 12-15 person steering committee.

Participants: The program will involve 110 community and state leaders. The same individuals will be involved in both conferences.

> Community teams: 70-80 of the 110 participants will be recruited from 12-15 Minnesota communities. Individuals will represent diverse interests and have positions and abilities enabling them to set community agendas and influence opinion.

Statewide leaders: 30-40 of the 110 participants will be representatives of government and diverse statewide public and private associations in business and labor, health, government, social service, foundations, and media.

#### Outcomes:

- Increased knowledge about AIDS and related issues.
- Creation of action-oriented leadership teams in 12-15 . Minnesota communities.
- Blueprint or checklist of strategies that can be used by communities statewide.
- Recommendations for state action.

Funding:

Support will be derived from Minnesota foundations and corporations.

> SPRING HILL CENTER P.O.BOX 288 WAYZATA, MINNESOTA 55391

#### AIDS: CONFRONTING THE CRISIS IN MINNESOTA

July 12-14, 1987

#### Sponsored by Spring Hill Center

Sunday.	July 12	1987
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2:00 - 3:00 p.m. Registration and Check In

3:00 - 3:15 p.m. Conference Welcome Room D

Jan I. Smaby, President Spring Hill Center

Kent E. Eklund, President and CEO

**Ebenezer Society** 

Steering Committee Chairman

3:15 - 6:00 p.m. The AIDS Epidemic in Minnesota Room D

Michael T. Osterholm, Ph.D., M.P.H.

State Epidemiologist

Minnesota Department of Health

**AIDS in America** 

Walter R. Dowdle, Ph.D.

Assistant Director, AIDS Branch Centers for Disease Control

Presentations and Discussion

6:00 - 6:30 p.m. Reception Main Lounge

6:30 p.m. Dinner Dining Room

7:30 - 9:00 p.m. Workshop I: Reacting in Crisis Room D

First of a three-part workshop series designed especially for Spring Hill Center by Evergreen

Learning Research

Jane Ferguson Otis, Principal and Karen F. Heegaard, Principal Evergreen Learning Research

9:00 p.m. Evening Refreshments Main Lounge

## AIDS: CONFRONTING THE CRISIS IN MINNESOTA Page 2

#### Monday, July 13, 1987

7:00 a.m.	Breakfast Buffet*	Dining Room
8:00 - 9:30 a.m.	Human Sexuality and AIDS	Room D
	Eli Coleman, Ph.D., L.C.P., Associate Professor and Kathy Harowski, Ph.D., Assistant Professor Human Sexuality Program, Department of Family Practice and Community Health University of Minnesota	,
	Presentation and Discussion	
9:30 - 9:45 a.m.	Briefing for Workshop II	Room D
	Jane Ferguson Otis and Karen F. Heegaard. Evergreen Learning Research	
9:45 - 10:15 a.m.	Break	
10:15 - 12:00 noon	Workshop II: Living with AIDS	Assigned Rooms
	Small group discussions led by Evergreen Learning Research	
12:00 noon	Lunch	Dining Room
12:45 - 2:00 p.m.	AIDS: The Disease	Dining Room
	Constance B. Wofsy, M.D., Associate Clinical Professor of Medicine San Francisco General Hospital	
	Presentation and Discussion	
2:00 - 2:30 p.m.	Break	
2:30 - 4:00 p.m.	Health Care, Financing and Social Services	
	Format: Four identical concurrent presentations and discussions focused on health care, financial and social service needs of AIDS patients.	

<sup>\*</sup>Breakfast buffet for overnight guests. Rolls and coffee available to day participants at 7:30~a.m. - Room D Foyer.

## AIDS: CONFRONTING THE CRISIS IN MINNESOTA Page 3

#### Panel A:

Room A

Frank S. Rhame, M.D., Assistant Professor, Infectious Diseases Section University of Minnesota Medical School

Eric L. Engstrom, Executive Director Minnesota AIDS Project

Jeri Boisvert. Economic Assistance Unit Supervisor, Hennepin County

#### Panel B:

Room B

Margaret Simpson, M.D., Staff Physician Division of Infectious Diseases Hennepin County Medical Center

Tom Agar, Director of Support and Social Services Minnesota AIDS Project

Hugh Strawn, Vice President Minnesota Insurance Information Center

#### Panel C:

West Lounge

Keith Henry, M.D., Staff Physician, Section of Infectious Diseases St. Paul Ramsey Medical Center

Daniel Brewer, Care Advocate Minnesota AIDS Project

Tom Hiendimayr, State Planner, Principal Minnesota Department of Health

#### Panel D:

Main Lounge

David Williams, M.D., Internist Infectious Diseases Park Nicollet Medical Center

Karen Wright, Director of Development Minnesota AIDS Project

Daniel B. McLaughlin, Administrator Hennepin County Medical Center

4:00 - 5:00 p.m.

Free Time

### AIDS: CONFRONTING THE CRISIS IN MINNESOTA Page 4

5:00 - 5:45 p.m.

Reception

Main Lounge

5:45 p.m.

Dinner

Dining Room

7:00 - 8:30 p.m.

AIDS: The Minnesota Response\*

Room D

Format: Live taping at Spring Hill of a roundtable discussion produced by Twin Cities Public Television for the Minnesota Public Television Association. The roundtable explores a hypothetical AIDS case set in a mythical Minnesota community.

Moderator: Stephen B. Young, Dean Hamline University School of Law

8:30 - 9:00 p.m.

Audience Discussion

Moderator: Jan I. Smaby

9:00 p.m.

**Evening Refreshments** 

Main Lounge

Note: The roundtable discussion will be broadcast July 29, 8:00 p.m. on Channel 2 and other public television stations. (Fargo/Moorhead, Saturday, August 1, 1987 at 4:00 p.m.)

#### Tuesday, July 14, 1987

7:00 a.m.

Breakfast Buffet\*

Dining Room

8:00 - 9:30 a.m.

AIDS and Minnesota Schools

Room D

Panel:

Marjorie Johnson, President State Board of Education

David R. Landswerk. Superintendent

Wayzata School District

Nan Skelton, Assistant Commissioner Minnesota Department of Education

Presentation and Discussion

<sup>\*</sup>Breakfast buffet for overnight guests. Rolls and coffee available to day participants at 7:30 a.m. - Room D Foyer.

# AIDS: CONFRONTING THE CRISIS IN MINNESOTA Page 5

9:30 - 10:30 a.m.	Drug Abuse and AIDS	Room D
	Dan Cain, Executive Director Eden Programs Inc.	
	Presentation and Discussion	
10:30 - 10:45 a.m.	Break	
10:45 - 11:45 a.m.	AIDS and the Workplace	Room D
•	Katherine L. Armstrong Health Programs Manager Bank of America	
	Presentation and Discussion	
11:45 a.m.	Buffet Lunch	Dining Room
12:45 - 2:15 p.m.	Workshop III: Reaching Out	Assigned Room
	Small group discussions prepared by Evergreen Learning Research	
2:15 - 2:30 p.m.	Break	
2:30 - 3:30 p.m.	The Legal Imperative: The Protection of Both County and Individual Rights	Room D
	Terry T. O'Brien, Special Assistant Attorney General Office of the Attorney General - Health Division	
	Presentation and Discussion	
3:30 - 3:45 p.m.	Where We Go From Here	Room D
	Kent E. Eklund Jan I. Smaby	
3:45 n m	Adjourn	



#### WELCOME TO SPRING HILL CENTER:

For the past six months, Spring Hill has been developing the program AIDS: CONFRONTING THE CRISIS IN MINNESOTA. Today, the real work begins.

This is a unique undertaking. The gathering today represents the first time in the nation that community leaders from across a state have been assembled to develop community strategies to combat, in advance, the projected AIDS epidemic of the 1990's and ensure adequate services now and in the future to assist persons with AIDS, their families and friends.

This first Conference has been designed to present you with the most current information regarding AIDS and an environment to discuss openly and vigorously many of the challenging and, at times, divisive issues which AIDS presents.

Prior to our second Conference in November, we shall work with you in developing a blueprint for community assessment and action. These interim activities will be guided by this project's steering committee under the leadership of Kent Eklund, President and Chief Executive Officer of Ebenezer Society. At the November Conference we will review and finalize the community blueprint, explore more fully the ethical and social implications of AIDS and address those issues which emerge as a result of your work in your community over the next several months.

Spring Hill wishes to acknowledge the financial support and advice of The McKnight Foundation whose initial grant to this project allowed us to begin. We also wish to acknowledge the funding support of Abbott Northwestern Hospital, Hugh J. Andersen Foundation, Cowles Media Company, Fairview Hospitals and Health Care Services, The Gelco Foundation, IBM Corporation, Lutheran Brotherhood and the Minnesota Department of Health.

While Spring Hill is fully responsible for this project, we have appreciated the advice and cooperation of the Minnesota Department of Health, the Minnesota AIDS Project, the Minnesota Business Partnership, KTCA-Twin Cities Public Television, Evergreen Learning Research, and many other individuals and organizations.

Most importantly, Spring Hill wishes to thank you. Your decision to participate in this project is critical to the achievement of a rational and humane response to AIDS in communities throughout Minnesota.

i. Smab

Sincerely.

Jan I. Smaby President

> SPRING HILL CENTER P.O.BOX 288 WAYZATA, MINNESOTA 55391

#### IX. AIDS PREVENTION IN LOS ANGELES

#### THE STATE OF CALIFORNIA

The situation in California with regard to AIDS is summarized on following pages which were provided by Art Agnos, a California Assemblyman from San Francisco.

Agnos is also the author of AB 87, a comprehensive AIDS law supported by the U.S. Surgeon General, Dr. Koop. This law would, among other things, establish a state AIDS commission, support statewide education programs, prohibit discrimination on the basis of seropositivity, ARC or AIDS and assure the confidentiality of test results. Because of its model character, even for other states and other countries, the bill, together with some supporting material, is attached in full to the present report (see Printed Material II, 2).

It is too early to predict whether this bill will eventually pass. The present legislative situation and the public support for the bill are illustrated in the recent Los Angeles Times editorial which is reproduced on following page.

#### THE CALIFORNIA AIDS EPIDEMIC

California was the first state, along with New York, to report cases of the disease we now know as AIDS in 1981.

By September 1987 about 10,000 Californians had been diagnosed with AIDS, and nearly 6,000 of those have died.

By 1991, California estimates that there will have been 50,000 Californians diagnosed with AIDS.

The cost of AIDS care in California will reach about \$8 billion by 1991, with about \$2.5 billion coming from public funds.

By 1991, AIDS care will account for about one of every ten dollars spend on public health in California.

In San Francisco, AIDS programs already account for 10% of the city's health budget.

About half the AIDS cases in California have occured in San Francisco.

The total number of San Franciscans who have died of AIDS now totals more than the number of San Franciscans who died in the Great Earthquake of 1906, World War I, World War II, Korea and Vietnam -- combined.

By 1991, some estimate that one out of every five gay men in San Francisco will have died of AIDS or be diagnosed with AIDS.

By next year, about one out of ten gay San Franciscans will have died of AIDS or have an AIDS diagnosis.

#### CALIFORNIA'S RESPONSE TO THE AIDS EPIDEMIC

The first California response to the AIDS epidemic came in 1983, when Assemblyman Art Agnos added \$500,000 to the state budget for AIDS education and information programs.

At that time, California had fewer than 300 diagnosed cases of AIDS.

That same year, California added \$2 million to the state budget for AIDS research through the University of California system.

Both appropriations represented the first AIDS funding by any state government in the United States, and came in response to serious criticism that the federal government was failing to provide leadership on the AIDS epidemic.

Also in 1983, California established the first AIDS Advisory Committee to review and make recommendations on the state's prevention program.

The first legislation dealing with public policy questions arising from the epidemic came in 1985, again by Assemblyman Agnos, with passage of a bill to ban AIDS antibody testing without written consent and with strict safeguards on disclosure. In addition, use of the test was forbidden to employers and insurers.

In 1987, AIDS had become a major issue in the state legislature.

Assemblyman Agnos invited U.S. Surgeon General C. Everett Koop and the co-chair of the National Academy of Science Institute of Medicine panel on AIDS, Nobel laureate Dr. David Baltimore, to speak at an historic Joint Session of the California State Legislature on the AIDS Crisis.

The Joint Session, the first in the nation, was held March 6, 1987.

More than 40 members of the California Legislature, about one in every three members, introduced bills dealing with AIDS during the current year.

#### HIGHLIGHTS OF THE CALIFORNIA AIDS PROGRAM -- 1987

California will have a \$63 million budget for AIDS programs in the year beginning October 1.

Among the highlights:

Information and education programs funded at \$12.6 million. Home health and hospice funded at \$1.5 million

Case management and housing funded at \$2.6 million

Foster care for children funded at \$1.1 million

Mental health services funded at \$700,000.

University research funded at \$9.5 million

Vaccine development research funded at \$6 million

Antibody testing programs funded at \$12 million

IV drug abuse programs funded at \$5 million

New AIDS research facility funded at \$5.7 million



A Times Micror Newspaper

Publishers
HARRISON GRAY OTIS, 1882-1917
HARRY CHANDLER, 1917-1944
NORMAN CHANDLER, 1944-1960
OTIS CHANDLER, 1960-1980

TOM JOHNSON, Publisher and Chief Emeutive Officer
DONALD F. WRIGHT, President and Chief Operating Officer
WILLIAM F. THOMAS, Editor and Executive Vice President
VANCE L. STICKELL, Executive Vice President, Marketing
LARRY STRUTTON, Executive Vice President, Operations

JAMES D. BOSWELL, Vice President, Employee and Public Relations WILLIAM A. NIESE, Vice President and General Counsel JAMES B. SHAFFER, Vice President, Finance and Planning

GEORGE J. COTLIAR, Managing Editor; ANTHONY DAY, Editor of the Editorial Pages JEAN SHARLEY TAYLOR, Associate Editor

# AIDS: Raising the Risks

The California Legislature responded to the AIDS pandemic with a variety of bills in the final days of the session, but unfortunately failed to approve the single most important piece of legislation, AB 87, which would have created a state commission and implemented other recommendations of the U.S. surgeon general.

Of the bills approved in the final flurry of activity, one stands out as of special urgency, with strong reasons why Gov. George Deukmejian will sign it. This is SB 136—by Sen. Gary K. Hart (D-Santa Barbara), chairman of the Senate Education Committee—which would set in motion an urgently needed program of secondary-school education on the perils of acquired immune deficiency syndrome.

Under this legislation, the superintendent of public instruction and the director of state health services would select video cassettes to be used in an AIDS educational program for students in grades 7 through 12. Parents and guardians would receive written notification in advance of the instruction, and would be permitted to have their children excused from it. But the intent is clearly to reach as many students as possible with the message.

The program has been made more acceptable for those who are uneasy about any discussion of sexually related subjects by providing that the

instruction emphasize that sexual abstinence is the only completely effective method of escaping infection and that so-called "safe sex" methods, like the use of condoms, have limitations in preventing the spread of the disease.

Hart's AIDS education bill, unlike AB 87, has attracted bipartisan support and has been endorsed by numerous groups—among them the California Medical Assn. and the Roman Catholic bishops of the state.

AB 87 will be reconsidered in January, and there is good reason to think that it will win approval at that time. The unanimous opposition of the Republicans is likely to yield as the position of the California Medical Assn. becomes better understood. The CMA dropped its opposition to the bill after significant amendments were accepted by the author, Assemblyman Art Agnos (D-San Francisco), but the CMA, for reasons that we do not grasp, continues to withhold its active support. As now written, the bill is strictly limited, with the principal emphasis on the creation of a state AIDS commission. The need for such a commission has been demonstrated over and over again in recent months as state and local officials have sought coordination of their efforts.

Delay in creating the state commission, and delay in launching the education program in secondary schools, only serves to raise the risks.

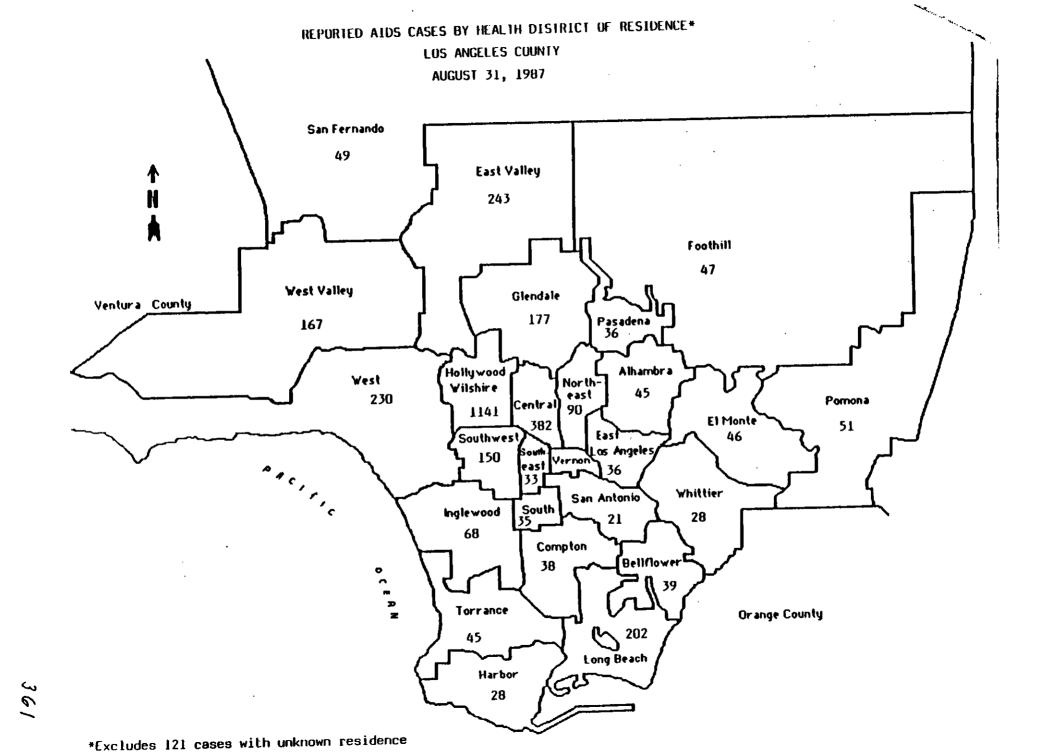
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#### THE CITY AND COUNTY OF LOS ANGELES

The epidemiological situation in Los Angeles County is summarized in the following graphs and charts provided by the Los Angeles County Department of Health Services.

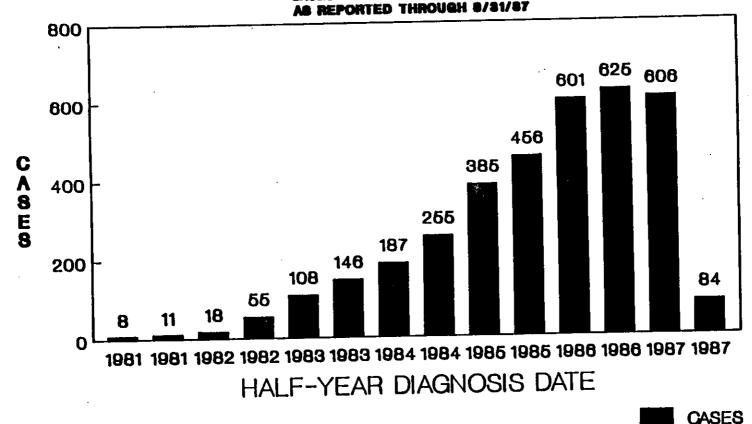
The present and future programs aimed at fighting the epidemic are summarized in two documents: a recent summary of AIDS services and activities and the transcript of testimony given by Dr. Schunhoff, acting assistant administrator of the AIDS Program Office.

Finally, on June 16, 1987, a special ordinance established a Los Angeles County Commission on AIDS to "study, advise and recommend to the board of supervisors and to the director of health services on matters related to acquired immune deficiency syndrome" and to "make reports to the board of supervisors and the director of health services on matters referred for such review by the board of supervisors or the director of health services. The commission may make reports to the board of supervisors or the director of health services at such other times as the commission determines it appropriate to do so." The list of Commission members is reproduced also in order to convey an impression of its composition. As is evident, among the members there is a religious leader as well as representatives from the AIDS Project Los Angeles, the gay and lesbian community services and the medical profession.



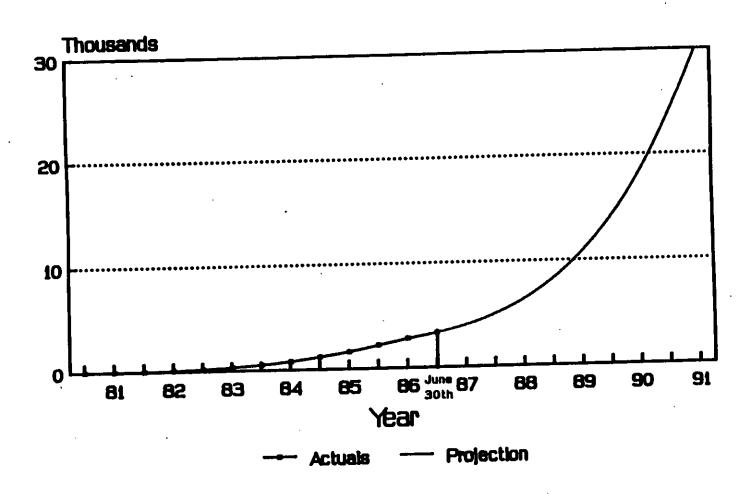
## CASES OF AIDS BY HALF YEAR OF DIAGNOSIS LOS ANGELES COUNTY

CASES DIAGNOSED 1/1/61-8/31/87
AS REPORTED THROUGH 8/31/87

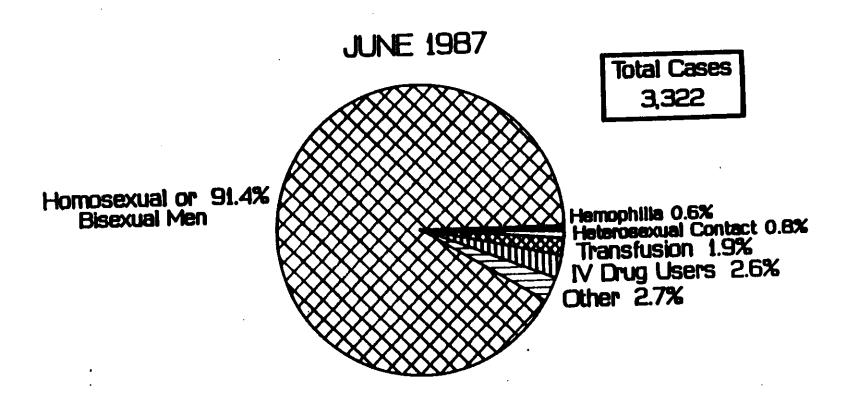


\*EXCLUDES 3 CASES DIAGNOSED PRIOR TO 1981. DATA FOR RECENT MONTHS ARE INCOMPLETE.

# CUMULATIVE CASES OF AIDS LOS ANGELES COUNTY 1981-91



# ADULT AIDS CASES LOS ANGELES COUNTY BY PATIENT CHARACTERISTICS



#### LOS ANGELES COUNTY - DEPARTMENT OF HEALTH SERVICES

#### AIDS SERVICES AND ACTIVITIES - AUGUST 1987

As of June 30, 1987, 3,340 AIDS cases have been reported in Los Angeles County. Of those diagnosed, 2,069 (62%) have died. Recent estimates project that by 1991 there could be more than 30,000 cases.

Over 90% of the cases in Los Angeles County to date have been among homosexual or bisexual men. Small, but slowly increasing percentages of cases are among IV drug users, female sexual partners of bisexual men or IV drug users, and children born to infected women. Blacks and Latinos constitute disproportionate percentages of these latter categories.

#### AIDS PROGRAM OFFICE

In 1985 the Board of Supervisors allocated funding to establish an AIDS Program Office (APO) to provide AIDS risk reduction education, coordinate all AIDS-related activities within DHS, develop AIDS-related policy recommendations for Departmental and Board consideration, and plan for future services. The APO also administers federal and state grant-funded AIDS service and treatment programs. For example, DHS is the recipient of a three-year \$2.5 million AIDS Service Demonstration Grant from the U.S. Health Resources and Services Administration (HRSA), which augments AIDS-related services in Los Angeles County provided through DHS facilities and community-based organizations. In addition, the APO provides an extensive ongoing education program, designed to reach health care providers, school age youths, minority communities, high risk individuals and the general population.

#### **EPIDEMIOLOGY**

The AIDS epidemiology unit in the Disease Control Section of Public Health Programs verifies AIDS diagnoses and collects data to track the progress of the virus in our community. Among other activities, funding from the Centers for Disease Control has underwritten an investigation of the transmission of the virus through blood transfusions.

#### DRUG ABUSE PROGRAMS

Compared with New York City, where 30% of the AIDS cases are among IV drug users, Los Angeles has experienced a relatively low rate (2%) of such cases. However, concern about transmission among this population and the potential for transmission into the heterosexual population has been the reason for a growing AIDS education and prevention program in the Drug Abuse Program Office (DAPO). DAPO has assisted each of its contractors in

training an AIDS resource person to provide information to its clients. DAPO also applied recently for a grant from the National Institute of Drug Abuse to fund an ambitious educational outreach program to street users.

#### PATIENT CARE

One of the nation's leading medical programs for AIDS is conducted at the Los Angeles County/University of Southern California Medical Center (LAC/USC), with patient care for over 700 persons coordinated through the Outpatient Clinic. Inpatient care is provided on various LAC/USC wards. LAC/USC is participating in a number of national research studies and treatment protocols. In addition, all of the other hospitals in our system are now treating AIDS/ARC patients. In fact, DHS facilities are treating approximately thirty percent of the AIDS patients in L.A. County.

#### HIV ALTERNATIVE TEST SITES

Los Angeles County began its state-funded alternative testing program in October 1985 by contracting with the Edmund D. Edelman Health Center of the Gay and Lesbian Community Services Center in Hollywood. On April 24, 1987, two additional HIV alternative testing sites were opened in DHS facilities at the Ruth Temple Health Center and the Edward R. Roybal Comprehensive Health Center. In addition, testing is provided by the Long Beach Health Department at two sites. Over 20,000 people have been tested at these sites in Los Angeles County since June, 1985. DHS has received proposals for contracted testing sites in the South Bay area and the San Fernando and East San Gabriel Valleys. The expected opening of these sites in September 1987 will achieve the current goal of making anonymous testing with counseling readily available to all of the geographic areas of the County. Additional sites will be opened as the demand for testing warrants.

#### CONFIDENTIAL TESTING

With Centers for Disease Control grant funds, we will soon begin pilot programs for voluntary confidential testing of persons identified as high-risk by our family planning, prenatal and STD clinics.

#### FIVE-YEAR PLAN

DHS has received proposals from consulting firms for the preparation of a Five-Year Plan for AIDS services in Los Angeles County. Utilizing funds from the HRSA AIDS Service Demonstration Grant, DHS will soon recommend a contract to the Board of Supervisors for preparation of this plan, which should be completed by the end of the year. This plan will guide our planning for AIDS services for the crucial next several years.

#### LOS ANGELES COUNTY - DEPARTMENT OF HEALTH SERVICES

#### TESTIMONY BY

JOHN F. SCHUNHOFF, Ph.D.

ACTING ASSISTANT ADMINISTRATOR, AIDS PROGRAM OFFICE
DEPARTMENT OF HEALTH SERVICES, LOS ANGELES COUNTY

#### BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY
U.S. SENATE COMMITTEE ON FINANCE
SEPTEMBER 10, 1987

#### A. INTRODUCTION

- I am John F. Schunhoff, Acting Assistant Administrator, AIDS Program Office, Los Angeles County, California. Thank you for the opportunity to testify today.
- 2. I would like to give background information first, then describe our current patient load and financial picture, describe our projections for the future and finally discuss alternatives we are exploring.

#### B. BACKGROUND

- Los Angeles County operates six hospitals, forty-seven ambulatory care and health centers, and two rehabilitation centers. The County also contracts with private hospitals, doctors, and other service providers for health care.
- 2. The County's mission is to prevent disease, promote health and provide high-quality personal health service within the County.

3. Los Angeles County maintains a special responsibility for the care of the medically indigent and those otherwise without access to health services.

Approximately four-fifths of the people the County cares for are poor. Of these, about two-thirds are County indigents, those not qualified for Medi-Cal or other payment programs.

#### C. CURRENT AND PROJECTED CASE LOAD

- 1. As of July 31, 1987, there were 3,459 cumulative cases of Acquired Immune Deficiency Syndrome (AIDS) in Los Angeles County. Of those, 1,294 are alive and in need of medical services. We have estimated that Los Angeles County will have as many as 30,000 cumulative AIDS cases by the end of 1991. Assuming a constant mortality rate, as many as 11,400 persons could be living with AIDS in the County in 1991. This is nearly a ninefold increase in persons needing medical services.
- 2. The AIDS case statistics do not show the entire picture. Many more persons are HIV-infected and the number of persons with AIDS-Related Complex (ARC) is estimated to be up to ten times the number of AIDS cases.
- 3. Ninety-two percent of the diagnosed AIDS cases in Los Angeles County to date are among homosexual/ bisexual men. Only two percent are heterosexual IV drug users. Thus, Los Angeles has yet to see the large number and percentage of IV drug-related cases, as seen in New York and New Jersey.

- 4. We estimate that a third of the AIDS/ARC patients in Los Angeles County are being treated in County facilities. We have a caseload of over 800 patients in our outpatient clinics and an average inpatient hospital census in excess of 40. This inpatient census constitutes about 1.3% of our budgeted inpatient census capacity of 3,000.
- 5. A recent study of the AIDS outpatient clinic at LAC/USC General Hospital, confirmed that the County patient population contains greater percentages of Blacks and Latinos than found in the overall AIDS case statistics.
- 6. The patients seen at our hospitals and clinics are also less likely to have private insurance and are more dependent on Medi-Cal or are County patients.
- 7. Due to the 24-month waiting period, very few of our patients are eligible for Medicare.
- 8. Assuming that the County will continue to provide medical care for a third of all of the AIDS/ARC patients in Los Angeles County, if our case projections are correct, the outpatient clinics could be following over 6,000 persons by the end of 1991 and our average inpatient census could reach 350, or twelve percent of our current budgeted hospital capacity.

#### D. FINANCIAL IMPACT

1. Total spending for AIDS in the Department of Health Services rose from \$9,348,000 in 1985-86 to an estimated \$15,079,000 in 1986-87. Eighty-five percent of the expenditures in the past two years

have been for inpatient and outpatient medical care in our hospitals.

- 2. Of the estimated \$12,628,000 spent for medical care in 1986-87, 65% was reimbursed by Medi-Cal, 5% was reimbursed by patients, insurance and other payors, 0.1% was received from Medicare and the remaining 29% was paid from County funds.
- 3. Utilizing the case projections cited previously, and using an average inpatient cost per day of \$725, Los Angeles County's annual inpatient hospital costs alone could exceed \$92 million by the end of 1991. Total medical care costs could exceed \$110 million. With current reimbursement percentages, the County's share of that would be \$32 million.

#### E. DEVELOPMENT OF ALTERNATIVES

- Because of the high costs of acute inpatient care and the projections of caseloads in the near future, a top priority of the Los Angeles Department of Health Services is the development of alternatives to acute inpatient care to enable us to care for patients in the most cost-effective manner.
- 2. In Los Angeles County there are essentially no available options between acute inpatient care and home health care. Even home health care is restricted due to the limited reimbursement under Medi-Cal for such services. This problem should be alleviated somewhat by the approval of the waiver application which the California Department of Health Services will soon submit for Medi-Cal reimbursement of a broader spectrum of home-based services, without which patients must stay in acute beds longer than necessary.

- 3. In addition to increased home health services, we are working with community-based and private sector providers to develop other alternatives to acute inpatient care, including subacute care, skilled nursing care, and adult day care.
- 4. Another vital need is housing for AIDS patients who are unable to maintain themselves at home. The County is currently working with several community-based AIDS service organizations on the development of residential and residential/hospice facilities. A key problem here is also financing.
- 5. Because of the increased needs and expected overall cost savings, the Los Angeles County Department of Health Services has budgeted \$1.5 million of its \$38.5 million 1987-88 AIDS budget for a pilot program of alternatives to inpatient care. Included in this pilot will be an enhanced case management system, supplemental funding for home health care, a pilot day care project and supplements for residential and skilled nursing care.

#### F. CONCLUSIONS

1. As briefly demonstrated here, AIDS is having a major impact on the health care system of Los Angeles County. We are only beginning to feel its effects. Without additional state and federal resources, we will be faced regularly with the difficult task of cutting other vital health care services in order to pay for the increasing costs of AIDS patients. 2. Now is the time to develop innovative alternatives and cost-effective programs in order to withstand the projected growth in cases in the next five to ten years.

JS:lv

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John E. Vadnais

Sheridan Weinstein, M.D.

Kenneth O. Williams, M.D.

- Board Appointment

- Board Appointment

- Board Appointment

- Board Appointment

- Hospital Council of So. California

- King/Drew Medical Center

- UCLA School of Medicine

- Saint Vincent Medical Medical Bldg.

- AIDS Project Los Angeles

- American Red Cross

- Board Appointment

- Gay & Lesbian Community Services

- State Dept. of Mental Health

- Board Appointment

- Board Appointment

- Center for Disease Control

- United States Surgeon General

- Los Angeles Medical Association

#### THE AIDS PROJECT LOS ANGELES (APLA)

The AIDS Project Los Angeles is a professionally run organization, very similar to the San Francisco AIDS Foundation, which offers a wide range of AIDS-related programs and services, especially educational services. It also publishes a quarterly periodical under the title "Issues." The organization has recently acquired a new executive director whose qualifications are an indication of the professional way in which APLA is run. The following pages try to convey a first impression of APLA's work by the reproduction of its mission statement, its work statistics and its budget report for the fiscal year ending June 1987.

For further information see the complete APLA information packet attached to the present report (see Printed Materials, II, 2).

#### AIDS PROJECT LOS ANGELES

#### MISSION STATEMENT

The purpose of AIDS Project Los Angeles is:

- -to support and maintain the best possible quality of life for persons in Los Angeles County with AIDS and AIDS-related ill-nesses, and their loved ones, by providing and promoting public and privately-funded vital human services for them;
- -to reduce the overall incidence of Human Immunodeficiency Virus infection by providing risk-reduction education and information to persons primarily affected by and at risk for AIDS, and the general public;
- -to reduce the levels of fear and discrimination directed toward persons affected by AIDS, and to enhance and preserve the dignity and self-respect of those persons, by providing and promoting critically-needed education to the public, health care providers, educators, business and religious leaders, the media, public officials, and other opinion leaders; and
- -to ensure the ongoing support for all of these services by involving, educating and cooperating with a wide range of organizations and individuals in AIDS-related service provision, and by supporting efforts at all levels of the public and private sectors to secure adequate development and finance of AIDS research, education, and human service programs.

Approved by the APLA Board of Directors on February 22, 1987.

