THE PRESIDENTIAL COMMISSION on the HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

Preliminary Report to the President

December 2, 1987

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

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Admiral James D. Watkins (Ret.)

DEC 2 1987

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of all members of the Presidential Commission on the Human Immunodeficiency Virus (HIV) Epidemic, I submit to you our preliminary report. According to provisions of your Executive Order, this report was to be submitted on December 7, 1987, the specified 90 days after the Commissioners were officially designated (September 9, 1987). Having finished our preliminary work, including identification of several areas of concern which will need special focus in the near term, we wished to submit this report early to get on with fulfilling the many assigned tasks demanded of us by the final reporting date of June 24, 1988.

In order to place in priority the wide range of efforts needed to address the complex issues raised by the HIV epidemic, and to identify obstacles to progress in AIDS prevention, cure and care, we met with those who are on the front lines of this infectious disease. We have heard testimony and presentations from more than 200 individuals, most of whom are AIDS patients, family members of persons with AIDS, volunteers and staff of many community-based and religious organizations, health care providers, and local, State and Federal Government officials charged with responsibilities of directing AIDS-related efforts.

One observation that we can clearly make from testimony to date is that there is, both in reality and perception, significant disagreement and controversy at all levels of decision making, public and private, about the many difficult issues surrounding AIDS.

However, as is often true in the most difficult of situations, a large body of Americans, particularly those volunteers and staff of community-based organizations, have responded tirelessly to challenges placed before them by the HIV epidemic. The Commission has been deeply

impressed by the heroic spirit of self-sacrifice, helpfulness and compassion which members of community-based groups and church organizations have demonstrated in meeting previously unmet needs of persons with AIDS.

Consistent with your request that our report be prepared in a timely fashion, a rigorous hearing schedule has been developed. Additionally, we see a number of emergent issues that cry for early resolution and may require one or more substantial interim reports before June. For example, four issues that fall into this category will be the subject of our work in December and January and should allow us one interim report to you in February 1988.

On the first of these issues, the question is raised as to why there is still so much debate over the estimates of prevalence of the HIV infection. A meaningful response to the epidemic is made significantly less conjectural by a valid baseline of data. Answers to so many of your challenges to us in the Executive Order depend heavily on reliable prevalence information.

Second, the need for home health care programs and other out-of-hospital care programs for AIDS patients is enormous, yet the reality at the local level is that many AIDS patients do not have access to alternative care settings. Alternative care settings available in adequate numbers are urgently needed.

Third, there are still too few drugs available for use by AIDS patients and HIV-positive individuals. The deadly nature of AIDS demands new and streamlined approaches to drug and vaccine development.

Fourth, intravenous drug abuse is one leading method of HIV transmission, and yet there seems to be a large gap between demand for both services and treatment programs, and actual programs available. For example, in-patient and out-patient drug abuse treatment programs are still unavailable to many HIV-infected individuals. Yet we know that without such programs there will be little chance to halt the growing spread of the virus among this segment of the population.

On these issues and more, we will provide recommendations so that obstacles to progress in prevention, care and cure in the AIDS epidemic can be addressed aggressively and eliminated in both public and private sectors.

The HIV epidemic will only be controlled by developing a national strategy that combines the best research, health care, legal, educational, public health, and financial wisdom available. In the challenging months ahead, the Commission will seek to develop a body of insight and experience from the country's best experts, so that together we can find answers to this devastating problem. I believe the Commission is now on a solid footing to do just this. We are also encouraged that we can carry out the demands of your Executive Order within the time allotted.

Respectfully,

James D. Watkins
Admiral, U.S. Navy (Retired)

Enclosure

PRELIMINARY REPORT

of the

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

Admiral James D. Watkins (Retired)
Chairman

December 2, 1987

PRESIDENTIAL COMMISSION
ON THE HIV EPIDEMIC

PRELIMINARY REPORT

December 2, 1987

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Introduction

The Executive Order creating the Presidential Commission on the Human Immunodeficiency Virus (HIV) Epidemic mandates an examination of a broad range of specific issues regarding the HIV epidemic. Results of these investigations will be used to make recommendations to Federal, State, and local officials, as well as the private sector, on measures to protect the public from contracting HIV, to facilitate development of a cure for AIDS, and to best care for those who already have the disease.

Issues surrounding the HIV epidemic are complex, and each has potential to evoke impassioned discussion reflecting fears of a society confronted by a fatal disease for which there is no known cure. Questions about validity of epidemiologic projections, the burden placed on clinical and research medicine to offer both immediate aid and future solutions, societal attitudes toward sexuality and substance abuse, and difficult economic and financial realities of the epidemic, all challenge the Commission to develop practical solutions that are both immediately relevant and forward looking.

The Commission, hearing the pleas of those infected with HIV and their families, who must live in a world in which hope continues to wane, has begun intense investigations into its chartered areas, because answers must be found quickly. One area of

immediate concern is direct patient care and support for those who have already contracted the virus. A second set of issues involves securing the health of those who have not been infected. A third set of issues is associated with the rapidly increasing body of knowledge regarding retroviruses and drugs that affect them, leading the search for a vaccine and a cure for HIV-related illness.

The Commissioners realize the urgency of their task, as well as the complexity of issues before them. Each member is sensitive to the fact that an honest confrontation with the HIV epidemic forces into public discussion the most intimate acts of human behavior, as well as an open recognition of widespread illegal activity surrounding drug abuse. This Commission will deal directly with these and other controversial issues, such as discrimination and the protection of both individual civil rights and the general public health, and will confront each and all in an extensive course of public hearings. (Appendix A: Hearing Schedule)

The Commission recognizes that education is a pivotal measure for preventing continued spread of the virus, and is examining types of information disseminated, whom the information actually reaches, and whether or not it is effective in both informing the public and reducing the risk of infection. Behavior modification counseling and therapy are critical resources for both those who are infected with HIV and those who are not, to change or

eliminate behaviors that allow virus transmission.

Further, so that some measure of hope may be given to those infected by HIV, the health practices which have been demonstrated in other immunosuppressive diseases to prolong life must be identified and communicated. The Commission will hear testimony regarding these health behaviors, their role in influencing the progression from an asymptomatic to symptomatic state, and their potential to prolong or improve the quality of life for the HIV-infected individual. These measures would prove to be especially vital during the period in which effective drug therapies for HIV are still under development.

New information about HIV is breaking rapidly, and valid channels of communication between researchers, health care professionals, their patients and the general public have become increasingly critical. During the course of its term, the Commission will seek to determine the means by which the public can be better informed, and through which the partners in the finance-research-health care provider-consumer chain can better communicate.

Executive Order

To meet the goals mandated by its Executive Order, the Commission is undertaking a series of thorough evaluations of the following aspects of the HIV epidemic: incidence and prevalence of HIV infection; educational efforts planned and underway, and their

degree of effectiveness; anticipated economic impact of the epidemic; the epidemic's effect on the health care delivery system; the direction of AIDS-related research activities, including drug and vaccine development; legal and ethical issues; and the role of the U.S. in the international AIDS pandemic. (Appendix B: Executive Order) Within each of these major areas, as well as within subsidiary areas, we will seek to clarify the status of the problems relative to the HIV epidemic, identify the obstacles to progress, and make recommendations for their removal.

An enormous amount of work related to the HIV epidemic has already been completed or is in progress by a wide variety of individuals and institutions throughout the country, and the Commission does not intend to duplicate such efforts where the data prove reliable. The Commission has heard and will continue to hear testimony from the country's leading experts in every field affected by the HIV epidemic, and from every field that may help find answers to the great problems posed by the epidemic.

More than two hundred individuals representing information and care agencies, practitioners, public health workers, and researchers, as well as persons with AIDS and their families, have volunteered information and assistance to the Commission as it proceeds to establish its own resource network. To all those who have volunteered their help and testimony, the Commission has extended an invitation to submit recommendations and to maintain

contact during the course of its deliberations. The doors of communication will remain open to all who come forward to help us in our work.

Substantive answers necessary to construct meaningful recommendations will be developed through a variety of mechanisms. This preliminary report is based on testimony received in hearings, information gathered first hand on site visits, Commission members' expertise and debate. It describes the method the Commission will use to assemble the data necessary for its final report.

Where We Have Been: A Baseline Review

Since the Commission's inception, testimony has been submitted and information received from a wide variety of sources, broadly categorized as Federal, State, and private sector or community-based. The complexity of issues surrounding the HIV epidemic, the multiplicity of information sources, the fact that the epidemic in the United States is now several years in duration, and increasing individual and national anxiety in response to its growth have necessitated the Commission's first clearly articulated task: to sort out and clarify the information available on the HIV epidemic.

To accomplish this, the Commission called for a baseline review, an assessment of where we are as a nation in response to this

epidemic. We have sought and received testimony from the heads of Federal departments and agencies, had a detailed briefing on the status of State legislation, and held site visits and hearings in three high impact communities to hear from the people most immediately affected--persons with AIDS, their families, and those responsible for providing and funding their care.

The following is a brief description of testimony received and information gathered under each of these broad headings. A summary of the testimony from each witness who has appeared before the Commission through Nov. 12, 1987, can be found in Appendices C and D.

The Federal Government and Legislation

Representatives from more than twenty departments and agencies within the large and complex structure of the Federal government have testified before the Commission to date. Their testimony has laid the groundwork for the Commission's oversight function, and has clarified roles played by each department and agency, as well as the coordinative function of intra- and inter-agency AIDS-related task forces and committees.

Departments and agencies represented include the Office of the Secretary, Department of Health and Human Services; Health Care Finance Administration; Office of the Surgeon General; National Institute of Allergy and Infectious Diseases; Centers for Disease Control; Alcohol, Drug Abuse and Mental Health Administration;

Health Resources Services Administration; Food and Drug Administration; Veterans Administration; and Departments of Labor, Defense, State, Education, and Justice. (Appendix C-1)

We have opened channels of communication and information exchange with these departments and agencies, and will continue this dialogue as our work proceeds.

The Commission has been briefed about the more than fifty pieces of Federal legislation pending before the United States Congress on the wide range of HIV-related issues, many of which have been the subject of contentious debate in the past year. A number of members of Congress have been extremely helpful in the Commission's work, and will actively participate in forthcoming hearings. Their expertise, advice and personal involvement is greatly welcomed by all Commissioners. (Appendix C-2)

State Programs and Legislation

The Commission heard testimony provided by the George Washington University Intergovernmental Health Policy Project, based on its work, AIDS, a Public Health Challenge, commissioned by the Department of Health and Human Services, and released in October of this year. This three-volume document presents a comprehensive review of AIDS-related state legislation and programs, both existing and pending. (Appendix C-3)

Testimony outlined health policy issues within the jurisdiction of state and local governments that have direct impact on the HIV epidemic. These include, among others, the activities of state and local health departments, access of individuals to treatment for illness, licensure of health care professionals, development of educational priorities and curricula, Medicaid reimbursement rates and eligibility, and regulation of the insurance industry.

Testimony indicated that many states have taken steps, including the enactment of legislation intended to meet the immediate HIV-related health needs of their citizens. It was reported that some state and local governments have learned a great deal about management of HIV-related patient care, psychosocial aspects of the disease, funding requirements, and obstacles within the law, public policy and health care systems that have affected their ability to deliver appropriate public health and medical care.

What is clear is that as areas of the country have witnessed the need for action, some state and local governments have responded well, but that this level of response is not universal. The response in many instances has not been proportional to the level of spread of HIV, and further understanding of the dynamics of state efforts may help in planning responses elsewhere. Existing organizations of state and territorial health officials have shared information on the HIV epidemic, and this information should also be shared on a regular basis with other public officials, legislators, and the private sector.