A I D S
PROJECT

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Lantel Sichramen
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David E. Ganding
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Hen. Stephen MI, Lacks
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Corothe States Jarreng, PM
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Vicanno Zapeno, 54(0, DrPri

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PROJECT LOS ANGELES NT SERVICES DIVISION

'visional Statistics for August 1987

	PREVIOUS YEAR CURRENT MONTH AUGUST '86 AUGUST '87		INCREASE OVER PREVIOUS YEAR	YEAR TO DATE TOTAL
ENTS SERVED				
Caseload at beginning of month	732	1,035	41%	995
Number of new cases added	75	128	71%	223
Number of Clients Served During Month		1,163	44%	1,218
Number of Clients Deleted	36	<b>51</b>	423	106
TOTAL CASELOAD AT END OF MONTH	771	1,112	443	1,112
HNICITY OF CLIENTS SERVED DURING MONTH				
Astan	7	5	-14%	6
Black	58	92	644	98
Caucasian	606	891	47%	934
Hispanic	. 81	140	, 73%	14/
Native American	15	23	53%	25
Other .	5	11	120%	11
Unknown	1	. 0	-100%	
TOTAL	771	1,163	51%	1,218
MUER OF CLIENTS SERVED DURING MONTH				
Male	745	1,129	52%	1,182
Female	26	34	31%	3(
TOTAL	771	1,163	51%	1,210
EPHONE CONTACTS				
Client	657	2,097	219%	4,34
Registration	148	228	54%	339
Family/Significant Other	187	250	34%	42
Crisis Intervention	65	45	-31%	6
Volunteers	518	575	114	1,21
Community	<b>668</b>	997	49%	2,09
TOTAL	2,243	4,192	87%	8.48

IDS PROJECT LOS ANGELES .IENT SERVICES DIVISION

#### Divisional Statistics for August 1987

	PREVIOUS YEAR AUGUST '86	CURRENT MONTH AUGUST '87	INCREASE OVER PREVIOUS YEAR	YEAR TO DATE TOTAL
MENTAL HEALTH			•	
Support Groups				
Total Number of Groups	*	18		34
Total Number of Unduplicated Clients Total Number of Sessions	*	164 71		340 133
Counseling				
Clients Served	*	45		89
Family/S.O. Served	*	9		23
TOTAL Served	*	54		112
Sessions	•			
Crisis/One Session	*	3		7
Individual Conjoint/Family	* .	· 130		260 16
TOTAL Sessions	*	142		283
Hospital Visitation				
APLA Clients	19	51	168%	96
Non-Clients Total Number of Visits	28 145	81 461	189 <b>%</b> 218 <b>%</b>	183 982
TRANSPORTATION				
Transportation Requests	102	129	26%	289
Requests unable to fill Requests cancelled by client	7 10	2 15	-71 <b>%</b> 50 <b>%</b>	4 - 45
•			_	
TOTAL (Clients Served)	85	112	32%	240

IDS PROJECT LOS ANGELES :ENT SERVICES DIVISION

Divisional Statistics for August 1987

	PREVIOUS YEAR AUGUST '86	CURRENT MONTH AUGUST '87	INCREASE OVER PREVIOUS YEAR	YEAR TO DATE TOTAL
PCESSITIES OF LIFE PROGRAM				
NOLP Clients	*	431		866
Orders Filled	*	956		1,651
Mileage - Deliveries	*	4,720		9,051
Volunteers	*	142		253
Volunteer Hours	*	1,421		2,046
OOD VOUCHERS (prior to 11-1-87)				
Number of Individuals Served	148	*		*
Total Number of Vouchers	542	1		
Cost of Youchers	18,970.00			•
CUIDDY PROGRAM				
Number of Buddies provided to clients	166 <b>5,</b> 312	196 <b>6</b> ,272	18 <b>%</b> 18 <b>%</b>	368 11, <i>1</i> 76
R. E. GREENE DENTAL CLINIC				
Patients Treated	41	117	185%	195
Procedures Performed	58	243	319%	380
Volunteer Hours				
Dentist	48	64	39%	115
Staff	53	250	372%	557
TOTAL Volunteer Hours	99	314	· 217%	\$82
ATTENDANT CARE				
Number of Clients Served	* .	0		0
Number of Hours of Service Provided	#	Q		0
Direct Cost of Service	*	0		0

PROJECT LOS ANGELES INT SERVICES DIVISION

ivisional Statistics for August 1987

	PREVIOUS AUGUST		CURRENT MON AUGUST '8		INCREASE PREVIOUS		YEAR TO DATE TOTAL
_ = = = = = = = = = = = = = = = = = = =						**********	BBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBBB
SING							
Emergency Housing				•			
Number of Clients Served Number of Nights of Shelter Provided		3 34		0		-100% -100%	5 25
Mansfield House					,		÷
Number of Clients Served Number of Nights of Shelter Provided		6 186		3 78		-50% -58%	5 140

Exhibit H

IDS PROJECT LOS ANGELES	06/23/87	CLIENT	FRICATION	CARCAICIAC	APM(1)
987-88 OPERATING BUDGET PROGRAM SUMM PLA GRANT FUNDS DNLY Y FUNCTION		SUPPORT	ETOCALION	FUNDRAISING	MOTION
EVELES					
GRANT REVENUES		1,365,342	-		24,620
DOWNIDS	0 1	•	0	-	0
SPECIAL EVENT INCOME	0 :		0	•	C
SALES/SERVICES	0 :		0	_	0
<b>ME</b> R	0 1	0	0	0	(
TOTAL REVENLES	2,387,153	1,365,342	997,191	0	24,620
XPENSES				<del></del>	
TOTAL PERSONEL	903,221	493,656	384,945	0	24,620
ATTENDANT CARE	564,628	564,628	0	. 0	(
FOOD PROGRAM	119,859	119,859	0	0	(
SHELTER PROGRAM		10,734	0	•	(
OTHER OLIENT SUPPORT	44,625	44,625	0	0	(
ADVERTISING	104,920	. 0		. 0	(
EDUC TRAINING MATERIALS	31,344	5,460	25,884	0	1
HOTLINE	59,106	. 0	59,106	. 0	1
PRINTING/DUPLICATING	53,372	13,358	40,014	0	4
CONFERENCE/MORKSHOP SPONSORSHIP		5,000			
HEALTH SURVEY	. 0 :	•	. 0		(
OTHER EDUCATIONAL SUBCONTRACTS	75,175	0	75,175	0	(
FUNDRATSING EXPENSES	0	0	0	. 0	•
STAFF/VOL DEVELOP/RECOGNITION	2,568	1,200	1,368	0	(
TRAVEL/CONFERENCES	23,747	3,985	19,762	0	(
OTHER AIDS ORG SUPPORT	0 1	•	0		
OTHER SUBCONTRACTS	160,676		134,676	-	ı
Total Program Support	1,264,404	794,849	469,555	. 0	
An man a man		1			
SUPPLIES	15,411		•		
POSTAGE/DELIVERY	19,162	• .	15,736		
LEGAL SERVICES	0 :		0	-	
ALDIT SERVICES	15 000		15 000	•	
MET INFO SYSTEMS SUPPORT	15,000		15,000		
OTHER OFFICE SUPPORT	5,650		5,550		
INDIRECT GRANT COSTS	65,481 l	2,622	62,859	0	
TOTAL OFFICE SUPPORT	120,704	11,647	109,057	0	
OVERHEAD	60,755	34,785	25,970	•	
EQUIPMENT	38,069	30,405	7,664	0	1
TOTAL EXPENSES	2,387,153	1,365,342	997,191	0	24,62
ONTRIBUTION TO/USE OF APLA FUNDS	0	0	0	0	
ERCENT OF TOTAL EXPENSES		57.2X	41.8	x 0.0x	1.

#### X. AIDS PREVENTION IN SAN FRANCISCO

#### THE SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH

The San Francisco Department of Public Health, in March 1987, has produced a "Status Report and Plan for Fiscal Year 1987-1988" which was attached in full to my previous report of April 30, 1987. This comprehensive and very detailed planning document is still in use and should be consulted for all relevant questions. There is no need to repeat the information here. The epidemiological development in San Francisco since April is summarized in the City's latest AIDS update of August 31. It is reproduced on the following pages.

Following the update are two newspaper articles on the further deepening of the AIDS crisis in San Francisco within the next four years. It seems that it will be very difficult to take care of the increasing patient load, especially since many of the patients will be suffering from neurological disorders, will be unable to care for themselves even if otherwise relatively well, and will need constant care and supervision.

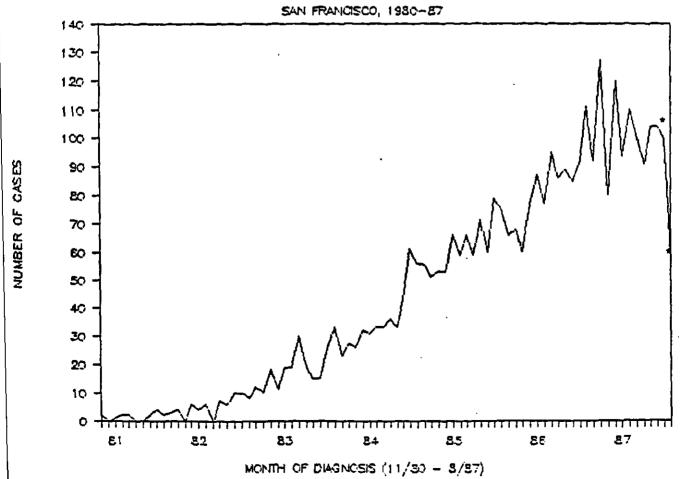
The City of San Francisco is therefore considering the creation of a large nursing facility specializing in the care of AIDS patients. This is deemed necessary in spite of the fact that the general policy in San Francisco has been and will remain to reduce the time of hospitalization as much as possible. The City is forced to realize, however, that with the growing number of cases, many of whom suffer from mental deterioration, new special facilities will be needed.

## AIDS REPORTED CASES

(from 7/81 to 8-31-87)

Total	San Francisco Cases:	3,661
Tota?	San Francisco Deaths:	2,152
Total	S.F. cases month to date: _	116
Total	S.F. Deaths month to date:	59
Total	California cases: 9,341 ca (as of 7-31-87)	ses; 5,011 deaths
Total	U.S. cases: 41,366 cases;	23,884 deaths

### AIDS CASES BY MONTH OF DIAGNOSIS



\* Reporting for recent months is incomplete.

Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report Summary of Cases Meeting the CDC Surveillance Definition in San Francisco Cases Reported through - 08/31/87

AIDS Cases by Transmission Category and Sex, San Francisco, 1981 - 1987(1)

Transmission Category(2)	1	9	EX		To	al	
	M	ale	Fe	ale	N	×	
	N.	×	N	×			
Adult/Adolescent Homosexual or bisexual male Intravenous (IV) drug User Homosexual/bisexual IV drug User Hemophiliac/coagulation disorder Transfusion recipient Heterosexual contact(3) None of the above/Other(4)	3094 34 445 5 21 10	85.4 0.9 12.3 0.1 0.5 0.3	0 11 0 0 9	0.0 39.3 0.0 0.0 32.1 28.6	3094 45 445 5 30 18	84.8 1.2 12.2 0.1 0.8 0.5	
Subtotal: Adult/Adolescent Children (0-12 years) Transfusion recipient Child of high risk/AIDS parent(5)	3622 4 2	66.7 33.3	28	20.0 80.0	3650 5 6	45. 5 54. 5	
Subtotal: Children	6		5		11		
Total	3628		33		3661		

#### AIDS Cases by Age Group

AGE	Cases	¥.
0 - 4 5 - 12 13 - 19 20 - 29 30 - 39 40 - 49 50 - 59 60 +	8 3 5 507 1829 951 287 71	0.2 0.1 0.1 13.8 50.0 26.0 7.8
Total	3661	

#### AIDS Cases by Race or Ethnic Group

	Adult/Adol	escent	Children (	D-12 years)	Total			
	N	×	N	2	N	*		
White Black Latino Asian/Pac I. Native Amer.	3117 219 253 57	85.4 6.0 6.9 1.6 0.1	6 3 2 0 0	54.5 27.3 18.2 0.0 0.0	3123 222 255 57 4	85. 3 6. 1 7. 0 1. 6 0. 1		
Total	3650		11		3661			

#### AIDS Deaths and Cases By Primary Disease Group

Primary Disease	Adul	t/Adole	scent		Chil	dren (O-	12 year	r <b>s</b> )	Total			
	Deaths		Cases		Deaths		Cases		Deaths		Cases	
	N	×	N	*	N	1	N	×	N	\$	N	1
KS without PCP PCP without KS Both KS and PCP DI without KS or PCP	392 1139 388 227	18.3 53.1 18.1 10.6	816 1982 488 364	22.4 54.3 13.4 10.0	2000	0.0 55.7 0.0 33.3	0 6 0 5	0.0 54.5 0.0 45.5	392 1143 388 229	18.2 53.1 18.0 10.6	816 1988 488 369	22.3 54.3 13.3 10.1
Total	2146		3650		6		11		2152		3661	

(1) Cases reported through 08/31/87.

(2) Cases with more than one risk factor (other than the combinations listed in the tables) are tabulated only in the most likely transmission category.

(3) Includes persons who have had heterosexual contact with a person with AIDS or at risk for AIDS and persons without other identified risks who were born in countries in which heterosexual transmission is believed to play a major role although precise means of transmission have not yet been fully defined.

(4) Includes patients on whom risk information is incomplete (due to death, refusal)

to be interviewed or loss to follow-up), patients still under investigation, men reported only to have had beterosexual contact with a prostitute, and interviewed patients for whom no specific risk was identified.

(5) Epidemiologic data suggest transmission from an infected mother to her fetus

or infant during the perinatal period.

#### Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report Summary of Cases Meeting the CDC Surveillance Definition in San Francisco Cases Reported through - 08/31/87

AIDS Cases by Transmission Category and Year of Diagnosis, San Francisco, 1981 - 1987(1)

Transmission Category(2)	Year of Diagnosis													
	1981		190	1982		1983		1984		85	1985		1957	
	N	*	N	*	N	*	N	1	N	*	N	× ×	И	×
Adult/Adolescent										(				
Homosexual or bisexual male	24	85.7	97	95.1	241	84.9	447	83.1	679	84.2	954	83.6	652	85.6
Intravenous (IV) drug User	0	0.0	0	0.0	2	0.7	4	0.7	8	1.0	21	1.8	10 77	1.3
Homosexual/bisexual IV drug User	2	7.1	3	2.9	37	13.0	83	15.4	101	12.5	142	12.4	77	10.1
Hemophiliac/coagulation disorder	0	0.0	0	0.0	0	0.0	0	0.0	2	0.2	2	0.2	1	0.1
Transfusion recipient	0	0.0	! 0	0.0	0	0.0	0	0.0	11	1.4	10	0.9	9	1.2
Heterosexual contact(3)	0	0.0	. 0	0.0	3	1.1	2	0.4	2	0.2	7	0.6	À	0.5
None of the above/Other(4)	1	1.6	0	0.0	0	0.0	5	0.4	2	0.2	3	0.3	5	9.7
Children (0-12 years)				}	ì			1	j	j		)		ì
Transfusion recipient	0	0.0		0.0	1 1	0.4	0	0.0	l t	0.1	lι	0.1	ح ا	0.3
Child of high risk/AIDS parent (5)	Ì	3.6	Ž	2.0	Ò	0.0	Ŏ	0.0	Ō	0.0	i	0.1	Ž	v.3
Total	28		102		284		538		806		1141		762	

#### AIDS Cases by Race/Ethnic Group and Transmission Category, San Francisco, 1981 - 1987(1)

Transmission Category(2)	Race/Ethnicity(6)										
	White	White		Black		Latino		Pac I.	Native Ame		
	N	×	N	%	N	¥	N	*	N (	*	
Adult/Adolescent Homosexual or bisexual male Intravenous (IV) drug User Homosexual/bisexual IV drug User Hemophiliac/coagulation disorder Transfusion recipient Heterosexual contact (3) None of the above/Other(4)  Children (0-12 years) Transfusion recipient Child of high risk/AIDS parent (5)	2669 14 397 4 19 10 4	85.5 0.4 12.7 0.1 0.6 0.3 0.1	152 21 30 0 4 7 5	68.5 9.55 13.50 13.0 13.2 2.3	222 8 15 12 14	87.1 3.1 5.9 0.4 0.8 0.4 1.6	48 a 2 0 5 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	84.25 3.55 0.8 0.0 0.0	11111		
Total	3123		555		255		57		4		

(1) Cases reported through 08/31/87.

(2) Cases with more than one risk factor (other than the combinations listed in

(2) Cases with more than one risk factor (other than the combinations listed in the tables) are tabulated only in the most likely transmission category.
(3) Includes persons who have had beterosexual contact with a person with AIDS or at risk for AIDS and persons without other identified risks who were born in countries in which beterosexual transmission is believed to play a major role although precise means of transmission have not yet been fully defined.
(4) Includes patients on whom risk information is incomplete (due to death, refusal to be interviewed or loss to follow-up), patients still under investigation, men reported only to have had beterosexual contact with a prostitute, and interviewed natients for whom no specific risk was identified.

interviewed patients for whom no specific risk was identified.

(5) Epidemiologic data suggest transmission from an infected mother to her fetus

or infant during the perinatal period.

(6) Risk groups for Native American cases are not disclosed because it would compromise the confidentiality of those cases.

## Acquired Immunodeficiency Syndrome (AIDS) Monthly Surveillance Report Summary of Cases Meeting the CDC Surveillance Definition in San Francisco Cases Reported through ~ 08/31/87

#### Asian/Pacific Islander Ethnicity(1)

Ethnicity	N	% of Asian Cases
Chinese Japanese Filipino Vietnamese Polynesian/Hawaiian	11 15 26 2	19.3 26.3 45.6 3.5 5.3
Total	57	100.0

#### Aids cases by year of diagnosis and race. (1)(2)

Race/ Ethnic	Year of Diagnosis													
	1981		1982		1983		1984		1985		1986		1987	
	. <b>N</b>	*	N	×	H	×	N	×	N	¥	N	¥	N	*
White Black Latino Asian/Pac I. Native Amer.	24 2 2 0 0	85.7 7.1 7.1 0.0 0.0	88 6 7 1	86.3 5.9 6.9 1.0 0.0	257 16 10 1	50.5 5.6 3.5 0.4 0.0	477 23 34 4 0	88.7 4.3 6.3 0.7 0.0	685 46 61 14	85.0 5.7 7.6 1.7 0.0	967 75 78 18	84.3 6.6 6.8 1.6 0.3	625 54 63 19	82.0 7.1 8.3 2.5 0.1
Total	28		102		284		538		∌96		1141		762	

#### AIDS Cases by Race/Ethnic Group, Sex, and Age Group, San Francisco, 1981 - 1987(1)

AGE	Race/Ethnicity(3)										
White		1	Black		Latin	0	Asian	/Pac I.	Native Amer.		
	Male	Fesale	Male	Female	Male	Female	Male	Female	Male	Fesale	
0 - 4 5 - 12 13 - 19 20 - 29 30 - 39 40 - 49 50 - 59 60 +	2 2 418 1536 825 245 56	1 0 1 7 7 1 3 4	0 0 1 44 100 48 14	30013130	2 0 38 131 58 19	00000-00	0 0 0 6 29 13 3	000000000000000000000000000000000000000		-	
Total	3105	18	211	11	254	1	54	3	-	-	

Cases reported through 08/31/87.
 This table cumulates cases by DATE OF DIAGNOSIS rather than DATE OF REPORT. Because of this difference, totals may differ from those in other tables and will change with late reports and new data or information.
 Age and sex of Native American cases are not disclosed because it would compromise the confidentiality of those cases.

# Bay Area AIDS hospital 'key' in City effort As the nation struggles to cope

As the nation struggles to cope with the growing number and cost of AIDS patients, more cities are considering the concept of an AIDS hospital. Today, in the second of a two-part series, The Examiner looks at San Francisco's effort to develop facilities to handle the crisis.

By Jayne Garrison of the examiner staff

David Werdegar, San Francisco's director of Health, is a subdued man whose tone is usually even, calm.

But when he talks about the strain of AIDS on city health services, concern creeps in his voice.

"We need several hundred doctors." Today, 30 to 40 do most of the work. "We need skilled nursinghome beds." The City has access to only 25.

Without them, he sighed, "We could all look very foolish... in the future."

A key to Werdegar's hope for smooth health care in a future groaning under the weight of AIDS cases is a regional AIDS hospital proposed at 15th Avenue and Lake Street in San Francisco.

This hospital, however, has more differences than similarities to the struggling Institute for Immunological Disorders in Houston. There, the private AIDS institute staffed by five university doctors hoped to

The City's AIDS needs vs. resources 1991 ,000 Projected needs on any given day 5,000 patients with AIDS Acute 200 oscital beds home beds What's available 1987 for them today 1,372 patients with AIDS \*Estimale Source: Estimates from the San Francisco Health Department

Examiner graphics

draw paying patients from their personal physicians with the most up-to-date experimental drugs and decorator-designed rooms.

Instead, The City is proposing a high-tech nursing home, a place for all doctors to send their patients when intensive hospital care can do no good but the patient still is too sick to return home. Most important, this nursing home would be run largely with federal dollars.

"The disease is larger than our ability to fund care," insisted Phillip Sowa, executive director of San Francisco General Hospital. "A public-private partnership is absolutely the only answer to this epidemic."

By 1991, the U.S. surgeon general predicts, 145,000 patients will need AIDS-related health care, at a cost of \$8 billion to \$16 billion. At least 5,000 of those patients will live in San Francisco. Their health care bills from diagnosis to death could range between \$225 million and \$350 million, based on current costs per patient in this city and state.

Everyone — all levels of government, insurance companies, patients and taxpayers — will dig in their pockets to pay that bill. The City's share, if current spending were to rise proportionately, would come to \$70 million.

To hold down those enormous costs, Werdegar envisions a network of care that includes county-

run S.F. General and San Francisco's 12 community hospitals; 200 to 300 physicians; and like tuberculosis sanitariums of 50 years ago, a nursing home devoted to AIDS patients in the old U.S. Public Health Service Hospital at 15th Avenue and Lake

The proposal has raised eyebrows among some health professionals. "Isolating AIDS can create image, psychological problems," Werdegar acknowledged. "I prefer skilled-nursing beds in many smaller facilities."

But The City's existing nursing homes, with about 3.000 beds, are filled to capacity with elderly people. There are precious few nursing beds for AIDS patients. As a result, hospitals often keep patients in acute-care beds longer than necessary, at a daily cost of \$700 to \$1,000, while a skilled-nursing home could provide the same care for \$200 to \$250.

As AIDS takes its toll on victims' brains, causing dementia that leaves people confused as though they were senile, the situation will worsen.

"We aren't feeling a serious financial crunch yet... but the handwriting's on the wall," said Chery' Fama, chairwoman of the local hospital council's AIDS Coordinating Committee. "These patients require intensive resources.... I can't imagine one hospital providing all that unless it's a government hospital."

Under the proposal being put to the federal government, the mothballed hospital would open before 1991 to as many as 350 Bay Area AIDS patients who no longer need acute medical care. Dubbed a "regional AIDS center," it would be run by S.F. General staff but would be funded largely (city officials hope 85 percent) by the federal government.

The City hopes to establish a second outpatient clinic for people with AIDS on the center's spacious grounds to relieve crowding at S.F. General. Patients on experimental drugs could be treated at the new site. Werdegar hopes the center could also double as a training ground for other private nursing homes willing to take AIDS patients.

He even plans a day-care program in which patients, especially those confused by dementia, could spend the day safely and still go home to family or friends at night.

Unlike the institute in Houston, this AIDS center would allow private physicians to admit their patients and track their care, he says.

That is the vision.

Today, the Army has agreed to relinquish the 56-year-old hospital, where it runs a language school. But the federal government has not yet agreed to pay the hospital's operating costs, which could run as high as \$25 million a year. Negotiations brokered by California Republican Sen. Pete Wilson and Rep. Barbara Boxer, D-Greenbrae, are continuing.

Doctors who run S.F. General's Ward 86 — the AIDS ward — are taking more immediate steps to

build a wide base of physicians willing and able to treat AIDS patients.

Today, about 30 to 40 doctors work often into the night to treat most of The City's 1,372 patients with AIDS. Dr. Paul Volberding, S.F. General's chief of AIDS activities, warns in every public speech about the danger of losing these experts to emotional and physical burnout.

This fall, S.F. General will begin intensive, two-week crash courses in AIDS care for a dozen private doctors at a time.

Still. Werdegar worries that training alone won't lure enough doctors to AIDS care. "There needs to be some financial incentive built in," he says. Instead, the opposite is true.

Most people, struck with AIDS early in their careers, end up losing their jobs and health insurance. California's safety net, Medi-Cal. pays doctors an average of 45 percent of their bills, making many reluctant to accept those patients.

Nor does Medi-Cal pay for attendants who care for patients in their home, a service that costs comparatively little — about \$100 a day.

Ironically, the one area Medi-Cal reimburses without question — hospitals — is the one area in which there is no shortage.

Werdegar estimates there are 1,000 empty acute-care hospital beds in The City, more than enough. And though hospitals, too, are unhappy with the rates Medi-Cal pays, any state money helps ease the cost of overhead.

"When I talk to thospital executives), they're quite comfortable admitting AIDS patients," Werdegar says. "The holdback is the lack of doctors" and the lack of payment. \*\*

# A Grim Challenge for S.F.

## AIDS in 1991 —

#### By Randy Shilts

The refrain comes from public health officials and AIDS doctors from New York to Los Angeles, from Houston to Chicago — Nobody has an AIDS program on a par with San Francisco.

And almost every day some team of doctors or health experts troops through San Francisco General Hospital to learn how to imitate what has become known internationally as "the San Francisco mod-"el" of AIDS care.

Years of planning and careful coordination have given the city the best record of any locale in the world in coping with AIDS.

will present the greatest challenge to San Francisco's health care system since the great earthquake and fire of 1906, requiring not only an unprecedented commitment of medical resources but also assiduous planning.

#### AIDS in 1991

AIDs experts paint this grim scenario for 1991:

Nearly 15,000 San Franciscans have been stricken with the disease and 10,000 have died.

San Francisco General is so filled with AIDS patients that ambulances with nonemergency patients are diverted to other hospitals with empty beds. Although intended as a place for nonacute patients, the Public Health Service Hospital in the Richmond District, which the city secured from the federal government, has become a modern charnel house with all its 350 beds filled with the dying.

The lack of volunteers commensurate with the demand for services has forced hundreds more patients who once stayed at home into AIDS nursing homes being hastily built throughout the city.

Although this is not an optimistic prognostication, neither is it the most pessmistic. As one prominent hospital administrator says privately, "We could have people dying in the streets."

#### **Already Strained**

At San Francisco General, there is considerable anxiety about the future because the strains of today are so evident. The daily AIDS patient census hovers between 35 and 40 a day, meaning that 30 percent to 35 percent of the hospital's nonsurgical adult medical beds are filled with AIDS patients.

"We're essentially at saturation now." said hospital executive director Phil Sowa. "We're going to have to put a cap on the number of AIDS patients in this institution, because this is the public hospital and we have other missions to fulfill."

Ambulances with nonemergency patients have sometimes been diverted to other hospitals, Sowa said, because there are not enough spare beds at S.F. General.

If such a problem exists today, when about 140 AIDS patients are hospitalized citywide on any given day, administrators like Sowa cringe when they think of the estimated 600 AIDS patients who will be in acute-care hospital beds every day in 1991.

Theoretically, San Francisco should be able to provide the beds, because empty rooms are available in the city's 14 community hospitals.

#### SAN FRANCISCO'S AIDS FUTURE

•	July 1987	December 1991 <i>projected</i>
THE ABS	TOLL ALL EN	ESER
Cases	3,402	15,000
Deaths	2,030	10,000
Living AIDS patients	1,372	5,000
NEEDS FOR A	IDS CARE	et.
Acute-care hospital beds per day	140	600
Sub-acute/skilled nursing care	· 25	350
Home health care capacity	60	400
Total visits to doctor by AIDS patients	30,000	120,000

some of which are half-vacant now. The city's public health director, Dr. David Werdegar, recently started meeting with the hospitals' chief executive officers to secure the facilities' cooperation.

"It appears the hospitals will be cooperative," said Sowa. "Unfortunately, hospital administrators don't admit patients. Doctors do. That's the problem."

#### **Enlisting AIDS Doctors**

Few people are more acutely aware of why this is a problem than Dr. Bill Owen, one of the city's most prominent gay physicians.

Owen's typical workweek of between 80 and 100 hours bears grim testimony to a central reality of AIDS health care delivery in San Franciso: The weight of virtually the entire epidemic is being borne by 20 to 30 private doctors.

Owen, for example, has treated 150 of the city's 3,400 AIDS patients. Currently, he has 40 living AIDS patients and 75 more patients suffering from the debilitating AIDS-related complex. Of more concern, however, are 600 to 700 of his patients who are infected with the AIDS virus but have yet to display symptoms. According to current projections, at least 300 of them will get sick with either AIDS or ARC during the next five years.

"I'm handling almost all the patients I can now," said Owen, 38. "You've got to keep in mind that, for the gay doctors who are doing almost all the work, this is very heart-wrenching. We're seeing not only patients but friends and peers—and they're dying."

Some San Francisco gay doctors already have closed their practices.

#### Effect of AZT

Because so few doctors are dealing with the epidemic, AIDS pa-

tients tend to be concentrated at just a handful of hospitals. Moreover, new antiviral drugs such as AZT will probably increase the need for doctors, because patients will live longer and need careful monitoring for side effects.

Dr. R. Eugene Tolls, president of the San Francisco Medical Society, estimates that by 1991 AIDS patients will require 120,000 doctors' office visits a year just in San Francisco. To spread this work more evenly, he and Werdegar hope to enlist 500 physicians to promise to take 10 AIDS patients each by then.

One major obstacle, Toils says, is that Medi-Cal reimbursement rates are so low that many doctors will not want to treat AIDS patients, many of whom lose their private insurance once they fall ill and lose their jobs.

Even if this problem is solved, experts warn, many doctors still may not be eager to treat gay men and intravenous drug users, the two groups hardest hit by the epidemic. With only an estimated 700 private practicing physicians in town, anything less than a resounding response to a call for AIDS service will not be enough.

"Let's face it, doctors have not stepped forward, raised their hands and said, 'I want to care for AIDS patients,' " said Dr. Paul Volberding, the director of San Francisco General's AIDS Clinic. "Can we count on them to do it in the future? I don't know."

Without such involvement, San Francisco General and a few other hospitals will have to meet the demand, usually at the expense of other types of patients. The U.S. Public Health Service Hospital, envisioned as a skilled nursing facility for subacute patients, will become an acute-care hospital, creating the need for more skilled nursing facilities.

Without local doctors to care for AIDS patients, Werdegar says the city may ultimately have to recruit AIDS doctors from other parts of the country. Other experts think the federal government may have to create a corps of AIDS doctors.

#### **Volunteer Shertage**

Even if the local doctors are found, another potential crisis looms in providing skilled nursing care and home health care for the huge AIDS caseload.

As it is, a disproportionate number of local AIDS cases have been able to remain at home — and out of hospitals — because of agencies, such as the Shanti Project and Hospice of San Francisco, that use a large number of volunteers to provide services to ailing patients.

One reason the city is eager for the federal government to turn over the vacant Public Health Service Hospital at 15th Avenue and Lake Street is that its 350 beds can fill the gap in skilled nursing wards. Even with the hospital, which the city hopes to open in late 1988, hundreds of patients will continue to depend on community groups that are finding that they already need a steadily increasing number of volunteers.

So far, most of the AIDS volunteers have been from the homosexual community, but this may well prove to be a shrinking base as more gay men themselves fall ill or are left to tend their own ailing friends and lovers. Although lesbians and heterosexual men and women are volunteering for AIDS work, their numbers are not great enough to come near to handling the work that needs to be done.

Without the volunteers, officials worry, more patients will be forced into already-crowded hospitals or skilled nursing facilities.

#### **Measure of Humanity**

Local health officials need look no farther than New York City to see how mounting AIDS cases can cripple a health care system left unprepared for the epidemic. More than any other city in the nation, however, San Francisco has made contingency plans.

The AIDS Clinic at San Francisco General is preparing training programs for the new AIDS doctors the city hopes to enlist. Werdegar plans to appeal for higher Medi-Cal reimubursement rates for doctors and hospitals to ensure that nobody loses money by treating AIDS patients.

The opening of the Public Health Service Hospital and the expansion of home health programs will ease the pressure on volunteer groups, Werdegar hopes.

Meanwhile, the city hopes federal and state money will finance the vast AIDS prevention and education programs, particularly among minorities and intravenous drug users, so that the virus does not spread further. The 1991 projections, after all, are based only on the level of AIDS within the gay community and optimistically assume that that the disease will make no new inroads locally.

"It's not a crisis situation yet because we've had good planning," said Werdegar. "We have enough lead time to proceed in a fairly orderly fashion, year by year. It's essential that we keep a step ahead of the epidemic, though."

#### THE SAN FRANCISCO AIDS FOUNDATION

The history and function of the San Francisco AIDS Foundation have been described in my earlier report of April 30, 1987. For this update it seems sufficient to attach its latest information packet in full under separate cover (see Sources: Printed Material).

#### THE SHANTI PROJECT AND HOSPICE OF SAN FRANCISCO

Both of these programs have been described in my previous report of April 30, 1987. The information given there is still valid. Furthermore, the relevant programs of Shanti and the San Francisco AIDS Foundation are now available in German translation in Haeberle/-Bedürftig, eds. "AIDS -- Beratung, Betreuung, Vorbeugung" Berlin: de Gruyter 1987. The second edition of this book will also contain a translation of the relevant Hospice material.

#### AIDS EDUCATION IN SAN FRANCISCO SCHOOLS

Attached to my previous report of April 30, 1987 was a curriculum and resource guide on AIDS written in San Francisco for use in schools (Marsha Quackenbush and Pamela Sargent, "Teaching AIDS -- A Resource Guide on Acquired Immune Deficiency Symdrome" 1986). As mentioned earlier in this report, AIDS education in California public schools remains inadequate, as State legislators and the Governor have not yet been able to agree on a comprehensive state law addressing this issue (see chapter 4 -- AIDS in Late 1987: Features of the Political Landscape).

In the meantime, at least some schools in the San Francisco Bay Area have taken the lead as described in a newspaper article reproduced on the following pages.

Also reproduced is a list of current videotapes, films and curriculum guides for teaching about AIDS, as well as a description of a very recent educational AIDS video for teenagers.

#### THE CATHOLIC ARCHDIOCESE OF SAN FRANCISCO

In the meantime, the Archdiocese of San Francisco has become active in the pastoral and practical care of AIDS patients. In this context, it has produced a very instructive information kit which may also be useful to Catholics in other parts of the U.S. and indeed other countries. Because of its potential significance even for German and other European policymakers, the kit is attached in full to the present report (see Sources: Printed Material).

The Introduction and Summary are reproduced on the pages following the newspaper article on San Francisco Bay Area schools.

S.F. Chronicle March 17, 1987

# Bay Area Schools Taking the Lead In AIDS Education

By Bill Gordon

While state legislators, federal health officials and religious leaders debate the best way to teach teenagers about AIDS, students in many Bay Area classrooms are already hearing blunt warnings about specific sex practices and strong pleas to use condoms.

Students from the seventh to 12th grades discuss vaginal, oral and anal intercourse, watch films of junkies injecting drugs and often examine condoms in the classroom.

"That's exactly what has to be done. We're talking about survival," says Millicent Kellogg, coordinator of AIDS education programs for Santa Clara County.

Many Bay Area schools hold special one-time classes on acquired immune deficiency syndrome to warn students that the deadly disease spreads through certain types of sexual intercourse and the sharing of intravenous needles. Virtually all area school districts plan to incorporate the subject into curricula next school year.

Nationwide, only about half of the 73 largest school districts offer some type of AIDS education, according to a recent survey by the U.S. Conference of Mayors.

A bill introduced by state Senator Gary Hart, D-Santa Barbara, would make California the first state to require all public schools to offer AIDS education. It has been passed by the state Senate and sent on to the Assembly.

#### **Student Support**

Students in a pilot program in San Francisco support Hart's proposal.

"We should make adults go to classes about AIDS), too," suggested 13-year-old Sonny Lam.

The San Francisco Unified School District and the city's Department of Public Health began developing a model AIDS curriculum last year with a grant from the national Centers for Disease Control. When complete, the CDC will offer the program to schools across the country.

The district recently taught a draft version of the curriculum over four class periods in several San Francisco schools to evaluate the response of students and teachers.

At Francisco Middle School, eighth-grade science teacher Joyce Porter recalls feeling uncomfortable at first talking about some of the sexually explicit material with

'It's too embarrassing. Our parents don't want to talk to us about it'

her class. Porter said that she overcame her "false modesty" as she grew to understand the tragic impact of the disease on individual lives and on society.

For many students in Porter's class, the study program was the first time anyone had spoken directly to them about the disease. Friends who did not receive the instruction still rely on television or gossip for information about AIDS, they said.

"It's too embarrassing. Our parents don't want to talk to us about it. Nobody talks about it," said Elizabeth Yi.

Other students said they did not know enough about the disease to feel embarrassment.

"I thought the only way you could get AIDS was through blood transfusions." said Lam.

When the study program began. Bless Losa Valecruz believed

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#### rrom Page 6

that she could contract AIDS by shaking hands with someone infected with the disease. Now she laughs at that idea and can quickly tick off the ways the disease has spread — "by sharing needles, through blood transfusions and by having sex with someone."

When a film on AIDS discussed the protection condoms provide, the students felt confused but comfortable enough to ask about them.

f 1st in jt: "We didn't even know what a condom was. We had to ask our teacher," said Johnny Gee. Porter's reply left them with a clear understanding that they should use condoms when they become sexually active, they said.

#### Naționwide Push

The nationwide push to educate students about the disease follows a call last year by Surgeon General C. Everett Koop for frank discussion in schools about AIDS and ways to avoid it.

"Education about AIDS should start in early elementary school," Koop said in a report last October. "There is now no doubt that we need sex education in schools and that it should include information on heterosexual and homosexual relationships."

The threat of the disease prompted Koop, a no-nonsense conservative, to urge schools to teach sexually active youngsters to use condoms. His statements startled many conservatives, including Secretary of Education William Bennett and leaders of the Roman Catholic Church, who countered that children should be taught that the best protection from AIDS is sexual abstinence.

Bennett argued against any sex education program that failed to deliver a clear message that children should avoid sexual intercourse.

Health and Human Services Secretary Otis Bowen yesterday approved a comprehensive AIDS education plan, which calls for federally sponsored information to encourage "responsible" sexual behavior "based on fidelity, commitment and maturity, placing sexuality within the context of marriage."

"Any health information provided by the federal government that might be used in schools should teach that children should not engage in sex, and it should be used with the consent and involvement of the parents," Bowen said.

Health educators, however, generally accept as more realistic Koop's campaign to urge condom use.

"We need to give teenagers the knowledge that it's OK to be abstinent, but we can't emphasize it. Teenagers are sexually active. If we emphasize abstinence, we lose credibility with them," said Marcia Quackenbush, coordinator of San Francisco's Youth and AIDS Prevention Program and author of one of the first published AIDS-education curriculum plans.

Paul Gibson, an AIDS educator with the San Francisco Health Department's city clinic, opens his presentations to high school classes with assurances that all teenagers are not sexually active and should not feel pressured to be.

"But whether you become sexually active in three months or three years, you need to know how to protect yourself from AIDS," Gibson told a class of juniors at a recent presentation at Lowell High School.

"When we say protection we

basically mean rubbers — prophylactics, condoms," he added.

#### **Passing Them Around**

Gibson sometimes passes packages of condoms around for students to examine. He and other health educators argue that students must be "desensitized" to the idea of buying and using condoms by letting them see one of the

myth-fraught objects.

"I tell them to touch it, feel it, taste it or do whatever they need to get acquainted with a condom and understand that it's just a piece of latex," says Allisa Ralston, who teaches AIDS prevention in Marin County high schools.

Raiston and other AIDS educators agree that students must be

told that abstinence provides the greatest protection. But most also agree that students deserve to be told how to protect themselves if they are sexually active.

The debate among AIDS educators in the Bay Area centers on the tone of the message about safe sex.

"There's a fine line between giving kids adequate tools to protect themselves and encouraging them to go out and engage in sex," Ralston said.

The problem leaves some school officials more circumspect on the subject of condoms.

"I'm not sure the presentation should have a sense of advocacy. We need to give information and education, not pressure to use condoms," says Jack Eltzroth, director of student services for the San Jose School District.

#### A Full Discussion in Concord

In Concord, the Mount Diablo School District plans to teach about AIDS and condoms in a "value-free context," but curriculum planner Dick Merrill promises the classes will include a full discussion of methods of AIDS transmission and the protection condoms provide.

"The concept of safe sex will start to emerge at grade seven," Merrill said.

A survey of San Francisco high school students last year showed more than 92 percent knew sexual intercourse is a mode of transmission of AIDS, and more than 80 percent knew the disease also can be contracted from sharing hypodermic needles.

Only 60 percent knew, however, that using condoms during sex decreased risk substantially. And just 68 percent knew it is safe to shake hands or engage in other casual contact with AIDS victims, according to the study in which psychologist Ralph DiClemente teamed with other researchers.

Teenagers elsewhere in the country have shown far greater levels of ignorance in similar surveys. Diclemente said. The results of his study, conducted after the pilot AIDS education program in San Francisco, will be published later this year in the American Journal of Public Health.

By the 1987-88 academic year, the San Francisco Unified School District plans to offer the AIDS education program as a regular part of family life, science, social studies and other classes. All teachers in the district will eventually go through a four-day training program.

Students outside the Bay Area may have to continue to rely on the media and gossip to learn about the disease.

"Many of the smaller districts in the state haven't started to deal with AIDS. Because it is tied in with sex education, it remains controversial," said Amanda Mellinger, a coordinator of AIDS programs for the state Department of Education.

## How to get AIDS films

EXAMPLES STAFF REPORT

Various nonprofit and commercial organizations have developed videotapes, films and curriculum guides for use in teaching about AIDS. Shipping and handling costs are extra in some cases. They include:

• "AIDS in Your School," a 23-minute videotape for high school classes:

costs \$100. It features Mervyn Silverman, president of the American Foundation for AIDS Research, and the music of Jefferson Starship. Peregrine Productions, a nonprofit organization

at 330 Santa Rita Ave., Palo Alto, 94301; telephone: (415) 328-4843.

 "AIDS: What Everyone Needs to Know," an 18-minute film for high school students and adults, is available as a videotape for \$275 or as a film for \$390; free previews can be arranged. "AIDS - Answers for Young People," geared to younger audiences (ages 10-14), is scheduled for release in May. Churchill Films, 662 N. Robertson Blvd., Los Angeles 90069; telephone: (800) 334-7830.

• "AIDS," an 18-minute film, videotape or filmstrip, is designed for students in grade seven and up. Actress Ally Sheedy is host. Prices are \$489 for the film; \$367 for the videotape: \$75 for the filmstrip: \$60 for a three-day rental. Walt Disney Educational Media Co., Customer Service Division, 10316 N.W. Prairie Wiew Road, Kansas City, Mo. 64153-9990;

telephone: (800) 423-2555.

"Beyond Fear," a film or videctape produced by the American Red Cross for general audiences, including high school students. Schools and organizations may borrow it for free. The production is available as a single one-hour program or in three 20-minute segments - "The Virus," "The Individual" and "The Community." Modern Talking Picture Service, 5000 Park St. North, St. Petersburg, Fla. 33709; telephone: (813) 541-5763.

• "Sex, Drugs and AIDS," a 19-minute film or videotape produced last year by O.D.N. Productions for the New York City Board of Education, with actress Rae Dawn Chong as host, Cost is \$400 for the film, \$325 for the videotape. Local nonprofit youth-serving agencies can obtain the film for \$35. O.D.N. at 74 Varick St., Suite 304, New York, N.Y. 10013; telephone:

(212) 431-8923

"AIDS Alert," a 17-minute cártoon videotape designed to reduce anxiety about the disease, costs \$125. Creative Media, 123 4th St. N.W., Charlottesville, Va. 22901; telephone: (804) 296-6138.

 "AIDS: Suddenry Sex Has Become Very Dangerous," a three-part videotape series for students age 12 to 16. The series includes a 21-minute videotape for classroom use, a longer version of the same tape that includes a message for parents and teachers. and a third tape for "mature students;" parents and teachers that deals with. medical facts about the disease. The videotapes cost \$195 each, or \$495 for a package of all three tapes and a teacher's manual, which can be bought separately. Goodday Video Inc., 115 N. Esplanade St., Cuero, Texas 77954; telephone: (800) 221-1426.

• "The AIDS Movie," a 26-minute production aimed at teen-agers and featuring conversations with three AIDS victims, is available on film for \$450, or on videotape for \$385. The film can be rented for \$50. New Day Films, 22 Riverview Drive, Wayne, N.J. 07470-3191; telephone: (201) 633-

"AIDS: Fears and Facts," 26-minute videotape produced by the U.S. Public Health Service, featuring Dr. James Curran of the federal Centers for Disease Control. Tapes are available for \$55 each, National Audiovisual Center, Order Section, 8700 Edgeworth Drive, Capitol Heights, Md. 20743-3701; telephone: (800) 638-1300. Free loans are available from Modern Talking Picture Service, 5000 Park St. North, St. Petersburg, Fla. 33709.

• "AIDS: Profile of an Epidemic," a one-hour videotape for adults and high school and college students, with actor Ed Asner as host. Copies cost \$180 each, or can be rented for \$35, Indiana University Audiovisual Center, Bloomington, Ind., 47405; telephone:

(812) 335-8087.

● "An AIDS/S.T.D. Education Plan." a teacher-training program and cumicolum guide on AIDS and other sexually transmitted diseases, for use by state education departments, school districts and individual schools. Stephen R. Sroka, 1284 Manor Park, Lakewood, Ohio, 64107; telephone: (216) 521-

● "Teaching AIDS: A Resource Guide on Acquired Immune Deficiency Syndrome," a 124-page curriculum guide by Marcia Quackenbush and Pamela Sargent, costs \$14.95. E.T.R. Associates Network Publications, 1700 Mission St., P.O. Box 1830, Senta Cruz, 95061-1830; telephone: (408)

429-9822

• "AIDS: What Young Adults Should Know," a teaching manual and a student guide, by William Yarber, an Indiana University professor of applied health science, is designed for use beginning at the junior high school level. The teacher's guide costs \$8.95 and the student manuals are \$1.75 to \$2.50, depending on the number of copies purchased. American Alliance Publications, P.O. Box 704, Waldorf, Md., 20601; telephone: (301) 476-3481. Reprinted with permission from Education



#### Peer Education Health Resources

Post Office Box 3262 Minneapolis, Minnesota 554O3 612/823-6257

AREA PREMIERE

### All of Us and AIDS

#### NEW VIDEOTAPE FOR TEENAGERS MODELS SEXUAL DECISION MAKING

Teenage sexual communication in the age of AIDS is the subject of a new videotape produced by Minneapolis-based Peer Education Health Resources (PEHR).

#### PUBLIC PREVIEW

Young people, AIDS educators, parents, teachers, clergy, youth work professionals, and human service providers are invited to a public screening of the videotape on Thursday October 22, at 3:30 pm in the main auditorium of the downtown Minneapolis Public Library, 3rd and Hennepin. Intermedia Arts Minnesota (formerly UCVideo) is co-sponsoring the preview.

\* \* \* \* \*

"ALL OF US AND AIDS" models, through peer interactions, new modes of decision making regarding sexual activity. The focus of the 30 minute videotape is teenagers talking to teenagers—using their own language, humor, and contemporary music to move beyond the basic facts of AIDS transmission. The young people explore effective prevention strategies, including abstinence and safer sex behavior, according to PEHR Executive Director Catherine V. Jordan.

Jordan points out that "ALL OF US AND AIDS" is frank and explicit. "We're talking about explicit sexual issues regarding disease prevention and healthy sexuality," she emphasizes. "Much of the dramatic content involves young people making decisions about their current and future sexual activity. They are exploring such broad values as friendship, romance, love, and down-to-earth practical issues including whether or not to 'do it,' and how to buy condoms." The videotape also addresses homosexuality in a candid manner, says Jordan.

"ALL OF US AND AIDS" was co-directed by Twin Cities playwright John Fenn and film-maker Kathleen Laughlin, both of whom are also co-writers on the project. John Kalbrener, Editor of The Phoenix Health and Wellness News, was also a co-writer. Elizabeth Jerome, M.D., Medical Director of Minneapolis Children's Hospital's Teenage Medical Service (TAMS) served as medical advisor to the project. New York playwright and composer Peter Ekstrom wrote and recorded the theme music, "ALL OF US," a rock song with choreography by Minnesota-based Shawn McConneloug. The cast of 14 includes nine teenagers, all of whom are professional actors.

"ALL OF US AND AIDS" was funded by the Minnesota Department of Health; Dayton's and Target Stores; Edward Memorial Trust; General Mills Foundation; Emma Howe Fund; Ruth Mott Fund; and the Ripley Memorial Foundation.

\* \* \* \* \*

Peer Education Health Resources (PEHR) is a non-profit health organization whose primary focus is developing educational media and curriculum that utilize a peer communication system.

#### CATHOLIC SOCIAL SERVICE

An agency of Catholic Charities of the Archdiocese of San Francisco
"Sharing in United Way funds"



#### AIDS/ARC PROGRAMS



MAIN OFFICE: 1049 MARKET STREET, SAN FRANCISCO, CALIFORNIA 94103

August 28, 1987

Dear Friends,

We are pleased to provide this second edition of our <u>Information and Pastoral kit</u>. This Kit attempts to provide updated information specifically for <u>religious professionals</u> which Archbishop John R. Quinn recommended in a <u>letter to the Board of Directors of Catholic Social Service</u>, San Francisco on May 20, 1986:

"While there are a variety of excellent resources concerning the factual dimensions which we may be able to coordinate and make available to our parishes and institutions, we have yet to develop a comprehensive pastoral educational program for our priests and other ministers... I would like to see us begin to develop such a program."

These materials represent an overview of many different approaches for dealing with AIDS. While some elements of these approaches certainly differ from an authentic Catholic teaching, their inclusion does not imply our agreement nor promotion. Rather, the truth of Catholic teaching requires an informed and prudent consultation especially of those charged with pastoral responsibility. We hope these materials will be of help in your pastoral ministry.

The development of a successful AIDS ministry can be further realized if our pastoral concern is founded on the mission of the Church which is the work of Christ. AIDS ministry means caring for God's people who have AIDS, including their families and friends. A first step is to care for and teach ourselves, those we love, our families and each other.

Please let us know if these materials are helpful.

Sincerely yours in Christ,

Fr. Leo J. Hombach, S.J. & Chaplain

Monbach, &

AIDS/ARC PROGRAMS

Archdiocese of San Francisco

For confidential AIDS information and referrals call the San Francisco AIDS Foundation Hotline - San Francisco, 863-AIDS; toll free in Northern California, 800-FOR-AIDS: TDD, 415-864-6606. Brochures addressing specific issues are available by writing to the San Francisco AIDS Foundation, 333 Valencia Street, Fourth Floor, San Francisco, CA 94103

#### CATHOLIC SOCIAL SERVICE

An agency of Catholic Charities of the Archdiocese of San Francisco "Sharing in United Way funds"



#### MAIN OFFICE: 50 OAK STREET, SAN FRANCISCO, CA 94102 • 415/864-7400

"(AIDS) is a human disease. It affects everyone and it tests the quality of our faith and of our family and community relationships."

Archbishop John R. Quinn (June 28, 1986)

At the AIDS and ARC Programs of Catholic Social Service, it is our intention to continue to serve the various needs confronting people with AIDS/ARC and their loved ones and to continue to advocate on behalf of our clients and their loved ones by creating an increased awareness and sensitivity among the clergy and laity towards persons with AIDS/ARC and encouraging discussion of social and moral responses.

As a resource agency, we seek to provide educational materials and pastoral and factual information about AIDS/ARC and our services. We encourage parishes to assess their present and future needs and to explore the possibilities of beginning support groups and lay ministry to meet the needs of persons with AIDS/ARC and their families and loved ones.

Services provided include financial assistance for medicallyrelated purposes; referrals to other service providers; advocacy within the Church and with other religious, medical and social service organizations; minority outreach and education; development of parish-based educational programs and support groups; individual and family pastoral counseling; sacramental care; and volunteer training.

By continuing to promote comprehensive, compassionate and non-judgemental social assistance to those affected by this human disease, we also envision the formation of a strong interfaith ministerial network which will respond to the spiritual needs of those affected by AIDS and ARC.

Please assist us in our efforts to serve those who are impacted by AIDS, AIDS Related Condition or other life-threatening illnesses by sending your tax free donation to:

> AIDS & ARC PROGRAMS CATHOLIC SOCIAL SERVICE 50 Oak Street, Room 202 94102 San Francisco, CA

Enclosed is my contribution: () \$5 () \$10 () \$25 () Other

Please send me \_\_ copies of the Pastoral Kit @ \$5/package. I am interesting in volunteering. ()

#### CATHOLIC SOCIAL SERVICE

An agency of Catholic Charities of the Archdiocese of San Francisco
"Sharing in United Way funds"

AIDS AND ARC PROGRAMS

MAIN OFFICE: 50 OAK STREET, SAN FRANCISCO, CA 94102 • 415/864-7400

#### PASTORAL INFORMATION PACKET

Dear Friend - Peace!

Enclosed you will find a representative selection of pastoral statements and essays concerning the response of various Christian and Catholic leaders to persons with AIDS, persons with ARC, their families, friends, and loved ones. We are providing them to you to assist you in your own AIDS ministry, and to foster your reflections on this ministry as you set an example in your own church community.

The packet is divided into four sections:

Section I contains some case studies drawn from several sources which try to put the problems of AIDS and ARC into a human context.

Section II attempts to give some very brief indications for pastoral ministry and suggestions for parish response.

Section III contains a number of addresses and articles from Catholic and other Christian and religious sources which may offer some thoughts on theological and spiritual dimensions of ministry to those with AIDS/ARC.

 $\underline{\text{Section IV}}$  is a selection of informational booklets which are available at the office or on request.

Because statistics, medical and social responses, and public policy regarding AIDS and ARC change so quickly, it is difficult for any one person to remain up-to-date. It is the hope of the AIDS and ARC programs that if you desire further information, we will be able to provide it to you.

#### XI. A REPORT ON AIDS IN THREE AMERICAN CITIES

The following is a newspaper account of a recent visit to three American cities by the San Francisco Chronicle reporter, Randy Shilts. He is an experienced observer of the American AIDS scene, as evidenced by his book "And The Band Played On" (see IV, 1 -- A Critical History of AIDS in the U.S.).

The report, printed in three installments, offers local epidemiological updates as well as summaries of local AIDS prevention activities. Especially interesting are the reports on New Orleans, where the Catholic church has begun to cooperate with the gay community, and on Houston, where the city government has practically abdicated its responsibility with regard to AIDS.

In its totality, this three-part report rounds out the preceding summaries on New York, Chicago, Minneapolis, Los Angeles and San Francisco.

# The Heartland Loses Its Innocence

By Randy Shilts
Chronicle Correspondent

""Aurora, Ill.

Settled comfortably mamong cornfields and split-level ranch homes, the people of Kane County pride themselves on being in the heart of America's heartland.

This is where the smokestacks of the industrial Midwest end and its vast farmlands begin. People take a certain pride in the fact that trends always arrive here last.

In this summer of 1987, however, everybody agrees that something new has arrived, and it is something they understand will change their lives for many years to come.

It is AIDS.

Until the last few months, nobody here thought much about this acronym, viewing it as a problem for people in New York, San Francisco, or, maybe, in Chicago, 45 miles away.

Then the county Health Department reported in May that the number of acquired immune deficiency syndrome cases in Kane County had increased from four to 11 in just six months, and the U.S. surgeon general was on TV every night talking about condoms.

No matter where you turned, it seemed everybody was talking about AIDS.

There are the obvious



changes in American life you can see in every city in America nowadays. Condoms have been taken from beneath the pharmacy counter and are displayed prominently near drug stores' check-out stands.

Page 6 Col. 1

Jessica lives in a brick, two-bedroom home near West Aurora Senior High School, where she is in the class of 1990. The home is not far from where her divorced mother, Lynn Hibben, a 1970 graduate of West High, grew up, and where her grandmother, a graduate of West High's class of 1949, still lives.

"I had already had my talk with Jessie about sex, pregnancy and birth control," said Hibben, the owner of a secretarial service.

"About three months ago, I had to update the talk, to include condoms and AIDS. I realized this is something that she will have to cope with for the rest of her life."

The revised version of "The Talk" came as Jessica and her friends already were hearing more about AIDS and drastically changing their views on sex.

A week ago, Jessica's best friend walked out on a boyfriend who proposed love-making without a condom. Another friend thwarted her boyfriend's advances when his prophylactic broke.

"I was really proud of her," Jessica said, "because I knew that if she wouldn't give in — when it was her first time and she was real excited — I wouldn't give in either."

AIDS also has caused Jessica's mother to rethink her lifestyle. She and her boyfriend have decided to be monogamous and are talking about taking the AIDS antibody test.

"I was a child of the '70s, with 'free love' and the 'sexual revolution.' " says the 34-year-old Hibben. "I have re-evaluated my lifestyle. I wonder why I'd want to sleep with people before I knew them. Even if there were a cure, I think the changes I've made will stick. Everything's changed now."

#### Closet Doors Slamming

For Mike Schulz, the AIDS epidemic arrived in Aurora only a few weeks ago, the morning he went to Dominick's supermarket at Westgate Shopping Center and ran into an acquaintance.

Once stunningly handsome, the man had lost 50 pounds and could walk only with the assistance of two canes. On his face, Schulz could see the lesions of an AIDS-related skin cancer.

"I had never seen anyone who was sick with AIDS except on the news," said the 35-year-old Schulz, who is an administrator at a local recreation center. "I hadn't known him well, but I went over to talk to him and his lover, because everybody else was giving them such wide berth. It was like they were walking around in a bubble."

Schulz did not realize he was gay until after his graduation from West High in 1969. He lived briefly in Nebraska but returned home when his mother became ill. He grew to like the slower pace of small-town life, and after his mother died he and his lover of 13 years moved into the home his father built 50 years ago.

Although gays in San Francisco and Manhattan get all the press, more of the nation's homosexuals are probably like Schulz, living quietly in small towns and suburbs. It is here, on the edges of gay life, that shifts of America's attitudes toward gay people are first felt and the effect of AIDS is palpable.

In the 1970s and early 1980s, when gay liberation was a chic social cause, there was a gay bar downtown and a Fox Valley Gay Men's Chorus was organized.

"It seemed like it was going to be just a couple of years and everybody was going to change and there wouldn't be any more prejudice against gay people," Schulz said.

By 1983 and 1984, when the first news reports about AIDS were appearing in the Chicago Tribune, Schulz noticed his four brothers and sisters began asking more pressing questions about how he was feeling.

By the time actor Rock Hudson was diagnosed in 1985, it seemed that AIDS arose as a family discussion topic whenever Schulz walked in the room, and relatives got less comfortable around him.

"I don't hear from anybody unless I call them first," he said. "I have one sister I talk to regularly, but that's about all the contact I have with my family."

The gay bar is gone, the gay chorus folded, and Schulz does not run into the gay couples he once saw at the shopping center or riding along the bike paths along the Fox River.

"It's almost like you can hear closet doors slamming all over," he said. "You don't sense that straight people are opening up around you, the way they were a few years back. It has changed."

Gay people are not dogged by much overt harassment or stigma, but life is not as friendly here as it once was, he observed.

Life in the urban gay meccas no longer seems like a picnic, either. When Schulz loses track of a gay friend who moved to San Francisco or New York, he now assumes the person is dead.

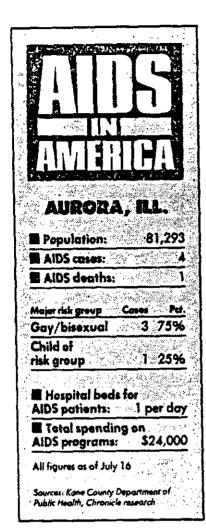
"It's kind of like wagon trains," he said. "You circle up. It's definitely you against the world."

#### Dr. Luck: Forgetten People

"There's not a hospital in Illinois that has not had one AIDS case," said Dr. David Luck of the Dreyer Medical Clinic, Aurora's largest clinic.

"Every doctor in Aurora now has at least one person with AIDS or ARC (AIDS-related condition), or who has tested positive (on the AIDS test). It's in every county now and every small town."

For Luck, AIDS arrived in Aurora last summer, a few weeks after he moved to Kane County from Chicago. He had just completed his training in infectious diseases at



Loyola University Medical School. He instantly recognized that an ailing baby boy, brought to him by baffled colleagues, was suffering from AIDS.

The child, the state's only pediatric AIDS case outside Chicago, was the son of an intravenous drug user from the East Side, the poor part of Aurora.

Since then, Luck, the only local doctor with any training in AIDS, has come to treat more than half the city's AIDS patients.

He has watched the medical and health system slowly come to grips with the fact that the problem has arrived. As in most of America, AIDS presents a major challenge for a medical and health system that is not set up for an outbreak of a new infectious disease.

Until 20 months ago, Kane County did not even have a county health department. Its Infectious Disease Bureau was put into operation only last November.

There are no public clinics or hospitals, so indigent patients cannot receive publicly financed treatment unless they are suffering from a medical emergency. Rates of Medicaid reimbursement are so low in Illinois that few doctors will accept public assistance patients.

The people who will suffer most can be found late at night among the whitewashed windows of the downtown district, a onceprosperous area now deserted because shoppers go to mails.

They are the forgotten people of Aurora, blacks and Hispanics, who became unemployed as local farm-equipment plants closed down. Many took to shooting drugs, and now David Luck is seeing them and their wives turning up with early AIDS symptoms.

"These are the hardest people to reach, because they are outside the system and suspicious of it," Luck said. "But they pose the biggest future problem for AIDS in Aurora, and AIDS in the nation."

At the new county Health Department. Beverly Beethan also worries about these forgotten Aurorans. What AIDS education has taken place locally has come from schools and meager state financing. Even the brochures come from the San Francisco AIDS Foundation.

The county would like to do more about AIDS. Beethan said, but the money is not there. "We just try to get by the best we can," she said, "and hope that more money will be

coming from state and federal sources."

#### **Heighborly Compassion**

There is another trend about AIDS in Kane County that just. about everyone mentions, even though it is not the kind of thing that gets the publicity of hysterical-calls for testing or quarantining AIDS patients.

For example, Beethan constantly gets calls from people who want to help. Lawyers are stepping forward to volunteer their services for AIDS patients, and churches are offering food. One hospital has offered to set aside three free beds for AIDS patients.

"A couple years back, you'd hear people say they should set aside the state of Idaho for AIDS patients, but as knowledge has increased, the hysteria has gone down and people now want to do something to help," said Hugh Epping, director of the Open Door Clinic, a venereal disease clinic in Elgin, north of Aurora.

"Out here, there's a sense that we're dealing with our neighbors," said Epping. "This isn't somebody you don't know. It's small enough that people know each other and they want to help their neighbors out."

There is also the cultivation of something as native to the Midwest, as corn and soybeans: hope.

AIDS will not drive America apart, but bring everyone together, people hope, and some day it will all, be over.

"When I'm 85 and in my rocking chair, I can see one of my grand-kids coming up to me and crying that she got a shot," said 14-year-old Jessica MacAlister. "I'll explain that she shouldn't cry because the shot was for a disease called AIDS, and I can remember a time in my life when people were dying of that."

#### THE AIDS SERIES

■ Wednesday: In the Deep South, the Catholic Church steps in.

Three women reach out to patients.

■ Thursday: Official indifference in Houston.

## AIDS IN AMERICA/A SPECIAL REPORTA

Saw Francisco Arronicle 29. July 1987

## In New Orleans, he Church Pitches In

By Randy Shilts Chronicle Correspondent

New Orleans

When gay organizers here needed an AIDS hospice, the man who took up the cause was the city's most outspoken opponent of gay civil rights, Roman Catholic Archbishop Phillip Hannen.

For tough negotiations, headers of the New Orleans AIDS Project sometimes bring along Sister Anthony, director of Associated Catholic Charities.

Although divided by tradition, religious

teachings and political ideology, the Roman Catholic Church and the gay community have formed an alliance to fight the AIDS epidemic in New Orleans.

The Rev. Paul Desrosiers, head of the New Orleans Council of Priests, explains why.

"I don't believe we asked people who were

dying in the streets what their religion or sexual orientation was during the yellow fever or cholera epidemic," said Desrosiers. "Our tradition is to help people, and that's what we're doing today."

The New Orleans experience could be a sign of what is to come, as America begins to grapple with acquired immune deficiency syndrome as a national problem and mainstream institutions learn to fight the disease by reaching out to gays.

In New Orleans, all AIDS funds are admin-

istered through Associated Catholic Charities. The AIDS hospice, one of the few such facilities in the Deep South, is managed by the archdiocese, and home health care workers are dispatched by Hotel Dieu, the local Catholic hospital.

It is an uneasy partnership, but in a city with a substantial Catholic population, where the church wields major influence, it also has proved to be a potent alliance.

Just about all who are involved agree that with the power of the church, organizers of AIDS efforts have been able to make inroads they would never have been able to accomplish alone.

"It has opened doors that would be closed to a group that was perceived as being from the gay community," said Larry Pate, project administrator of the New Orleans AIDS Project.

#### **Desperate Necessity**

Although tourists still clog Bourbon Street to enjoy Dixieland jazz in the sultry summer heat, life

The AIDS Volunteers

SEE FAGE 21

is not normal in parts of New Orleans. In truth, it is the new harsh times that for gays have created an alliance of desperation with the Catholic archdiocese.

### ADS IN AMERICA/ A SPECIAL REPORT

# Church, Gays Fight Together In New Orleans

New Orleans is suffering through a recession caused by the slump in the domestic oil industry. With an economy heavily reliant on petroleum production, Louisiana now has the nation's highest unemployment rate. Plummeting oil revenues have forced huge cuts in government spending.

For much of last year, for example, all New Orleans municipal employees were cut back to four-day workweeks: more than 1,100 were laid off altogether. Even if the state or city were disposed to finance AIDS programs — and there is little indication that such an interest, exists — there would not be much money to spend.

The city's whole appropriation for AIDS education during the five-year epidemic has amounted to \$21,000, a sum allotted by the City Council two years ago.

Without much city or state involvement, education and prevention programs in the first years of AIDS came largely from the NO-AIDS Task Force, a group made up largely of gay volunteers.

Education was handled out of a tiny storefront on Bourbon Street in the heavily gay French Quarter. Except for the help that an alwaysharried corps of gay volunteers could provide, AIDS patients were left to largely fend for themselves.

"AIDS was considered a gay problem and a gay disease, and nobody else gave a damn." said Richard Devlin, the task force board chairman.

The lack of official interest quickly translated into a chilling environment for the growing numbers of AIDS patients in New Orleans, a city with the 10th-highest per capita AIDS rate in the country.

NEW ORLEANS
Population: 559,000
AIDS cases: 340
M AIDS deaths: 225
National rank
Major risk group Cases Pet.
Gay/bisexual 267 79%
Gay/Bisexual IV drug user 26 8%
Heteresexual 300 3%
Transfusion 11 3%
Hospital bods for AIDS patients: About 25 per day
Total spending on AIDS programs: \$1.2 million for state of Louisiana. Half is federal, half is private money;
no state or New Orleans city funds.
Figures as of July 17
Sources. Epidemiology Branch, Loviciano State Department of Health Chronicle research

. The average time between diagnosis and death for a Louisiana AIDS patient is only 5.9 months, about half the survival time in the rest of the country. It was not unusual for AIDS patients to sit in the Charity Hospital emergency room for 14 hours, gasping for breath, before they could find a doctor to examine them.

#### Traditional Church Role

The lack of housing for AIDS patients was what first drew the attention of Archbishop Hannon, who, before 1985, was known to the gay community chiefly for his role in vitriolically opposing a proposed city ordinance to ban discrimination against homosexuals.

"When I heard that AIDS patients did not have any place to go, I felt we had to do something about it;" said Hannon, who is regarded as one of the most conservative archbishops in the United States.

Hannon donated church property for an AIDS hospice, Project Lazarus, and is searching for a site for a second hospice.

For all his conservatism on issues such as gay rights and sexual

morality, Archbishop Hannon maintains that the unprecedented role his archdiocese has taken in the AIDS issue is within the church's tradition.

"I don't see any contradictions," said the 74-year-old prelate.
"I believe the church should be involved in the most difficult issues of society, and AIDS certainly is the most difficult issue facing us today. If there are people who are sick or hungry, the church wants to help."

Links between the archdiocese and the gay community were strengthened when the Robert Wood Johnson Foundation's San Francisco-based AIDS program announced it was distributing \$17 million in grants so other hard-hit cities could establish coordinated services for AIDS patients along the lines of San Francisco's programs.

The grant application mandated cities to involve a variety of established local groups. Most applicants coordinated their applications through city or state health departments.

Anger directed at those agencies persisted within New Orleans'-major AIDS group, however, because of the dearth of previous official involvement or concern about AIDS. And there were fears of what could happen to AIDS programs if they were entangled in the conservative politicking of either the Louisiana Legislature or New Orleans City Council.

That was when Associated Catholic Charities, the state's largest private social service agency, offered to serve as the administrative agency for a grant. Gay organizers were receptive. As the AIDS Project's Pate said, "There wasn't anybody else we could trust."

"There were a lot of questions at the beginning of whether it would work," said Desrosiers, the Catholic Charities pastoral director.

The grant required the archdiocese to sign an affirmative action statement saying that it would not discriminate against gays — at the same time that Hannon was fighting a proposed gay-rights law.

The archdiocese signed, however, and the three-year, \$1.6 million grant has allowed the city to establish an AIDS inpatient ward and outpatient clinic at Charity Hospital, as well as a health care program and education programs.

The consortium of agencies operating under the umbrella of the New Orleans AIDS Project is directed by Pate, who is openly gay and also the director of the NO-AIDS Task Force.

"We haven't had any conflict at all, even in regards to condoms and safe sex instruction," said Pate, a former Red Cross administrator.

Although there is no other American city in which any church has played such a prominent role in AIDS organizing. AIDS experts expect such coalitions to become more common. as mainstream religious groups become more involved with the epidemic.

The trend comes after several years in which the voice of organized religion was largely used to brand AIDS as the wrath of God being visited upon sinning sodomites.

"It's amazing the constructive role the church is playing now, particularly in the Deep South," said Morrison.

In Dallas, Episcopal, Catholic and Southern Baptist churches have taken a key role in AIDS organizing

In Houston, volunteers from 150 Catholic, Protestant and Jewish congregations are active in the Clergy Consultation on AIDS, which

#### THE AIDS SERIES

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■ Tomorrow: Official indifference in Houston.

helps to provide food, housing and practical support workers for AIDS sufferers.

In New York City, Cardinal John O'Connor, another conservative who has opposed gay rights, recently pledged to work an hour a week with AIDS patients.