The George Washington University study covered legislative proposals considered through June, 1987, and therefore serves as a baseline review for this area of our study. The Commission will continue to follow state legislative and policy actions throughout its term, and will call for a comprehensive update in the spring of 1988, before issuing a final report. The Commission will also hear directly from state and local public health authorities regarding the application of new and existing statues on the control of this epidemic, and about programs which show the most promise of success. This testimony will create a better understanding of both the dynamics of decision making at the state and local levels, and the forces which might support or hinder the national effort to control the epidemic.

The Private Sector

The Commission is aware of the many private sector efforts underway that have made major contributions, especially in the areas of research, education, and patient care. We have begun to receive testimony on such efforts and will hear substantially more in the future. The Commission is especially interested in partnership activities between the public and private sectors. Listed below are two major areas of private sector activity on which the Commission has heard testimony to date.

Community-based organizations

Throughout much of the nation, community-based organizations serve as initial points of contact for, and provide primary assistance to, the individual seeking information about AIDS. In some locations, these organizations also provide care to individuals with AIDS who may otherwise be left without assistance. As a group, community-based organizations, and in particular those in the gay community, were the first to respond to the HIV epidemic, even prior to the official diagnosis and designation "AIDS."

The community-based organization is typically staffed by volunteers, and must annually raise sufficient funds from private and, in some cases, public sources to meet its costs. Most of the AIDS-related organizations were created in response to a growing crisis in their community that was not being adequately addressed. Many are minority or special-population based, and work within specially defined cultural or communication networks. Many religious organizations have also been leaders in providing compassionate patient care.

During its hearings and site visits to New York City, San Francisco, and Florida, the Commission heard testimony from individuals who work in these organizations, and individuals who are served by them. A list of participants in each of these visits can be found in Appendix D. In each instance, the Commission was impressed with the often heroic spirit of self-

sacrifice and tireless devotion to their work of the volunteers. Clients related their critical need for services provided by these organizations, and frequently stated that they were unable to receive similar services elsewhere.

One area in which community-based organizations have provided unique assistance is in development of alternative care settings and congregate living facilities. Based on the biodynamics of AIDS, care providers have begun to pursue unique case management approaches as an alternative to totally hospital-based care. In non-acute phases of illness, the AIDS patient can be managed as an outpatient, or with in-home care. In many locations, the number of homeless people with AIDS (PWA's) has necessitated creation of special congregate housing for individuals who have lost their means of support and their homes.

In each of these instances, community-based organizations, most prominently those in the gay community, have demonstrated an ability to step in and fill the void left by municipal or other governmental entities, offering creative approaches to problem solving, and often leading the way for government to respond. Solutions offered for housing and home-based care have proven to provide the greatest assistance to the individual in the most cost-effective and compassionate manner, allowing the individual to remain independent.

Obstacles to progress cited by community-based organizations were four-fold:

- care provider fatigue and "burnout,"
- insufficient funds and volunteers to meet the growing need for services,
- municipal ordinance and zoning restrictions, and
- lack of communication within the service-providing network and between the network and appropriate government agencies.

Zoning restrictions are being challenged in some locations. Regulations and ordinances are being addressed and, in some areas, gradually modified on a case-by-case basis. Although many community-based organizations have greatly enlarged their volunteer and contribution base, problems of funding and worker fatigue remain a serious threat to their continuing ability to provide services.

National AIDS-related organizations that serve as multi-agency coordinators have begun to emerge, and have helped to build stronger communication and support networks. Many of these organizations serve specific population groups, such as national minority coalitions, while others combine community-based non-profit organizations with business and other profit sector entities on an information and resource sharing basis.

University and Hospital-based Research Facilities

Research on retroviruses, new drugs and vaccines is currently underway in three types of settings in this country: in the laboratories operated or funded by the Federal government; in private sector chemical and pharmaceutical companies; and in settings funded by both the public and private sectors, such as university and hospital-based laboratories.

While in Florida, the Commission visited one such research center, the P-3 biosafety-controlled virology laboratory at Mt. Sinai Medical Center, in Miami Beach. Commissioners were briefed on virology research in general, and latest developments in retrovirus research in specific, and were given the opportunity to enter the laboratory to observe living virus-infected tissue, following strict biosafety precautions.

This first hand experience was invaluable for the Commission, and will serve as a baseline from which to evaluate extensive future testimony required to adequately address both research and workplace safety issues.

Process for the Future: Identify the Obstacles to Progress in Prevention, Care, and Cure

The broad mandate provided in the Commission's charter necessitates immediate action in areas of critical importance. Where it is found that issues are already being addressed

adequately, the Commission will acknowledge these successful efforts and accept their conclusions, and turn its attention to the most serious remaining obstacles to progress in the primary areas of prevention, care and cure.

To structure its investigations and deliberations, the Commission has developed a comprehensive outline that will serve as the format for its final report. This outline will be used as the baseline from which we conduct our investigations, and although we consider it comprehensive and complete, the Commission recognizes that adjustments may be made as deliberations dictate. (Appendix E: Final Report Format)

Based on areas of individual expertise, Commissioners will chair comprehensive hearings and lead team investigations into specific aspects of the HIV epidemic. The Commission believes that the public hearing format is the most productive method for obtaining the necessary information from all segments of society, as well as in some instances being an effective means to bring new information to the public. Additional site visits and hearings in Washington, D.C. and elsewhere will be necessary in order to see first hand the efforts being made on local and state levels, and to hear from individuals who might otherwise be unable to address the Commission.

Review Groups

In an effort to obtain the assistance of experts in specific areas of its work, the Commission will form review groups comprised of individuals with proven abilities in those areas. Groups currently formed or under consideration include experts in the disciplines of medicine, law, public health, and finance, as well as those with expert experience-based information on minority communities. The Commission may form additional groups in areas dictated by its work.

Physician Review Group

The Commission's first such team, the Physician Review Group, has been established, and met for the first time on November 6, 1987. This group is composed of clinical and research physicians with specific areas of recognized expertise related to HIV, and will continue to meet periodically. Members of this initial group reside within the Baltimore-Washington-New York area, facilitating continuous access at minimal cost to the taxpayer. (Appendix F: Physician Review Group)

The purpose of this group is to evaluate incoming data for scientific and medical validity, and to advise the Commission on structure and approach to problem-solving when addressing specific medical and research issues.

A second outside review group, the Health Sciences Review Group, is currently being organized. This group will be composed of

clinicians and scientists of national stature or international stature, each of whom has made major contributions within the fields of HIV treatment or research. This group will meet when required to provide the Commission with the highest level review of conclusions and recommendations for accuracy, completeness, and scientific merit.

A General Call

The Commission is issuing a general call to the health care community, inviting specific and direct input from health care providers involved in day-to-day care of patients with HIV-related disorders, other health care professionals, and from researchers at each level within the HIV research arena. This general call is designed to be mediated through a prominent health care journal, and seeks to identify for the Commission perceived obstacles to progress encountered by "front line" personnel. Through these and other mechanisms, the Commission intends to achieve a thorough understanding of clinical care and research experience, progress and needs.

The Commission will issue a similar call to the public health and education communities in an effort to solicit the best information and assistance available in the areas of prevention, education, and behavior modification.

Reimbursement issues

Problems of reimbursement associated with non-physician provided, and non-hospital based care must also be addressed, as well as other reimbursement issues such as the gap between Medicaid reimbursement rates and actual hospital costs, and the variability of Medicaid reimbursement for AZT and other HIV therapies. In one hospital we visited, the Medicaid reimbursemnt rate for AIDS patients was approximately 60% of the actual hospital cost, thereby placing demand on charity or bad debt funds, or driving the cost for other patients higher. The Commission will examine this issue together with Medicaid and hospital officials.

The relationship between the federal and state governments in the provision of essential services, and the determination of eligibility for services will be examined. These and other difficult reimbursement issues such as insurance eligibility and coverage will be addressed in a series of finance hearings already scheduled by the Commission.

Some Critical Areas Which May Require Interim Reports

The Commission has targeted some areas in which it will gather and evaluate testimony in the immediate future, to make recommendations that could be of near-term benefit to individuals with AIDS, their families, their health care providers and those

involved with allocating funds. These areas are:

Incidence and Prevalence: Estimates of the incidence and prevalence of HIV infection vary widely, and it is unclear to the Commission why there is still debate over disease projections. In planning prevention and care strategies, there is a clear and pressing need to gain a concrete assessment of the number of people who currently may be infected, and the number that may be expected in the future. This information is critical in determining the size and target of resources allocated for prevention programs, education, and health care.

In order to understand fully the many aspects of incidence and prevalence of the disease, the Commission will need to hear from many experts. These would include: federal and state, and local health officials; experts on special populations, i.e., gay and bisexual men, hemophiliacs, teenagers, women, I.V. drug users, infants, and ethnic groups; biostatisticians and actuaries who can provide technical assistance to our projection deliberations; experts in data collection, pharmaceutical research and development experts with views on the potential impact of new drugs and vaccines on the incidence of the disease; those allocating funds and establishing policy with respect to prevention, and researchers examining the conversion rate of HIV infection to AIDS, and all possible means of deterring that conversion.

The Commission has also scheduled a hearing on the subject of the accuracy of available antibody and antigen tests, rate of false positive and false negative results, the efficacy of these tests with low-incidence populations, and their role in both individual diagnosis and blood and organ bank protection.

Patient Care: A consistent refrain heard by the Commission from the local level was the immediate need for more home health and hospice care alternatives. The Commission will attempt to identify in the near term why these alternative care settings are unavailable in adequate numbers.

Patient care needs of those who are symptomatic with AIDS present some special challenges for health care as the natural history of HIV infection continues to unfold. There is a need to develop team-based care plans for HIV patients that deliver quality care during the illness, addressing both physical and psychosocial needs. The status of awareness of all members of the health care team must be examined so that new patients are accurately diagnosed and assessed, and receive comprehensive treatment. Physicians and other primary care providers must be made aware of all available treatment options. The safety of all health care workers must be examined to insure that appropriate safeguards are implemented. Assessments of who should be delivering care and in what kinds of settings need to be developed to insure provision of appropriate and compassionate care.

One large and very serious obstacle to progress associated with patient care is the growing shortage of nurses and other non-physician health care workers in the United States. As more patients receive care in non-acute care settings, greater numbers of out-of-hospital case management health care workers will be needed, and it is clear that health-related professions must be prepared to develop and implement comprehensive care plans, with a focus on case management. The complexity of this out-of-hospital delivered care will require nurse clinicians and other health care professionals with post-baccalaureate educations who are experienced in clinical interventions including counseling.

With schools of nursing around the country experiencing a drop in enrollment, prospects for solving the nursing shortage appear bleak. The need for programs of scholarship support, work-study and other avenues of student aid which may encourage students to seek nursing careers must be rapidly assessed. Solutions that are cost-effective, cost-efficient and creative must be found to allow people to receive high quality nursing education on both the professional and technical levels. Issues involving professional liability insurance for physicians and non-physician professionals must be examined, along with staffing problems, "burnout," and financial compensation, to assure an adequate supply of health care professionals in the future.

The Commission seeks testimony from experts in the following areas: physicians in a variety of sub-specialties; nurses; non-acute care providers; social workers; pre-hospital care providers, such as paramedics, firefighters and police; insurers; respiratory and other therapists; volunteers who have been providing care; families of persons with AIDS; and laboratory professionals.

New Drug Development and Availability: The Commission is concerned that after eight years, there are so few drug therapies available for AIDS and ARC patients. Many HIV-infected individuals have expressed their frustration that, despite the reportedly large sums being spent on research, access to drug development programs is not fast enough, that the number of different drugs currently being tested is inadequate, and that the government agencies responsible for these programs have moved too slowly. The Commission is currently investigating these claims and will hold extensive hearings on this subject in the near future. The Commission will also examine the high cost of AIDS-related drug therapy.

To evaluate adequately the validity of expressed concerns, we will require greater detailed testimony regarding new drug approval mechanisms within the Food and Drug Administration, the

local drug testing and approval, and a study of non-federally sponsored, community-based drug trials.

Substance Abuse and HIV:

Intravenous Drug Abuse

Intravenous drug abuse is estimated to be implicated in up to 25% of all HIV infection, and the Commission will hold hearings to determine the extent of the spread of HIV infection among I.V. drug abusers, their sexual partners and their children; to evaluate the extent of drug-related prostitution and its impact on the spread of HIV; to evaluate outreach education and prevention programs for this population; to review the impact of drug abuse on our law enforcement system; to review the impact of HIV infection on minority populations; and to review the availability, or lack of treatment facilities for I.V. drug abusers; to discuss comparative modes of treatment; and to evaluate the experience of other nations with this problem.

From the local level, the Commission has repeatedly heard about the serious lack of both inpatient and outpatient treatment facilities and programs slots available to drug-abusing adults and adolescents, especially those who are HIV-infected. In addition, the Commission is also concerned by reports of denial of primary care to I.V. drug abusing, HIV-infected individuals. This is of serious concern to all Commissioners, as without adequate treatment programs, there will be little chance to halt the growing spread of HIV within this segment of the population,

and as the Commissioners also believe that no individual should be denied access to primary care because of HIV infection or a history of drug abuse.

Alcohol and other drugs

The Commission will also investigate the judgement impairing role played by alcohol and other drugs in transmission of HIV, as well as their reported role as immunosuppressive co-factors in both acquiring and developing the disease.

To address these issues adequately, testimony will be required from a very broad range of experts, including leaders of state and federal drug agencies, treatment providers, social work agencies, researchers, law enforcement experts, and educators.

Conclusion

The complexity of issues surrounding the HIV epidemic cannot be overstated, for the very subject of AIDS evokes strong reaction from all segments of American society. While the many controversies arising from the HIV epidemic will require response, the central concerns of the Commissioners will be: to eradicate the silent spread of the virus; to provide consistent, appropriate and compassionate care for those who need it; to develop strategies to locate necessary resources; and to do everything necessary to encourage research.

It is the firm belief of the Commission that there is much to be done, that too much time has elapsed and too many people have become afflicted while questions remain unanswered. This Preliminary Report describes what the Commission has already accomplished in its investigations and what format its future activities will take as it compiles information and formulates recommendations. Because of the urgency of much of its work, the Commission will not wait until its final report to issue recommendations. As a result, interim reports will follow many of the hearings, and will contain recommendations on specific strategies for achieving selected near term objectives.

Obviously, hearings and recommendations alone will not solve problems of this magnitude, problems which can only be resolved by a comprehensive national response. There is much more that all levels of government and the private sector in partnership can do to fight this epidemic, and much more that is required from each individual as well.

The need to set aside prejudice and fear in favor of compassion and a renewed sense of personal responsibility will be the challenge to leadership. A call for collective dedication in the same spirit as volunteers, doctors, and nurses across the country have shown in providing dignified, humane and sensitive care needs to be issued. We must commit ourselves to the open and effective education of our citizens, as has been undertaken

by our private sector volunteers, educators and public health workers. The Commission will continue to conduct its investigations openly and thoroughly in this spirit, as well as in the spirit of our under-rewarded researchers who seek to unlock the mysteries of HIV.

PRESIDENTIAL COMMISSION ON THE HIV EPIDEMIC

Preliminary Report

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APPENDIX A

PUBLIC HEARING SCHEDULE

DATE	SUBJECT	SITE
Nov. 24	Institute of Medicine Report American Medical Association Report	Washington D.C.
Dec. 10/11	Incidence and Prevalence	Washington, D.C.
Dec. 17/18	IV Drug Abuse and HIV Infection	Washington, D.C.
Jan. 13/14/15	Care (Education of Health Care Workers/ Pediatric Care)	Washington, D.C.
Feb. 1/2/3	Research: New Drugs/Vaccines/Facilities	New York, NY
Feb. 23/24/25	Prevention: Education (Mass Media)	Washington, D.C.
Mar. 10/11	Workplace: Safety	San Francisco, CA
Mar. 16/17/18	Discrimination: Workplace/Housing/Schools Ethics: Denial of Care/Research Testing: Confidentiality/Duty to Warn	Nashville, TN
Apr. 5/6	Finance	Washington, D.C.
Apr. 26/27	Societal Concerns/Legal	Washington, D.C.
May 9/10/11	Public Health Measures/Local Community Response	Chicago, IL / Indianapolis, IN
May (?)	International	Washington, D.C.
June 7/8	Open	Washington, D.C.
June 20/21/22	Legislative Review: Federal/State	Washington, D.C.

Dates and locations subject to change.
Additional topics to be added.

Presidential Documents

APPENDIX B

Executive Order 12601 of June 24, 1987

Presidential Commission on the Human Immunodeficiency Virus Epidemic

By the authority vested in me as President by the Constitution and laws of the United States of America, including the Federal Advisory Committee Act, as amended (5 U.S.C. App. I), and in order to create an advisory commission to investigate the spread of the human immunodeficiency virus (HIV) and the resultant acquired immune deficiency syndrome (AIDS) in the United States, it is hereby ordered as follows:

Section 1. *Establishment.* (a) There is established the Presidential Commission on the Human Immunodeficiency Virus Epidemic to investigate the spread of the HIV and the resultant AIDS. The Commission shall be composed of 11 members appointed or designated by the President. The members shall be distinguished individuals who have experience in such relevant disciplines as medicine, epidemiology, virology, law, insurance, education, and public health.

(b) The President shall designate a Chairman from among the members of the Commission.

Sec. 2. *Functions.* (a) The Commission shall advise the President, the Secretary of Health and Human Services, and other relevant Cabinet heads on the public health dangers including the medical, legal, ethical, social, and economic impact, from the spread of the HIV and resulting illnesses including AIDS, AIDS-related complex, and other related conditions.

(b) The primary focus of the Commission shall be to recommend measures that Federal, State, and local officials can take to (1) protect the public from contracting the HIV; (2) assist in finding a cure for AIDS; and (3) care for those who already have the disease.

(c) In particular, the Commission shall (1) evaluate efforts by educational institutions and other public and private entities to provide education and information concerning AIDS; (2) analyze the efforts currently underway by Federal, State, and local authorities to combat AIDS; (3) examine long-term impact of AIDS treatment needs on the health care delivery system, including the effect on non-AIDS patients in need of medical care; (4) review the United States history of dealing with communicable disease epidemics; (5) evaluate research activities relating to the prevention and treatment of AIDS; (6) identify future areas of research that might be needed to address the AIDS epidemic; (7) examine policies for development and release of drugs and vaccines to combat AIDS; (8) assess the progression of AIDS among the general population and among specific risk groups; (9) study legal and ethical issues relating to AIDS; and (10) review the role of the United States in the international AIDS pandemic.

(d) The Commission shall make a preliminary report to the President not later than 90 days after the date the members of the Commission are first appointed or designated. The Commission shall submit its final report no later than 1 year from the date of this Order.

Sec. 3. *Administration.* (a) The heads of Executive departments and agencies, to the extent permitted by law, shall provide the Commission, upon request, with such information as it may require for purposes of carrying out its functions.

APPENDIX B

(b) Members of the Commission may receive compensation for their work on the Commission at the daily rate specified for GS–18 of the General Schedule. While engaged in the work of the Commission, members appointed from among private citizens of the United States, to the extent funds are available, may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by law for persons serving intermittently in the government service (5 U.S.C. 5701–5707).

(c) The Office of the Secretary of Health and Human Services, subject to the availability of appropriations, shall provide the Commission with such administrative services, funds, facilities, staff, and other support services as may be necessary for the performance of its functions. The heads of other Executive departments and agencies, to the extent permitted by law, shall cooperate with the Commission and provide such personnel and administrative support as may be necessary for the performance of its functions.

Sec. 4. *General Provisions.* (a) The functions of the President under the Federal Advisory Committee Act, as amended (5 U.S.C. App. I), except that of reporting annually to the Congress, which are applicable to the Commission, shall be performed by the Secretary of Health and Human Services, in accordance with guidelines and procedures established by the Administrator of General Services.

(b) The Commission, unless sooner extended, shall terminate 30 days after submitting its final report to the President.

Ronald Reagan

THE WHITE HOUSE,
June 24, 1987.

[FR Doc. 87-14537
Filed 6-25-87; 4:14 pm]
Billing code 3195-01-M

Presidential Documents

APPENDIX B

Executive Order 12603 of July 16, 1987

Presidential Commission on the Human Immunodeficiency Virus Epidemic

By the authority vested in me as President by the Constitution and laws of the United States of America, including the Federal Advisory Committee Act, as amended (5 U.S.C. App. I), and in order to increase the number of members of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, it is hereby ordered that Section 1(a) of Executive Order No. 12601 of June 24, 1987, is amended by changing the number of members of the Commission from 11 to 13.

Ronald Reagan

THE WHITE HOUSE,
July 16, 1987.

[FR Doc. 87-16588
Filed 7-17-87; 11:28 am]
Billing code 3195-01-M

APPENDIX C-1

FORMAL TESTIMONY BEFORE THE COMMISSION

ACTIVITIES & RECOMMENDATIONS

9 September 1987

Dr. Otis Bowen (Secretary of Health and Human Services)

Dr. Bowen's testimony was an outline of actions already taken by HHS in the AIDS crisis. (Following is a summary of current activities.)

Activities

1) A national toll free AIDS information hotline was instituted in July 1983 by the PHS and remains in operation 24 hours a day, 7 days a week.

2) Fifty-four alternate test sites around the country have been established by the CDC to ensure that persons engaging in high risk behavior would not donate blood and plasma at blood centers.

3) Recently, a vaccine developed by a private company received FDA approval for testing on human volunteers at NIH.

4) The PHS is funding treatment evaluation units at 19 medical centers around the country.

5) Projects have been established to test innovative care methods for AIDS patients.

6) There has been increased funding for the care and treatment of AIDS patients and funding has been provided for the AZT purchase program.

7) Research is occurring throughout the PHS including work in ADAMHA on the psycho-social and psychological aspects.

8) The PHS continues to issue a series of guidelines and recommendations designed to deal with the prevention and control of AIDS.

Recommendations

The Commission should support the HHS proposal that Congress establish an AIDS awareness and prevention month.

--TESTIMONY--

Dr. William Roper (Administrator, Health Care Financing Administration)

Activities

1) The Federal Government is the largest payor of health care for AIDS patients. The predominant assistance program is Medicaid which is administered by the States under a broad Federal framework. An estimated 40% of AIDS patients are served by Medicaid.

2) HCFA has approved several innovative state proposals for health care delivery systems (e.g., NJ, NM, NC).

3) Medicare pays for only 1% of the total now being spent for AIDS health care because (a) the majority of people with AIDS are under 65, and (b) after an AIDS patient becomes disabled and receives social security disability, there is a 24-month waiting period before Medicare coverage begins.

4) HCFA has an AIDS coordinator within the agency to frame the agency's policy.

5) There are AIDS coordinators in HCFA's 10 regional offices.