The San Francisco archdiocese has established an AIDS/ARC program at Catholic Social Services and donated a convent building to be the city's first AIDS hospice.

Experts think the involvement of religious groups may ultimately prove a buffer against those who would use AIDS as a reason to take punitive moves against homosexuals or others at risk of getting the disease.

"I think as the battle lines are drawn more clearly with the politics of AIDS in this country, we're going to see more of a division," said Morrison. "More of the large churches, like the Episcopalians and Catholics are going to be on one side. The Jerry Falwell types, who will try to exploit AIDS, will be on the other."

Archbishop Hannon belives that, ultimately, the role of the church in the AIDS epidemic will be to heal, not to divide.....

"To a certain extent, it will bind the country together," he said. "I think there will be a much greater outpouring of charity. This can be a blessing, having people more involved with their neighbors. That ispart of the message of Christ, too."

## AIDS IN AMERICA / A SPECIAL REPORT

## In Houston, 'AIDS Is Spelled G-A-Y'

By Randy Shilts
Chronicle Correspondent

· · · Houston

Three months ago, 200 chinting gay protesters collapsed on the steps of Houston City Hall, hoping their "Death-In" would shame the city into launching an AIDS educational program.

Despite the furor and the public resignations of several members of the miyoral AIDS task force to protest the lack of city action, Houston today still has no AIDS program.

Although Houston has the fourth-highest AIDS caseload of any city in the nation, neither the city, county nor state health departments has launched anything resembling an AIDS prevention program for the sprawling metropolis.

The AIDS education and social service pro-

grams that do exist have been undertaken almost exclusively by the gay community and volunteer groups.

"In Houston, AIDS is spelled G-A-Y." says Joe Tumlinson, chairman of the AIDS Foundation of Houston, the largest AIDS service group in the city. "Fighting AIDS means helping gays and that's not a popular thing to do with some voters."

The city's official indifference to the AIDS

threat is perplexing, given the fact that Houston is home to a highly visible and politically powerful gay community.

The city's posture is not extraordinary: While some cities race to construct AIDS service programs, a disturbing number of cities continue to ignore the AIDS threat, leaving the work to whatever volunteers will join the battle.

Some experts worry that this disparity is creating two Americas: one in which concern about AIDS is a reality, and another in which the epidemic remains somebody else's problem.

#### Tarnished Armor

When Kathy Whitmire was elected Houston's first female mayor in 1981, she was the "knight in shining armor" to a gay community that was flexing its nascent political muscle.

The formula for power was not unlike that used by San Francisco gays. Gays were concentrated in one neighborhood, the Montrose. It churned out huge majorities for Whitmire, the first local politician to campaign openly for gay votes. Homosexual voters supplied her margin of victory.

By 1984. Whitmire and a sympathetic City Council had enacted a gay civil rights ordinance, and a maelstrom of controversy ensued. Fundamentalist Christians and conservatives led an initiative campaign, and voters repealed the law by a 4-to-1 ratio.

## In Houston, Lack of Funds, Lack of Commitment

#### HOUSTON

Population:	1,70	000,00
AIDS cases:	٠.	1,300
AiDS deaths:		803
National ran	<b>(:</b>	4
Major risk group	Cases	Pct.
Gay/bisexual	1,085	84%
Gay/Bisexual IV drug user	126	10%

Mospital beds for AIDS patients: 75 per day

Heterosexual

IV drug user

■ Total spending on AIDS programs: \$840,000 in mostly private money, some federal and city money, no county or state money.

20

2%

Figures as of July 17

Sources: Division of Epidemiology, Industrin Department of Health; Chronicle research Conservatives escalated their attacks in the 1985 municipal elections when they ran a "Straight Slate" of anti-gay candidates against Whitmire and every City Council member. The slate lost — after its mayoral candidate said on television that his solution to the AIDS problem would be to "shoot the queers."

However, the effect of the turbulent politicking was to make the city's establishment wary of all things gay-related. Gay leaders say that since 1985, Whitmire has kept herself at considerable distance from the gay community and that the city's refusal to undertake any AIDS education or service programs reflects this.

"She's stabbed the gay community in the back," complained Chris Kihnel, president of the People With AIDS Coalition of Houston. "She hasn't done a damn thing. She's disassociated herself from AIDS because of the anti-gay backlash."

Mayor Whitmire's spokesman, Paul Mabry, heatedly denied the charge and noted that local tax revenues have been hard-hit by the downturn in Texas' oil-dependent economy.

"In Houston, to spend money on AIDS means cutting from another part of the budget," Mabry said.

Robert Faletti, the AIDS coordinator at the Houston Department of Health, acknowledged that the city's education program had been "a little slow to gain momentum," but said he could not be certain whether money was the entire problem.

"It's hard to say if we had the money whether we'd do it or not." he said.

When asked to grade the city's AIDS efforts, Faletti said, "No comment."

Whitmire spokesman Mabry bridled at the suggestion that the lack of funds for AIDS meant that the city was indifferent to the epidemic.

"I don't think there's any question that every city in the country could do more," he said.

That may be true, but it would be difficult to find a city that is doing less, and no other governmental agency has come to the rescue.

Despite pleas from U.S. Surgeon General C. Everett Koop in two appearances before the state Legislature, the Texas state government has not financed AIDS programs.

All state, county and federal AIDS spending in Houston totals \$200,000, of which the city contributes about \$65,000. Such spending in San Francisco, a city with less than half the population, totals \$24 million, of which the city provides \$13.1 million.

#### **Private Funds**

To fill the gap, the gay community has been left to raise \$550,000 this year to finance prevention programs and support services administered by the AIDS Foundation of Houston. Church volunteers largely staff the city's private AIDS hospice, Omega House, as well as raising the \$90,000 spent annually to run the hospice.

"People here think of gay people as the problem when in fact the gay community is taking the lead in creating the solution," complained Tumlinson.

Frustration, however, has followed almost every effort the gay community has made. Most recently, a billboard company donated a billboard to the AIDS Foundation of Houston, which was glad to have the chance to advertise its AIDS hot-line number.

After the billboard was put up in the gay Montrose neighborhood and drew protests from heterosexual residents, the company hastily relocated it to a less controversial site.

Today, the billboard in the Montrose is whitewashed and blank, while the AIDS hot-line number stands above an empty lot on a remote edge of downtown where few will see it.

"That's the only public notice of our hot line," said Tumlinson.

Kihnel added bitterly, "In the end, people will die because of this. I have no doubt that AIDS is spreading much faster down here because the city just won't take this threat seriously."

#### 'Criminal Negligence'

The Houston scenario is repeated in a number of major cities across America.

Local government support for AIDS programs in Miami, for example, has been virtually absent, despite the fact that the city has the sixth-highest number of AIDS cases

in the country. The Florida state government has recently stepped in to augment private fund raising.

In Chicago, the seventh hard-

est-hit city, frustration with city inaction grew so heated that the mayor's AIDS task force broke away from the city last year and is creating its own AIDS program out of existing gay and minority organizations and social service agencies.

As in Houston, there is political irony to this. Chicago Mayor Harold Washington was elected with substantial backing from gays, one of the few blocs of white voters to support the black mayor. Moreover, City Hall insiders have said that Washington's own chief of staff died of AIDS.

Authorities in Los Angeles, which will soon surpass San Francisco as the city with the second-highest number of AIDS cases in America, also have been slow to respond to the epidemic's threat.

Los Angeles County, which is in charge of major health programs, did not allocate any funds for AIDS until late 1985, after the chairman of the governor's AIDS task force accused the Board of Supervisors of "criminal negligence" for ignoring the epidemic.

Even with a substantial infusion of state funds, the AIDS Project-Los Angeles still must turn to private fund-raisers to finance 70 percent of its \$9 million annual budget. With the funds, it provides most of the AIDS prevention and service programs in the nation's second-largest city.

As the dimensions of the AIDS epidemic continue to grow, few believe that such private fund raising can keep pace with the demands for services. In the end, experts say official inertia will translate to the one common denominator of the AIDS scourge — death.

"Ignoring AIDS won't make it go away." said Tumlinson. "It merely allows the disease to spread faster so that once you decide to do something, the problem is that much worse."

#### Two Americas

Dr. Adan Rios looked through a window toward the bustling Houston freeway and talked of the different world outside his hospital.

Rios. an AIDS researcher, knows everybody in America is talk-

ing about AIDS, about condoms, safe sex and "The Test."

Still, he wonders whether there are two Americas: one in which AIDS is a merely the topic of the moment, like Tammy Faye Bakker, and another America, in which AIDS is indeed understood as a catastrophe that will, in the end, touch everyone's life.

"When I hear people say they are concerned about AIDS and I don't hear anguish, I know they are not concerned and that they don't understand," said Rios, who had done AIDS research for five years.

"AIDS is knowing about children dying in Africa and the thousands of mothers in America who are burying their children," he said. "AIDS is a state of mind."

For Rios, anguish is the stuff of his daily life. He is assistant medical director of the troubled Institute for Immunological Disorders, the nation's first AIDS hospital, which was opened by a Beverly Hills-based health services corporation, American Medical International. It probably will close its doors later this year because not enough paying patients live in Houston to keep the facility solvent.

When Rios talks of the epidemic's future, he recalls John F. Kennedy's call to put a man on the moon. "We decided that we would put a man on the moon," he said. "Nobody knew whether it could technically be done, but we decided to do it and we did."

America is now of a split mind on AIDS. Once America is of one mind and ready to assert a similar national will to conquer the disease, there will be an end to the scourge. Rios says.

The doctor pulled a well-worn volume of Dante from the shelf and reads from the last lines of the "Inferno." which describe Dante returning from his sojourn in hell....

We mounted, he first, and I following fond. To glimpse those things whose beauty nothing mars... Thence issuing, we beheld again the stars.

"One day AIDS will be over," Rios said. "We will see the stars, again."

## XII. POSSIBLE FUTURE DIMENSIONS OF THE AIDS EPIDEMIC IN THE U.S.

As mentioned in the introduction, during the preparation of this report the author encountered a number of health professionals who had become deeply concerned, indeed in some cases frustrated and cynical, about the future of AIDS prevention in the United States. Actually, there are disturbing indications that a sound public health strategy against AIDS is beginning to be defeated by short-sighted politicians on all levels -- federal, state and local. As also mentioned earlier in this report, President Reagan and his cabinet have so far prevented the immediate and efficient implementation of the recommendations contained in the report of the U.S. Surgeon General, Dr. Koop. Even more unsettling is the fact that they have virtually ignored the report of the National Academy of Sciences (see my previous report of April 30, 1987).

Many critical observers now fear that the present federal administration will remain incapable of taking any appropriate and timely action, prefering to leave the entire problem to its successors. If this fear should be borne out, the necessary and urgent prevention measures would be delayed until at least the middle of 1989. The loss of two additional years for effective AIDS prevention, however, could prove to be disastrous. In fact, it may become impossible to make up for the time now being lost.

Even today, in late 1987, there are some ominous hints at potential social problems which could develop rather quickly, and for many citizens quite unexpectedly, if federal leadership does not assert itself soon.

It is not easy to give a correct assessment of the future dimensions of the AIDS epidemic in the U.S., even from a strictly medical point of view. The potential socio-political long-term and side effects are all the more difficult to anticipate. However, many observers, including this author, believe that these effects must be carefully monitored if the medical catastrophe of AIDS is not to be aggravated, within a few years, by an even more serious political catastrophe.

In the following pages, the author has reproduced a few key documents that may illustrate the possible dangers, together with the means to avert them. He hopes that these documents will also make clear that the correct decisions today can only be made on the political level. However, in democracies such decisions depend on the support of an enlightened public. The improved education and information of the voting public, therefore, seems to be the indispensable first order of the day.

#### 1. A PUBLIC HEALTH STRATEGY

As frequently mentioned in this report, American public health professionals have quickly arrived at and since then maintained a broad consensus as to the appropriate AIDS prevention stategy.

The following article, written by two public health officers, summarizes this consensus. It is true that the authors speak only for themselves, and that some of their colleagues may differ slightly on minor details, but on the whole the article represents the generally accepted American public health position. One of the authors, Dr. James Chin, has, in the meantime, moved to the WHO headquarters in Geneva, where he undoubtedly will continue to act on the principles he has outlined here.

# The Prevention of Acquired Immunodeficiency Syndrome in the United States

# An Objective Strategy for Medicine, Public Health, Business, and the Community

Donald P. Francis, MD, DSc, James Chin, MD, MPH

Human immunodeficiency virus (HIV) is one of the most virulent infectious agents ever encountered. This virus, estimated to kill up to a half of those infected, has spread to more than 1 million Americans. There is no safe and effective treatment. Nor is there a vaccine. From our understanding of HIV transmission, further spread of the virus can be stopped by the use of various techniques. The combined use of education-motivation-skill building, serologic screening, and contact tracing/notification could eliminate or substantially reduce transmission. To accomplish this reduction an immense concerted effort by physicians, public health practitioners, business, and community organizations is required to get across the simple prevention messages. Those messages are: (1) Any sexual intercourse (outside of mutually monogamous or HIV antibody-negative relationships) must be protected with a condom. (2) Do not share unsterile needles or syringes. (3) All women who may have been exposed should seek HIV-antibody testing before becoming pregnant and, if positive, avoid pregnancy. Only through a concerted, vigorous, and sustained prevention program that deals frankly with this problem will those individuals at risk be reached and motivated to take personal responsibility to protect themselves. Without such an effort, acquired immunodeficiency syndrome will continue to kill ever-increasing numbers of Americans.

(JAMA 1987;257:1357-1366)

AS OF early 1987, about 30 000 cases of acquired immunodeficiency syndrome (AIDS) were reported in the United States, and it is expected that another 250 000 or more will be recorded by 1991. In some communities, such as San Francisco, where the toll of over 1000 deaths recorded as of early 1986 had already exceeded the number of deaths of soldiers and sailors from this city for World War I, World War II, the Korean War, and the Vietnam conflict combined, the pain and suffering of patients, their families, and their friends has been immense. In addition, the

etiologic agent of AIDS has been present in localized areas of central Africa for at least several decades, and only

mous<sup>2</sup> and is still increasing.

See also pp 1357 and 1376.

social damage—in terms of valuable and

productive persons lost and medical ex-

penditures incurred—has been enor-

Current evidence suggests that the

during the past few years has it been spreading extensively in Africa, the United States, Haiti, and Western Europe.<sup>2</sup> The large numbers of cases of AIDS now being documented in the United States, and throughout the world, are primarily a result of infections that occurred in the 1970s and early 1980s, before the causative virus was isolated and its pathogenesis and transmission understood. As such, the current disaster was, to a large extent, an unpreventable one that now requires

an immediate and effective medical and social response to minimize the pain, suffering, and social upheavals caused by these silent infections of years past.

With our current understanding of AIDS, it is clear that virtually all future infections can, at least theoretically, be prevented. Given the opportunity (ie, information, motivation, and skills), individuals should be able to modify their behaviors to protect themselves from infection. The major question is, can our society unite to impart effectively the needed information, motivation, and skills to those at risk to stop this epidemic? The answer to this question depends on, first, having a commitment to intervene effectively; second, developing a reasonable, scientifically and socially sound intervention plan; and third, implementing that plan as rapidly as possible.

This report will review the current knowledge regarding the pathogenesis and transmission of the AIDS virus in the United States, outline a prevention plan based on that knowledge, and describe the major problems confronting effective prevention and control.

### THE VIRUS AND ITS PATHOGENESIS

Human immunodeficiency (HIV)\* (also known as lymphadenopathy-associated virus. human T-cell lymphotropic virus type III,4 and AIDSassociated retrovirus'), the etiologic agent for AIDS, is a retrovirus capable of replicating in a limited number of cells in the human body, including lymphocytes, 17 macrophages, and cells of the central nervous system. 9,10 Typical of retroviruses, HIV integrates its genome into the genome of the host cell, after which progeny viruses are produced. Soon after infection, antibody to several proteins of HIV develop, but these antibodies are not necessarily protective. Indeed, one of the most remarkable aspects of HIV is its propen-

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The opinions expressed in this manuscript are those of the authors and not necessarily those of the Centers for Disease Control or the California Department of Heath Services.

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sity for producing a persistent viremic ("carrier") state in a high proportion of infected people despite the presence of antibody (see "The Significance of Seropositivity" section). The pathogenesis of HIV is related to the destruction of the "helper" (T4) subset of T lymphocytes, which are critical in maintaining immunologic competence. In addition, neurologic disease appears to be a direct result of HIV-induced destruction of brain cells."

### **TRANSMISSION**

Transmission of any human virus requires a portal of exit, survival through the environment into which it is released, and entrance into a susceptible host with establishment of infection in a cell capable of supporting replication. The HIV has been isolated from fluids obtained from a variety of body sites, including blood, 6.7.11 semen, 12.15 vaginal fluid, 14.16 tears, 16 and saliva.17 Epidemiologic studies have established that those fluids that provide sufficient virus for transmission seem to be limited to blood, 18-30 semen, 22-30 and vaginal secre-tions. 28-30 Presumably, the presence of lymphocytes in these fluids increases the concentration of infectious virus and may be important, or even essential, for transmission.

Those sites best suited for the establishment of infection after exposure appear to be the vascular system (including open wounds of the skin<sup>28</sup>), the penis (presumably the urethra), the vagina, and the rectum. The oral mucosa appears relatively inhospitable to the establishment of infection, as yet the infection of an infant, presumably through breast-feeding, leaves room for concern regarding the placement of potentially infectious fluids on upper gastrointestinal tract mucous membranes (at least of newborn infants).

### Sexual Transmission

The HIV is effectively transmitted by sexual contact between men," from men to women, 25.34.25.20 and from women to men. 25,34,30-33 The difference in transmission efficiency, if any, between anal intercourse and vaginal intercourse is not known and continues to be disputed. What is known is that many persons have been infected by both types of intercourse. Between men, it appears that receptive anal intercourse is a more effective means of transmission than is insertive anal intercourse or any type of oral-genital intercourse.24 With vaginal intercourse it appears that transmission rates from men to women or from women to men may be similar.34 The exact risk of infection for a susceptible person having a single sexual encounter

with an infected partner is unknown. There are individuals, both heterosexual and homosexual, who have had repeated sexual relations with known infected persons without having been infected. Yet there are others who report having had only one sexual encounter and have then developed AIDS. In addition, a report from Australia" that four of eight women developed an infection after they were inseminated with semen from an infected sperm donor, and a report of infection of a female chimpanzee by intravaginal inoculation, suggest that a single encounter with HIV is sufficient in some situations to infect.

#### **Blood-Borne Transmission**

Inoculation of HIV intravenously appears to be an efficient means of transmission regardless of whether the inoculum contains cell-free virus20 or cell-associated virus. " The major determinant of outcome of exposure appears to be the amount of virus inoculated. Large inocula given in the form of transfused blood almost universally result in infection, whereas small inocula of blood on the end of a needle seldom result in infection. This appears to be a function of the concentration of infectious virus in blood, which is relatively low," and the amount of blood on the end of a needle, which is small. The lack of hospital- or laboratory-acquired HIV infections indicates that unbroken skin is probably a good barrier to transmission; however, reports of presumptive infection through inflamed skin are of potential concern.25

### **Perinatal Transmission**

Transmission from infected mothers to their infants can apparently occur in utero, adving parturition, adving postpartum breast-feeding. The relative efficiency of perinatal transmission is probably quite high but has not been well established and may vary considerably between women.

### Other Routes of Transmission and Potential for Change

Despite detailed serologic studies of close contacts of infected persons<sup>30-41</sup> and investigations of AIDS cases, <sup>41</sup> no other form of transmission has been documented. A single episode of possible intrahousehold transmission between two brothers has been reported. <sup>41</sup> The few instances of transmission to hospital workers can be attributed to contact with or inoculation of blood. <sup>41</sup> Two out-of-hospital instances of HIV transmission to individuals who performed duties similar to hospital nurses<sup>20-42</sup> are presumably similar to the rare in-hospi-

tal transmission episodes. In total, the relative absence of HIV transmission in hospitals, even to those who have received accidental needle sticks from infected patients, is striking and in direct contrast to the high infection rate seen with hepatitis B virus after such accidents.

Regarding future projections of transmission pattern changes, concern has been raised about the genetic variability of HIV. Could genetic changes of HIV result in increased transmissibility or transmission by other-than-recognized routes? Some have suggested that a dramatic mutation of a preexisting African strain allowed this virus to change its epidemiologic characteristics in Africa and eventually spread throughout the world. But there are no African isolates before 1976 to support or disprove this hypothesis. Moreover, other equally plausible explanations have some support in fact. For example, the apparent increased transmission recently observed in urban Africa is likely due to social rather than viral change. Over the past few decades there have been major population shifts from rural villages to urban centers in many African countries. This urbanization, together with the proliferation of prostitution in cities, and possibly the use of contaminated needles and blood transfusions in hospitals and clinics, could be the root causes of the amplification of transmission in Africa of a virus that may have changed little over the years.

Support for this hypothesis comes from the fact that despite considerable variation of the nucleotide sequences of various HIV isolates, the transmission patterns of the virus have remained remarkably consistent. Indeed, since the arrival of HIV in the United States, the transmission patterns have been marked more by consistency than by change. The proportional distribution of cases among the various risk groups has remained essentially constant despite a marked increase in the number of cases. multiple generations of passage through humans, and wide dispersion through different racial groups.

### **NATURAL HISTORY OF INFECTION**

Infection with HIV carries a poor prognosis. Although follow-up of sero-positive individuals in the United States has been limited by the relatively recent introduction of the virus into this country, already it is clear that the mortality from this virus is high. Between 13% and 34% of antibody-positive homosexual men, intravenous (IV) drug users, and hemophiliacs followed up for up to six years. At have developed AIDS. Such dramatic proportions of severe disease

development among infected individuals are frightening, making HIV among the most dangerous viruses affecting humans (Table 1). Furthermore, when these mortality figures are joined with the high prevalence (25% to 40%) of other AIDS-related conditions, the possibility of eventual encephalopathic conditions." and the realization that the current observation times for infected persons represent only a fraction of the potential time during which diseases may become apparent in the natural history of this virus, concern regarding the severity of HIV grows even greater.

Many have speculated that there may be cofactors for the development of AIDS. Such cofactors could have a major effect at two quite separate timesone early on, affecting the acquisition of infection, and one later, affecting the progression toward disease once infection has occurred. Some have hypothesized that preexisting conditions, such as immunosuppression or antigen exposure, may increase the likelihood of becoming infected after exposure to HIV. This has not been confirmed in laboratory experiments with chimpanzees, where infection has been readily established with IV or intravaginal exposure to HIV in the absence of immunosuppression or stimulation with other antigens.\* Yet outside the laboratory, certain conditions, especially those that facilitate transmitted virus coming in contact with susceptible target cells (macrophages or lymphocytes), may improve the chance of successful transmission. Thus, one could hypothesize that conditions that increase the populations of macrophages or lymphocytes at potential sites of virus exit and entry may well be cofactors for infec-

Few cofactors for disease progression have been found. Some have hypothesized that reexposure to HIV may increase one's chances for disease, yet there are no other models in virology, at least that we are familiar with, that would support this. Furthermore, such a hypothesis is difficult to reconcile with the observation of AIDS following exposure to 1 unit of infected blood." Yet, something must determine why some infected persons progress rapidly to develop AIDS, while others either progress slowly to the irreversible immune state or do not develop AIDS. One major factor is time. Those who have been infected the longest have the highest risk of developing AIDS. Indeed. until cohorts of infected individuals are followed up long enough to observe the entire natural history of this infection and the collected information used to control for the time factor, it is extremely difficult to sort out the importance of other possible cofactors.

Despite these limitations, some other factors (eg, age) appear to be important. Evidence indicates that infants may have extremely high rates of progressive disease (M. Rogers, MD, written communication, Centers for Disease Control, Atlanta, June 1986). At the other extreme of the age spectrum, older homosexual men appear to have higher disease progression rates than younger ones. Since pregnancy may also increase the rates of AIDS in infected women. hormonal levels may also influence outcome. Repeated stimulation with foreign antigens, another possible cofactor, has often been hypothesized as a potential enhancer of viral replication since, in the laboratory, lymphocytes stimulated with mitogens replicate the virus more efficiently than do nonstimulated lymphocytes.5

Other in-combination influences have been studied in regard to Kaposi's sarcoma, since it is so prevalent in homosexual patients with AIDS as compared with others. Amyl and butyl nitrite ("poppers"), stimulants commonly used by some homosexual men, were originally proposed as possible causes of AIDS. They have subsequently been suggested as cofactors in Kaposi's sarcoma, so but this latter issue remains open as other factors (eg, coinfecting viruses) have not been thoroughly investigated.

### THE SIGNIFICANCE OF SEROPOSITIVITY

The serologic tests for detecting HIV antibodies have proved to be extremely sensitive and specific. Individuals whose serum tests strongly reactive by enzyme-linked immunosorbent assay (ELISA) or, if borderline reactive by ELISA, are also positive by appropriately done Western blot or immunofluorescence asssay may be considered to have been infected by the virus. But, in some situations, misinformation can be generated by ELISA testing alone. The ELISA test, when used in groups with a high prevalence of infection. like sexually active homosexual men, has a high positive predictive value. However, when it is used in groups with a low prevalence of infection, most of the "positive" results are low-reactive ones and generally turn out to be false-positive. 32 Also, as with other viral infection models, immediately after infection viral replication can occur in the absence of a detectable serologic response. For HIV this "window phase" appears to be a matter of a few weeks in most individuals." but it has been known to last up to six months."

Table 1.-Mortality From Viral Infections\*

Infection	% Deaths	
Rabies	99	
Ebole/Marburg	25-80	
Smallpox Major	30	
Intermediate	3-11	
Minor	1	
HIV (AIDS)†	25-50	
Hepatitis B (acute and chronic)	5	
Lesea	3-5	
Polio	<0.1	

\*Data from Evens.40 †HIV indicates hus \*Data from Evens.\*\*

†HIV indicates human immunodeficiency virus:

AIDS, acquired immunodeficiency syndrome. A National Academy of Science/Institute of Medicine committee has projected that 25% to 50% of persons will develop AIDS within five to ten years of acquiring an HIV infection. The also stated that an even higher percentage progressing to frank AIDS after ten years cannot be ruled out with the available data.

(J. Groopman, MD, written communication, January 1987). Except during this window phase, current data indicate that a negative ELISA test result means in virtually all instances that the individual has not been infected with HIV.

Since HIV integrates in the host's genes and, thus, can presumably stay latent in an infected host, all antibodypositive persons must be considered potentially infectious. In actuality, only about 65% of antibody-positive persons have had recoverable virus circulating in their blood at any given time, based on one isolation attempt. Whether the antibody-positive but virus-negative persons are truly free of infectious virus or whether they represent only a transient virus-negative state, or whether currently available laboratory techniques are not sensitive enough to detect infectious virus in them, will be clarified only by additional studies.

### PREVENTION OF TRANSMISSION

At the present time, there are no effective vaccines or chemoprophylactic drugs for the prevention of HIV infections. Likewise, no effective treatment exists for HIV infection once established. Since there are no known animal or insect vectors and the virus is not transmitted by the respiratory or fecaloral route, prevention of HIV transmission must be directed at person-to-person spread via sexual, blood-borne, and perinatal routes (Table 2). (J. C. Chermann. MD, in a June 1986 presentation at Colloque des "Cent Gardes." Paris. reported that he detected HIV-related nucleic acid in a variety of insects in Africa, but no evidence of viral infections of insects or transmission by insects exists )

The following approaches for prevention are presented according to the imTo Stop Needle-Borne Transmission: Don't share unsterile needles or syringes To Stop Sexuel Transmission:

If you are going to have sex.† use the following guidelines to decrease your risk of infection.

Absolutely Safe

Mutually monogamous relationship: Extremely Safe

Noninsertive§ sexual relations

Very Safe Insertive sexual relations using a condom( (and nonoxynol 9-containing spermicide)

Anything else
To Stop Perinatel Transmission:

If you could have been exposed to HIV, get tested for antibodies; if you are positive, don't become pregnant

\*AIDS indicates acquired immunodeficiency syndrome; HIV, human immunodeficiency virus. †Vaginal or rectal intercourse. Decreasing one's sexual partners will decrease the chance of being exposed to an

ectious person.

\$Assuming neither partner previously exposed or proven to be noninfected (by antibody test).

\$Excludes veginal or rectal intercourse. Oral-genital risk: see text.

\$Condoms must be properly used at all times with all partners.

portant and documented routes of HIV transmission in the United States. They represent the only available methods of limiting or preventing HIV infections at the present time and in the foreseeable future. These methods should be actively implemented. The exact effectiveness of some of the proposed measures has not been fully documented. Nevertheless, they should be implemented, as soon as possible, together with parallel efficacy evaluation studies.

### Sexual Transmission

Sexual transmission of HIV can be avoided if infected persons do not have vaginal or anal intercourse with susceptible persons or if, during intercourse, effective barrier techniques are used.

There is no risk of sexual transmission of HIV for those who practice sexual abstinence. Furthermore, there is no risk of infection if neither partner is infected. This would be the case for couples who have been mutually monogamous since the introduction of HIV in the United States (presumably in the mid-1970s). It would also be true (to the limits of current laboratory technology) for couples who have been shown to be free of infection by serologic testing (see "Couple Counseling" section).

Outside of these situations, individuals who choose to have sexual relations place themselves and/or their partners at risk of infection. However, the extent of that risk can be decreased by, first, limiting the number of sexual partners. Statistically, the fewer different partners one has, the less likely that one will be exposed. Second, exposure can be further limited by selecting sexual partners at low or no risk of infection, since the prevalence of infection varies greatly by sex, geography, and sex practices (Table 3). Third, the practice of "protective sex" should be able to prevent transmission even if one partner is infected. Epidemiologic studies

indicate that sexually acquired HIV infection is due to vaginal or anal intercourse where semen, vaginal fluid, or blood is shared between partners. Yet such studies are not capable of detecting isolated transmission due to other types of sexual activities. The "protective sex" guidelines given here are based on data available as of early 1987. Unfortunately, true efficacy data evaluating these guidelines are not available. Thus, these guidelines must be understood to be interim ones, requiring periodic revision as evaluation data become available.

Protective Sex.-Protective sex refers to sexual activity where no semen, vaginal fluid, or blood is exchanged between partners. Since the skin and oral mucosa appear to be relatively resistant to virus passage, protective sex can involve practices such as kissing (if no oral lesions are present), hugging and caressing, and genital manipulation (if no skin lesions exist). It also can involve vaginal and rectal intercourse, provided a condom is worn at all times. The recommendation for condom use is made because condoms (of high qualitysi) have been shown to be effective barriers to viruses, including HIV, \*\* and preliminary data suggest that sexual partners of infected people may be protected by the use of condoms.\* However, as with the use of condoms for pregnancy prevention, failures can be expected, especially if the condoms are not used consistently and continuously with all sexual partners. The use of nonoxynol 9-containing jelly (sold as over-the-counter spermicide) may be a useful protective adjunct to condoms since this substance has been shown to inactivate HIV and kill lymphocytes. 42

Specific Issues and Problems.—Homosexual Men.—Transmission of HIV among homosexual men appears to be due almost exclusively to receptive anal intercourse.34 As of 1987, unprotected

receptive anal intercourse with a homosexual or bisexual man carried a considerable risk of infection. The prevalence of infection in this group today is extremely high in most urban areas. Even with profound decreases in the number of sexual partners, the risk of infection in this community remains high because of the present high chance that any single sexual partner is infectious."

Considerable confusion has surrounded the issue of what homosexual sex practices are safe. This confusion has been due to several factors: (1) the difficulty in obtaining and interpreting sex practice-specific risk data, (2) discomfort on the part of the heterosexual majority regarding discussions of homosexual sex, and (3) the political vulnerability of government institutions, including public health agencies, to claims of advocating homosexuality if they promulgate safety guidelines for homosexual sex. The result has been either absent or confusing recommendations from traditional public health authorities. In this vacuum, various local groups have made their own, often conflicting, guidelines.

Controversy has surrounded the issue of homosexual bathhouses. Any setting that encourages unsafe sexual practices between individuals will increase the transmission of HIV. As such, those bathhouses that encourage such practices adversely affect AIDS prevention. Yet those bathhouses that encourage protective sex practices can serve as important contact points for educational material and support for protective sex.

The risk of oral-genital sex is apparently low, but, as semen can harbor virus, this practice may carry some risk of infection.

Heterosexual Men and Women .-The frequency with which a person chooses to practice unprotected sex depends on the risk that he or she is willing to take. The current risk of infection of a given heterosexual contact in the United States is low, but infections and AIDS cases are certainly being acquired by heterosexual contact. Logic would dictate that those outside of mutually monogamous relationships who wish to minimize their risk should limit their total number of partners and practice protective sex all of the time.

The efficiency of heterosexual transmission, especially from women to men, continues to be an issue. At least in Africa and in the limited studies in the United States, such transmission certainly occurs. Although the exact risk for a given sexual encounter remains unknown, one must presume that in the United States HIV is transmitted sexually in both directions. Infection with this virus has potentially dire consequences; therefore, sexual partners should carefully weigh the risks of unprotected sexual encounters outside of mutually monogamous relationships.

Prostitutes are a major source of infection in central Africa24 and probably in some European countries. Some may have moderate to high rates of infection in the United States -- especially those who are users of IV drugs.

As with homosexual men, the risk associated with oral-genital sex is apparently low, but, as semen and vaginal secretions can harbor virus, this practice may carry some risk of infection.

### **Blood and Blood Products**

Infection from donated blood and blood products could be prevented if material from infected donors could be identified and discarded before administration. The Food and Drug Administration has instituted regulations and guidelines to protect blood and blood products from HIV infection. These include (1) self-deferral of donors belonging to high-risk groups (instituted in March 1983); (2) testing of all blood and plasma for HIV antibodies and discarding units that test positive (instituted in April 1985); and (3) heat inactivation of products, like factor VIII, that can tolerate heating (initiated in 1984 for factor VIII). These precautions should virtually eliminate the risk of HIV infection from the use of these products. Products derived from plasma that have steps in their manufacture that physically remove and/or chemically inactivate virus, like immunoglobulin and hepatitis B vaccine, have always been considered safe, " and all of the laboratory and epidemiologic data collected on these products in recent years have confirmed their safety. 67.68

### Needle and Syringe Sharing

Needle- and syringe-associated HIV infection could be avoided if unsterilized injection paraphernalia were not shared among individuals. The message for AIDS prevention is obvious: stop the use of IV drugs, or, at a minimum. eliminate sharing of unsterilized injection paraphernalia. For some addicted IV drug abusers, this is difficult or impossible, and other options, such as disinfection with readily available agents (eg, bleach), should be advocated. Furthermore, addicted persons who desire to enter rehabilitation programs should be encouraged and allowed to do so. Outside the addicted population, there is evidence that substantial numbers of persons experiment with drugs. Educational programs directed toward teenagers, drug-using communities, and staffs of drug clinics need to emphasize the potential dangers of sharing drug paraphernalia.

Specific Issues and Problems.-Intravenous drug users often have little foresighted health interest and, thus, may prove to be the greatest challenge for instilling behavior change.

Intravenous drug use is illegal throughout the United States. However, systems have been designed to deal with addicts in medical facilities without threatened incarceration.

Discussions of drug use and, more specifically, of means by which to render drug use safer have been interpreted by some as an advocation of drug use. As a result, many health educators have avoided the subject.

Intravenous drug abusers often do not engender sympathy from those responsible for providing funding for intervention programs or those responsible for public health.

Slots for drug treatment clinics are often not available, preventing those who want to stop using IV drugs from doing so.

Intravenous drug abusers, if HIV transmission persists, will likely serve as a major entree of the virus into a segment of the heterosexual community, most prominently in the urban poor communities. Indeed, an early, aggressive prevention effort is required to prevent further extension of this virus into social/ethnic minority urban communities.

Provision of sterile needles and svringes to drug users is a controversial. yet possibly effective, control modality that requires further evaluation.

Drug use, in a broad sense, affects other AIDS prevention activities, especially protective sex. The use of drugs in association with sexual practices is prevalent in many communities, including the homosexual male community.

### **Perinatal Transmission**

Mother-to-infant HIV infection could be avoided if infected women would not become pregnant. Because of the potential high risk of infant infection and the preliminary clinical findings that pregnancy itself may accelerate the development of AIDS, it seems reasonable at this time to recommend that infected women postpone pregnancy until more is known about the risks and prevention of perinatal infection. The question is then, how can infected women be identified? With the low infection rates in most female populations of childbearing age, general, routine screening is not warranted at this time. However, there

is general agreement that women who are in high-risk groups (IV drug users, prostitutes, women with multiple sexually transmitted infections, women from HIV endemic areas, or sexual contacts of high-risk-group men) should be screened and counseled.

### THE ROLE OF CONTACT TRACING/NOTIFICATION Purpose of Tracing

The purpose of tracing sexual or needle-sharing contacts of infected people is to trace the chain of transmission to its terminus. At that point there may be an infected person having risk-provoking contact with another susceptible person or persons. With appropriate education and motivation of the infected and susceptible contacts, further transmission can be prevented. The specific guidelines to be given to the interfacing contacts would be the same risk-specific ones presented above (Table 3).

### Specific Issues and Problems

Although contact tracing/notification could be useful for interrupting chains of HIV transmission, the cost of finding, testing, and counseling individual sexual or needle-sharing contacts of infected individuals is considerable. Even under the best of circumstances, the task is expensive, but often with individuals who have the largest numbers of contacts, the identifying information on contacts may be limited, and the task becomes even greater. Thus, for these "fast lane" individuals, the assumption must be made that all within the group should come in for testing and counseling. For persons with fewer contacts (including homosexual men and IV drug users in lower-risk settings and especially women in the childbearing age) whose locating information may be more readily available, more intensive efforts, both by physicians and health departments, is justifiable.

There is concern, especially in the homosexual community, regarding the confidentiality of contact tracing/notification. Few dispute the need or the potential beneficial effect of referring contacts for testing and education. The concern rests with individuals who, being uncomfortable with notifying their own contacts, ask the physician or health department to do the tracing and volunteer the names to these third parties. This is a delicate situation, but one that has been successfully addressed for decades in public health clinics. For those physicians not comfortable or trained in contact tracing, referral to highly experienced health department staff should be available.

Table 3.—Prevalence of HIV Infection (Antibody) in Various US Population Groups (1985-1986)\*

Group	% infected
Homosexual men STD clinic (San Francisco)	72
Rendom (San Francisco)	49
IV drug users New York City	59
San Francisco	9
Hemophiliacs (factor VIII)	74
Female prostitutes Seattle	5
Migmi	40
Haitians New York City	4
Miami	8
Women Blood donors (Atlanta)	0.01
Military applicants	0.06

\*Data from *Morbidity and Mortality Weeldy Re*port.\*\*\* HIV indicates human immunodeficiency virus; STD, sexually transmitted disease; IV, intravenous.

### THE ROLE OF SEROLOGIC TESTING

The serologic test for HIV antibody is potentially an important tool for prevention. There has been considerable misunderstanding and controversy in the past about the value of serologic testing, the accuracy of the test, and the fears of violation of confidentiality.70 However, this controversy appears to be declining as the value and accuracy of the test are documented and as assurances of confidentiality are maintained and strengthened. Indeed, encouragement of serologic testing has been recommended" for several reasons, and they are outlined below according to the target groups involved.

### Infected Persons

If all infected (antibody-positive) individuals could be identified through voluntary and confidential testing programs and if these individuals could be counseled on ways to prevent exposure to others, then a major step toward decreasing AIDS could be achieved. Infected men and women could be advised of their risk to sexual partners or those exposed to their blood. Infected women could be advised to avoid pregnancy. Along with this beneficial preventive effect, serologically identifying infected persons could have significant clinical benefit to individual patients. The knowledge by the patient and physician regarding infection by this virus could lead to earlier recognition and treatment of life-threatening opportunistic infections, especially Pneumocystis carinii pneumonia. Infected patients who are tuberculin test positive could receive early prophylaxis, and parents of infected children could be informed about the relative contraindication of live viral or bacterial vaccines. Furthermore, because (at least in the laboratory) immunologic stimulation of lymphocytes accelerates viral replication, exposure to foreign antigens may accelerate disease progression in humans. Thus, individuals who discover that they have been infected with HIV should be encouraged to decrease their antigen exposure by decreasing their number of sexual and IV drug encounters.

### Susceptible Persons

If uninfected (antibody-negative) individuals at increased risk of infection could be identified and counseled, their risk-taking behavior might decrease substantially. The value of one-on-one counseling centered around knowledge of one's serologic status can enhance the effects of education programs on behavior modification. For example, serologic testing, combined with counseling, can have a profound effect on encouraging low-risk sexual practices among some but not all<sup>23,74</sup> homosexual men.

### Coupie Counseling

The serologic test also has a role for couples of which one partner has been possibly exposed. If individuals desire to have unprotected sex and one or both have been at any risk of infection, it is reasonable to test the at-risk individual for HIV antibodies. If he or she has a negative result and has not been at any continued risk of exposure over the past six months, then one can presume the absence of infection. If a seronegative individual has been possibly exposed in the past six months, then a second test six months after the last possible exposure is required before infection can be confidently ruled out. For greatest safety, protective sex should be practiced during this interim period. A similar approach may be useful for women who may have been exposed to an infected person in the past and now want to become pregnant. Serologic testing with follow-up testing in six months, where indicated, should be helpful in giving advice to such persons.

### **Evaluation**

Serologic testing is also an important tool for evaluating the effect of any prevention program. For individuals, physicians, and public health practitioners, periodic repeated testing of antibody-negative individuals is the only accurate measurement of the success of their prevention efforts. Uninfected persons, especially those with presumed or known continuing exposure, need periodic reassurance that their efforts to remain uninfected have been successful. Moreover, physicians

and public health practitioners providing advice and guidelines to at-risk individuals need assurance that the provided guidelines have been effective.

### **Testing Facilities**

The facilities for free or low-cost and confidential testing, together with riskreduction counseling, have been provided by the national alternate test site program. Testing is also available through many physicians offices. The use of these facilities by at-risk individuals should be encouraged by all. In addition to patient-initiated serologic testing, physicians should encourage at-risk individuals who may benefit from testing to be serologically tested either in their offices or at public facilities. Specific efforts should be directed at the highest-risk groups: homosexual or bisexual men, prostitutes, heterosexual men and women who have multiple sexual partners, patients with sexually transmitted diseases, patients known to use IV drugs, and patients from HIV-endemic areas such as Haiti and central Africa.

In summary, serologic testing allows for knowledgeable clinical and preventive counseling of patients, including medical evaluation and early intervention, personal counseling regarding decreasing transmission, contact tracing/notification, and counseling to prevent perinatal transmission.

### Specific Issues and Problems

For most individuals the process of testing is a stressful one. To maximize the use and benefit of test-linked counseling, the staff of these facilities must be sensitive to the stresses of the individuals and provide counseling and, where appropriate, referral.

### DISEASE AND INFECTION MONITORING (SURVEILLANCE)

Conditions related to HIV are of a wide clinical spectrum, ranging from asymptomatic infections. AIDS-related conditions, frank AIDS, and primary peripheral and central neurologic conditions. Surveillance (the collection, analysis, and dissemination of data relevant for prevention or control) for clinical AIDS has formed the foundation for our current understanding of this newly imported disease, and physicians should always report cases according to local requirements. But with the long incubation period after infection before AIDS develops, surveillance for clinical AIDS is a rather insensitive and delayed indicator of HIV infections. Thus, the future of public health surveillance will have to rely more heavily on serologic surveillance. Ideally, the serologic status of members of all of the major risk groups would be known. along with the annual seroconversion rates and reasons for seroconversion. Unfortunately, because of the expense of collecting such information and because of fears of confidentiality breaches, such data exist for only limited populations studied in research settings. At a minimum, systems should be devised to monitor the rates of infection in selected groups ranging from lowrisk individuals (eg, blood donors) to high-risk individuals (eg, homosexual men, patients at methadone clinics, sexually transmitted disease clinic patients, etc). If the ideal situation of absolute confidentiality cannot be assured, periodic testing of serum unlinked to personal identifiers is an alternative. Additional useful data are potentially available from the military's nationwide recruit testing program and the proposed sentinel hospitalized-patient (without personal identifiers) testing program of the Centers for Disease Control. Atlanta.

### Specific Issues and Problems

Some physicians, to protect the confidentiality of patients and families, resist reporting cases or including AIDS on death certificates. The resulting reporting errors could markedly affect future surveillance, especially in regard to the occurrence in suburban and rural areas. Sensitive situations can generally be worked out with local health departments on an individual basis.

### PHYSICIAN, PUBLIC HEALTH, BUSINESS, AND COMMUNITY ROLES IN AIDS PREVENTION Physician

The physician's role in AIDS prevention is critical. At a minimum, the physician must understand the myriad symptoms of HIV-related diseases and provide effective medical treatment and support for the individual and the family. În addition, the physician must take a major lead position regarding prevention. Specifically, nonjudgmental discussions of sexual orientation, sexual activities, IV drug use, and ways to prevent AIDS should become standard parts of medical care. These should include (where appropriate) recommendations for serologic testing, protective sex guidelines, and contact tracing/notification of sexual and IV drug-sharing contacts. As part of this process, physicians should become well versed in HIV transmission so that individual and community questions regarding appropriate preventive practices can be knowledgeably answered to maximize preventive intervention and minimize ill-based and extremist overreaction.

### **Public Health**

The central role that federal, state, and city/county health departments and laboratories traditionally have held in communicable disease control will have to continue for AIDS. The necessities of infection and disease monitoring, educating physicians and the public about AIDS, establishing appropriate guidelines for prevention, and providing the needed personnel and resources for education, counseling, testing, and contact tracing/notification will be large tasks for public health agencies, especially in these times of constrained funding.

#### Business

The impact of AIDS on the private sector is large and growing. The direct medical costs, the benefit support costs, and the general social upheaval (due primarily to unfounded concerns about the possibility of casual-contact transmission) will continue to take a major toll within the business community. Much of this toll is preventable, including that related to unfounded fears of infection. Indeed, the workplace could serve as an important access point to convey the essentials of AIDS prevention. After all, working adults have been the major target of this virus. Education programs sponsored by businesses directed toward all sexually active employees, regardless of sexual preference, together with information on the risks of needle sharing, could have a major impact on HIV transmission. Furthermore, support by the business community for funding of public AIDS prevention programs could prove invaluable in stimulating the traditionally slow government funding process so that more extensive AIDS prevention programs could be started without undue delay.

### Community

The need for rational community programs for AIDS prevention based on facts rather than fears is urgent. Too often schools, religious organizations, and other community groups have been reticent to discuss, or even obstructed from discussing, ways to prevent the sexual or needle-borne transmission of HIV for fear of seeming to support sex and drug use. Such issues are difficult, but denial of real-life practices can serve only to extend further this already deadly epidemic. Community groups and public media are essential for spreading the rather simple words of AIDS prevention. In addition, together

with business, their support of health department efforts, their aid in the defense against extremist measures, and their support for additional resource allocations for AIDS prevention are essential.

In summary, the concerted efforts of physicians, businesses, and community groups and public media, together with provision of up-to-date educational materials and consistent prevention messages issued by health departments, are essential to interrupt transmission of this extremely severe virus infection effectively.

# SOCIAL ISSUES AND CONFIDENTIALITY Quarantine/Isolation

The purpose of AIDS prevention programs is to interrupt the transmission of HIV in a manner that will minimize social disruption and maximize individual freedom. The issue of quarantine (this term will be used interchangeably with isolation or enforced isolation) needs to be discussed openly because of the concerns expressed by at-risk groups, especially the homosexual and hemophiliac communities, and because some ill-informed political groups have called for extreme measures (eg, quarantine) to control AIDS. Many of these overreactive proposals have been due to unbalanced information that, although appropriately stressing the dangers of HIV infection, has inappropriately stressed the ease of acquisition. In the hospital setting, recommendations are that blood and secretion precautions (a form of medical isolation) be taken for persons known or suspected to be infected with blood-borne agents such as hepatitis B virus or HIV. But within the general community, there has never been any official public health recommendation or movement toward the isolation or quarantine of carriers of these difficult-to-transmit agents. Quarantine has a limited role in the control of some communicable diseases, but there is little or no role for it in the prevention of AIDS. As mentioned above, except for perinatal infection and (in the past) blood product-associated infection, HIV is transmitted almost exclusively between consenting adults, both of whom have some choice regarding the AIDS risks they are willing to take. Thus, transmission of this virus in our society is preventable by individual action, not government-imposed isolation. The threat of quarantine hinders AIDS prevention. It turns a nonissue into a wedge between advocates of prevention and the groups at risk for AIDS.

The issue of mass quarantine aside, what should be done with the uncooper-

ative infected person who continues to expose individuals through sexual intercourse or needle sharing? For example, what about the infected female or male prostitute who continues to ply the streets for business? These are difficult issues. State laws generally forbid one from knowingly exposing others to infectious diseases, and local or state health officers generally have authority (following observance of due process) to incarcerate noncompliant individuals. In some situations, incarceration may be necessary, but in most situations there are two persons involved in the transmission of HIV. Thus, it could be said for the example given above that the client of the prostitute is "volunteering" for infection. The major task ahead is to get accurate information out to the public so that they can make informed choices. Considering the danger of this virus, most persons will presumably take the personal steps necessary to avoid infection.

### Patient-Physician-Public Health-Community Relations

For physicians and public health workers to effect risk-reducing behavior changes in individuals, considerable patient trust is necessary, both to initiate contact and to seek advice and follow guidance. After all, the behavior changes sought to decrease AIDS risk involve the most personal of behaviors. To stimulate individuals to take responsibility for themselves and make the necessary risk-reducing changes is often difficult and requires a good deal of trust and understanding from both the patient and the health worker. This relationship can be seriously jeopardized if the individual in need of guidance is frightened away from professional services by hostile threats of reprisals (eg, quarantine).

### Confidentiality

Maintenance of confidentiality is central to and of paramount importance for the control of AIDS. Information regarding infection with a deadly virus, sexual activity, sexual contacts (both within and without primary relationships), and the illegal use of IV drugs and diagnostic information regarding AIDS-related diseases are sensitive issues that, if released by the patient or by someone involved in health care, could adversely affect a patient's personal and professional life.

Confidentiality has always been a strictly observed principle in medicine and public health. Sensitive topics have always by necessity been a routine part of interviews and records in these fields. However, for AIDS, because of the so-

cial disdain toward the two highest-risk groups, and the illegal status of IV drug use, and the numerous antisodomy laws, even stricter assurances are required. In some states, like California, legislation has been passed to strengthen these confidentiality assurances. In some situations such laws have caused problems and have prevented essential communications between physicians and practitioners of public health. But this is an evolving field and, as such, there is constant change and adjustment. The public's confidence in the public and private sectors' protection of their privacy depends on repeated examples and public stands taken by all involved in AIDS treatment and prevention. With positive examples many of the difficulties centered around serologic testing and contact tracing/ notification will abate.

### Insurance

Insurance companies are considering requiring serologic testing for selected applicants for life and individual health policies. In areas where the use of HIV testing for this purpose is not allowed, surrogate tests such as lymphocyte subsets are being considered. This is a sensitive issue in that identification of infection can be used to infer life-styles unpopular with some employers and coworkers. Possible solutions, including insurance pools that cover costs of HIV-related conditions, need to be considered nationally or regionally.

### INSTITUTIONAL ISSUES

As repeatedly stressed in this review. HIV transmission has essentially occurred only through sexual encounters. blood/needle sharing, or from mothers to their infected infants at or near birth. Despite these observations, there has been much concern regarding "casual" transmission in public places such as offices, public buildings, and schools. In some situations, a combination of misinformation and a desire to structure "norisk" settings has resulted in considerable social disruption, such as exclusion of children with AIDS from school. Future approaches will have to take into account existing information and move away from these extreme views. These major issues will be addressed by institutional category.

### Public Buildings, Offices, Schools, and Mental institutions

No risk of transmission has been documented (either by serologic studies or investigation of AIDS cases) outside of established modes. Indeed, aside from the possible spread from brother to brother. In o transmission has occurred

(outside of sexual contact) in households having infected individuals38-41 and no transmission has occurred from patients to their nurses (except by needle or open wound exposure) in hospitals. If no transmission has occurred in these settings, which have traditionally been at-risk settings for similarly transmitted agents like hepatitis B virus," then one can be confident that no HIV transmission occurs in any more casual settings like offices and public facilities. The purveyors of health information need to maintain a high level of public knowledge regarding the latest findings of HIV transmission so that unfounded anxieties can be allayed and appropriate actions can be taken.

Schools are of special note because, in the past, they have served as a battleground over the issue of excluding pediatric patients with AIDS. More information is now available, specifically regarding the lack of transmission from children to their household contacts, including those with whom they have shared toothbrushes, towels, etc29; thus, schools, having far less intimate contact than households, become even more remote prospects for transmission. With these data, the Centers for Disease Control have promulgated guidelines for the handling of infected children in schools.™

The only remaining area of concern is children who, because of age or mental incompetence, do not have control of their bodily functions. Although these children are very unlikely to be at risk of HIV transmission, previous experience with a variety of infectious diseases in facilities for the mentally retarded and day care centers requires some concern for these areas. Before firm recommendations can be made for these latter facilities, further study is required.

### Prisons

Especially on the east coast of the United States," prisons have had a considerable number of AIDS cases. The acquisition of infection for these cases has, by history, been due to high-risk activity (primarily IV drug use) before entering prison. Yet, risk-provoking exposures such as percutaneous injections and homosexual sex do take place in prisons, and, in some instances, these exposures occur in involuntary settings. The provision of AIDS prevention information and the motivation of all prisoners to avoid infection are essential. The question is, can education alone prevent high-risk exposures, or will screening of prisoners and the provision of separate housing facilities for persons with positive and negative HIV antibody findings have to be considered? Because of the potential expense and the difficulty in implementing the latter option, and the lack of data to suggest a high risk of HIV transmission in prisons, further study of this situation is clearly justified before objective decisions can be made.

#### **Bathhouses**

Business establishments such as bathhouses, bars, and adult book stores, where multiple, usually anonymous sexual encounters take place among a male homosexual clientele, have facilitated the spread of HIV infections. Public health agencies in some areas, such as San Francisco and New York, have attempted to close these establishments. Only a few such closings have taken place, and they have, to a great extent, been largely symbolic to discourage the use of such facilities for unsafe sexual activities. The closing of such establishments should be required if unsafe sexual activities cannot be eliminated. However, prior to compulsory closing, some type of regulatory inspection of these establishments should be carried out to maintain environmental and sanitation standards (such as improved lighting and removal of doors to private rooms) to discourage unsafe sexual contacts.

### CONCLUSION

Human immunodeficiency virus is a dangerous infectious agent that spreads effectively only through the sharing of blood, through sexual intercourse, and from infected mothers to their infants. The combined use of education/motivation/skill building, serologic screening, and contact tracing/notification could eliminate or substantially reduce at-risk behaviors and infection. The accomplishment of this reduction requires a considerable effort by physicians, public health practitioners, business, and community organizations to get across the relatively simple AIDS prevention messages. Only through a concerted effort by all of these groups will the reluctance of individuals and society to deal with the difficult issues inherent in AIDS prevention and control be overcome. The eventual extent of HIV transmission and the resulting morbidity and mortality will be determined by how well we as a society can design and implement a concerted AIDS prevention effort and how we as individuals heed the messages of that prevention effort and take personal responsibility to protect ourselves. It is clear that if a total effort is not developed and sustained, the impact on present-day America will be protean, and subsequent generations of Americans will inherit an expanding rather than a confined infectious disease problem.

Since the preparation of this article, two relevant documents have been released: the Surgeon General's report on AIDS<sup>70</sup> and the Institute of Medicine/National Academy of Sciences report entitled Confronting AIDS: Directions for Public Health, Health Care and Research."

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### 2. AIDS IN THE 1990s: A STUDY PROPOSAL

While the previous article lays out an AIDS prevention strategy from the point of view of public health professionals, there is an increasing awareness in the United States that AIDS is much more than a medical problem. In fact, it is becoming more and more obvious that the social, legal, economic and political implications of the epidemic are enormous and need immediate, thorough study.

Unfortunately, most American universities, Institutes for Advanced Studies and the like, have not yet shown a sufficient interest in these problems. Thus, it has mostly been left to private "think tanks" to anticipate future developments. The well-known Hudson Institute, for example, has recently developed a study proposal devoted to "AIDS futurology." Extensive excerpts from this proposal are given on the following pages. The author hopes that they will prompt the German and other European academic establishments to get involved in the investigation of possible socio-political scenarios related to the growing AIDS epidemic.

If, however, the necessary interest should not become manifest fairly soon, the author recommends that the German and other European national governments create interconnected "AIDS think tanks" on their own and support them generously with the necessary funding. He is convinced that, in the interest of controlling AIDS in the future, it is essential to begin "thinking the unthinkable" now.

# A Proposal for a Study on

# AIDS IN THE 1990s: SCENARIOS AND POLICY CHOICES

July 6, 1987

Hudson Institute Proposal No. 1367



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Hudson Institute Proposal No. 1367

### AIDS IN THE 1990s: Scenarios and Policy Choices

### INTRODUCTION

It is increasingly likely AIDS will have huge social, political, and economic implications for American society during the 1990s. There is accumulating evidence that the virus is becoming more broadly dispersed in the sexually active population, both homosexual and heterosexual, and that infection will lead to disease and death in at least a majority of those infected. The difficulties of developing and testing an effective vaccine, coupled with the apparent limits to date on the effectiveness of therapeutic drugs, make the threat to society appear increasingly grave. With estimates of the currently infected domestic population ranging between one and two million persons, it seems likely that AIDS could be killing several hundred thousand Americans annually by the early 1990s, and many more as the decade progresses.

The U.S. insurance industry will be among the first to struggle with the potentially catastrophic implications of the epidemic. Long before society at large or the federal government in particular is forced to begin dealing forthrightly with the enormous social and financial costs of the disease, the insurance industry will be faced with important policy questions regarding possible cost increases, reduced earnings or losses, difficult coverage and eligibility questions, and potentially contentious legislation.

These problems will be compounded by the social context in which the epidemic has arisen. Because the disease is largely sexually transmitted and originally emerged among homosexuals and drug users, the social stigma

attached to it is immense. Although by the 1990s AIDS likely will be widely spread among all segments of society, this history will color political and social attitudes throughout the rest of the century. Such an environment' will further complicate the task of developing realistic strategies for the policy community. Therefore it is critically important the private sector immediately begin to provide the leadership necessary to initiate a comprehensive study of the social, political, and economic consequences of AIDS.

There is almost no doubt that the huge costs associated with treating and caring for AIDS victims will have to be broadly shared by society, either through government programs, general increases in health and life insurance premiums, or reductions in corporate income. The aversion most members of society feel toward the perceived lifestyles of the earliest groups of AIDS victims promises to delay any conscious collective decision to undertake equitable cost sharing. Attempts by some to paint the AIDS problem as purely a moral question or as an affliction of a small segment of the population will retard such action even further.

Formulation of effective private and public strategies in the face of these likely conditions will be an enormously complex and difficult task. It is therefore essential that the private sector, begin to help others understand the nature of the AIDS especially those industries most immediately affected by the spread of the disease, epidemic and how it is likely to develop, not only in medical terms, but in social, political, and commercial terms as well. How, for example, does the coming epidemic compare with the plagues of earlier centuries? Are there instructive parallels in

the way societies reacted then and what may happen in the future? If "unthinkable" steps such as universal mandatory testing, quarantines, or other measures are eventually needed to control the spread of the disease, how can society's consciousness concerning these issues be raised without triggering a backlash? Can or should the private sector attempt to develop and recommend a collective government and industry policy for dealing with increased costs, rather than simply engaging in a musical chairs game of cost-shifting and risk selection?

These and other issues will form the core of Hudson Institute's proposed study on <u>AIDS in the 1990s: Scenarios and Policy Choices</u> -- a study aimed not only at synthesizing what is known and not known about AIDS, but at detailing the little-considered but potentially catastrophic implications of the continuing spread of the disease.

### STATEMENT OF THE PROBLEM

Acquired immunodeficiency syndrome (AIDS) is a deadly and, to date, incurable disease whose unchecked spread threatens to produce huge and potentially cataclysmic human and economic costs for the United States, and much of the rest of the world, before the close of the century.

Since AIDS was first identified in the United States in 1981, science has learned much about the disease but remains far from a full understanding of its causes or mechanisms, and even further from an effective palliative or a cure. What is known is that the AIDS infection is viral in nature, and is transmitted by sexual contact, through blood or blood products, and by an infected mother to her fetus or newborn child. The disease does not appear to be spread by non-sexual contact with an infected person or by insects.

The AIDS disease results from the destruction of white blood cells, called T-lymphocytes, by the human immunodeficiency virus (HIV). The immune system thus weakened, an AIDS patient becomes susceptible to other infections and unusual forms of cancer. For instance, more than half of the AIDS cases in the United States are diagnosed with Pneumocystis carinii pneumonia, and a substantial number of AIDS patients suffer from Kaposi's sarcoma, a previously rare type of skin cancer. In addition, HIV can infect and damage the central nervous system, resulting in dementia or severe early senility.

### AIDS IN THE UNITED STATES

The AIDS virus in the United States initially was concentrated among homosexuals and intravenous drug users. However, because HIV infection can spread from men to women or vice versa during sexual intercourse, AIDS poses a growing threat to the non-drug using heterosexual population as well. Indeed, of the some 34,000 confirmed cases of AIDS, more than 19,600 of whom have died, at least 2,300 cases have occurred among women and heterosexual men. The Centers for Disease Control (CDC) estimate that in states with the highest AIDS rates, roughly one of every 30 men and one of every 260 women is infected with the virus, compared to states with the lowest rates, where one of every 1,430 men and one of every 25,000 women is infected.

At present, a total of between one and two million persons (some experts believe as many as four million persons) are thought to harbor the HIV virus. Of these, in addition to the 34,000 confirmed victims mentioned above, an estimated 100,000 Americans suffer from a lesser manifestation of the HIV infection known as AIDS-related complex (ARC), characterized by immunodeficiency and symptoms such as swollen glands, fever and weight loss; most experts believe such ARC patients will eventually develop AIDS. A

further, and growing, AIDS problem involves infants and children. Pediatric AIDS was first recognized in 1981 and, as of April, 1987, 479 cases had been reported, with half of the children infected under the age of one. Already, in some hospitals in New York City and Newark, New Jersey, 15 percent of the pediatric beds are occupied by AIDS patients.

By 1991, according to U.S. Surgeon General C. Everett Koop, the number of AIDS cases is expected to reach 270,000, including 3,000 cases of pediatric AIDS, although Koop has recently suggested the figure could go much higher. Between ten and 30 percent of the million or more Americans currently infected with HIV are expected to develop a full-blown AIDS within the next five years, with the rate growing at about five percent per year thereafter. Most infected persons -- more than 90 percent -- do not realize they carry the AIDS virus, and can unknowingly transmit the disease to others. It is difficult, however, to predict how rapidly the disease may spread, particularly among the heterosexual population, in part, as Drs. Ann Hardy and Mary E. Guinan note in a recent study, because there is no reliable information about sexual behavior patterns. Also complicating the situation is the long period between infection and the onset of the disease -- from five to ten years, and perhaps as much as 20 years. Moreover, once infection occurs, it lasts for the lifetime of the individual.

### AIDS WORLDWIDE

Globally, the problem of AIDS is of even more immediate concern. The World Health Organization (WHO) has reported AIDS cases in 91 countries. Conservatively, the organization estimates a total of 100,000 full-blown AIDS cases worldwide, including the more than 30,000 in the United States and 50,000 in Africa. However, they believe that some five to ten million people

may be infected with HIV, and that as many as 100 million may become infected in the next five years if current rates of infection continue. If so, the results will be catastrophic.

In Western Europe, the incidence of AIDS probably parallels that in the United States. In Asia and the Near East, AIDS and HIV infection are still rare, but both the virus and the disease have been identified, indicating that AIDS may become epidemic in these areas as well. The situation is most critical in Africa, however, where the disease is found predominantly among heterosexuals and where, according to Dr. Myron Essex of the Harvard School of Public Health, as many as 25 to 30 percent of young adults may be infected. In some African cities, ten percent of the pregnant women and five percent of newborns are infected. Moreover, because AIDS may be so easily masked by other common African diseases, such as tuberculosis and malaria, the actual incidence of the disease, the WHO projects, may be understated by as much as 500 to 1,000 percent.

### SOCIAL AND ECONOMIC IMPLICATIONS OF AIDS

Analysts are only now beginning to gauge the frightening social and economic implications of AIDS. In the United States alone, just the cost of caring for AIDS patients could impose an enormous burden on the economy as a whole, and on the insurance industry and federal health programs in particular. For instance, Anne Scitovsky of the Palo Alto Medical Research Foundation has estimated that, by 1991, AIDS medical bills could total as much as \$14 billion annually. Such figures, of course, do not include the costs of lost productivity occasioned by the incapacitation or death of prime-aged workers, of compensating or protective measures, or of fear-occasioned changes in social and commercial practices.

The U.S. health care and insurance systems will be among the first to suffer the economic effects of the continuing spread of AIDS. The average health care costs for an individual AIDS patient range from \$50,000 to \$150,000 from diagnosis to death, and the current concentration of AIDS in urban areas is already straining some major metropolitan health care facilities. These two factors will work to drive up health care expenses overall to the point where huge investments of federal funds, sharply higher private health insurance rates, or both, will be required to defray these added costs. Such potentially huge costs may threaten the solvency of federal programs, employer-provided health plans or individual insurance firms or, on the contrary, may compel dramatic reductions in the extent of or eligibility for insurance coverage, lowering U.S. health care standards and increasing political pressures on the health care and insurance industries.

Over the longer term, the spread of AIDS could lead to far-reaching changes in commercial, social and political behavior. Individual and corporate rights will increasingly compete with public health concerns in the legal and political marketplace, with the result that currently abhorrent social practices, such as discrimination and restrictions on freedom of association, could become conceivable public or private policy options. Political leaders likely will attempt to avoid resorting to these extreme practices by transferring to the business sector much of the costs of preventing and indemnifying against AIDS, as well as of caring for those already suffering from AIDS through tighter regulation of employers and service providers and such devices as mandatory risk pooling.

The United States could also be severely affected by AIDS epidemics overseas. The collective effects of greatly increased domestic and inter-

national demands on U.S. financial resources, altered U.S. budget priorities, and changing international relationships caused by severe AIDS epidemics in already poor Third World countries could significantly affect the U.S. government's ability to implement an effective foreign and national security policy.

### PROSPECTS FOR HALTING THE SPREAD OF AIDS

The most immediate hope for halting the spread of AIDS -- a disease already likened by some public health officials to other major killer epidemics such as the bubonic plague and small pox -- lies in the development of an anti-AIDS vaccine and education of the public to change sexual behavior and reduce drug use.

The United States currently is spending more than \$400 million annually in AIDS-related research and education. Such research already has helped isolate the HIV virus. And, in 1985, scientists developed and won approval of a simple blood test for AIDS, called the ELISA (enzyme linked immunosorbent assay), that detects antibodies created by white blood cells in response to the AIDS virus. In addition, U.S. scientists last year developed a palliative treatment, azidothymidine (AZT), for AIDS victims. The drug, given to more than 3,000 patients so far, not only prolongs life but produces clinical improvements such as weight gain, increased energy, and improved neurological functioning.

AZT is not a cure, however, and has serious drawbacks. It must be taken every four hours to be effective, and can cause severe bone marrow damage and anemia in some patients. It is also expensive, with a year's supply now costing as much as \$8,000. Moreover, a vaccine against AIDS is not expected to be developed for at least five years or more. The creation of such a

vaccine is hampered not only by a lack of basic scientific knowledge, but by the fact that the AIDS virus multiplies and changes its outer coat so rapidly that a single vaccine may not be effective against all strains. Nor can even highly sophisticated public education campaigns be expected to appreciably diminish the rate of spread of AIDS, at least in the short term. The fact that so many carriers do not know they have AIDS, combined with the unlikelihood of any dramatic immediate reduction in unmarried sex, make it probable that the disease will continue to proliferate for some time.

Together, these factors suggest that the potential social and economic implications of AIDS throughout the 1990s and beyond deserve serious analysis, and that those institutions and industries most likely to be hardest hit would profit by the early development of public and private strategies to address and combat the potential social, political, and economic effects.

### RESEARCH APPROACH

Predicting the future course of any major policy problem is a chancy enterprise under the best of circumstances. In the case of AIDS it is especially risky, because so little is known about the disease itself, its incidence, and potential cures. Hudson Institute does not believe such uncertainties make informed projections of AIDS trends and related events impractical. But we believe that in order to be useful, such pictures of the future must be more than mere mechanical forecasts. Instead, useful projections need to carefully assess the entire collection of factors that may play an important role in the evolution of a given problem.

To begin this assessment, Hudson Institute, in consultation with a variety of outside experts, will define the key issues that need to be investigated. We will then undertake a comprehensive survey of existing

published and unpublished literature and consult with authorities in the relevant fields of study, allowing us to rigorously review and analyze three bodies of information: (1) knowledge, to the greatest extent possible, of the current state of the problem; (2) knowledge of the course of previous, similar problems; and (3) realistic models of the environment in which the development of the problem and its manifestations will play themselves out.

Drawing from this base of information, Hudson will craft a set of alternative scenarios for the course of the problem under consideration. Scenarios are a methodological tool designed to focus attention on the processes and decision-points that can determine the course of future events. Scenarios describe a sequence of future events and are used to both suggest the possible evolution of various trends and indicate key points at which such developments might be prevented or facilitated. These scenarios will be more than simply mathematical extrapolations of current trends using different rates of growth. Instead they will be "big picture" models of U.S. society that depict the potential, complex interactions of social, economic and cultural forces whose combination can lead to widely different outcomes. Such scenarios thus will hopefully allow policymakers to prepare future courses of action with a much-improved understanding of the possible environment in which they may be forced to act.

For instance, in the case of the proposed AIDS study, Hudson would match the potential AIDS trends against projected evolution of other economic, social and political conditions. This research then would serve to support the creation of three alternative scenarios:

Scenario 1 -- This scenario would assume that the trend lines for the spread of AIDS begin within a short time to flatten out, perhaps because the virus does not spread widely through the heterosexual population, or perhaps as a result of education campaigns, public anxiety and lifestyle changes. Under this scenario, concern about AIDS never reaches a crisis level in society, and no radical steps are taken to deal with the disease. Society proceeds as if little had happened, and the insurance industry shoulders most of the cost burden of current and future AIDS victims.