6) HCFA is funding research to look at more cost-effective ways of providing services.

7) HCFA is the primary source of information on AIDS health care and the cost of AIDS health care.

8) HCFA is sponsoring special conferences and meetings for States to coordinate their Medicaid efforts and facilitate information among the States.

Recommendations

1) Payment for AIDS health care services should be made through the pluralistic health care system. It should not be done through an AIDS-specific program. (The Federal Government should not be in the position to decide who is more important: persons with one disease versus those with another.)

2) States should be assisted in responding to their diverse situations. (In New York and New Jersey, one-third to one-half of all AIDS patients are IV drug users, while in California that group is less than one-fiftieth of the caseload.)

Dr. Robert Windom (Assistant Secretary for Health, (Public Health Service, Department of Health and Human Services)

Activities

1) ADAMHA:
   a) has a number of research projects focusing on high-risk behavior;
   b) has an information and education campaign aimed at changing those behaviors.

2) CDC:
   a) is responsible for epidemiology and surveillance activities;
   b) has the lead in our national public information and education programs;
   c) has prepared and distributed the infection prevention guidelines for health workers, food service employees and others.

3) FDA:
   a) reviews and approves all AIDS therapies;
   b) is responsible for the safety of the nation's blood supply;
   c) in FY '87 is spending $6 million on vaccine development.

4) HRSA:
   a) is funding demonstration projects in patient care;
   b) will spend $6.6 million next year on education and information programs for health care workers;

5) NIH supports biomedical research and clinical trials to develop safe and effective AIDS therapies and develop a vaccine.

6) State governments have earmarked over $120 million for AIDS-related programs.

7) There is a PHS Executive Task Force on AIDS which coordinates AIDS-related activities throughout the PHS.

8) There is a Federal Coordinating Committee for AIDS information, education, and risk reduction. Members are from seven Federal Departments, six independent agencies, and three offices from within the White House.

9) There is an inter-governmental task force on AIDS health care delivery.

Dr. C. Everett Koop (Surgeon General)

Recommendations

1) We need to consider how to prevent physicians and other health care workers from refusing to treat AIDS patients.

2) As costs rise, how should we respond to the possibility that the American people may not want to continue support for AIDS-related care.

3) In looking at the issue of individual privacy versus the need to protect the community from danger, how much leeway do we have, as a free but responsible people?

4) The United States should pay its full assessment to the United Nations and thus enable the World Health Organization to be an effective world leader in the fight against AIDS.

Dr. Anthony Fauci (Director, National Institute of Allergy and Infectious Diseases, National Institutes of Health)

Activities

1) NIAID coordinates its activities with other agencies in the PHS through the NIH AIDS Executive Committee.

2) A list of NIH research activities was provided. Dr. Fauci highlighted the following areas:
   a) Epidemiology and Natural History
      NIH works closely with the CDC in this area. A current research project in this area is the estimation of percentage conversion from HIV infection to AIDS.
   b) Etiologic Agent
      Studies on the virus' life cycle have revealed numerous targets for specific therapy.
   c) Pathogenesis
      Research is being done on understanding the mechanisms for the virus' expression as a productive infection after its extraordinarily long latent period.
   d) Anti-retroviral Therapy and Immunological Reconstitution
      Much research is focused on a "targeted development of drugs". National Cooperative Drug Discovery Groups are involved to insure collaboration between the Government, industry,and academicians. There are Treatment Evaluation Units for clinical studies.

Work in bone marrow transplantation is going on in the field of immunological reconstitution.

e) Vaccine Development and Evaluation
Vaccine development is proceeding with Vaccine Evaluation Units for clinical studies. The first Phase I clinical trials of a vaccine are now taking place at NIH.

Dr. James O. Mason (Director, Centers for Disease Control)

Activities

1) Surveillance:
   a) CDC gives technical and financial assistance to 37 State and local health departments to support active AIDS surveillance;
   b) CDC is monitoring four sentinel populations: military recruits, blood donors, sentinel hospitals, and the Jobs Corps;
   c) A 1988 National Health and Nutrition Evaluation Survey (initiated by the National Center for Health Statistics) will give data on HIV seroprevalence and AIDS-related sexual risk behavior;
   d) Surveys are being conducted at STD clinics, drug abuse treatment centers, and family planning centers.
   e) A system of anonymous testing of sera from well and hospitalized children is being developed for areas at high risk for perinatal AIDS.

2) Epidemiology:
   a) Longitudinal studies of the natural history of HIV infection in pregnant women and their children are being conducted;
   b) Cohort studies are being done to determine the type and frequency of manifestations of HIV infection and to determine possible co-factors.

3) Information and Education:
   a) for the public:
      (1) There is a well established AIDS hotline;
      (2) Public service announcements and other materials have been prepared in collaboration with the American Red Cross;
      (3) Copies of the Surgeon-General's report are being distributed;
      (4) The CDC is establishing a national AIDS clearinghouse system for information;
      (5) There will be an "America Responds to AIDS" campaign which involves:
         (I) a national information outreach program;
         (II) an attempt to reach people through their organizational affiliations;

(III) the laying of groundwork to encourage the participation of additional groups the next year;
(IV) several tactics will be used in 5 different States to evaluate possible future strategies for delivery of prevention information and education more effectively

b) for minorities:
Initiatives are being established through a recent supplemental appropriation. They include risk reduction projects and community-based demonstration projects.

c) for school-age children:
A program of technical and financial assistance to State and local education agencies and national organizations has been established.

d) for persons at high risk:
(1) A major part of the effort is directed toward assisting State programs;
(2) Various approaches toward risk reduction are being developed and evaluated.
(3) Three pilot programs have been established to explore means of preventing perinatal transmission of AIDS.

e) for health workers:
The CDC disseminates information and updates guidelines through the Morbidity and Mortality Weekly Report.

Dr. David Sundwall (Administrator, Health Resources and Services Administration, Department of Health and Human Services)

Activities

1) The agency funds service demonstration projects:
a) One grant has demonstrated that the cost of patient care can be lowered with an emphasis on home care, outpatient management and a team approach.
b) These grants have also served to pull sporadic, uncoordinated local efforts together. This has been done through the creation of community advisory committees.

2) The agency is funding educational training centers for health professionals. When fully operational, HRSA hopes to train 1,000 primary care providers per year in diagnosis, counseling, and management of patients and their families.

3) HRSA has awarded $30 million from a supplemental appropriation to an AZT purchase program.

Recommendations

The HRSA should not provide an on-going delivery system but should just provide start-up models and then give technical assistance.

Findings & Recommendations from Task Force on AIDS Health Care Delivery
(The task force was chaired by Dr. Sundwall)

Findings

1) There are gaps in the education, training and experience of health care professionals in caring for persons with AIDS.

2) Availability of acute hospital care is not the problem.

3) There are gaps in alternatives to hospitalization.

4) There are gaps in financing to cover the specific health needs of AIDS patients. There is also insufficient data on the cost of the health care delivery system for AIDS.

Recommendations

1) Health professional schools should place a greater emphasis on the care of AIDS patients and HIV-infected individuals in curricula and training.

2) Funds should be used to support education training centers, and one of their efforts should be directed at Federal programs, i.e., community health centers, migrant health centers.

3) The document "The Evaluation of Adult Patients Infected with HIV" should be made available to help professional organizations.

4) HRSA, ADAMHA, and NIDA should cooperate with the private sector to find ways of expanding drug abuse treatment centers and new methods of addressing health services for IV drug abusers.

5) The Assistant Secretary for Human Development should appoint a working group to examine sample State regulations related to day care and foster care.

6) The HUD program designed to provide Federal loan insurance guarantees for development of long-term care facilities, should develop an initiative specifically for AIDS.

7) A working group should be established to study problems related to confidentiality to provide recommendations to the Office of Civil Rights to investigate discrimination.

8) They do not recommend any changes in the Medicare/ Medicaid system now. But HCFA should review rules relating to hospice coverage for AIDS patients. HCFA should meet with State Medicaid officials to develop more uniform policies on dealing with AIDS patients.

9) More can be done to stimulate a better response in the private sector.

Mr. Paul Parkman (Acting Director of the Center for Drugs and Biologics, Food and Drug Administration)

Activities

1) The FDA has responsibility for the development and approval of drugs.
   a) The FDA has created a new top priority category in the drug approval process, 1-AAA. This gives the product the highest priority for review.
   b) FDA has approved more than 100 ongoing human studies to test potential drugs for AIDS.

2) The FDA is responsible for the development and approval of new biologics.
   a) There are presently seven ELISA tests and a Western Blot technique to test for the presence of HIV.
   b) The FDA is looking at questions of test quality, performance, availability and quality of counseling.
   c) The FDA recently approved a clinical trial of the first AIDS vaccine.

3) The FDA is responsible for the approval of medical devices used to treat, or prevent the transmission of, AIDS. In this area, the agency is currently involved in addressing issues of quality control of condoms.

4) The agency is actively involved in the prevention of health fraud in AIDS.

5) The FDA's educational efforts are directed through their publications, the "FDA Consumer" and the "FDA Drug Bulletin" for medical and professional audiences.

Dr. Don Goodwin (AIDS Coordinator, Alcohol, Drug Abuse, and Mental Health Administration)

Activities

1) Research in ADAMHA on examining AIDS from a neuroscience perspective:
   a) research that may lead to the possibility of a vaccine;
   b) anti-viral strategies being examined which are based on the use of neuropeptides;
   c) research on brain/immune system interaction;
   d) research on behavioral and psychological co-factors has led to preliminary evidence that the rate of conversion from seropositivity to AIDS or ARC is faster in patients with a prior history of certain psychiatric disorders.

2) ADAMHA is involved in service delivery programs.

3) Another of ADAMHA's major responsibilities is education.

Dr. Samuel Thier (President of Institute of Medicine, National Academy of Science)

Activities

1) The IOM will update "Confronting AIDS."

2) Future plans include modeling the spread of the disease.

Recommendations

1) The CDC figures and projections should be used as the basis for further discussion.

2) Concentrate on public education. Specifically target groups and monitor the educational activities for effectiveness.

3) Screening should be vigorously encouraged and programs should be set up so that everyone who wants to be tested has the opportunity to be. The results should be confidential.

4) Given what we know of the mode of transmission there is no reason for quarantine or other coercive measures,

recognizing there could be appropriate incarceration for those who knowingly spread the infection.

5) Little attention has been paid to the issue of children with AIDS.

6) There should be carefully evaluated demonstration projects on effective care delivery including community-based care and alternative delivery care.

7) There will be a growing need for primate animal models. This in turn will mean an expansion of primate facilities.

8) Basic biomedical research must continue.

9) New information on sexual behavior is needed.

10) International issues require a great deal of attention. WHO has mechanisms in place but bilateral agreements are also necessary.

11) We called for a Presidential-Congressional Commission to undertake the oversight and the coordination of the activities bringing together the public and private sectors in a coordinated national effort.

12) It would be necessary in drug development, and perhaps vaccine development, to have a public private partnership to move forward

13) A broad overview of the manpower needs for dealing with AIDS is important.

Afternoon Session

Mr. Paul Kawata (Executive Director, National AIDS Network)

Activities

1) The goals of all the organizations on the panel are:
   a) to implement a national education/information/ risk reduction AIDS campaign;
   b) to expand support for basic biomedical research;
   c) to legislate confidentiality and non-discrimination protections for persons with HIV infection.
   d) to get "access to and reimbursement for treatment and clinical services";
   e) to establish a full-scale federally-sponsored, anti-IV drug use campaign.

2) One major activity of NAN is "networking", i.e., the development of partnerships, especially bringing together community-based AIDS service providers with other public and private organizations responding to AIDS.