- Scenario 2 -- This scenario would assume a steady rise in the incidence of AIDS over the next decade or so. Under this scenario, a growing level of alarm is followed by a series of local, state, and federal government and private actions that begin to change the structure of society and industry, at least at the margins. AIDS-free communities arise, an AIDS risk pool is created with government assistance, and employers and others begin covertly and overtly discriminating against AIDS-infected people. Economic growth is constrained as society transfers substantial new resources into health care.
- Scenario 3 -- This scenario would assume a rapid rise in AIDS incidence over some finite period, with the total number of AIDS cases rising very rapidly. Under this scenario, society begins to exhibit panic reactions, AIDS-infected cities begin depopulating, AIDS sufferers become the victims of government-sanctioned restrictions, and international trade and economic activity decline precipitously.

Scenarios such as these then would form the basis for our projections of the potential effects of the AIDS epidemic on specific sectors of society, such as social institutions, the health care system or the insurance industry, and the development of policy recommendations -- both for government and private industry -- to cope with the effects of the epidemic.

In order to ensure that the sponsor has the benefit of the best advice and judgment on the study issues, and to begin to develop the widest range of interest and support for changes that may be needed, Hudson will create an Advisory Committee for the project made up of a small group of nationally recognized individuals from medicine, academia, business and government. This group will meet to help organize the research effort, and again to review and discuss the work of the research team. The group will be chosen by Hudson Institute in consultation with the studies' sponsors. Hudson has found these groups to be extremely effective in focusing and guiding a research effort.

### SCOPE OF WORK

Hudson Institute proposes to carry out its proposed approach to this research project through the completion of five principal tasks:

### Task One

Research Inventory. Hudson will collect and synthesize existing information on the nature and extent of the AIDS problem through a survey of the most recent published and unpublished research on the subject. The objective of this task will not be to survey exhaustively the medical literature about AIDS, but rather to gather enough information about the disease and its pathology so as to make realistic assumptions about its nature and consequences.

<u>Subtask A. Nature of the disease</u>, including a description of what is known about the AIDS-related viruses, the clinical manifestations of the disease, the pathogenesis of the disease, means of its transmission, and the disease's historical development.

<u>Subtask B. Definition of groups at risk</u>, including specifications according to demographic profiles, residence, sexual and drug habits, and other variables.

<u>Subtask C</u>. <u>Extent of the disease: U.S.</u>, including best current estimates of infection, transmission, illness and death rates, broken down by geographical regions.

<u>Subtask D. Extent of the disease: world, including best current estimates of infection, transmission, illness and death rates, broken down by regions of the world and, where possible, by country.</u>

<u>Subtask E. Knowledge limitations</u>, including an analysis of factors that impair our ability to understand the disease and to estimate its impact and spread, and of how this imprecision might affect the current best estimates of the extent of the disease.

### Task Two

<u>Future Course of the Disease</u>. Hudson will use the information developed in Task One to estimate the potential course of AIDS over the time period 1988-2010. In order to frame realistic estimates, we will carry out the following subtasks:

<u>Subtask A.</u> <u>Specification of scenarios</u>, including a priori definition of low, mid-range and high infection and transmission rate scenarios, both domestically and throughout the world, along with the identification of the underlying scientific developments and changes in social behavior that would be implied by each.

Subtask B. Quantification of scenarios, including attempts to realistically predict the incidence of the disease over time under each of the three scenarios, based on a careful analysis of current government and private sector forecasts, both domestically and throughout the world, with allowance made for the presently severe knowledge limitations.

### Task Three

General Effects of the Disease. This task will describe the potential general effects of the continuing spread of AIDS under each of the three alternative scenarios. In order to realistically specify these potential effects, we will carry out the following subtasks:

<u>Subtask A. Historical analysis</u>, including a brief description of the principal effects of plagues and other pandemic diseases during the last several centuries, and a determination of the extent to which these effects might parallel those that could arise from the continuing spread of AIDS.

<u>Subtask B.</u> <u>Domestic U.S. effects</u>, including general effects on population size and demographics, the macroeconomy, and the structure of society, as well as estimated costs of AIDS treatment.

<u>Subtask C. International effects</u>, including general effects on population size and demographics, local and regional macroeconomies, and the structure of societies, as well as estimated costs of AIDS treatment, broken down, where possible, by region or country.

### Task Four

<u>Specific Effects of the Disease</u>. Task Four will describe the specific effects of the continuing spread of AIDS under each of the three scenarios. We will analyze each specific effect in the context of a separate subtask, as follows:

<u>Subtask A.</u> <u>Social and family relationships</u>, including effects on social and sexual practices, public morality and social mores, communities and community institutions, education, social ostracism, and employment and other discrimination.

<u>Subtask B. Legal issues</u>, including protection of individual rights, discrimination law, liability law, insurance coverage and requirements, and administrative law.

<u>Subtask C. U.S. labor markets and production</u>, including general and specific sectoral effects, particularly as related to the potential diminution of the aged 20-40 work force.

<u>Subtask D. U.S. health care system</u>, including effects on facilities, quality of care, costs of care, means of service delivery, medical practices, and denial of services. The implication of the disease for the pharmaceutical industry would also be examined in this task.

<u>Subtask E. U.S. private insurance system</u>, including effects on costs, coverage requirements, premium formulation, employer-provided plans, operating environments, and short- and long-term industry viability, and differential effects on health, life, and disability and group and individual coverage.

<u>Subtask F. U.S. social insurance system</u>, including effects on Medicare, Medicaid, and Social Security.

<u>Subtask G. U.S. political system</u>, including effects on interest group politics, national versus state/local responsibility, government institutions, and the philosophy of democratic government.

<u>Subtask H. U.S. government budget-making</u>, including demands on resources, availability of resources, and shifts in priorities.

<u>Subtask I. International relationships</u>, including travel, tourism, immigration, and social, cultural, economic, and political relationships.

### Task Five

<u>Policies for Coping with the AIDS Epidemic</u>. Building on the information and analysis developed in the earlier tasks, Hudson will consider private and public policy options for dealing with the spread of AIDS under the three scenarios. Hudson will carry out this work in two separate subtasks:

<u>Subtask A. Private policies</u>, including voluntary steps insurance companies, employers, and other heavily affected organizations and institutions might undertake to minimize the cost of, and adverse public reaction to, the AIDS problem, and to reduce the spread of AIDS.

<u>Subtask B. Public policies</u>, including steps the federal and state and local governments might undertake to minimize the costs of AIDS; promote equitable sharing of the costs of caring for AIDS victims, of insuring high-risk populations, and of controlling the spread of AIDS; and reduce the transmission of the disease. Both moderate and radical steps will be considered in the context of the three scenarios of AIDS incidence rates.

### PRODUCTS AND SCHEDULE

### Products

Hudson Institute will produce a set of four products under this project:

1. Research Essays. Hudson will produce a series of research essays, organized around the five research tasks, that will serve as the information base for the remainder of the project. (A draft list of essays is presented in Appendix A.)

- 2. <u>Briefings</u>. As the study proceeds, Hudson will present briefings on its findings for top corporate officials and other invited parties.
- 3. <u>Final Report</u>. At the conclusion of the study, Hudson will compile the results of its research into a comprehensive final report. (A draft outline for this report is presented in Appendix B.)
- 4. <u>Conference</u>. Following completion of the study, Hudson will host a major conference to discuss the results of its research, with a special session to focus on the effect of AIDS on the insurance industry.

### <u>Timetable</u>

Hudson will complete its research tasks and project products according to the following schedule:

July 1	Illustrative project start date
August 1	Completion of Task One
September15	Completion of Task Two
October31	Completion of Task Three; first briefing
December31	Completion of Task Four
February15	Completion of Task Five; second briefing
April 1	Completion of draft final report
May 1	Completion of final report
May30	Conference

### Appendix A

### An Illustrative List of Research Essays

- 1. The nature, manifestations, and transmission of AIDS
- 2. The incidence of AIDS in the United States
- 3. The worldwide incidence of AIDS
- 4. The relevance of historical plagues to the AIDS epidemic
- 5. Scenarios for the spread of AIDS, 1988-2000
- 6. The effect of AIDS on U.S. social relations
- 7. Legal issues in dealing with AIDS
- 8. The effect of AIDS on U.S. labor markets and production
- 9. AIDS and the U.S. health care system
- 10. AIDS and the private insurance system
- 11. The effect of AIDS on the U.S. international relations
- 12. The effect of AIDS on the U.S. politics and budgets
- 13. The effect on AIDS of public education and changes in social behavior
- 14. The effectiveness of radical steps in fighting AIDS

### Appendix B

### An Illustrative Outline for the Final Report

### AIDS IN THE 1990s Scenarios and Policy Choices

### Introduction

### PART I. THE DIMENSIONS OF THE AIDS EPIDEMIC

1. The Nature, Manifestations and Transmission of AIDS

 The Incidence of AIDS in the United States
 The Worldwide Incidence of AIDS Chapter

Chapter

### PART II. SCENARIOS FOR THE SPREAD OF AIDS

4. The Relevance of Historical Plagues Chapter

5. Factors Governing the Spread of AIDS6. Scenarios for the Spread of AIDS Chapter

Chapter

### PART III. IMPLICATIONS OF THE SPREAD OF AIDS

Chapter 7. The U.S. Social System

Chapter 8. U.S. Labor Markets, Productivity and Standard of Living

Chapter 9. The U.S. Health Care and Insurance Systems Chapter 10. The U.S. Legal System Chapter 11. The American Political System

Chapter 12.U.S. National Security

Chapter 13. International Development and Standard of Living

### PART IV. POLICIES FOR COPING WITH THE AIDS EPIDEMIC

14. Private Sector Policies Chapter

Chapter 15. Public Sector Policies

### Conclusion

### 3. A FRIGHTFUL SCENARIO

Since the American academic establishment (with the exception of the National Academy of Sciences) has, so far, not yet shown a any interest in developing future AIDS scenarios of sufficient complexity, it has been left mainly to worried academic outsiders to articulate personal visions of potential developments.

One of these outsiders who has attracted considerable attention is the Los Angeles physician, Dr. Neil R. Schram. On August 10, 1986, he published a fictional scenario in the Los Angeles Times sketching the political situation with regard to AIDS in the year 1991. Obviously, his purpose in writing the article was a pedagogical one. He tried to frighten more competent scientists into an interdisciplinary academic effort to prove him wrong. Unfortunately, this has not happen so far. In fact, Dr. Schram felt compelled to rewrite and update his article in June of this year for a medical journal. Both his earlier Los Angeles Times article and his recent manuscript are reproduced on the following pages. Certainly in their intent they are as topical now as they were at the time of their writing.

The author of the present report feels compelled to include Dr. Schram's scenarios not because he necessarily agrees with his conclusions, but mainly because he hopes that German and European readers will finally begin to work on some rational planning designed to prevent this and similar nightmares from becoming reality.

# AIDS: 1991

BY NEIL R. SCHRAM

The following fictional scenario is based on what is known about acquired immune deficiency syndrome, AIDS. It is meant to summarize the latest information on the disease and to describe choices that could confront society if the virus continues to spread unchecked. The author has been a persistent advocate of increased government spending on education and prevention to help stop the spread of AIDS.

t is Sept. 17, 1991, and the White House has just announced that the vice president's daughter and her 5-month-old son have AIDS. Shocked and declaring that "this brutal, uncontrolled epidemic must be stopped—and stopped now," the President appoints a blue-ribbon commission to find ways to quickly halt the spread of the disease in American society.

By any measure, it is an awesome task. Since June, 1986, when the U.S. Public Health Service predicted that the number of AIDS cases would jump tenfold in five years, to almost 270,000, millions more have become infected with the AIDS virus. Estimates now put the total at 3 million to 4 million—about one in every 70 Americans—and each is considered capable of spreading the disease to his or her sexual partners.

Researchers have a far better understanding of the AIDS virus than they did in 1986 and can blunt its attack on the immune system, the body's natural defenses against disease. But five years later, there still is no vaccine to prevent new infections, no cure for the disease itself. Today, as in 1986, more than 80% of the patients diagnosed as having full-blown AIDS will die within two years as their weakened immune systems are overwhelmed by diseases healthy bodies can easily repel.

As federal health officials projected in 1986, more than 54,000 Americans will die from the disease this year—almost as many people who died in the entire 40 years of the polio epidemic. There are so many AIDS patients that acute-care

Neil R. Schram is a physician and chairman of the Los Angeles City/County AIDS Task Force.

Continued

services at many hospitals have been in chronically short supply for years now. Insurance companies have been bankrupted. Every American is paying higher medical bills and insurance premiums.

The signs of trouble have been apparent for years, even before actor Rock Hudson died of AIDS in 1985 and the press erupted with reports about the disease. "Not since syphilis among the Spanish, plague among the French, tuberculosis among the Eskimos and smallpox among the American Indians has there been the threat of such a scourge," the prestigious Journal of the American Medical Assn. had warned that year.

But only this year, as the vice president's daughter and grandson fall victim, and as the AIDS toll exceeds the annual slaughter on the nation's highways, does the nation finally

recognize that a health crisis of historic proportions is at hand.

THE PRESIDENT'S COMMISsion, headed by a retired Supreme Court justice, quickly gets down to business. It just as quickly discovers that its choices of recommendations are amazingly few. Despite years of increasingly dire warnings from public health officials, little has been accomplished to check the spread of the disease. The greatest effortsand almost all of the money-have been aimed at producing a vaccine and drugs to treat the disease. Nothing suggests that the general public, after years of denying that this "gay plague" could affect them. knows enough to take the protective measures that would help to contain it.

Faced with this grim reality, the commission produces a set of drastic recommendations. The AIDS virus, the panel notes, is spread in three major ways: by sexual contact, by intravenous drug use, and from mother to child (during pregnancy or through breast feeding). Any approaches that don't block these routes of transmission can't be effective, and AIDS could be expected to spread indefinitely.

Nonetheless, the recommendations create a firestorm of

The report calls for mandatory AIDS virus testing of every U.S. resident. Everybody will have to carry a photo identification card describing his or her test results. Those who are infected will be barred by law from having sex with uninfected people. Anyone found to have spread the infection will be jailed. Sex outside of marriage will be outlawed. Sodomy laws will be reinstated. If an infected woman becomes pregnant, she will be forced to have an abortion. Everyone entering the country—businessmen, tourists and Americans living abfoad—will be quarantined for two weeks and then tested for the virus. All Americans will be tested for intravenous drugs, and drug users will be forced into treatment programs or jailed.

To many, it seems that George Orwell's dark vision of a pervasively monitored society has arrived seven years later than he predicted. It appears that the nation is quickly becoming a society at the marcy of AIDS, divided between those who are infected and those fearing infection. The whole world is beginning to consider the United States a diseased country.

As the President endorses the recommendations, Congress pauses to investigate how the situation could have gotten so far out of hand. How, it asks, could the country be left with so few—and, to a free society, such repulsive—options? The AIDS virus, after all, had been identified almost a decade ago. What went wrong?

he answer, congressional investigators find, can be traced at least to June 12, 1986, to the Public Health Service report that predicted a quarter of a million additional cases of full-blown AIDS within five years and that called for quick action to educate the public in ways to prevent it. "We must inform and educate both infected and uninfected people," Donald Ian Macdonald, acting assistant secretary for health, said then. "Special efforts

will be directed to pre-adolescents, adolescents, minorities, women and healthcare providers, in addition to the people whose behavior puts them at risk for infection and AIDS."

The report drew frontpage headlines across the country. While the raw projections were startling, even more disquieting was the fact that they were based primarily on the number of Americans then thought to be infected with the AIDS virus-1 million to 1.5 million people. The report did not emphasize that the problem would grow even greater as Americans continued to become infected after 1986.

Moreover, there was evidence that even the figures the health service used were understated. Studies by the Centers for Disease Control

indicated that accurately diagnosed cases of AIDS were being underreported on death certificates by 10%, apparently to spare survivors the stigma of the disease. A 1985 California Department of Health Services study put the problem at 17%.

But a Justice Department legal opinion quickly overshad owed the PHS report and enormously complicated the task of convincing infected men and women to practice the kind of sexual behavior that could keep the disease from spreading. On June 23, 1986, the department said that an employer could legally fire employees with AIDS simply if the employer feared or suspected—even without scientific evidence—that the virus could spread in the workplace. Companies quickly extended the idea to include individuals who had taken a blood test that detected antibodies to the AIDS virus (the only test available at that point)—people the Public Health Service said were infected with the virus and able to infect others, though not suffering from the disease itself.

To those in the groups at highest risk of contracting AIDS—gay and bisexual men, intravenous drug users, hemophiliacs, and the sexual partners of each—the implication was clear. Since 1985, a positive antibody test had meant trouble obtaining health and life insurance; now it also meant a real chance of being summarily fired.



June, 1989. The Centers for Disease Control report the first case of AIDS infection traced to blood that had tested negative for presence of the virus. (On June 20, 1986, a similar case involving the AIDS antibody test was reported by the CDC.) Other studies show it is possible to have the virus in the blood for up to two weeks at a level too low to cause a positive test, but at a level high enough to infect transfusion recipients. (This contrasts with the antibody test, which may not become positive for several months after infection.) Researchers com-

pare the situation to the hepatitis B virus: Even though donated blood has been routinely tested for hepatitis B since 1971, infections through blood transfusions still occur.

October, 1989. Federal officials report the first full-blown AIDS case traced to blood that had tested anaibody negative in 1986. Colorado, taking its cue from a measure proposed in 1986 by California state Sen. John Doolittle of Citrus Heights, makes it a felony for a homosexually active man to donate blood. The law is repealed when blood donations fall sharply.

February, 1990. An AIDS vaccine is ready for human trials. Although widespread use of a vaccine is years away, and though millions will remain infected and the vaccine will not help them,

health officials finally have hope of stopping new infections. When a hepatitis B vaccine was tested on humans, researchers asked the gay community for volunteers, since the disease

was most prevalent among male homosexuals. But when asked to participate in AIDS vaccine trials, gays adamantly refuse.

Politicians, hoping to protect the heterosexual population and recognizing that the male homosexual population in some cities has been saturated with the virus for years, are outraged and perplexed. But gay community leaders cite a Catch-22 situation: The vaccine trials can only use men who are not already infected; thus, all potential participants must be tested for the virus; but those with positive results could lose their jobs and health insurance. In the growing climate of fear, gay community leaders scoff at promises of confidentiality.

May, 1990. An Illinois case clearly demonstrates the spread of the AIDS virus from an intravenous drug user to a female sexual partner, to another man with whom she had sex. to another woman, to another man. Like so many developments, this one had been expected by researchers since as early as 1986, when a study in Ohio reported the spread of AIDS from a man to a woman and to another man. (Also that year, at the international AIDS conference in Paris, the Centers for Disease Control had presented a study of men and women who had contracted AIDS from blood transfusions. The wives of seven of the 41 men in the study had begun to test positive for the AIDS antibody; so had the husband of one of the 16 women.)

Even then, evidence of heterosexual transmission of the

AIDS virus had been around for years. AIDS had been rampant among heterosexual men and women in central Africa and Haiti. At the same Paris AIDS conference, studies showed that about 6.5% of all adults (8% of all pregnant women) in Kinshasa, the capital of Zaire, were infected with the AIDS virus. And in the United States, the 1986 Public Health Service report had predicted almost 7,000 heterosexually transmitted AIDS cases by 1991, or more than 9% of the total.

"In case you aren't listening," the CDC's Curran said in Paris of heterosexual spread of the disease, "this means you, too, gang."

But the study finally and convincingly indicates to the public that AIDS may be starting to spread through the entire sexually active population, gay and straight. Women no longer feel safe by avoiding gays and drug users; they at last realize that they

must know not only the AIDS risk of their current sexual partner, but the risk of all his prior sexual contacts as well.

January, 1991. By now, 196,000 cases of AIDS have been diagnosed. Another 74,000 will be diagnosed by year's end. More than 125,000 Americans already have died from AIDS: 54,000 more will succumb by the end of the year. The numbers are difficult for the average citizen to comprehend, as they were when the PHS made its initial projections in 1986. But AIDS is now the No. 2 cause of death nationwide, exceeded only by heart disease. More people will die from AIDS this year than die from either cancer or accidents. And still the disease is spreading.

March, 1991. Several insurance companies have gone out of business because of losses due to AIDS. To salvage the industry, Congress permits all remaining life-insurance companies to refuse to cover anyone with a positive AIDS virus test.

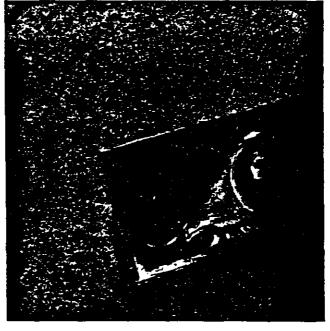
Heterosexual men and women who are thinking of becoming intimate with each other flock to testing centers to determine whether either carries the virus, only to learn that the results aren't valid unless they refrain from any sexual contact for two weeks before being tested. And, to their shock, the 1986 Public Health Service projections hold true: in about one in 108 heterosexual couples, one of the partners tests positive. Suddenly, even heterosexuals do not want to be tested.

July, 1991. The daughter of the vice president of the United States is ill. Rumors that she has AIDS persist. Although married for three years, she had one prior sexual relationship, in 1987. Attempts have been made to locate her former boyfriend, but he cannot be found. Her baby is not gaining weight and has remained hospitalized since birth.

Sept. 17, 1991. The President announces the grim diagnosis and appoints the commission, dubbed CRASH: the Commission to Reassess American Safety and Health. "Society cannot afford the continued spread of this virus," he says in a televised speech. "It can touch anyone-even innocent women and children. No option can be overlooked.'

Nov. 23, 1991. The report is released. It reads:

"We have a crisis that requires drastic measures. Failure to Continued on Page 28



## Aids: 1991

Continued from Page 15

follow these recommendations will undoubtedly lead to a need for even more drastic measures in the future.

"Health officials estimate that 3 million to; 4 million Americans are now infected with the AIDS virus. Since 30% to 40% of them are likely to develop AIDS by 1998, we can expect 900,000 to 1.6 million cases of AIDS by that year. Most important, if we do not prevent those 3 million to 4 million Americans from infecting others, the number of AIDS cases will rise indefinitely.

"A major financial commitment—one that should have been made long ago—js needed. But the money must be accompanied by important legislation that addresses the known routes of transmission: sexual activity, drug use, from mother to child.

"SPREAD BY SEXUAL CONTACT. While gay and bisexual men still represent more than 50% of AIDS cases, an increasing percentage of cases is due to heterosexual spread of the virus. Therefore we must prevent sexual behavior that can spread the virus. Thus, all sexual contact outside of marriage must be illegal, including oral and anal sex (both homosexual and heterosexual) and vaginal sex. In addition, in marriages where one partner is infected, the couple must not engage in sexual contact.

"We believe that Americans are law-abiding citizens. Voluntary compliance is anticipated in large measure.

"Nevertheless, how can compliance possibly be monitored? We urge a crash program to test every man, woman and child in this country for the AIDS virus. For those who are negative, repeat testing will be done every three months. All Americans will carry a photo identification card listing their AIDS virus status. The card must be carried at all times and will be checked routinely in all business transactions—from receiving a paycheck to applying for employment, a driver's license, a bank account, a car loan or a passport.

"Anyone whose test shifts from negative to positive will be interviewed, and their sexual partners will be tested to determine the source of the infection. It will constitute a felony for any infected individual to have sex with an uninfected individual, with mandatory jail sentences if the partner becomes infected.

"The commission considered quarantining all individuals who test positive for the AIDS virus. But the cost of quarantining 3 million to 4 million people could reach \$100 billion per year, not including the cost of building new facilities. [In 1986, the average cost of guarding, housing and feeding a prisoner was about \$25,000.1 And because there is

ample evidence that a person remains infected for years and perhaps a lifetime, long-term incarceration would be needed. That does not include the economic cost of removing these people from the workplace.

'In order for these policies to succeed, we must prevent the entry into this country of any person infected with the virus. We therefore must use the armed forces to close and fortify both our northern and southern borders. Foreign visitors will not be permitted to enter the country without certification that they are free of the virus. Even with such certification, because of the nature of the virus test, foreign visitors must undergo a two-week quarantine and repeat testing.

"INTRAVENOUS DRUG USE. We must institute a nationwide testing program for intravenous drug use. Drug and alcohol testing programs already in place in many companies and schools can easily be expanded. Drug users who do not have jobs must be apprehended. Those who test positive must enter drug programs and submit to weekly checks. Further use of drugs, or failure to stay in a program of drug prevention, will lead to jail sentences.

MOTHER TO CHILD. All pregnant women must be tested and their fetuses aborted if they test positive. Any mother who is not tested before the sixth month of pregnancy, and who subsequently tests positive, will be jailed.

"This commission does not make these recommendations lightly. But the most compelling argument for mandatory abortion is a 1985 Centers for Disease Control report showing that an infected woman runs a greater risk of developing AIDS if she bears a child. Therefore, in addition to preventing the spread of the virus from mother to child, abortions will protect the health of the mother—a justification that even most abortion opponents have long recognized as valid.

The recommendations are stringent, but necessary. The nation is under siege. While the commission does not wish to deal in moral issues and recognizes that it benefits from hindsight, we must make clear that this epidemic was made possible by the moral disintegration that has occurred in this country over the past four decades."

fter brief public hearings, Congress passes the legislation, despite its own profound misgivings and legal challenges from an unusual coalition of civil liberties and anti-abortion groups. Some in Congress take their cue from bublic opinion polls, including Los Angeles Times polls in 1985 and 1986 showing that 51% of those surveyed would support making it a crime for an AIDS patient to have sex with another person, and that 48% would support issuing ID cards to those who tested positive for antibodies. Forty-six percent supported the idea of quarantining AIDS patients, and 15% even agreed that AIDS patients should be uncoed.

The measures are repugnant to many people, but until a vaccine or drugs that kill the AIDS virus are developed, there doesn't seem much choice. And, as the Public Health Service predicted in 1986, even today a vaccine is still years away from being put into general use.

A congressional staff report accompanying the legislation predicts that the laws will cause severe societal and economic disruption, as well as the greatest assault on personal liberties since the Japanese-American internment during World War II. Nonetheless, the report predicts, the Supreme Court is likely to uphold the measures' constitutionality. given the public health emergency.

Mexico, Canada and most other countries, which by now have major AIDS problems of their own, can be expected to retaliate by refusing entry to Americans who do not submit to quarantining, the study says. Saudi Arabia instituted such a policy in 1985, and as early as January, 1986, Brazilian health officials asked visitors to Rio de Janeiro's camival to fill out questionnaires about homosexuality and AIDS. In December, 1985. authorities in Peking, seeking to prevent "epidemic diseases from being introduced to China," had even burned tons of secondhand clothing donated by foreigners. With its immigration "safety valve" closed in the southwest United States, Mexico-already irritated by U.S. policy in Latin America-might sever its diplomatic ties and align itself with the Soviet Union.

Within the United States, deep divisions that cut across racial and economic lines can be expected. Those who are infected with the AIDS virus will be pitted against those who are not. Suspicion will focus first on single individuals, straight and gay, whether they test negative or positive. But stress will also devastate couples—gay or straight—in which one member tests negative and one tests positive, since if the uninfected partner becomes infected, the other would go to jail.

Within months, the congressional report predicts, such couples, along with many single Americans who test positive, will try to leave the country rather than be branded as pariahs at virtually every turn in their lives. In short, the

country may witness an amplified vesion of the Vietnam exodus, in which young men of draft age fled to Canac . Sweden and other sympathetic coutries rather than fight in the armed forces. This time, with the borders sealed in both directions and with passports denied to those who test positive, some of those leaving will try to depart by boat-either to Latin America or Canada. But no country will be willing to offer asylum to carriers of "the U.S. disease," and their navies will attempt to intercept the American "boat people."

The trauma will be indiscriminate: Politicians, judges, sports heroes, clergymen, skilled professionals and company presidents will be among those testing positive. In 1986, most of those heterosexuals infected were drug users: after five years of uncontrolled spread. that is no longer true.

Already, the congressional staff report notes, economic dislocation is apparent. Hundreds of thousands of Americans began slipping across the border as soon as the CRASH report was released. disrupting the workplace and causing a sudden shortage of skilled labor. Economists are predicting a severe recession. and stock values have dropped sharply. Foreign countries have removed billions of dollars in assets from U.S. banks. threatening their survival. The travel industry is languishing. Foreign trade has dried up. Thousands of foreign businessmen have left the country to avoid forcible testing, devastating the real estate market, especially in California and New York.

The shame of it, the congressional report says in summary, is that the U.S. Public Health Service report in 1986 also called for appointment of a blue-ribbon commission to deal with the epidemic. But the choices available to it then would have been far greater, far less repressive than those the CRASH panel faced in 1991. Then, in fact, the best option was still available: development of major educational and prevention programs to deal realistically and effectively with slowing the spread of the AIDS virus.

Despite the best efforts of the scientific community, biomedical research cannot eliminate the problem of AIDS in the short term," Harvey V. Fineberg. dean of the Harvard School of Public Health, wrote in the New York Times that year. "The fact is, however, that we require no new technological breakthroughs to limit the spread of the AIDS virus." The Journal of the American Medical Assn. agreed. "Individuals," it said, "have the power to protect themselves more than science currently can.

In 1986, it had not been too late.

# AIDS - The Coming Crisis Neil R. Schram, M.D. June 15, 1987

Since the recognition of the AIDS epidemic in 1981, the strategy of the Reagan administration has been clear: Because the disease primarily affected gay men and IV drug users, call it the "number one health priority" and spend as little money as possible on it. Indeed the Reagan administration's budget request for fiscal 1988 was increased over the prior year for the first time - every other year Congress had increased the appropriations for AIDS. The change, this year, is due, of course to the Recognition at last that heterosexuals are also at risk.

The U.S. Public Health Service, the National Academy of Sciences and U.S. Surgeon General C. Everett Koop have repeatedly warned that a vaccine or a cure for AIDS are at least 5-10 years away and that the only weapon available now is education. However, as poor as the Reagan administration's response has been in terms of funding for research it has been far worse for education because in their view educational programs would of course be teaching "safe sodomy" or safe IV drug use.

The medical community continues to recognize the need for teaching about condoms and spermicides while the Reagan administration wants to preach abstinence, monogamy and "values". So, while the debate goes on about what to teach, little changes except more spread of the virus.

The inaction and lack of funding was terrible enough, but now with the recognized threat of the epidemic, the administration has decided that politicians should dictate public health decisions, even though their polities

are conflict with the advice of the U.S. Surgeon General, the U.S. Public Health Service, and the National Academy of Sciences.

In the simplest terms, politicians see AIDS in terms of the classic public health strategy for an infectious disease epidemic: identify those who are infected and separate them from those who are uninfected. Never mind the fact that this infection is incurable, lasts for life and that 1.5-2 million Americans are already estimated to be infected.

The Administration has already started the first part of the strategy hence the regulations or recommendations to test military personnel, immigrants, some other federal employees, people admitted to hospitals, people getting married and more reasonably, people attending sexually transmitted disease clinics, drug treatment programs, and family planning clinics. They fail to explain how testing and immediatelying infected people will stop the epidemic. In fact, it is obvious based on several studies of people at risk (sexually active people with multiple partners or whose partner has multiple partners, and IV drug users) that testing conversely alone does nothing. It has been found that with testing as an adjunct helps many but by no means all people to change to lower-risk behavior. The counseling that will be needed to change behavior in tens of millions of people is desparately needed and tragically lacking.

Since the Reagan Administration will not fund the education and counseling programs that are needed why do they want to know who is infected? First, if they can show that the virus is spread by casual contact - eq: mesquitoes, then they can try to quarantine all those who are infected. However, since the virus is not spread that way, they will try to separate people based on their behaviors.

I will examine the ways they are likely, over time, to try to create

laws to stop the epidemic and why they will fail, and indeed lead to the destruction of our free Society as we know it.

The most common method of spread of the virus will continue to be via sexual intercourse, male-to-male, male-to-female and female-to-male. After pre-marital testing is instituted in most or all states politicians will finally recognize the reality that Public Health experts understand now: Mandatory pre-marital testing will not work to prevent infections of women and babies. A study of women with AIDS as of March 1985 showed only 22% were married. Most infected babies are born to IV drug using women or sexual partners of IV drug using men. In one study of pregnant IV drug using women, only 15% were married. Equally distAubing is information about heterosexual couples where one is known to have AIDS or be infected with the virus. Large numbers of those couples failed to use condoms and spermicides consistently. Finally, if people want to avoid mandatory pre-marital testing, they will simply live together and continue sexual activity.

Thus, to try to stop sexual spread of the virus, politicians will try to enforce a law in existence in most, if not all states: It is illegal for someone with a sexually transmitted disease (HIV Infection) to have sex with, or infect, someone not infected. By the time they try to enforce this law I am assuming there will be a test for the virus that will become positive within 2 weeks compared to up to 3-6 months for the currently available Antibody test.

It is immediately obvious that it would be impossible to monitor everybody having sex to ensure that someone infected does not have sex with

someone not infected. A simpler procedure would be developed: Test everyone in the country every 3 months (at their expense of course). After the initial test, everyone will carry a photo card indicating their test result, which will, of course, be reported to the government. Anyone who goes from uninfected to infected on subsequent tests will be interviewed about who his or her sexual partner(s) were and whichever sexual partner is positive will go to jail. To ensure that everyone is tested, the card will be required for employment, business transactions such as purchasing groceries, automobile license renewals, etc.

Of course tourists and immigrants could also spread the virus, so all tourists will have to be tested in their country before coming here, quarantined for 2 weeks and retested to make certain their test is still negative, before entry into this country. The borders between the U.S. and Canada and Mexico will be more securely patrolled, possibly requiring a wall on our northern and southern borders. Of course all people coming in will have to be tested. Equally naturally Canada and Mexico will refuse entry to Americans who test positive.

While this would seem like a workable solution, there are a few potential problems. Most of the infected people would probably try to flee the country. The ones at greatest risk, of course, would be those who are part of a couple, gay male or heterosexual, where one is infected and the other is not, since if the other becomes infected the originally infected one goes to jail. This is actually a major problem since in studies of both heterosexual and gay male couples 50% or more partners of infected people are uninfected, and the potential for infection if they remain sexually active is significant.

Since other countries will also have reciprocal laws against infected

U.S. citizens entering their country, Americans will have to try to leave by boat and escape efforts by the U.S. and other navies to stop them.

As a result of millions of Americans, mostly in their late teens, twenties, and thirties, fleeing the country by boat, we will see a brain drain unequalled at any time. Foreign nationals will also leave the country to avoid this AIDS Society since they would be tested too. As a result of those consequences, the tourist and travel industries would be horribly hurt, real estate market, especially in California and New York, would collapse, and the economy would enter a depression worse than in the 1930's. The savings of tens of millions of Americans would be wiped out, and the whole world banking system would be endangered.

Dealing with IV drug users requires a different strategy. Mandatory testing for drugs on everyone also would be performed every 3 months. Anyone who tests positive would be required to enter a drug rehabilitation program (although who would fund the program is unclear). If the individual does not complete the program, or is later found to be back on drugs he or she would go to jail.

Many IV drug users would drop out of Society if they can not flee the country. They will live in an underground Society like the Jews in Europe in World War II. People will be less likely to house and feed them. So even the many IV drug users who currently work will have to survive by stealing.

The most difficult problem will be preventing the spread from infected mother to baby. This could be accomplished by making it illegal for any infected woman to get pregnant. Since that too is impossible to enforce, all pregnant women would be tested within the first 3 months of pregnancy with abortion required if the mother is infected. Any woman not tested

within the first 3 months of pregnancy would go to jail.