3) The other major activity is delivery of services to member agencies. These programs include:
   a) technical assistance to and representation of minority concerns;
   b) production of resource directories and technical assistance packets;
   c) updates on effective strategies;
   d) provision of skilled professionals to assist grassroots organizations;
   e) distribution of seed grants for model service programs.

Recommendations

1) A national AIDS education program must be established with a targeted minority education program. Minority communities at risk for HIV infection and minority people with AIDS are comparatively and dramatically underserved by current AIDS programs.

2) We need to look at the value of the "continuum of care" model for AIDS service, which would view AIDS as a community problem, so an acute care hospital is one component of an integrated network of community-based medical and psychosocial support services.

3) Gaps are forecast for the future, especially in meeting the chronic care, skilled nursing care, and housing needs of people with AIDS.

4) Success of this model depends upon thousands of valuable hours.

Ms. Ann McFarren (Executive Director, AIDS Action Council)

Recommendations

1) A massive AIDS education program needs to be established immediately. This should include:
   a) a general public campaign including: local public information programs; targeted education; expansion of school health programs; development and training of AIDS educators; risk reduction, counseling and testing programs; advertising spots; use of sit-coms, print media, and a national house-to-house mailing;

b) targeted programs for minorities and groups at high risk, as well as for health care workers and counselors and school age and college
c) an expansion of school health programs;
d) risk reduction and counseling programs.

2) Strong confidentiality and anti-discrimination legislation should be enacted.

3) There should be an expansion of anonymous testing programs.

Mr. Stephen Beck (Executive Director, National Association of Persons with AIDS)

Recommendations

1) The Commission needs to actively seek out and listen to the concerns of people with AIDS.

2) The Commission needs to act quickly and boldly to cool hysteria and to calm the people of this country.

Dr. Mathilde Krim (Founder, American Association for AIDS Research)

Activities

1) Since November 1985, the American Foundation for AIDS Research (AmFAR) has disbursed more than $5.3 million in support of 89 research projects.

2) The Association has produced two publications for professional education.

3) The Association is expanding into the international arena and are supporting a Second International Conference on AIDS.

4) AmFAR believes there is much that can be done by private sector resources and ingenuity in the HIV Epidemic.

Recommendations

1) The President must be urged to offer his personal, political, and moral leadership to the national effort to confront the scourge of AIDS.

2) The public must be alerted to the modes of HIV transmission, ample expert counseling resources

must be developed, and technically proficient antibody testing facilities must be widely available.

3) Legislation should be enacted to protect confidentiality of medical information and establish anti-discrimination policies.

4) A higher level of cooperation among government, industry, and academia must be encouraged by Presidential leadership.

5) A significant acceleration in the pace at which government fulfills its obligations to channel financial resources into AIDS research is needed.

6) The Federal Government can take innovative action such as subsidizing the production of promising experimental drugs and expediting their clinical testing.

7) Community physicians should be included in the clinical testing of drugs. This would provide a greater number of patients in clinical trials.

8) The President should become involved in international efforts.

Mr. Don Edwards (Executive Director of the National Minority AIDS Council)

Activities

The Minority Council has four objectives:

a) advocacy;
b) education of policy makers;
c) promotion of minority-community-based AIDS projects;
d) application of minority economic resources.

Recommendations

1) Treatment facilities for IV drug users need to be increased.

2) There should be increased funding for STD clinics, maternal/child health clinics, and community health centers.

3) There is a need to establish training programs for health professionals.

4) Changes must be made in the process of how requests for proposals are initiated insuring that minority academic and health care institutions are properly notified.

5) Minority communities need more food banks, housing for the homeless with AIDS, financial support for home health care, medication and transportation.

6) Foster care programs are needed for HIV-infected children.

7) More money should be allotted to education programs.

Dr. Edward Brandt (National Leadership Coalition on AIDS)

Activities

This organization has five objectives:

a) to increase public-private sector collaboration in responding to this crisis;
b) to promote approaches to AIDS which are consistent with American traditions of justice, fairness, and compassion;
c) to highlight emerging needs;
d) to stimulate the development of information campaigns;
e) to serve as a resource-sharing and planning body for national AIDS organizations.

Recommendations

Our primary weapon against further transmission of AIDS is education.

SITE VISIT REPORTS OF THE COMMISSION

Dr. Walsh

In two days in New York, the Commission delegation traveled with Congressmen, and State legislators, meeting with over 200 people including those with AIDS and ARC. They visited institutions providing acute patient care, housing facilities treating terminal cases and the Department of Infectious Diseases at Sloan-Kettering.

The visit emphasized the quality of what has been done by the Gay Men's Health Crisis Center and by the Hispanic and Black minority groups in New York.

Other Commissioners participating in the visit were: Dr. Mayberry, Cardinal O'Connor, Mr. DeVos, Mr. Creedon, Dr. Lee, Dr. Conway-Welch and Dr. Lilly.

Dr. Myers

The Commission delegation site visit to San Francisco included Dr. Mayberry, Dr. SerVaas and Dr. Myers. They visited the San Francisco Health Department, the San Francisco AIDS Foundation where they were briefed on the Shanti Project, the Bay View Hunter's Point Foundation, the Coming Home Hospice, and San Francisco General Hospital.

Community outreach and coordination were features of virtually all of the efforts that Commissioners were briefed on.

PUBLIC COMMENT

Mr. Larry Kramer (Co-founder, Gay Men's Health Crisis Center)

Activities

Community research initiatives have been established in New York. Through these programs, drug manufacturers are providing the drug, personnel, and money for clinical studies and the gay community is supplying the patients.

Questions

1) Often valuable drugs are controlled by inexperienced, poor, or inept companies that don't know how to deal with FDA. Why is there no mechanism to actively help these companies?

2) Why is there no mechanism to put promising drugs into immediate studies?

Dr. John Grauerholz (Medical Coordinator of the National Democratic Policy Committee)

Recommendations

1) AIDS must be treated as a communicable infection requiring application of a full spectrum of available public health law to prevent the spread of infection. This would include extensive use of testing and quarantine measures in certain specific cases.

2) More attention must be paid to co-factors in the progression from infection to active disease.

3) Institutions must be created to enable the infected, asymptomatic individual to continue making productive contributions to society, while eliminating the risk of transmission to others.

4) The government should suppress the drug traffic rather than distribute drug paraphernalia in the form of sterile needles.

5) A Biological Strategic Defense Initiative should be implemented creating a multidisciplinary scientific mobilization to apply the most advanced technologies

of biophysics to AIDS and the life process.

Ms. Amy Ashworth (President, NY Chapter of Parents and Friends of Lesbians and Gays)

Recommendations

1) Government must make coordinated research a priority.

2) A massive effort of education must be undertaken to stop the growing panic which leads to so much additional discrimination.

Mr. Dave Goddy (Editor, Scholastic Update)

Activities

A full program of educational materials is being produced by Scholastic Update. The materials will be reaching the schools this year.

These materials will be appropriate for age and will be developed in coordination with CDC, religious organizations, and public health authorities.

Dr. Michael Applebaum (Vice President of CareCard, Inc.)

Activities

CareCard is producing a plastic card which is used to communicate the result of an HIV blood test.

Recommendations

1) The Federal Government should promote voluntary interpersonal disclosure of HIV blood test results.

2) This Commission should consider the usefulness of a tangible item, such as a CareCard, in encouraging individuals to participate in HIV blood testing programs, and to communicate the results responsibly.

Mr. William Bahlman

Recommendations

1) It is extremely important to stop the spread of the virus through safer sex education, the availability

of condoms and the distribution of clean needles.

2) The Government needs to develop and fund programs to help stop the onslaught of opportunistic infections in AIDS sufferers..

3) The use of placebo-controlled trials in testing treatments for a life-threatening disease, such as AIDS, is highly immoral.

Mr. Martin Robinson

Recommendations

It is in our interest, as members of society, to hold on to those who are imperiled, and to protect them from discrimination, and from the loss of their lives, as our paramount responsibility.

Mr. Henry Yeager

Recommendations

1) Against any sort of compulsory HIV testing -- whether it be called mandatory or routine.

2) Quarantine is totally unjustified, inappropriate for a syndrome like AIDS.

3) We need a public commitment to the kind of sexual education that will entail an unprecedented willingness to suspend moralism and judgment.

Ms. Rebecca Cole

Recommendation

Educate every man, woman, and child on the prevention of HIV transmission.

Dr. Michael Rosenberg (Executive Director, American Social Health Association)

Activities

The Association has the National AIDS Hotline and AIDS educational programs as well as the National STD Hotline.

Recommendations

1) There is the need for effective information about how AIDS is spread, and about how people can protect themselves.

2) There is a need for sites where anonymous and/or confidential testing can be performed.

3) Other STD's must not be neglected in our fight against AIDS.

APPENDIX C-1

ACTIVITIES AND RECOMMENDATIONS

10 September 1987

Dr. Ralph Bledsoe (Executive Secretary, Domestic Policy Council)

Activities

The Health Policy Working Group within the Domestic Policy Council met numerous times beginning in 1985 to discuss AIDS-related issues and develop interagency policy recommendations. They recommended, among other things, that the Surgeon General publish a report and that the Presidential Commission be formed.

Federal agency coordination was necessary. The Council and the Working Group were intended to be the coordinating body over this period of time.

Dr. Robert Sweet (Deputy Executive Secretary, Domestic Policy Council)

Activities

1) The Federal Government has already taken many actions in the AIDS crisis.
   a) In education:
      (I) The PHS has produced consensus recommendations on the prevention of transmission of AIDS;
      (II) Recommendations have been made for protection of the blood supply through blood bank testing;
      (III) Guidelines have been produced for protective measures for health care workers, schools, and the workplace;
      (IV) The Surgeon General has published a report.

   b) Other Federal actions:
      (I) DOD tests recruits and active duty personnel;
      (II) The VA is establishing AIDS treatment units;
      (III) The HCFA is targeting Medicaid on AIDS;
      (IV) The State Department and Peace Corps are testing personnel who are going overseas;
      (V) The FDA is expediting drug approval.

2) There are several principles that the President approved:
   a) There should be an aggressive Federal effort in AIDS education.
      (I) The Federal Government should focus on developing and conveying accurate health information on AIDS to educators and others,

not mandate a specific curriculum. The scope and content of the school portion should be locally determined and should be consistent with parental values.

(II) Information developed by the Federal Government that will be used for education "should encourage responsible sexual behavior, based on fidelity, commitment, and maturity and placing sexuality within the context of marriage."

(III) Information used in schools should teach that children should not engage in sex. All information should be used with the consent and involvement of parents.

b) A Presidential Commission should be established.

c) The President has asked the Department of Health and Human Services to carry out a comprehensive program to determine the nationwide incidence of the HIV virus and to predict the future of its occurrence.

d) The Administration has issued a final rule placing the HIV virus on the list of dangerous contagious diseases and will require tests for aliens and immigrants.

e) The President has directed the Justice Department to submit a plan for expanded testing of Federal prisoners for the AIDS virus and recommend ways to protect uninfected inmates and families to which they are released.

f) The President also directed that the Federal Government will encourage States to offer routine testing for the AIDS virus, while recognizing individuals' rights, where medical examination blood testing occurs, or in STD clinics, drug abuse clinics and before a marriage license is issued.

g) The Federal Government will also encourage States to require routine testing for the AIDS virus in State and local prison facilities.

h) Guidelines have been published by the PHS August 14 on counseling and antibody testing to prevent the infection, AIDS. That has been distributed to hospitals and public health people all over the country.

Dr. Howard Cohn (Deputy Assistant Chief Medical Director of the VA)

Activities

1) The VA is the nation's largest public fully integrated, centrally operated health care system providing everything from acute care to ambulatory care as well as alternatives to hospitalization for eligible veterans.

2) The VA conducts the nation's largest coordinated education and training program for those in the health professions.
   a) The VA publishes a series of directives, circulars, and informational letters.
   b) The VA has several centrally funded Regional Medical Education Centers.
   c) There are also programs being run by CHEP's (Cooperative Health Manpower Education Programs).
   d) VA dental education centers are sponsoring a variety of programs.
   e) The VA has participated in the distribution of the Surgeon General's report.
   f) The Office of Academic Affairs has established a national AIDS education program.
   g) Plans are being made to target high-risk groups, for example, patients in the VA's 51 drug dependent treatment programs.

3) The VA has established a number of partnerships with other Federal agencies and private groups.
   a) The VA has been working closely with the DOD to exchange information about research projects and to make decisions regarding the transfer of patients.
   b) The VA is a member of the Federal Coordinating Committee on AIDS Information, Education and Risk Reduction.
   c) The VA is represented on the Special Committee on HIV Infection/AIDS Policy of the American Hospital Association.

4) The VA currently has one AIDS clinical treatment unit in Manhattan with plans for two more.

5) The VA is heavily involved in biomedical research and clinical testing.
   a) There are plans for three AIDS research centers at VA medical centers.
   b) Basic research: Studies of how the virus infects target cells.

c) Clinical research: Examining the impact of infection on the immune system and looking at infection of the nervous system.
d) The VA is carrying out controlled clinical trials of the efficacy of AZT.
e) The VA runs a well-respected Virology Reference Center.

6) The VA is also examining the issue of financing.
a) An AIDS Reimbursement Task Force has been established in the VA central office to develop a model for reimbursing those facilities caring for HIV infection.

7) On the issue of testing:
a) The VA looks to the CDC for guidance;
b) The VA supports the use of mandatory testing for donors of blood, blood fractions, and organs;
c) Testing as an aid in the diagnostic work-up of patients suspected of being infected with HIV is routine;
d) The VA is participating in the Red Cross "Look Back" program which offers testing and counseling for patients who received blood transfusions between 1978 and 1985.
e) An implementation plan has been developed to extend testing to patients in the drug dependent treatment clinics and the STD clinics.

Dr. Jarrett Clinton (Deputy Assistant Secretary of Defense for Professional Affairs and Quality Assurance, DOD)

Activities

1) Testing of all applicants to the military services began in 1985. Those individuals who are HIV positive are disallowed from joining the military.

2) The testing of all active-duty personnel, begun in 1986, has almost been completed. Those testing positive by Western Blot are provided an extensive counseling process and a most complex medical evaluation in one of the DOD medical centers. For those with HIV positivity and no other pathology, as long as they can do their job, they can remain in the services, if they choose.

3) Voluntary testing is offered for dependents.

4) Information from the PHS, the American Red Cross and the Surgeon General's report has been widely distributed.

5) Information about case contacts is provided to DOD's health authority, if the contact is a DOD beneficiary. If not a DOD beneficiary, the information is provided to State or local health authorities, unless that jurisdiction prohibits this.

6) The DOD has a modest research program that builds on their capacity to follow HIV-positive individuals and study the progression, if any, of their infection. They also build on their institutional capacities for vaccine development.

Mr. William Walsh III (Coordinator for Biomedical Research and Health Affairs, Department of State)

Activities

1) The United States strongly supports the leadership of the World Health Organization (WHO) in its efforts to control AIDS.

2) This year, the Agency for International Development has contributed $5 million to WHO and coordinates another $14 million that it donates bilaterally to countries around the world in coordination with WHO's programs in those countries.

3) Since October 1985, the Soviet Union has carried out a false campaign of disinformation against the United States, operative in about 80 countries. The general theme of the campaign is that the United States created the AIDS virus at Fort Detrick and is spreading AIDS around the world. There are some recent signs that the Soviets are letting up on the campaign and now want to join other nations in fighting AIDS.

4) A bilateral U.S./Japan AIDS panel has been established.

5) All immigrants and refugees seeking permanent residence must be tested for AIDS.

6) The Department of State has been testing its own employees and dependents over the age of 15 since January 1, 1987.

7) Representatives of U.S. A.I.D., the Census Bureau, WHO, the Institute of Medicine and State have met and are working to obtain more accurate data on the epidemiology and the incidence of AIDS worldwide.

Mr. John Walters (Special Assistant of the Secretary, Department of Education)

Activities

1) Secretary Bennett has been active in the formulation of Administration AIDS policy.
   a) Secretary Bennett serves on the Domestic Policy Council.
   b) The Department is involved in the development of the AIDS Education/Information Plan and the coordination of AIDS efforts through the Federal Coordinating Committee on AIDS Information, Education and Risk Reduction.

2) The Department is very involved in the preparation of reliable information for use by parents and teachers.
   a) They have issued a set of principles with the Surgeon General to guide AIDS education in schools.
   b) A publication is being prepared for parents and and educators to go out this fall containing information about AIDS education.

Recommendations

Education will be most effective in conjunction with sound public health measures.

Mr. Steve Galebach (Senior Special Assistant to the Attorney General, Department of Justice)

Activities

1) The Bureau of Prisons commenced a pilot program on June 15 to test all incoming and outgoing Federal prisoners. Counseling has been provided for those who test positively.

2) The Immigration and Naturalization Service is prepared to begin testing of persons seeking to enter the United States as permanent residents beginning December 1, 1987. Testing will take place at the country of origin or the place of departure.

3) Advice for law enforcement officials:
   a) The National Institute of Justice is to collect information on incidents alleged to involve transmission of the AIDS virus to criminal justice professionals in the line of duty.
   b) There has been distribution of reference materials on AIDS in relation to the criminal justice system.
   c) The National Institute of Justice has set up an information hotline regarding AIDS for the law enforcement community.
   d) The Office provides technical assistance and training.

Mr. Roland Droitsch (Deputy Assistant Secretary for Policy, Office of Policy, Department of Labor)

Activities

OSHA is involved in the problem of AIDS as an occupational hazard in the workplace.
   a) Non-mandatory recommendations and guidelines for health care workers were developed by the Center for Disease Control, which emphasize precautions appropriate for preventing transmission of blood borne diseases, including the AIDS virus and the hepatitis B virus.
   b) The precautions recommended by CDC represent prudent practices that apply to preventing transmission of blood borne infections in the workplace. Recommendations such as these should be used routinely with all patients.
   c) The question for OSHA is how best to achieve compliance with the guidelines. (OSHA does not cover a significant portion of these workers-- i.e., State or local municipal employees.)
      (I) OSHA has begun immediate enforcement of provisions dealing with personal protective clothing and maintenance of a clean work place including targeted inspections of health care facilities.
      (II) There will be joint notification by the Department of Labor and HHS to ensure that hospitals and affected employees are aware of the guidelines regarding blood borne diseases.
      (III) DOL and HHS are beginning intensive education of health care workers.
      (IV) DOL will publish an advance notice of proposed rulemaking to enable work toward consensus on the scope and necessary steps to protect health

care workers from the threat of blood borne diseases.

d) There is no known risk to workers in other occupational settings who share the same work environment.

2) The Job Corps AIDS policy:
   a) Since March 1, all incoming residential corps members have been tested for the AIDS virus antibody. If they test positively, they are counseled and are placed in a Job Corps "non-residential component" if one is available. If none of these are available, the individual is medically terminated and referred to a health facility with expertise in AIDS. There is a follow-up after 90 days.
   b) All incumbents are offered the opportunity for voluntary testing.
   c) There is a comprehensive educational program which deals with the causes, spread and prevention of AIDS.

3) In the area of anti-discrimination policies:
   a) The Rehabilitation Act prohibits discrimination against qualified handicapped persons in employment and in the provision of services, benefits and training.

   b) The DOL's Office of Federal Contract Compliance Programs administers Section 503 of the Rehabilitation Act of 1973, as amended, which applies to government contractors, while the Equal Employment Opportunity Commission and the Department of Justice, respectively, have the lead enforcement authority for Sections 501 and 504 of the Act which apply to the employment practices of Federal agencies and to federally conducted and assisted programs.

Mr. J. Michael Dorsey (General Counsel, HUD)

Activities

1) HUD's educational activities are aimed primarily at the HUD workforce and at those managing and occupying public housing. HUD's role is that of information clearinghouse for owners and occupants confronted with specific problems.

2) HUD operates a market rate loan insurance program for intermediate and long-term care facilities which is available for both private profit and private non-profit companies to provide nursing home, intermediate care or

board and care beds for use by AIDS patients. (No applications oriented to the AIDS patient have been received yet.)

3) HUD administers Section 504 of the Rehabilitation Act of 1973 in protecting individuals from discrimination based on handicap.

Question and Answer Session

(Walters) There is no safe sex. There is safer sex, and condoms can provide some assistance in that. But they are not utterly safe. And to say that condoms provide adequate protection, period, without telling the failure rate we think is incomplete.

(Clinton) Estimates are with Western Blot, there are about 1 to 3 false positives per 10,000.

APPENDIX C-2

RECOMMENDATIONS

30 September 1987

Senator Robert Dole

1) Scientific research should receive the highest priority, for only by the development of a vaccine or a successful method of treatment for everyone will we reach our goal of eliminating the spread of the disease.

2) The Commission can provide advice to the Senate on such issues as discrimination, testing and confidentiality.

3) The Federal Government can play a leadership role, but as everything else in the AIDS challenge, it will have to be a partnership, the States and the Federal Government working together.

4) Fundamentally, the goal has to be balancing of the needs of those who are infected with the needs of those who are not.

5) Medicare requirements ought to be modified in regard to the two-year waiting period for eligibility for persons with AIDS.

Senator John Danforth

The most important thing that we can do with respect to the subject of AIDS is education. To impart basic information to the public, the President could go on nationwide television and have a briefing in which the three leading experts on the subject of AIDS brief the President.

Senator Edward M. Kennedy

The bill Senator Kennedy introduced with Senator Hatch's cosponsorship and virtual unanimous committee support has been reported out of the Senate Labor and Human Resources Committee and is based on a four-point plan:

a) To educate all Americans about AIDS risks and enable them to make informed choices to protect themselves;
b) To develop home and community-based treatment alternatives for people with AIDS that are more economical and appropriate;
c) To accelerate the search for AIDS vaccines and

cures by among other initiatives streamlining the procedures for getting Federal funds into research labs and clinics;

d) To assure access to voluntary and confidential AIDS testing and counseling.

e) Senate Bill 1575 and House companion legislation seeks to set a reasonable Federal standard to insure confidentiality and outlaw senseless discrimination.

Senator Kennedy urged Commission support of these measures.

With regard to discrimination, to have 50 different types of legislation is not sensible. State boundaries do not restrict the movement of the virus. Confidentiality doesn't mean it's confidential in one State and not in another. The problem deserves a uniform approach.

There is a limited role for mandatory testing such as in the Armed Forces and maybe foreign service officers.

Representative Silvio Conte

The Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies has called for the creation of a network of outside advisory committees to help the CDC, NIH, and ADAMHA to interact more effectively and draw more on private sector talent and expertise.

They also directed that an AIDS Advisory Board be set up to regularly report to the Secretary of HHS and the Congress. The Board will be ongoing with a virtually unlimited agenda.

The most immediate need we have is for information; on how you can get AIDS, so that people can protect themselves; information on how you can't get AIDS, so that people don't cling to unfounded fears.