Naturally, those women who became pregnant in spite of efforts not to, or who were willing to assume the approximately 50% chance that the baby would not be infected would simply seek medical care too late for abortion, or, more likely find underground clinics that will be established for such women. These clinics will be part of the entire medical underground set up by health care providers infected with the virus.

Is all this inevitable? Yes and no. If medical science develops a vaccine or a drug that makes people non-infectious quickly, it will not happen.

Estimates from 1986 were that 270,000 Americans would be diagnosed with AIDS by the end of 1991, with 54,000 deaths in 1991 alone. The 1.5 million Americans estimated to be infected with the virus in 1987 is likely to increase to 4 million by 1991, at least 25% of whom are expected to develop AIDS. It is the additional 2.5 million infections that we have the knowledge to prevent.

However, while many people are currently aware of AIDS, they are slow to change high risk behavior. A People magazine survey in April 1987 reported that over 95% of high school, and college students were aware that AIDS was heterosexually transmitted, yet only 26% of high school students and 15% of college students had changed their behavior. No information was given, but I suspect that changes occured in casual sex rather than in consistent use of condoms for established couples. The fact that more high school students than college students changed behavior suggests that the longer people are sexually active, the more difficult it is to change behavior.

A survey by Mentor Corporation, which distributes condoms, in May 1987 showed that 78.5% of women age 22-34 were very concerned or somewhat con-

cerned about their personal risk of AIDS. While 80.5% recognized that condoms can block the AIDS virus, only 7.9% were using them. Equally disturbing, for the 21.5% of women who were not too concerned about their personal risk of AIDS, the most common reason was not that they were in a monogamous relationship but rather because they did not know someone with AIDS. Considering the many years after infection before AIDS occurs, it is frightening to contemplate how widespread the virus will be if women insist on the use of condoms only after they know someone with AIDS.

What can change behavior? Clearly, testing alone can not do it.

Rather, it will require a massive governmental effort, funded by billions of dollars. It will mean repetitive messages and individual counseling.

That counseling will need to be done by health care professionals who currently have neither the expertise nor the desire to do so. Major increases in drug treatment programs are needed, with both sexual and drug use counseling. While we await the hoped for money for these programs it is imperative that health care professionals make taking sexual and drug use histories with appropriate counseling the standard of medical practice.

Every school, community organization, religious group, and the media must educate about AIDS. Health and life insurance companies must educate their clients.

Family planning clinics and pre-natal clinics and health care personnel must be trained.

While all this will be very expensive, will the human race be the same if the United States stops being the free Society it has been for 200 years? This epidemic threatens that freedom as well as the lives of hundreds of thousands or even millions of Americans. The clock has been ticking for years. How much longer will the Reagan Administration and the rest of Society especially including health care professionals continue to ignore reality?

#### 4. SIGNALS FROM THE GAY COMMUNITY

#### WORDS OF WARNING FROM AN ACTIVIST

As is well known, by far the most AIDS patients in the United States are still homosexual and bisexual men. It is also known but not always admitted that the American gay community has been in the forefront of fighting the disease and, after some initial hesitancy, has, as a group, drastically changed its sexual behavior. Where gay community efforts at safer sex have been financially supported and allowed free reign (such as in San Francisco and New York City) the rate of infection through homosexual activity has dramatically declined.

However, lately these stategies that have proven so successful have come under attack from "conservative" politicians and their constituents who do not want to see them applied to the heterosexual population. Moreover, even the programs designed by gays for the gay community are now beginning to suffer political interference. This is possible, above all, because of a lack of federal leadership. Whether they are deliberate or not, the actions as well as the inaction of the Reagan administration are beginning to convey the message to some gay leaders that the government is indifferent to their plight.

The most outspoken gay critic of administration policies has been, and is, the writer Larry Kramer, author of the successful Broadway play "The Normal Heart." He has long been considered strident even in many gay circles, and is by no means representative of American gay leaders in general. Nevertheless, his repeated angry warnings bear inclusion in this report because they may foreshadow future attitudes of a growing gay radical faction. Indeed, in Kramer's latest pronouncements there have been hints of "educational terrorism," i.e. acts of desperation and civil disobedience designed not to hurt but to frighten the still complacent general public.

It cannot be ruled out that Larry Kramer's statements, which today are largely meant symbolically and are dictated by his desire to educate, might, at some future date, be taken literally by less sophisticated men and women once they become disenfranchised. It is not inconceivable that in the future many infected individuals might be singled out and marked as such, suffering increasing and unjustified discrimination. This group of impoverished, second-class citizens would probably not be entirely gay, but would include growing numbers of Blacks and Hispanics from the urban ghettos. The various potential outcomes of such a development can hardly be imagined, much less predicted at the present time. However, it might be useful to heed the following words of warning at least to the extent that anticipatory studies are carried out now.

# THE ANGER AND ANGUISH OF

hen I was a kid," recalls playwright and gay activist Larry Kramer,

"I was very scrappy. If I didn't agree with my father or mother—or anyone else, for that matter—I let them know about it."

The 52-year-old Kramer hasn't changed much. He's still scrappy and lets people know what he thinks in no uncertain terms.

As the man who wrote both the controversial book Faggots and the controversial AIDS play The Normal Heart—the latter has been produced extensively both here and abroad—Kramer is, undeniably, full of impassioned opinions.

To many in New York, however, he is a hysterical doomsayer who broke with Gay Men's Health Crisis—one of the largest AIDS organizations in the country, and a group that Kramer helped found—because he couldn't have everything his way. "I'm not a team player," Kramer freely admits.

In April, The ADVOCATE spoke with Kramer in his New York apartment overlooking Washington Square. Here's what he had to say:

BY CENNY GETECK

There was a period when you were very vocal in your criticism of Gay Men's Health Crisis (GMHC), an organization you had helped to form. Why?

I'm still very critical of it. Basically, it became an organization that was much more concerned with being pastoral than with being political. There is nothing in the AIDS epidemic that is not political.

GMHC was formed by people who wanted to fight politically, but somehow it became controlled by care providers and social workers. They turned it around to an organization providing those services—services that are, without a doubt, essential. But there's no reason why GMHC could not be both, and it has completely lost sight of that mission.

## Assuming that what you say is correct—and there are, of course, many people in New York who would disagree with you—how did this state of affairs come about?

Unfortunately, there was a period where we threw anyone we could on the board of directors. We needed, I don't know, eight or 10 people, and we didn't have that many. So we threw in our chums, and they were not people from the world of politics. They were people from the Fire Island social scene, and they were all very frightened when it came to actually having to make some sort of political stand.

We had this terrible health commissioner, and I was very critical of him. One of our board members worked for the city health department and was terrified of losing his job. When I'd criticize his boss, he would break into tears. Literally, He would start crying at our meetings, I couldn't handle that; I'm not a team player.

## What did you have against the health department?

We couldn't get near anybody. I mean, it took us two years from the time we first called. If you had to name one person in this entire country who is more responsible than anybody else for letting this epidemic get so out of hand, it's Ed Koch.

## You've gone on record as calling him a murderer.

He is a murderer.

#### What did you want him to do?

I wanted him to pass on information. You tell people what's happening. You call the President and say that we've got a big health emergency in New York City.

But it wasn't just Koch. For a long time, the New York Times wouldn't write about AIDS. I mean, we had that terrible editor. Abe Rosenthal: he's a joke now, I'm happy

to say, but at the time he was the editor of the Times.

I have all the grim statistics in *The Normal Heart*. In the first 18 months of the epidemic, they wrote about AIDS a grand total of five times. Tiny articles in the back of the paper. In the course of one month of the Tylenol scare, the *New York Times* wrote innumerable major pieces about what was happening—including a number of pieces on the front page. And there had only been seven deaths! We'd had 1,000 deaths, and they still weren't writing about us.

We wanted desperately to get the word out about the epidemic, and we couldn't do it.

## But Mayor Koch finally did meet with gay leaders.

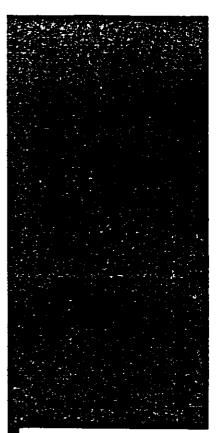
Because GMHC was getting more and more conservative, it wouldn't deal with anything that was remotely controversial. So we started another organization, the AIDS Network, which was an ad hoc community group. We wrote a letter, and I went around to all the gay organizations and got everyone to sign this open letter to the mayor. The letter said, you know, that this had been going on long enough. It was phrased nicely, but it was inherently a threat. That we had this terrible situation going on, and that we thought that acts of civil disobedience would take place. [He laughs] We should only wish! And that if he didn't meet with us in one month, we couldn't answer for the consequences.

Well, they ignored the letter. Basically, the mayor called our bluff. One Sunday, however, there was a medical symposium at Lennox Hill Hospital, and the mayor was there. About a dozen of us picketed; it was a rainy, miserable, cold morning, and we were supposed to have maybe 100 people. Only a dozen of us showed up and picketed the mayor, but it got on TV. The next morning we got a phone call saying that the mayor would meet with us right away.

You use those kinds of tactics, you get results. You have to pressure; that's the only thing politicians understand.

## What would you like to see happen in the fight against AIDS that's not currently happening?

I can tell you exactly. You need a Manhattan Project. You need to establish a whole independent unit to go after this with a specific goal in mind. You need somebody compassionate in charge, someone who will be cut free from government bureaucracy and regulation. Right now we have a situation where nobody is really in charge.



"I'm here to tell you that we haven't begun to see the horror stories. We have not begun to see the grotesqueness in our lives. By our passivity, we are contributing to our own genocide. We are literally being picked off man by man, and we're not fighting back."



**AUGUST 18, 1987** 

The man who is supposed to be in charge, Dr. Robert Windom, is a true asshole. The best way I can describe Dr. Windom is by relating what a congressional aide said to me: "If his I.Q. were any lower, you'd have to water him." And that's the truth. He's a political hack from Florida who Reagan appointed. This man couldn't care less about AIDS.

Now, I'm here to tell you that we haven't begun to see the horror stories. I don't know why people don't understand that. We have not begun to see the grotesqueness in our lives. By our passivity, we are contributing to our own genocide. We are literally being picked off man by man, and we're not fighting back.

## How do you view the research efforts that are going on?

There's like 90% agreement that HIV is the cause of AIDS. And maybe 10% of the people think that it's not the cause of AIDS—or not the sole cause of AIDS. We've put all of our research eggs in one basket, and if you don't belong to the team that plays with that team, you're left out. If you have some rival theory, forget it. It may be some crackpot idea, but let's face it, most of the major discoveries in science have been made by people who were not in the mainstream.

## Do you think that HIV isn't the cause of AIDS?

This is my philosophy: I will listen to anything and everything. No one is saying that we should stop investigating HIV. But a lot of people believe that there are cofactors involved in AIDS. Very little research is going on into possible co-factors.

What I do believe is that an awful lot of very second-rate people are running things. That certainly includes the NIH [National Institutes of Health] and the FDA [Food and Drug Administration] and the CDC [Centers for Disease Control]. And it certainly includes the health department of New York City. These are not top-rate people, and I'm simply not going to entrust my life to any of them.

## How big a role do you think homophobia has played in the government's response to AIDS?

[Surgeon General C. Everett] Koop himself has said that some of his right-wing friends seem more concerned with homosexual genocide than with human tragedy. I think that's exactly the message that's coming down from the White House: "We do not want to know. Take your own sweet time on all of this."

How has taking their own sweet time manifested itself?

For starters, there's the fact that the NIH has had an annual budget of \$47 million for testing drugs, and they haven't used a penny of it. There's the fact that there are 1,500 official treatment slots for drug protocols in various NIH-designated treatment centers around the country, and only 450 of them are filled. There are at least eight drugs that are as safe as, or safer than, AZT, but they're not being tested.

That AZT got through all the government red tape and made it out into the world is one of the triumphs of greedy commerce and slick public relations. I think there probably is value in the drug, and I'm glad that it's out there, but that we should be forced to pay for an experimental drug where we are the guinea pigs is heinous.

# Some gay leaders—Jeff Levi of the National Gay and Lesbian Task Force, for instance—have cautioned against the precipitous release of drugs, some of which might eventually prove to be very harmful.

I am not asking for the release of unsafe drugs; I am asking that drugs that have passed Phase One safety trials be allowed to be used in drug protocols by patients who want to take them. It's the patient's right to chose – not the government's and not the doctor's.

When the government doesn't move to make drugs available, you wind up with the situation that we've got in New York City. People are popping everything into their mouths that they can possibly get hold of. They don't know where it's from or what it will do, but they're desperate.

So we have to have the drugs tested much more quickly. They've got to be tested in more combinations. They've got to be tested in everything from lymphadenopathy to ARC to full-blown AIDS.

## There's certainly been an organized gay lobbying effort on AIDS. How effective do you think it's been?

Let's talk about the gay lobbying effort. We are now seven years into a horrendous medical epidemic, and we have just a handful of lobbyists representing our interests. General Motors has a couple of hunared lobbyists. The National Rifle Association has a couple hundred. You cannot tell me that 10 million gay men in this country don't have enough money to support a real lobbying effort. There are a lot of very rich gays out there.

Will the gay community need to turn or civil disobedience?

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I think we have to go out and start our own Irgun, which was the underground organization the Jews had when they were fighting to establish Israel. If you really want to know, I think we should blow up Gracie Mansion.

We've certainly got to become visible. That's why the upcoming March on Washington is so important.

One of my favorite notions is that we make fake blood and throw bottles of it in public places, and shout, "This is AIDS blood!" Let them think that it is. We have to scare people. We have to make their lives uncomfortable. I think we should be doing things like tying up expressways and blocking bridges.

The terrible thing is that we're all a bunch of nice, sweet boys and girls, and we don't know how to behave otherwise. I cannot for the life of me understand why everybody is not screaming and yelling like I am. People think I'm a hysteric.

#### Why aren't people more angry and upset?

If I could answer that question, I would have solved the biggest puzzle in my life. I do not understand it. I don't understand why every gay man is not so scared shitless for his own life that he isn't out there doing something extraordinarily forceful. But they're not. It's very hard to get this community off its ass; that's why I say that we are contributing to our own genocide.

I think we should be tying up whole cities. We should crippie this country. We should throw bombs. We should set fires. We should stop traffic. We should surround the White House.

I truly think that everybody has to become a radical. Look upon it as though you literally may not have more than two or three years left to live. What are you going to do with that time? Doesn't that change your priorities?

I don't know what people are thinking. They're hoping to go on with their lives as if nothing is happening, and you can't go on like that. There isn't any gay man in this country who hasn't been personally touched by this.

## Basically, you're saying that we can no longer afford to conduct business as usual.

You know, I went to a meeting of the Coalition of Gay and Lesbian Rights the other night to make a little speech. This is the old-time political organization, and you sit there and everybody gets up and they fight with each other and they make the same old political speeches that I've heard a hundred years. And nothing gets done.

Everyone was saying, "They've got to

"We should be tying up whole cities. We should throw bombs. We should stop traffic. We should surround the White House."

realize this..." and "It's the system's fault..." and bla bla bla. Yes, it's the system's fault, but we've got to start taking the responsibility for doing something about it. If I go to one more meeting where somebody stands up and says. "You've got to do this...and you've got to do that..." I'm going to turn around and shout, "I don't gotta do nothin! You've got to do something!"

At the coalition meeting, I finally said, "For Christ's sake, find a task for yourselves. Do something, Pick a task and do it! What do you think you can do?" One guy—this old-line fighter—gets up and says, "I think we can try to get some congressional oversight committee meetings going." I said, "Terrific. If you can form a committee, do it."

We need to take some responsibility for what's going on. We've talked about lob-byists. One of the most vital things we could do would be to have 50 lobbyists in Washington. It costs \$75,000 to maintain a lobbyist; why can't every city in this country be responsible for having a fund raiser to send one lobbyist to Washington? The gay community of San Francisco, the gay community of L.A., the gay community of Philadelphia...it's no big deal raising \$75,000 in a whole city. We could have 50 lobbyists in no time flat.

What we need is an infusion of new political people—men and women who haven't been political in the past. The thousands of volunteers GMHC has—those are the kind of people we need to be political. Not just to be nurses' aides, but also to be activists. That's what the gay movement needs right now.

# 30,000 and counting... Taking Responsibility For Our Lives

## **BY LARRY KRAMER**

Larry Kramer originally delivered the following remarks at a rally in Boston preceding that city's gay pride celebration. His speech has been reprinted nationally, now, raising a great deal of controversy wherever it's been read. Coming Up! has very mixed feelings about what Kramer is saying, but we reprint his remarks in their entirety here, because Kramer raises a lot of issues that have not been in the forefront of the discussion of issues surrounding the AIDS epidemic.

e have little to be proud of this Gay Pride Week. One by One we are being picked off by the enemy.

They are killing us.

I don't think you are going to like what I am going to say. It is the last time I am going to say it. I'm making a farewell appearance. I am not overly tired. I am certainly not suffering from burnout. I have a lot of piss and vinegar left in me—too much, in fact. No, I'm not tired. Not physically tired, at any rate. I am, of course, as are you, very tired of many things. I am tired of what they are doing to us. I am tired of what they aren't doing for us. I am tired of seeing so many of my friends die—I'm exceptionally tired of that, as I know you are, too.

I'm also tired of people coming up to me on the street and saying "Thank you for what you're doing and saying." They mean it as a compliment, I know. But now I scream back, "Why aren't you doing it and saying it, too?" Why are there so few people out there screaming and yelling? You're dying, too!

I'm telling you they are killing us. We are being picked off one by one and half the men reading this could be dead in five years and you are all still sitting on your asses like weaklings and therefore we, the gay community, are not strong enough and our organizations are not strong enough and we are going to die for it!

I have come to the terrible realization that I believe this gay community of ours has a death wish and that we are going to die because we refuse to take responsibility for our own lives.

Yes, most of all, I'm tired of you. I'm tired of the death wish of the gay community. I'm tired of our colluding in our own genocide. I'm tired of you, by your passivity, actively participating in your own genocide.

You do not have to have AIDS to acquire a system deficient and immune.

How many of you have given a thousand dollars or more at any one time to any gay organization or gay charity? Ten thousand? (For the rich readers: one hundred thousand dollars? A million?)

How many of you have spent at least an hour a week volunteering for a gay organization? Ten hours?

How many of you have left anything in your wills to anything gay?

And if you don't like any of the gay organizations, how many of you have spent how much time to make any of them better, instead of just bitching them into further weakness? Or helped raise them money to make themselves better?

How many of you have bothered to consider that by raising \$80,000 a year you could fund a lobbyist in Washington, to fight for us all year long — to join with a network of other gay lobbyists, paid for by groups in other cities, so that we could have as many lobbyists as General Motors or the National Rifle Association, or the National Council of Churches, or the American Medical Association, all of whom get what they want?

Is it such a big deal to get a group together to raise \$80,000 to save our lives? (Did anyone notice that when Paul Popham died, he asked that contributions be made to AIDS Action Council, a lobbying group, and not to Gay Men's Health Crisis, which he co-founded, and in whose ability to do anything but look after funerals he had lost confidence and faith?)

How many of you have written consistently or even irregularly to an elected official or testified to an official hearing on the subject of AIDS, or regarding treatment, or official lethargy in this city and state and country?

How many of you really trust that the National Institutes of Health are capable of coordinating research around a crisis of this scope?

How many of you even know what the NIH are, or how important they are in your life, and that your very own life is in its hands? You didn't know that, did you? That your very own life is in the hands of an agency you don't know anything about.

How many of you believe there is sufficient education to contain what is happening?

How many of you have children? How many of you have spoken to a school board about sex education?

How many of you have had sex with more than one person in the last ten years?

How many of you have protested actively against mandatory testing?

How many of you are willing to face up to the fact that the Food and Drug Administration is fucked up, the Centers for Disease Control are very fucked up — and that entering the seventh year of what is now a pandemic the boys and girls running the show at these organizations have been unable to make whatever system they're operating work?

How long are you prepared to wait for these systems to work?

How long are you prepared to wait before our own AIDS organizations provide us with adequate information on available treatments?

How many hours and days are you prepared to spend on the phone attempting, in vain, to find out what is going on and where and how it's doing and why can't my dying friends get it immediately?

How many of you believe you have no

responsibility to take action on any of these matters?

How many of you need to die or become infected before you feel you can take action on why every single branch of government in charge of AIDS, both local and federal, is dragging its ass?

What's the number at which you can decide to stop just sitting there quietly like the good little boys and girls we were all brought up to be—and start taking rude, noisy, offensive political action?

It always amazes me when I tell people they have the power, and they answer me, "Power? Me? What power?" How can you be so conservative, numb, and blind? You know what is going on better than anybody, and yet you are silent. You constantly, consistently, and con-

to use your power.

Your voice is your power! Your collective voices! Your group power! Your political power! Your names all strung together on one long list is your power. Your bank accounts are your power, if you weren't all so devastatingly stingy when it comes to funding anything gayer than a Halloween costume. Your bodies are your power, your *living* bodies all strung together in one long line that reaches across this country and could reach to the moon if we only let it.

You know that this country is not responding on a national political level or a local political level, and yet you sit by, along with everyone eise, and watch our men being picked off one by one by one by one.

No one is in charge of this pandemic, either

simple as that. And certainly no one who is compassionate and understanding and knowledgeable and efficient is even anywhere near the top of those who are in charge. Almost every person connected with running the AIDS show everywhere is second-rate. I have never come across a bigger assortment of the second-rate in my life. And you have silently and trustingly put your lives in their hands. You — who are first-rate — are silent. And we are going to die for that silence.

You know, it's not even a question of government funding anymore. For six long years we fought so hard to get the money. Finally Congress has appropriated masses of money. Can you believe me when I tell you it is not being spent. Two years ago, 19 official AIDS treatment centers, called ATEUs (for AIDS treament evaluation units), were set up by the NIH, and they still aren't being utilized beyond a fraction of their humane possibilities and intentions. One year ago, the NIH was given \$47 million just for testing new AIDS drugs — and they aren't spending it!

... Why didn't we know that? Where have we been for these long two years? Why didn't we know that this precious, precious time, during which how many dear, dear friends of ours have died, was being thrown out in the garbage because we didn't get on the phone and inquire politely: "Please, sirs, can you tell me what you're doing with all that nice money Congress gave you last May?" How could we have been so lazy and irresponsible - and trusting? We, of all people in this world, should know better. and know how not to trust. Where were our gay leaders? Where were all our AIDS organizations? Where were our people in Washington? Where was I? For I blame myself more than I blame anyone else. God damn it, I trusted, too!

When I found out about three months ago that \$47 million was actually lying around not being used when I knew personally that at least a dozen drugs and treatments just as promising as AZT, and in many cases much less toxic, were not being tested and were not legally available to us. I got in my car and drove down to Washington. I wanted to find out what was going on. Like most people, I have no notion of how the system works down there, who reports to whom, which agency is supposed to do what. What I found out sent me into as profound a depression as I have been in since this epidemic started.

My first meeting was at the White House, with the President's Domestic Policy Advisor, Gary Bauer, who advises Ronald Reagan on AIDS. I asked him if ignoring AIDS was intentional. He answered me that he had not seen enough evidence that the Black Plague was going on yet. He was particularly interested to hear from me that the current evidence indicates that the gay male population of the major cities is on its way to being totally exposed to the virus. He asked me if I thought female-to-male transmission was as potent as male-to-male transmission. I said the statistics were about the same. He said his advisors told him otherwise. I asked him if gay people who were AIDS experts could be on the President's AIDS Commission, and he told me no. I asked him why the President had refused to put anyone in charge - to appoint an "AIDS czar"? He told me the President is the AIDS czar. I asked him why the President had not only not read Surgeon General Koop's AIDS report, or the National Academy of Sciences AIDS report, both of which were then over six months old and both of which beg for immediate, all-out action. Reagan hadn't even met with Koop personally, his own Surgeon General. Bauer answered that the chain of command dictates that, in matters of health, the President talks only to his Secretary of Health and Human Services, Dr. Otis R. Bowen. It turns out that Dr. Koop has absolutely no power. His position is simply that of a figurehead. They do not like what he is saying. And I think that if you listen to what he is beginning to say now, Dr. Koop is being pulled back into line.

Dr. Otis R. Bowen would not see me. He is Reagan's third Secretary of Health and Human Services and he is supposed to be in charge of AIDS. Until he appeared as the closing speaker at the Third International AIDS Conference—where, I am happy to say, he was roundly booed (were any of you there to boo him?)—he had not been heard to say anything substantial at all about AIDS. The secretary of the main department of your government in charge of AIDS—the one man who can report to the President on the state of this nation's health—had yet to be heard saying anything about AIDS at the beginning of the seventh year of this pandemic.

I discovered that Dr. Bowen had passed the AIDS buck over to his Assistant Secretary of Health and Human Services, Dr. Robert Windom. Dr. Windom has been in his job just about a year. He's never worked in government before. He was a private physician in Sarasota, Florida, and he got his wonderful opportunity to work so close to his idol, Ronald Reagan, by contributing \$55,000 to Reagan's campaign fund. He is exceptionally ill-informed about AIDS. On a recent NBC Radio coast-to-coast call-in show he answered two questions incorrectly. My favorite description of Dr. Windom comes from a top legislative Congressional aide: "If his IQ were any lower, you'd have to water him."

You laugh — and Dr. Windom is in charge of your life! An uncaring dumb stooge who knows next to nothing about any of the drugs or treatments or research is in charge of your life, and you are laughing! Over half the men reading this article could be dead in less than five years and you are laughing at this crack about Dr. Windom:

Dr. Windom reports to Dr. Bowen, who reports to the President.

Dr. Windom has passed the AIDS buck to his assistant, Dr. Lowell Harmison. Dr. Harmison is sort of the power behind the power behind the throne. Dr. Harmison does not like gays. Dr. Harmison has been described to me by several Congressional contacts as "evil." "You cannot say enough bad things about Lowell Harmison," I was told by more than one. He is so frightened of gay people that he was terrified we would intentionally give blood, in order to pollute the nation's blood supply.

Dr. Harmison reports to Dr. Windom, who reports to Dr. Bowen, who reports to the President.

These are the four top men in charge of AIDS in the United States government, the government of all the American people. Your government. God (if there is one) help us, because these four Satans won't.

I am here to tell you that I know more about AIDS than any of these four inhumane men, and that any one of you here who has AIDS or who tends to someone who has AIDS, or who reads all the newspapers and watches TV, knows more about AIDS than these four monsters. And they are the four fuckers who are in charge of AIDS for your government — the bureaucrats who have the ultimate control over your life.

Next I went to the National Institutes of Health. The National Institutes of Health receives \$6.2 billion each and every year to look after the health of the American people. "To improve the health of the American people" is how the U.S. government manual describes the NIH's mission.

How many of you can tell me the name of the head of the NIH?

You don't know the name of the man who is given \$6.2 billion each and every year to help make you better if you have AIDS? You should be ashamed of yourselves.

His name is Dr. James Wyngaarden and he has never been heard to publicly speak our about AIDS, either. He is given \$6.2 billion every year, and not only doesn't he speak our about AIDS, but you don't even know his name!

Dr. Wyngaarden reports to Dr. Windom, who reports to Dr. Bowen, who reports to the President.

The NIH is like a coilege campus. It looks like Amherst, or like something from an old MGM musical. It's really made up of 12 institutes, which are sort of like dorms, or fraternities, all part of the whole. The grounds are manicured and you can't see any shit on the ground.

Seven years ago, when AIDS was first noticed, and you would think the NIH would have jumped on it fast, this is what happened. You would think that, because there was a cancer involved, called Kaposi's sarcoma, it should have gone to the institute in charge of cancer, the National Cancer Institutes of Health. The National Cancer Institute is the richest fraternity at NIH. In 1981, when AIDS first showed up and should have gone into this rich fraternity, the head of the fraternity didn't want it. He had one billion dollars of research money "to improve the health of the American people," and the head of the NCI didn't want it.

Now how many of you can tell me the name of the head of the NCI, then and now? The man who is in charge of the most important cancer research institute in the entire world, and you don't know his name? You should be ashamed

His name is Dr. Vincent T. Devita, and I have it on good authority that he is gay. In 1981, he didn't want AIDS. He didn't like the smell of it, and he didn't want to spend any of his institute's \$1 billion on it, so he too passed the buck.

Dr. Devita reports to Dr. Wyngaarden, who reports to Dr. Windom, who reports to Dr. Bowen, who reports to the President.

Dr. Devita passed the buck to a poor relation, a much smaller institute named the National Institute of Allergies and Infectious Diseases of the National Institutes of Health, which had a budget one-fourth the size of his and which was not nearly so popular a fraternity to rush. It was then run by a man named Richard Krause, who didn't want AIDS, either. Dr. Richard Krause is also a gay man. He subsequently resigned as

head of NIAID, and he was replaced by — now I am sure you can tell me the name of the man who is now the director of NIAID, the man who reports to Dr. Windom who reports to Dr. Bowen who reports to the President — the single most important name in AIDS today, the name of the man who probably has more effect on your future than anybody else in the world.

How many of you know this man's name? His name is Dr. Anthony Fauci. He's real cute. He's an Italian from Brooklyn, short, slim, compact. He wears aviator glasses; a natty dresser, a very energetic and dynamic man. After a recent meeting a bunch of us from New York had with him, during which absolutely nothing was accomplished, he asked me what we thought of the meeting. I told him: "Everyone thought you were real cute." And he blushed to the roots.

You are smiling, and this is the man who is not spending those \$47 million — which were given to him specifically to test AIDS drugs.

Everybody likes Dr. Fauci and everybody thinks Dr. Fauci is real cute, including me, and every scientific person I spoke to whispers off to the side, "Yes, he's real cute, but he's in way over his head."

Dr. Fauci is an ambitious bureaucrat who is the recipient of all the buck passing and dumping-on from all of the above. He staggers, without complaint, under his heavy load. No loudmouth Dr. Koon is he.

Dr. Fauci, with his devoted staff of several dozen - that's right, folks, no more than a couple of dozen doctors and scientists are fighting against AIDS at NIAID; I guess \$47 million doesn't buy what it used to buy - is chief administrator of the 19 AIDS designated treatment units around the country, and of all AIDS research and testing for the entire country. No major decision can be made without him. He works 18-hour days, goes into the wards after office hours to visit patients, his wife is an AIDS nurse in his hospital, he must summon committees, preside over meetings, supervise the selection of drugs to test, monitor the results, deal with pharmaceutical companies, keep up on the latest information (a new drug application can run up to 100,000 pages of evidence), attend conferences all over the world, and put up with complaints from absolutely everyone.

Dr. Fauci, of all the names in this article, is certainly not the enemy. Because he is not, and because I think he does care, I am even more angry at him for what he is not doing — no matter what his excuses, and he has many. Instead of screaming and yelling for help as loud as he can, he tries to make do, to make nice, to negotiate quietly, to assuage. An ambitious bureaucrat doesn't make waves.

Yes, Dr. Fauci reports to Dr. Wyngaarden, who reports to Dr. Windom, who reports to Dr. Bowen, who reports to the President.

Dr. Fauci has had this \$47 million for a year — and worse, the beds in his AIDS wards are empty. A whole floor in America's state-of-theart hospital, \$47 million given him to test new treatments, and his beds are empty, just as the majority of places on the treatment protocols of those 19 ATEU's around the country are empty.

What is going on here? Are they actually afraid they might learn something that might save us?

Research at NIH? I have not the space to go into the gory details. Let me just say that the research rivalries in and among all the institutes at NIH could make a TV series to rival Dynasty and Falcon Crest in competitiveness, hostility, selfishness, and greed. (Why doesn't the press write about these scandals, as they do about all others? Why doesn't the press ever investigate NIH? Is it so holy — like the Vatican?)

Now you know why NIH stands for Not Interested in Homosexuals.

What the fuck is going on here and what the fuck are you doing about it?

If I use gross, revolting language — go ahead, be offended — I don't know how else to reach you, how to reach everybody. I tried starting an organization. I co-founded Gay Men's Health Crisis, which becomes more timid as it becomes richer day by day. I tried writing a play. I tried writing endless articles in the Native and the New York Times and Newsday and screaming on Donahue and in front of every TV camera put in front of me. I helped start ACT UP, a small bunch of too few very courageous people willing to make rude noises. I don't know what else to do to wake you up.

I will tell you something else, to try and wake you up: If AIDS does not spread out widely into the white non-drug-using heterosexual population, as it may or may not do, then the white non-drug-using population is going to hate us even more — for scaring them, for costing them a fucking fortune, for our "lifestyle," which they say caused this. AIDS will stay a disease of Blacks and Hispanics and gays and it will continue to be ignored. It will be even more ignored.

The straight world is scared now because they're worried it's going to happen to them. What if it doesn't? Think about that for a while. If all this lethargy is going on now, think what will happen then, just as you are coming down with it and facing death.

Who is fighting back in any and all of this? Twenty-four million gay men and lesbians in this country, and who is fighting back? We have a

demonstration in Washington and we have 300 people and we think we're lucky. We get our pictures in all the magazines and newspapers for one or two days and we feel real proud. Sixty thousand Catholics march in Albany; 250,000 Jews march in New York against the treatment of Soviet Jews; one million people march for nuclear disarmament.

What does it take to get you off your asses? "You want to die, Felix? Die!" That's a line from *The Normal Heart*. In his immense frustration, Ned Weeks yells it at his dying lover. That's not only how I felt about Felix, but how I feel about all of you.

What does it take to make people hate? I hate Ed Koch (yet another gay "brother") because he is the one person in this entire world who could have done something in the beginning and didn't, and it took us two years to even get a meeting with him. We must always remember that, as Dr. Mathilde Krim tells us, "This is an epidemic that could have been contained." Now Koch has put yet another powerless wimp in place as his Commissioner of Health, and gay men and women in New York still kiss Koch's ass, as gay men and women still think Ronald Reagan is peachy wonderful and gay people in Massachusetts think that Ted Kennedy is wonderful — and he is in charge of health issues in the Senate and he has been silent and cowardly about AIDS for six long years. How many dead brothers have to be piled up in a heap in front of your faces before you learn to fight back and scream and yell and demand and take some responsibility for your own lives?

I am telling you that they are killing us and we are letting them.

Yes, I am screaming like an hysteric. I know that, I look and sound like an asshole. I told you this was going to be my last tirade, and I am going to go out screaming so fucking rudely that you will hear this coarse, crude voice of mine in your nightmares. You are going to die, and you are going to die very, very soon unless you get up off your fucking tushies and fight back!

Unless you do — you will forgive me — but you deserve to die.

I never thought I would come to say anything like that. Nobody deserves to die.

I recently spoke at a Village Voice AIDS

Forum in New York, on a panel with Dr. Ron Grossman, who has one of the largest gay practices in New York. "Larry," he said to me, "our most outrageous early pronouncements are short of the mark. And so have been our efforts. We are so behind."

AIDS is our holocaust. Tens of thousands of our precious men are dying. AIDS is our holocaust and Reagan is our Hitler and New York City is our Auschwitz.

Holocaust is another word for genocide, a word I hear myself and others using more and more frequently. You don't hear it as much as you hear words like "mandatory testing" or "no sex education in the schools" or "no condom ads on TV."

Why doesn't everybody realize that all the screaming and yelling going on about "education" and "mandatory testing" is one whale of a red herring?