Congressman Conte would appreciate having the Commission gather and share with the Congress as broad and complete a picture of public questions and comment as possible.

Representative Ted Weiss

1) The Subcommittee on Human Resources and Intergovernmental Relations (Chaired by Representative Weiss) has conducted an ongoing review of the Federal response to AIDS epidemic since January 1983. The Subcommittee issued a report on this topic as did the Office of Technology Assessment at the Subcommittee's request.

2) The theme which emerged from the review of the Federal response to the AIDS epidemic was that the dedicated public health specialists have not been afforded the leadership required to mount a truly effective Federal campaign against the disease.

3) The Congress has repeatedly forced funds on a reluctant Administration.

4) Funds authorized and appropriated for AIDS functions have not been spent, for example, of the $11 million set aside for the School Health Initiative to Prevent AIDS at CDC, almost half of the money has not yet been spent.

5) The pressure for increased AIDS funding has meant redirection of funds from other public health areas such as sexually transmitted disease research and education. This is alarming as there is scientific evidence that sexually transmitted diseases are cofactors in AIDS transmission.

6) The Federal Government must become a greater partner in the financing of health care for AIDS patients.

7) Representative Weiss has introduced legislation to waive the two-year waiting period and make Medicare benefits immediately available to those AIDS patients who qualify for Social Security disability status.

8) The Federal Government should do more to fund and encourage the development of creative programs to respond to the complex needs of persons with AIDS. Out-patients clinics, day care centers, supportive housing, alternative residential care facilities such as nursing homes, respite care centers and hospices are all needed by persons with AIDS.

9) Representative Weiss would like to convince the Administration to revise current rigid and restrictive Federal regulations and policies which do not allow for the spectrum of alternative services needed by AIDS patients.

10) The greatest failing in the Federal response to the AIDS epidemic is our inability to mount a widespread and effective information and public education campaign, which, in the absence of a vaccine or treatment, is the only available prevention strategy.

11) There is a lack of coordination among the agencies working on AIDS education as well as overlapping programs and competing interests in the research activities being carried out by, and funded by, the various Federal agencies.

12) Representative Weiss introduced legislation to create an ongoing scientific board independent from the influence of the executive and legislative branches to carry on a coordinating/advisory function.

Representative Jim Lightfoot

1) Education, with a message tailored to the group for which it is targeted, is very important.

2) We need to increase our search for a vaccine for the virus.

3) The FDA should be encouraged to allow for the experimental use of promising but not yet approved drugs for the treatment of AIDS patients.

4) We need greater coordination among different agencies of the Federal Government and among Federal, State and local governments.

5) The role of the private sector in fighting AIDS and the role of volunteers and volunteer groups is important.

Senator Lowell Weicker

1) The Commission has yet to prove that it is not merely an extension of the far right moralizing this Administration has employed in the AIDS battle.

2) There has not been a lack of information or recommendations from the experts in public health and biomedical research, but a lack of willingness by some to make decisions and policies based on the information we have from science.

3) You should seek to find out what happened to the $20 million Congress appropriated to prepare and distribute AIDS booklets to every household in America.

4) Our children should be educated about AIDS.

5) Our response to illnesses in the past has always been to treat the illness, not to moralize about how the illness may have been contracted.

6) We need research dollars for basic research and applied AIDS research.

7) We need a large scale education and prevention program which reaches as many people as possible and one that reaches a variety of age groups in a variety of ways.

8) We need to be preparing for the enormous health care costs associated with AIDS that we will be faced with in the next few years.

9) I hope you will recommend to the President that he is the only person in the nation who can lead the fight against AIDS.

Representative Charles Rangel

1) IV drug abuse has led to an increase in the number of babies being born with AIDS as well as a rise in the number of people who acquire the AIDS virus through sexual contact with a partner who has contracted it from the drug use.

2) The AIDS virus appears to be taking a heavier toll on this nation's Black and Hispanic communities.

3) While Blacks and Hispanics comprise about 18% of the population, they constitute about 4 of every 10 reported AIDS cases. The Black and Hispanic problem with AIDS is more connected with IV drug abuse than with any other group of AIDS sufferers in America.

4) AIDS threatens to affect all of us by either becoming victims ourselves or by having a family member or coworker become a victim.

5) Medicaid costs alone are expected to rise from $400 million this year to about $2.4 billion in 1992 to care for AIDS victims.

6) We need to establish some type of national network for the open sharing of information about AIDS>

7) We need to appropriate the necessary dollars for research, treatment and education.

8) We need to convene on at least a semi-annual basis, a conference of all agencies and medical authorities working on the eradication of AIDS.

9) We have to break down the racial economic class barriers, the myths that lead many to shun the AIDS crisis as a gay or a minority disease, or a disease of dope addicts.

10) We have to push harder for community outreach programs.

Representative Benjamin Gilman

1) They estimate that the illicit narcotics business in our country is over $130 billion. We have 600,000-700,000 heroin addicts in our country, not to mention the millions of cocaine abusers and those who abuse amphetamines and other narcotic substances.

2) They estimate that of the intravenous drug abusers conservatively 50% test positive for AIDS.

3) Of those infected with the HIV virus 25% are IV drug abusers, and the vast majority of these are heterosexuals.

4) Pediatric AIDS is a tragic problem. Infected mothers and the IV drug abusing population are overwhelming hospitals in New York.

5) AIDS is now the leading cause of death for women in New York City between the ages of 25 and 34.

6) Chairman Rangel and Representative Gilman introduced "The Intravenous Substance Abuse and AIDS Prevention Act of 1987" to authorize $400 million for AIDS-related treatment and drug abuse prevention services. The legislation aims to prevent, to treat and reduce the transmissibility of the HIV virus with a particular focus on IV drug related cases.

7) Representative Gilman suggested that the Commission invite Surgeon General Koop to sit side by side with the Commission and work closely in all aspects of inquiry and review.

APPENDIX C-3

ACTIVITIES AND RECOMMENDATIONS

16 October 1987

Dr. Gary Noble (AIDS Coordinator, PHS)

Activities

1) One of the most important HHS activities is a partnership between the States and the Federal Government in the fight against AIDS.

2) States have traditionally taken the lead in the protection of the public health working closely with the Federal Government.

3) Nearly three-fourths of all reported AIDS cases are in five States, however, at least 38 States have established State level advisory panels or task forces on AIDS. Most governors have appointed an AIDS Coordinator.

4) The Public Health Service has provided States with funds through research grants and cooperative agreements and a one-time $30 million distribution to States to pay for AZT for low-income AIDS patients.

5) The success of current PHS AIDS activities depends on a close working relationship between CDC and State and Territorial health officials. This partnership has been key in helping States expand counseling and HIV testing, conduct AIDS surveillance and undertake school health education initiatives.

6) PHS has issued a series of guidelines reflecting current scientific knowledge about AIDS and the AIDS virus, including guidelines for counseling and antibody testing. These guidelines caution that protection of confidentiality for medical and public health records of those tested is a key consideration. We want to assure that individuals are not discriminated against on the basis of their HIV antibody status.

7) HHS is currently reviewing its own policies for protecting information collected through Federal programs and ways to improve those protections. HHS is supporting State efforts to ensure confidentiality of AIDS or HIV-related records and protect against discrimination.

Mr. Steven Grossman (Deputy Assistant Secretary for Health Planning and Evaluation, HHS)

Activities

1) HHS will be releasing "AIDS, A Public Health Challenge" in early November.

2) PHS has a long-standing contractual relationship with the Intergovernmental Health Policy Project to look at many issues related to State activities, including AIDS. In a November 1985 report, they indicated that 17 States had had AIDS-related legislation introduced. Last year, we commissioned them to take another look at State activities. This report will be three volumes and document AIDS activities in every State.

3) The most important goal of the project was to facilitate information sharing among States. We hope the document will serve as a tool and resource for policymakers in their efforts to respond to the public health challenge of AIDS.

Mr. Dick Merritt (Director, Intergovernmental Health Policy Project)

(Summary of "AIDS, A Public Health Challenge")

1) This book is our attempt to address every major public policy issue a State legislator, governor, mayor or county commissioner needs to address regarding AIDS. It identifies a range of alternative solutions for consideration, and provides detailed descriptions of creative programs underway.

Broad Trends in State Policymaking

1) Measured by the growth in legislative proposals, the establishment of task forces, study commissions, panels, etc., AIDS has become a major public policy issue in the States.
   a) Over 550 AIDS-related bills have been introduced and considered in 48 States.
   b) In 1987, 90 AIDS-related laws in 31 States have been enacted.
   c) During the current fiscal year, 30 States have appropriated some general revenue dollars for AIDS programs and activities independent of Federal support.
   d) Since FY '82 and '83, including the current

fiscal year, States have spent, or obligated for spending, approximately $250 million for AIDS programs and other AIDS-related activities. This figure does not include Medicaid or local health department programs.

e) Projected expenditures for FY '87 and '88 by States are $128 million, about double the $66 million spent in FY '86 and '87. California, New York and three or four other States account for about 70% of that total.

f) Most of those State dollars are for education and prevention programs, surveillance and epidemiological concerns, research and support services.

2) There is a keen awareness among low-prevalence States that they have a significant opportunity to develop policies, plans and programs that can effectively curb the transmission of the AIDS virus.

3) There has been very little legislative activity or legislation enacted in States in the areas of mandatory testing, contact tracing,criminal penalties, isolation and quarantining.

4) In the absence of a cure or vaccine, the only weapon to control transmission of the virus is prevention and education efforts, which most public health professionals and State officials believe are most effective on a voluntary basis. There is support for the notion that voluntary testing and counseling must be bolstered by protections of confidentiality and enforceable safeguards against discrimination.

<u>Specific Areas Addressed in the Report</u>

1) Case reporting:

a) All States require reports of diagnosed AIDS cases, and a handful require reporting of ARC cases.

b) Only 12 States require the reporting of antibody positive test results. Most of those require that the reports be associated with identifiers.

c) Three States have enacted laws forbidding the disclosure of HIV antibody test results without written authorization of the person tested.

d) A major issue of contention is whether those practicing high risk behavior will be less likely to seek voluntary testing and counseling in the States requiring reporting of HIV infection.

e) Colorado was among the first States to require reporting of HIV positive results. The testing

program allows for pseudonyms. In 1986, the State ranked second in the numbers tested per 100,000 of 22 States surveyed.

This gives some credence to the belief that you don't have to have fully anonymous testing in order to get individuals to come forward. Colorado reports no breaches of confidentiality. Numerous security precautions were added to protect individual's records.

2) Contact Notification
   a) Most States are relying on partner referral efforts to get testing and counseling to contacts of individuals who are HIV antibody positive.
   b) Only on a statewide basis in Colorado and Idaho is active contact tracing occurring where the State seeks to discover the identity of sexual or needle sharing partners of infected persons and interrupt further transmission by testing and counseling.
   Colorado reports they have contacted 175 HIV antibody positive persons. Those persons named 340 contacts of which 290 were found and 225 came in to be tested of that 14% were positive.
   c) Most State task forces have advised against blanket contact tracing. Many suggest it may be most appropriate in low seroprevalence groups or it should focus on HIV positive drug users and bisexual males to locate women of child bearing age who may be unaware they are infected.
   d) Illinois is the first State to require active contact tracing by statute.