Why doesn't everyone realize that while all the hatred and fury from the right wing, from the fundamentalists, ecumenicals, Mormons. Southern Baptists, born-agains, Charismatics, Orthodox Jews, Phyllis Schlafly, Paul Cameron, Governor Deukmejian, Rep. Dannemeyer, Jesse Helms, Jerry Falwell, and all their equally vocal supporters, goes on - that while they are screaming and yeiling about the naughtiness of condoms and sex education and homosexuality, the killing culprit virus continues to spread and spread and spread and kill and kill and kill. While Rome burns, the Falwells fiddle, fanning their fundamentalists into fury against the faggots — and the junkies and the niggers and the spics and the whores and...

And they know it!

It is perfectly clear to me, no matter what Ronald Reagan and his henchmen say, that no substantial battle for a cure will be mounted while he is in office and that we must endure, at the least, another 18 months of untended, intended death. Very consciously they know that the more noise they can make, the more stalling tactics they can put into action, with the aid of their President, who supports them, and with the aid of his staff and his Cabinet and his Vice-President and his Attorney General and his Justice Department and his Supreme Court and his Secretary of Education and his various Secretaries and Assistant Secretaries of Health and Human Services and his director of the National Institutes of Health and his Centers for Disease Control — the more gays and Blacks and Hispanics will die.

They know this. I believe it is as conscious an act as this.

And we are allowing this. We have fallen into their tran!

Our leaders — such as they are — their energies are consumed fighting these battles against mandatory testing and : poetter education. No one is fighting the NFE or drugs and

increased protocol testing and faster research. I am telling you that there are drugs and treatments out there that can prolong our lives, and you are not getting them and no one is fighting for them and these drugs and treatments are caught up in so much red tape that they are strangled in the pipeline — and the Reagan Administration knows this, knows all this, and does nothing about untangling the red tape — and half the men reading this can die because of it.

Yes, by our passivity we are actively colluding and participating in our own genocide. We are allowing ourselves to be knocked off one by one. Half the men reading this could be dead in five years.

Our gay organizations are weak and still don't work with each other, and our AIDS organizations have all been co-opted by the very systems they were formed to make accountable. And you all sit by and allow it to happen when it's your lives that are going down the tubes.

Politicians understand only one thing: pressure. You don't apply it, you don't get anything. Simple as that. And it must be applied day by week by month by year. You simply can't let up for one single second, or you don't get anything. Which is what is happening to us.

For six years, I have been trying to get the gay world angry enough to exert this pressure. I have failed, and I am ashamed of my failure. I blame myself. Somehow I wasn't convincing enough or cute enough to break through your denial or self-pity or death wish or self-destruction or whatever the fuck is going on.

I'm tired of trying to make you hear me. I'm shutting up and going away. The vast majority of the gay world will not listen to what is so simple and plain. That around this country there are so few voices as strident as mine is our tragedy. That across this country there is not one single gay leader who has any national recognition like Gloria Steinem or Cardinal O'Connor or Jerry Falwell or Jesse Jackson is also our tragedy. Why is that? Why does every gay spokesman finally just collapse under the apathy of trying to make you listen — and failing, failing utterly.

Don't you ask yourselves quite often the Big Question: Why am I still alive? Untouched? At some point, I did something the others did. How have I escaped?

Don't you think that makes you obligated to repay God or Fate or whomever or whatever—if only your conscience—for this miraculous fact: I am still alive. I must put back something into this world for my own life, which is worth a tremendous amount. By not putting back, you are saying that your lives are worth shit—that we deserve to die, and that the deaths of all our friends and lovers have amounted to nothing.

I can't believe in your heart of hearts you feel this way. I can't believe you want to die.

Do you?

#### THE GAY MARCH ON WASHINGTON, OCTOBER 1987

Larry Kramer, frustrated in his attempts to radicalize the more established members of the gay community, has now involved himself with smaller faction called the AIDS Coalition to Unleash Power (ACT UP). The demands of this group are summarized in a flier which is reproduced on the next page.

Even the American "mainstream" gay community is no longer content with simply asking for financial handouts supporting the fight against AIDS. In fact, homosexuals now demand, with increasing vigor, their full civil rights and an end to their status as second class citizens. This second class status was, unfortunately, confirmed by a recent Supreme Court decision, which refused to declare states laws against homosexual behavior unconstitutional. At this time, homosexuals who follow their inclinations are legally criminals in 22 states of the Union.

In mid-October of this year American homosexuals from all parts of the country marched on the nation's capital, Washington DC, for a mass demonstration and accompanying acts of civil disobedience. The march assembled several hundred thousand participants (estimates vary from 200,000 - 500,000). The demonstration received extensive coverage in the national media, especially since the Rev. Jesse Jackson, a democratic presidential candidate, supported the rally in a personal address. It was also noted that the Mexican-American Cesar Chavez, the leader of the United Farmworkers of America, spoke to the demonstrators. Coincidence or not, the event thus brought representatives from three groups together that, in the foreseeable future, are likely to bear the main brunt of the epidemic in the U.S.: homosexual and bisexual men, Blacks and Hispanics.

The mass demonstration also evoked memories of similar anti-war and civil rights demonstrations of the 1960s. Indeed, the Rev. Jackson, a close collaborator of the late Dr. Martin Luther King, and Cesar Chavez, had personally participated in or lead many of these now legendary marches and demonstrations.

Just as the Vietnam war and Black rights were in the 1960s, so now AIDS and gay rights have become a political issue which is being taken into the streets. It is therefore no longer possible to deny that AIDS has become politicized. Indeed, the march on Washington itself immediately provoked a reaction from "conservative" Christian groups who announced their opposition and their intention to use any political means at their disposal to prevent any concessions from being made.

Under the circumstances, the prospects for a dispassionate, informed public debate seem to be dwindling. The rational public health strategy devised by professionals therefore is heading for rocky shores.

# AIDS and Death, AIDS and \$\$\$, AIDS and Politics

# WE ARE ANGRY

- At the Government's policy of malignant neglect
- ■At the irresponsible inaction of this president
- At the shameful indifference of our elected representatives
- ■At the criminal hoarding of appropriated funds by government agencies

# WE DEMAND

- A CONGRESSIONALLY-APPOINTED NATIONAL EMERGENCY AIDS COMMISSION to establish a "MANHATTAN PROJECT" FOR AIDS empowered to cut through red tape and direct national policy on AIDS!
- A COMPASSIONATE COMPREHENSIVE NATIONAL POLICY ON AIDS! We demand legislation to prohibit discrimination in employment, housing, insurance, and treatment.
- INTENSIFIED DRUG TESTING, RESEARCH, AND TREATMENT EFFORTS, with an emphasis on establishing a broader range of drug trials available to all people with AIDS.
- A FULL-SCALE NATIONAL EDUCATION PROGRAM committed to reaching all individuals, particularly those in the highest risk groups, with information and materials graphic and effective enough to do the job.

## AIDS and Death, AIDS and \$\$\$, AIDS and Politics

## A FACT SHEET

- Over 20,000 Americans have already been killed by AIDS, and over 1 million are already infected.
- By 1990, over 5 million Americans will be infected, and as many as 3 million of these may die from AIDS.
- In 1988, Congress proposes to spend \$970 million for AIDS research and education. The President proposes to spend only \$533 million. By 1991, AIDS will cost this country \$16 BILLION each year in direct medical expenses alone.
- By 1991, more Americans will die from AIDS <u>each year</u> than were lost in the entire Vietnam war.
- # In ONE DAY the Pentagon spends more than the <u>TOTAL</u> spent for AIDS research and education since 1982.
- On the issues of blood testing and education to prevent AIDS, Reagan continues to ignore the advice of U.S. Surgeon General C. Everett Koop, his appointed chief public health officer.
- In June 1986, \$47 million was allocated for new drug trials to include 10,000 people. One year later, only 500 people are currently enrolled. In that time, over 9,000 Americans have died from AIDS.
- \* In October 1986, \$80 million was allocated for public education on AIDS. Eight months later, there is still no national education program. In that time, over 10,000 new cases have been reported.
- In Great Britain, where less than 500 people have died from AIDS, a national education program has reached every home in the country. In the U.S., where over 20,000 Americans have died, we are still debating the virtues of abstinence.
- By refusing to consider the foreign data on Isoprinosine, Ribaviran, AL721, or Foscarnet (all thought promising AIDS drugs by our own National Institutes of Health), the Food and Drug Administration causes unnecessary delays in drug availability and needless deaths.
- After 36,000 cases and 7 years, the President's "policy" on AIDS consists of nothing more than a debate on "routine testing." There is NO national policy on AIDS in the U.S.A.



# Tuesday, October 13, 1987 at the U.S. Supreme Court, Washington, D.C.

This action is the culmination of the 5 days of events centering around the October 11 National March on Washington for Lesbian and Gay Civil Rights.

Come to the Supreme Court to stand up for our civil rights. With the Hardwick decision, the Court took away our right to love whom we choose, in the way we choose. The rights of people with AIDS continue to be eroded with each passing day. Now is the time for direct action.

## What you can do:

- join an affinity group and participate in the action—people willing to risk arrest and those able to provide support are both needed. Non-violence training workshops will be available to communities across the country. Contact your local community for dates and times or the national office to request that one be set up.
- organize your community—outreach materials are available from the national office.
- share your skills—Non-violence trainers, peacekeepers, medics, child care workers and people with legal experience are all needed both the day of the action, and sooner.
- contribute money directly to the C.D. so that expenses can be met.

## **National Contact:**

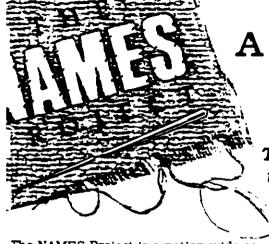
C.D. Coordinator
National March on Washington
P.O. Box 7781
Washington, D. 2000-

## **Local Contact:**

(415) 621-5620 P.O. Box 3491, Oakland, CA 94609

C.D. Training:

(415) 864-1988



## A National AIDS Memorial

Thousands of people across America are joining together to create this national AIDS memorial.

The NAMES Project is a nation-wide campaign to memorialize the tens of thousands of Americans who have already been lost to the AIDS epidemic.

We are creating a memorial composed of thousands of individual fabric panels, each bearing the name of a single person lost to AIDS. Designed and completed in homes across America by the friends, lovers, and families of people killed by AIDS, the panels will be assembled into one massive expanse of names. The inaugural display will take place on the Capitol Mall in Washington, D.C. on Sunday. October 11, 1987. A national tour will follow.

Inspired by the American folk art traditions of quilting and sewing bees. The NAMES Project is a positive expression of personal loss as well as a dramatic illustration of the impact of AIDS on American society.

Some people will choose to create their panel privately as a personal memorial to someone they loved. We hope, however, that many more will follow the traditions of quilting and sewing bees, involving friends, families and co-workers in designing and creating the panels.

Businesses and organizations such as sports teams, political and social clubs, churches, and professional associations are urged to sponsor panels for members who have died.

Have any questions? Call the national office of the NAMES Project at (415) 863-5511.

Please note: All materilas submitted to The NAMES Project become the sole roperty of The NAMES Project and cannot be returned or reclaimed by the ender. The NAMES Project retains all copyrights on all materials ubmitted.

How to create a memorial panel:

You need not be an artist to create a moving, personal tribute. Whether you choose to simply spray paint on a sheet, or sew elaborate embroidery, is up to you. Any remembrance is appropriate.

- 1. Select a durable and light-weight fabric of any color for the backround. Cut and hem the fabric to 3' x 6'. (We'll hem it for you if you leave 3" extra fabric on each side.)
- 2. Design the letters. Some suggestions:
  Applique: sew letters to background fabric
  Painting: brush letters on with paint, dye, or ink
  Stencil: spray paint cut-out letters
  Collage: glue on material with fabric glue
  Embroider: sew on beads, sequins or rhinestones
- 3. When the panel is complete, take time to write a one or two page description of the person you have memorialized. Tell us what this person meant to you and how you think he or she should be remembered.
  Enclose a photograph of the person if you have one and are willing to part with it we cannot be responsible for returning photographs or other mementos.
- 4. Wrap the panel securely before mailing it to
  The NAMES Project
  P.O. Box 14573
  San Francisco, CA 94114
- 5. Please include as generous a contribution as possible to help us meet our transportation and material costs. All contributions are tax-deductible.

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## 200,000 March in Capital for Homosexual Rights

### By LENA WILLIAMS

Special to The New York Times

WASHINGTON, Oct. 11 demonstration reminiscent of the civil rights demonstrations of the 1960's, 200,000 gay Americans and a diverse coalition of supporters marched here today, calling for more Federal money for AIDS research and treatment and for an end to discrimination against homosexuals.

Many demonstrators said they had



Organizers, who said 300,000 people marched, said it was the biggest gay rights march ever, exceeding one Washington in 1979 that drew 79,000.

"We are here today to show America and the world that the gay movement is larger, stronger and more diverse than ever." said Buffy Dunker, an 82year-old grandmother who announced! 10 years ago that she was gay. "We are: sending a message to our leaders here! in Washington that gays are a united! force that will have to be reckoned! with. And we will be persistent and unrejenting in our pressure."

Cloudy skies greeted the marchers this morning as they spread across the!

come to rekindle the spirit of the 1963 march on Washington led by the Rev. Dr. Martin Luther King Jr. and to seek the kind of political and social agenda that gave birth to the Civil Rights Acts of 1964 and 1965. Those laws banned racial, religious or ethnic discrimination in housing, employment, education and public accommodation.

The United States Park Police said about 50,000 people had gathered by 1 P.M. for the march past the White; House and a raily near the Capitol. By 5:30 the Park Police put the total at 200,000, explaining that it took the aftermoon to make an accurate count of

the marchers.



A demonstrator kneels on a huge quilt that was spread on the Mail. Each panel was dedicated to a person who has died from AIDS.

In a mall and the parklands between the Washington Monument and the Potomac River.

The rally began at 9 A.M. with music and a statement from Dan Bradley, a White House aide in the Carter Administration, who suffers from AIDS.

Mr. Bradley said he took greatest satisfaction in the fact that "after a lifetime of struggle and fear, I had the courage in 1982 to say, loud and clear: 'I am gay and I'm proud.'

#### A Broad Coalition

That message was echoed throughout the daylong demonstration, as a succession of speakers urged participants to stand up for their rights and to fight against the stigmas and sterrotypes often attached to homosexuals.

"We can no longer afford to stand idly by when fellow lesbians and gavs i are being beaten or insulted," John Bush, a longtime advocate for i civil rights causes. "All men are created equal. And we have to stand up j and say, 'We're gay and we're here.' It i is particularly acute for those of us of! color. We've paid our dues and it's been (

## 200,000 March in Washington, Seeking Gay Rights, AIDS Funds

#### Continued From Page 1

painful. It's time we stop paying and start collecting."

Organizers had hoped for as many as 500,000 participants today. Although they did not reach that goal, the march brought together groups representing a range of professions and political and religious affiliations.

At the same time, there appeared to be fewer labor leaders, elected officials and black civil rights leaders than had been expected, although more than 1,000 elected officials, including about 100 members of Congress, and other prominent civic, labor and religious leaders signed letters endorsing the march

#### Address by Jackson

In a speech this evening, the Rev. Jesse Jackson, a candidate for the Democratic Presidential nomination, pledged his support for gay rights, while calling for increased Federal spending on AIDS research and education.

He said: "We gather today to say that we insist on equal protection under the law for every American, for workers' rights, women's rights, for the rights of religious freedom, the rights of individual privacy, for the rights of sexual preference. We come together for the rights of all American people."

Mr. Jackson, noting that he declared his candidacy for the Democratic Presidential nomination on Saturday, concluded his speech by saying: "Today I stand with you, Election Day you stand with me."

Other speakers included two gay members of Congress, Representatives Gerry E. Studds and Barney\* Frank, both Massachusetts Democrats; Eleanor Smeal, former president of the National Organization for Women, and Cesar Chavez, president of the United Farm Workers of America.

#### **Small Counterdemonstration**

Pat Norman, co-chairwoman of the National March on Washington, the organizing committee that sponsored the demonstration, said Mr. Jackson and Representative Patricia Schroeder of Colorado, who until recently was considering a Presidential bid, were the only current or former Presidential hopefuls invited to address the marchers. Mrs. Schroeder declined, citing scheduling problems.

"We wanted Reverend Jackson because his platform embraces the kind of social and political agenda we in the gay community are seeking," Ms. Norman said. "And the gay community also played a major role in his 1984 Presidential bid."

The demonstration was peaceful and generally free of problems, considering the logistics of gathering, moving and tending to tens of thousands of people.

## Memorial Quilt Spread on Mall

Special to The New York Times

WASHINGTON, Oct. 11—The sound of sobs and the reading of names punctured the early morning quiet as pieces of material were unfurled and hooked together, creating a huge quilt intended as a memorial to 1,920 AIDS victims.

The patchwork quilt of panels created by friends, lovers and family members was laid out on the Mall today for the first time at National March on Washington for Lesbian and Gay Rights.

The idea for the quilt originated with Cleve Jones of San Francisco, who lost his friend and companion of 14 years, Marvin Feldman, to in 1986.

In July, the Names Project opened an office in San Francisco. "People just started walking in carrying pens, pencils, industrial sewing machines," said Mike Smith, general manager of the Names Project. "This is a way to get over the fear, the sadness and the paralysis."

The quilt, which measures about 150 feet by 470 feet, cost about \$50,000, mostly in small donations, to complete and transport, he said.

As the marchers made their way down Pennsylvania Avenune, passing in front of the White House, they were greeted by a small group of counterdemonstrators, carrying banners and signs, one of which read: "God is Angry with the Wicked." But the marchers, who had pledged to avoid a confrontation, responded by singing, "We Shall Overcome," considered the anthem of the civil rights movement.

The demonstration, which had a festive atmosphere, also had somber and serious moments.

"This isn't a parade." said Kay Osterg, a co-chairwoman of the march. "We have our gav rights parades to give us a sense of community, so we won't feel alienated. This is a march for freedom."

One of the most moving moments came when the actress Whoopi Goldberg greeted several AIDS sufferers seated in wheelchairs.

A tearful Ms. Goldberg embraced each of them at the south end of the Capitol, whispering, "God bless you." "This isn't about AIDS," Ms. Gold-

berg said in an impromptu news conference. "It's about human rights. I've lost 60 of my friends to AIDS. I'm here for me, my friends, my daughter and all of those who are surfering."

## Christian Lobbyist Speaks Out

## Gay Rights March Could 'Backfire'

## By Jerry Roberts Political Editor

The huge gay rights march on Washington could "backfire," ushering in a new period of hostility towards homosexuals, the leader of the nation's largest conservative Christian lobbying group said yesterday.

"This march of 200,000 sodomites and their lobbyists may further heighten the groundswell of reaction to the position of the homosexual community," said Robert Grant, chairman of Christian Voice.

"When you concentrate a couple hundred thousand people in a mock marriage ceremony and all kinds of similar nonsense," he added, "the average Joe Citizen looks at that with utter amazement and contempt and says. There are a lot of these people, and these are the people creating the health menace."

Grant's comments came in an interview in San Francisco, where he attended an unpublicized leadership conference of politically active, conservative evangelicals.

Christian Voice, a 10-year-old organization, maintains a political action committee and a full-time lobbying staff on behalf of what it describes as "family and traditional value issues."

Credited with playing an important role in President Reagan's two successful presidential campaigns. Christian Voice also distributes "moral issue report cards" on legislators and members of Congress across the nation as a guide to its 350,000 members.

Grant said Sunday's huge Washington march by gays and lesbians demanding a more vigorous federal fight against the AIDS epidemic could have an opposite effect.

"It could backfire on the gay community." Grant said, by heightening fears about AIDS and lending more credence to political efforts to impose widespread compulsory testing or even quarantines.

"That was a dumb move," he said of the march. "When the gay community) is already nervous about the supposed gains they have made and there is a direct linkage between homosexual behavior and a national health crisis, you don't get on television and parade the

"AIDS is clearly going to be a hot political issue" in the 1988 presidential race. Grant said, predicting it could spell trouble for "liberal Democrats. who are going to be hard pressed to deal with it."

fact."

Christian evangelicals have become increasingly visible in presidential politics in recent weeks, with the entry into the race of the Rev. Pat Robertson and several victories by his supporters in early organizing skirmishes in key primary states.

Grant said it was "dumb politics" for backers of Vice President George Bush to have circulated learlets urging Republicans to "keep religion out of politics" in organizing against Robertson in Michigan and for a party leader in South Carolina to have compared a Robertson meeting to "a Nazi pep rally."

"If the same rhetoric was used against Jews and blacks, it would be front page news," he said.

#### 5. THE JUDGEMENT OF HISTORY?

As the number of AIDS cases continues to increase around the country, as public awareness of the complexity of the related social problems grows, as more and more people realize that current prevention efforts are inadequate, and the failure of national leadership becomes obvious, even traditional voices and solid "middle of the road" publications such as the New York Times are beginning to worry.

In fact, on the eve of the Washington DC Gay Rights March the New York Times printed one of its sternest editorials ever on any subject. In unusually strong language, it accused the Reagan administration of endangering the health of the country and predicted a harsh judgement of history.

This editorial itself may, in the future, be seen as a historical document, marking a turning point in the American public debate on AIDS. It may also serve as a warning to other governments in other countries, that they have no time to lose developing and enforcing a vigorous AIDS prevention policy. Because of its significance the editorial is reprinted in full on the next page.

## The New York Times

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## The Reagan AIDS Strategy in Ruins

While the AIDS epidemic gets its grip on America, Mr. Reagan's Administration spouts, postures and neglects effective measures to curb it.

The President's commission on AIDS has begun to self-destruct. In July, the White House charged a panel of members, almost uniformly unqualified, to develop a national strategy. After three months of inaction and bickering, the staff director was ousted, and last week the chairman and vice chairman resigned.

Retired Adm. James D. Watkins, former Chief of Naval Operations, is to be the commission's new head. He is an able leader but knows even less about AIDS than his fellow commissioners. To expect this motley group to develop a competent strategy is like asking a panel of physicians to design the Navy's next attack submarine. The White House has no AIDS strategy and a commission with no chance of producing one.

Users of intravenous drugs are the main conduit by which the AIDS virus will spread further. Infecting each other by sharing needles, they may pass on the virus heterosexually to their partners. The Administration's top practical goal in curbing AIDS should have been to insure, years ago, that treatment was available for any addict seeking to quit drugs. Yet a shortage of drug treatment spaces persists throughout the country. Some addicts still must wait a year for treatment.

New York, unlike most states, has found money to expand its programs but community groups and local leaders have thwarted construction of any new treatment centers. So the state needs 8,000 more treatment spaces to eliminate its waiting lists. Meanwhile, those 8,000 addicts continue to spread the AIDS virus among themselves and their sexual partners.

If the AIDS virus breaks out from homosexuals and drug addicts, the first group likely to become infected are those at risk from other sexual diseases. A top priority of any serious AIDS strategy would be to educate such people in the use of condoms to protect against such diseases.

But syphilis has increased by 35 percent this year, and has roughly doubled in New York City and Los Angeles. Experts have not seen such a dramatic rise in 20 years. By this yardstick, Administration efforts to protect heterosexuals against the spread of AIDS have proved wholly ineffective.

AIDS is the most serious threat to public health in decades. Historians will look back in astonishment at the Reagan Administration's flaccid response during the first eight years of the epidemic's spread. They will ask how any President could fail to implement the most obvious public health measures, or tardily assign the making of national strategy to a quarreling commission with no recognizable expertise. They will wonder how his Cabinet members could be torpid spectators of the virus's spread, seeing it only as a pretext for impressing their own morals on others.

But the wondering historians will find no answers. Mr. Reagan's refusal to lead, to take a personal interest in AIDS or set a policy and see it effectively conducted is beyond comprehension or excuse.

SUNDAY, OCTOBER 11, 1987

Edination

## XIII. SUMMARY AND RECOMMENDATIONS

In the fall of 1987 the American epidemiological AIDS picture as such offers no surprises. The number of newly diagnosed cases continues to rise as anticipated. The only hopeful sign is a clear decrease in new HIV infections among homosexual and bisexual men who have been reached by extensive risk reduction campaigns. On the other hand, the spread of the virus among IV drug users continues unabated with the potential of reaching their sexual partners. The danger is particularly acute in Black and Hispanic urban ghettos, where IV drug use is rampant and where a recent sharp increase of syphilis has been observed.

Unfortunately, in spite of a well-advertised "war on drugs," the present administration has not provided sufficient funding for drug treatment centers so that even those drug users who want to "come clean" have to wait many months for an available "slot" in a detoxification program. If they are infected with HIV, they are likely to infect others during this waiting period. The problem here is quite clearly a political one: IV drug users do not vote and do not represent a powerful constituency for a politician. On the contrary, they are among the most stigmatized and unpopular groups.

With certain qualifications, this is even true for the group of homosexual and bisexual men. In many parts of the country they suffer outright discrimination and their sexual behavior is defined as criminal in nearly half of the states in the U.S.

Since, at the moment, AIDS affects mostly groups that are either widely defined as deviant (IV drug users, homosexuals and bisexuals) or are the object of persistent racial prejudice (Blacks and Hispanics), the prevention of this disease is not considered a high priority by many government officials and private citizens. The clear warnings and recommendations of public health professionals notwithstanding, and in spite of the well-reasoned proposals of the National Academy of Sciences, the necessary drastic steps have not been taken. What has been done so far remains "too little and too late."

As far as the five cities visited for this report are concerned, their likely future with regard to AIDS can be summarized as follows:

New York, Chicago and Los Angeles, which have a large IV drug-using populations as well as Black and Hispanic ghettos, are likely to turn into "AIDS disaster areas" over the next few years. They will have to deal with an enormous number of patients, many of whom will be unable to pay for their treatment.

The Twin Cities of Minneapolis and St. Paul, with their racially homogenous white populations, will find themselves well prepared for the epidemic as will the entire state of Minnesota. If any major problem should develop, it might be as a result of breaches of confidentiality in connection with Minnesota's mandatory reporting program ("Meldepflicht").

San Francisco, like the other large cities, will also have to take care of a very large number of patients for many years. However, the city may eventually experience some relief, because most of its AIDS cases are and will be homosexual and bisexual men, a group in which new infections have now become rare. This is the result of the city's extraordinary prevention efforts. If San Francisco's IV drug-users and Black and Hispanic minorities can be similarly educated, the distant future in San Francisco may look relatively hopeful.

It seems that the vast heterosexual majority is not in any immediate danger of infection at this time. Many public health experts fear, however, that this could change if no comprehensive AIDS education effort is made. In particular, heterosexual women with multiple partners and teenagers experimenting with drugs and sex may already be in danger of infection today. The experts believe therefore that it would be a tragic mistake to portray AIDS as a disease of unpopular minorities.

Members of these minorities themselves, as far as they do become ill, will increasingly suffer from discrimination. They will first feel neglected, then abandoned, and finally betrayed, and it is therefore not inconceivable that they will turn to violent protest along the lines indicated by Larry Kramer in his interview (see XII, 4, Words of Warning by an Activist, pp. 455-459). This potential for social unrest is one of the most worrisome aspects of the unfolding AIDS epidemic, because it can start a vicious cycle of repression which would aggravate the medical tragedy and lead to an unmanageable political situation.

The actual AIDS policies that are being pursued in the United States today represent a mixed bundle of uncoordinated and sometimes contradictory principles. A serious threat to the nation's health such as AIDS can, in principle, be met in two mutually exclusive ways: 1) the responsibility can be put on each individual citizen who retains his freedom to decide for himself, or 2) it can be assumed by the government which restricts the freedom of its citizens and decides for them.

The first strategy aims at educating all citizens to the point where they can make informed decisions to protect themselves. However, it follows logically that these citizens must assume all of their new sexual partners to be infected. Consequently, in every new sexual relationship both partners must practice safe sex unless and until their relationship remains exclusive for several years and/or by some mutual private agreement, they both obtain repeated negative HIV-antibody test results.

It is understandable that the average man and woman does not look foreward to shouldering such a burden. Instead, many would perhaps prefer to delegate the responsibility to the government. The government, however, can guarantee the health of potential sexual partners only by vigorously "weeding out" all those that are infected. This could be accomplished by ever more widening mandatory test programs and by isolating, for the rest of their lives, all those who are found to test positive. In theory, this would ensure that all those who remain at large are free of the virus. Thus, the individual citizen would not have to change his or her behavior in order to avoid infection. The state would have "taken care of the problem." However, any closer study of this proposition reveals that, in practice, no government can give the desired guarantee. Tourism and business travel alone, upon which modern economies depend, would either make a mockery of the mandatory measures or would have to be eliminated altogether by government fiat. No modern government can afford to take the latter step.

There seems to be no other workable solution than to choose individual freedom over government regulation and to educate every individual in AIDS prevention. This is, in fact, the postion taken by American public health professionals. As repeatedly mentioned in this report, however, they find themselves increasingly frustrated by politicians who are trying to assert government control over individual behavior, and who are responsible for mixing the above described irreconcilable strategies. The result is public confusion.

No matter how the political struggle is eventually resolved, it seems safe to make at least one assumption: HIV-antibody testing, both voluntary and "routine," is going to increase all over the United States. Indeed, even mandatory testing is likely to target ever larger segments of

the population. The reason for this is both economical (testing makes money and creates employment) and political (testing allows for the control of "undesirables").

From a public health point of view it is, of course, well worthwhile to test as widely as possible among those potentially infected. Learning one's seropositivity status might even become life saving once prophylactic drug therapies are available. Moreover, expert post-test counseling can help the infected to make their sexual behavior "safe." Obviously, however, such a testing program can be successful only as long as it remains voluntary and confidential. (In many cases, outright anonymity may be the best solution.)

The actual expected increase in testing programs (both voluntary and involuntary) is likely to lead to two major problems:

- 1. Increasing breaches of confidentiality and subsequent discrimination.
- 2. A lack of adequate post-test counseling and subsequent failure to prevent new infections.

As to confidentiality, it is true that many public health services (such as that of Minnesota) have an excellent record of keeping their files confidential. However, "routine" testing in hospitals or as a condition for employment is quite another matter. It is to be feared that under these conditions test results may become known to a wide range of "interested parties" or may lead to discrimination without becoming known. If this happens, more and more people will resist being tested, which, in turn, will prompt the government, hospitals, employers, insurance companies etc. to become more insistent. This will increase the resistance, which will increase the insistence, and so on, leading unavoidably to more and more mandatory testing. The resulting problems could be avoided only by very strong anti-discrimination laws. At the present time, however, the prospect for such laws does not look good either on the federal or the state level.

As for post-test counseling, the future may see the present counselors overwhelmed by an enormous increase of the demand for their services. It seems likely that counseling services will not be expanded as rapidly as the testing programs. Furthermore, most testing and counseling will probably take place in the offices of private physicians. The average physician, however, is ill-equipped to be an effective counselor. After all, he not only has to explain the meaning of the test (something he can easily do), but he also has to provide psychotherapeutic support. Most importantly, he has to explore with his patient (and ideally with the patient's partner) his or her individual sexual pattern and then try to change it in the direction of "safety." And this has to be done not once, but repeatedly in order to be effective. In the average physician's practice there is no time for such intensive and repeated counseling, and, above all, there is no provision for an adequate reimbursement. Ultimately, the task may have to be relegated to specially trained persons in the physician's employ, such as nurse practitioners. Even then, however, the problem of reimbursement will have to be faced. If nothing along these lines is done, however, it seems safe to predict that AIDS prevention will break down at this crucial point and that the expanded testing programs will end up doing more harm than good.

A recent study by a Harvard medical historian has put AIDS in some historical perspective. Allan M. Brandt, in his book No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880 (expanded edition, 1987, Oxford University Press: Oxford and New York), says of all sexually transmitted diseases, expressly including AIDS:

"The old scare tactics have failed; denial and repression of sexuality have failed; victimblaming and moralizing all have failed as effective public health mechanisms. While biomedical solutions offer much hope, they too have failed to free us of infectious disease. More creative and sophisticated approaches to this set of diseases are necessary. Now that we recognize that behavioral changes may be a significant factor in disease, we know that new techniques to assist those who seek to change are required. Moreover, we must recognize that behavioral change does not mean encouraging celibacy, heterosexuality, or morality; rather, it means developing means to avoid coming into contact with a pathogen." (pp. 202-203)

Sharing the belief of most of his interview partners, that successful AIDS prevention is impossible without the support of a well-informed, rational public, and realizing that American prevention efforts are still inadequate at this late stage, the author of the present report makes the following urgent recommendations:

- Establish a permanent transatlantic information bridge, taking advantage of the insights gained developing American AIDS prevention programs. A small archive in San Francisco could be established, for example, to collect and analyze relevant materials, sending them to Germany as the need arises. The archive could also produce reports such as this one on a regular basis.
- Establish a German national "AIDS think tank." There are, of course, several interdisciplinary academic institutions in existence in Germany. However, so far, they do not seem to have turned their full attention to the impending national health emergency. It may be necessary, therefore, to create a new interdisciplinary governmental or private AIDS institute along the lines of the Hudson Institute (see XII, 2, pp. 422-441). Another example would be the Hastings Center in Hastings-on-Hudson NY, which has produced several research papers on the socio-political and ethical questions related to AIDS. Obviously, such an institute would have to establish and maintain strong international links and would need constant input from appropriate foreign sources such as the one proposed above.
- Initiate and support a broad range of socio-political research projects related to AIDS within the established German academic institutions (universities, institutes, centers, academies etc.). Again, this research should have an international orientation and should therefore involve not only the German Research Community (DFG) but also the German Academic Exhange Service (DAAD).
- Initiate and support a series of conferences. These conferences should be of two basic types:
  - 1. Experiential retreats for policy-makers and community leaders along the lines of the Minnesota Spring Hill AIDS Conference (see VIII, pp. 344-354). These conferences should be held in every German state, ideally in remote centers such as the Evangelische Akademie, Tutzing.
  - 2. A series of public congresses moving through all major German cities and addressing both the actual and potential epidemiological and socio-political developments. These congresses would be a major tool in educating the mass media and the general public.
- Convene a special meeting with the general directors ("Intendantenkonferenz") of the two major German television networks in order to ensure an adequate public education campaign through the media. The present haphazard programs, which are initiated by various department heads ("Ressortleiter") are, as a whole, entirely inadequate and must be replaced by a single well-designed, structured campaign planned several years in advance in cooperation with all networks. Network competition can have no place in such a campaign in view of the

grave crisis confronting the entire country.

■ Create a national professional AIDS prevention organization along the lines of the San Francisco AIDS Foundation. This new organization should be at least semi-autonomous and should receive both public and private financing. It should act as an umbrella and protective shield for all existing prevention programs, self-help groups, etc. Such a large organization is necessary in order to spare the government potentially embarrassing situations. For example, an independent prevention organization can more easily develop and conduct detailed and drastic "safe sex" programs and seminars in all sorts of locations. At the same time, it can much more easily and generously support private self-help initiatives. Indeed, it can protect such initiatives from undue policial pressure.

Some of these recommendations have already been made in the previous report of April 30, 1987. They are repeated here with an added sense of urgency because the American experience within the last six months has shown how short the time really is for any preparation.

In addition, and for the same reason, this report itself has incorporated a great deal of "working material" that can immediately be copied and applied. Although the Federal Republic of Germany and other European countries still lag several years behind the American developments, they run a serious risk of arriving at the same crossroads as the United States sooner than they think. They should do anything in their power now to avoid politicizing the AIDS debate. Once public health strategies become embroiled in partisan politics, even the best prevention efforts may become ineffective. The time to educate the public and to win its support for sensible public health measures is now.