3) Confidentiality:
   a) Most States already have statutes pertaining to the confidentiality of medical records and the required reporting of personal medical information for public health purposes.
   b) However, there is concern as to whether existing confidentiality protections are sufficient for persons with AIDS and HIV infection.
   c) Some States have enacted new laws or amended laws to improve the confidentiality of medical records for HIV infection.
   d) Eight States have designated AIDS and/or HIV infection to be a communicable disease or a sexually transmittable disease under State law thereby adding confidentiality protections.
   e) Seven States enacted statutes protecting the confidentiality of HIV-related medical records. The statutes prohibit disclosure of HIV test

results without written consent of the test subject.

f) Two of the seven States, Massachusetts and California, passed very strict laws prohibiting disclosure of the HIV antibody test results or identification of the test to anyone other than the subject without the subject's written consent.

g) In Wisconsin, HIV test results may be disclosed without written consent to the test subject, the subject's designated health care provider, to persons procuring, processing or distributing donated organs, to appropriate State health and other agencies, to blood banks and plasma centers.

h) Several State task forces on AIDS have made recommendations somewhat similar to the statute in Wisconsin.

i) About 11 States require that emergency medical personnel be informed. About 8 States require that funeral personnel be informed if they are treating a body that was HIV infected.

4) Anti-discrimination:

a) Practically every State has a law or regulation prohibiting employment discrimination based on physical disability or handicap. About two-thirds of the State human rights or civil rights commissions have declared that AIDS is a protected handicap under those laws. A handful maintain that ARC is also covered.
In some States, the anti-discrimination protections do not apply in the private sector.

b) Four States have statutes prohibiting the use of the HIV antibody test for screening, determining suitability for or discharging a person from employment.

c) A few States have forbidden determining one's insurability on the basis of their willingness to take a blood test for antibodies to HIV or revealing the results of that test.

d) A Hawaii law prohibits discrimination against HIV infected persons in any land or real estate transaction.

5) Mandatory Testing:

a) No other AIDS-related issue has commanded as much attention at the State level as mandatory testing. Approximately 20% of the 550+ bills introduced this year relate in some way to mandatory testing. The majority of these focused on premarital testing.

b) Of the over 80 premarital testing bills introduced in 35 States, 32 failed outright, 28 were put off until next year, and 18 are still pending. Only

3 have been enacted.

c) Three States rejected mandatory premarital testing provisions and instead endorsed provisions requiring marriage license applicants to be provided with information about AIDS and about where they may be tested.

d) Prisoners are being routinely screened in States with relatively small prison populations.

e) Texas has a law providing that a person indicted for sexual or aggravated assault can be tested at the discretion of the court.

f) An Illinois law permits testing of persons convicted of sex crimes and drug abuse.

g) A Texas law provides that a patient may be required to be tested for AIDS or HIV if a medical procedure is to be performed that could expose health care personnel to AIDS or HIV infection.

h) Prostitutes are routinely screened in Nevada. Convicted prostitutes are tested in Florida.

6) Quarantine:

a) Many States have examined their old public health statutes and found them out of date, some of them giving the States more authority in the area of isolation and quarantine than many today feel they should have.

b) A few States have amended their statutes to authorize quarantine or isolation under very specific circumstances.

c) The Minnesota statute is an example of a statute which requires serial measures (14 in this case) to be taken before the State gets to a position where it actually restricts an individual's mobility.

7) Criminal Penalties:

a) Bills were introduced in more than 15 States applying civil or criminal penalties against:

I) Those who are convicted of prostitution and test positive yet continue to practice prostitution.

II) Those who are found guilty of sexual assault and knew at the time of the crime they were suffering from AIDS or HIV infection.

III) Those who intentionally expose another person to the HIV virus through sexual contact without the knowing and lawful consent of the other person.

b) There are a few bills regarding criminal penalties for those who donate or sell their blood while knowing they are capable of transmitting the virus.

8) Education:
   a) Most States have concentrated their resources here and initiated AIDS education programs for the general public and specific groups.
   b) In FY '87 and '88, 24 States report appropriating over $33 million for AIDS education and information programs.
   c) Some States have passed laws requiring that public information and risk reduction education programs be developed and funded for the general public.
   d) Some States have developed statewide plans to coordinate educational activities.
   e) Alaska and Massachusetts are now supporting through State funds mailing the Surgeon General's report on AIDS to every household in their State. Connecticut passed a law authorizing reimbursement to local municipalities that distribute the Surgeon General's report to all households.
   f) At State and local levels, public health officials are working with the media to disseminate information or develop a broader approach.
   g) Most States have either initiated or are developing professional education campaigns. Maryland legislated a statewide program to train providers in treating and preventing AIDS. Working with the IOM, New Jersey developed a continuing education program for hospitals, health care facilities and other provider organizations.
   h) Some States have worked closely with State professional associations to plan and implement provider education programs. Some States have recommended specialized training for attorneys and judges.
   i) Seven States have enacted legislation either mandating or encouraging AIDS education in the public school curriculum.
      I) Parental notification is a part of all laws. Parents are allowed to inspect instructional materials and exempt the child from the course.
      II) Most laws require that instructional materials stress abstinence from sexual activity as the preferred means of prevention.
      III) Laws differ with respect to the amount of discretion the State has in offering the programs.
      IV) In some States, the State tries to involve the parents in an active way, for example, by providing for parents, on a voluntary basis, an education program including human sexuality.
   j) Most State policies follow the CDC guidelines with respect to the admission of children with AIDS or

HIV infection in public schools. The guidelines hold that most of the children represent no threat for transmitting the virus in the classroom and should be provided an education in the usual manner.

9) Financing of AIDS Care and Services:
   a) Research reports that the cost of medical and related care for each AIDS patient is between $40,000 and $150,000 based on 18 months between diagnosis and death.
   b) The PHS's Executive Task Force on AIDS predicts total personal medical care costs will rise from $1.2 to $2.4 billion in 1986 to between $8 and $16 billion in 1991.
   c) HCFA actuaries provide estimates that in FY '86 $200 million in Medicaid funds were spent on AIDS and in FY '87 $400 million will be spent. In 1988, $600 million is projected.
   d) HCFA actuaries estimate that 40% of AIDS patients are assisted through Medicaid and 1% through Medicare.
   e) Medicaid and private health insurance are and are likely to remain the primary sources of payment for medical care for AIDS patients.
   f) SSA determined that a clinical diagnosis of AIDS confers a presumptive disability status and an automatic three-month eligibility for SSI, and therefore, in most States, Medicaid benefits. This does not relate to those with ARC or those who are HIV antibody positive.
   g) Many States are expanding their eligibility provisions in order to bring on more people with AIDS.
   h) Forty-four States do cover AZT under Medicaid.
   i) Three States are providing home and community-based services for AIDS patients under the Medicaid waiver program and this approach is likely to expand.
   j) Knowing that less than 10% of AIDS patients need in-patient hospital services at any given time, the challenge ahead is to develop the appropriate continuum of services necessary to respond to the diverse medical and social needs of AIDS patients.
   k) Support services are critical for AIDS patients and in most communities they are not available on the scale needed.
   l) New Jersey is a State which is aggressively financing support services such as a post-hospitalization care and service program for children with AIDS and children of parents with AIDS including placement in foster homes and educational programs for home-bound children.

m) Maryland has a foster care program for displaced persons with AIDs. The State reimburses friends or neighbors for providing room and board, supervision and personal care to persons with AIDS.

n) Washington, D.C. and Massachusetts finance housing or shelters for persons with AIDS.

o) In the area of private sector financing, one of the most difficult questions a State must face is whether to regulate the conditions under which insurance companies may use the HIV antibody test for underwriting purposes.

p) Currently, four States plus Washington, D.C. have passed laws either prohibiting the use of the antibody test for purposes of insurability or circumscribing conditions under which the test may be applied. Many State task forces have come out forcefully against unrestricted screening by insurance companies for HIV infection.

q) About 14 States have legislated health insurance risk pool programs whereby all third party insurance companies doing business in the State pool the risk and make available a comprehensive health insurance policy to those who are uninsurable. These plans are costly, and characterized by high premiums and co-payments. Nonetheless, a couple of new State risk pool laws were enacted this year in part because of the difficulties those with AIDS and AIDS-related conditions may face in obtaining health insurance coverage.

r) Only a couple of States provide some subsidies for low-income insurables. This approach is limited because ERISA forbids States from regulating self-insured plans. It is estimated that 75% of the employers with 50,000 or more are self-insured and that is growing.

s) Another approach some States have taken is mandating benefits which health insurance plans must make available such as hospice services or home health care. Self-insured plans are exempt as dictated by Federal law.

<u>Questions By Commissioners</u>

1) What have you found in the way of effective coordinating organizations that might share the lessons learned of past bills that have not been too effective and some of the good experiences in States?

The organizations that represent various State legislatures and governors have done a lot including the development of specific policy positions and a call for the re-examination of many public health statutes.

They are looking most internally re-examining their own State laws.

In December, the National Conference of State Legislatures is holding a conference with our project to highlight exemplary or innovative practices.

The Conference of State Legislatures had the Surgeon General as their keynote speaker at their annual conference.

The Association of State and Territorial Health Officials has been extremely active. Their task force has been examining the issues of confidentiality and discrimination.

The Federal Government has met with the National Governors Association and Dr. Bowen indicated that he would be contacting the governors and asking them to name a contact person for dialogue between the States and the Department with the hope of identifying model legislation.

2) Has there been any kind of a more formal coordination process among the various agencies or governors?

At this point, what they are doing is more of information sharing.

A month ago, the governors did a day and a half briefing on AIDS where they pulled together the governors' health advisors.

We (the Intergovernmental Health Policy Project) have an award to establish an AIDS policy and information center which is supposed to be of assistance to State governments as they wrestle with these problems.

3) Is the amount of proposed Federal legislation premature based on State initiatives being taken, particularly in the areas of confidentiality and testing?

States are taking initiatives in this area. We expect a considerable amount of legislative activity in 1988.

Dr. Bowen recently stated that he was "concerned about supporting federal legislation without a better understanding of the optimal solution and some greater certainty that a Federal effort will improve the situation without inadvertently creating additional problems."

4) Do you get any indication that Federal legislation will slow down State legislatures and actually discourage them from taking action while they wait for the Federal Government?

It has not been my experience that States are waiting for any kind of Federal legislation to happen.

5) Are the low incidence States demonstrating any resistance to Federal legislation?

I can't think of any particular instances where that may be true with the exception of the coverage of Retrovir. Of the six States that do not cover Retrovir, at least a couple of those, notably Florida and Texas, are not low incidence States.

Secretary Bowen has asked HHS General Counsel and others to work with States in developing model legislation to protect confidentiality and prevent discrimination.

6) Is there any legislation pending or in place providing financial assistance for patients who are infected to get psychological counseling and support services?

California introduced some legislation in the last session on that issue.

Medicaid provides for mental health benefits.

7) Why do we hear so much about discrimination occurring if States have legislation relevant to the problem?

Every State has some kind of statute or regulatory provision dealing with discrimination in employment with regard to physical disability. Most State Commissions have ruled AIDS as being covered.

The penalties for violating confidentiality are fairly stiff and fairly uniform and more than a misdemeanor in most instances.

There are a multitude of laws, however, States vary in the areas in which they guarantee protection.

Some States have started State-sponsored anti-discrimination units.

8) Why couldn't AZT be made available to patients at a lesser cost? Why should a single pharmaceutical company be permitted to control the only therapeutic approach we now have?

The costs for production for this drug exceed the cost for the production of all the company's other products. The uncertain nature of pharmaceutical research dictated this particular process.

On the average, Medicaid covers about 50% of those individuals who are really in poverty. In terms of AZT, all States can do right now is really either include it or not include it in their Medicaid coverage.

9) What are the options including changing laws to reduce the cost ultimately of AZT or prevent a similar situation from developing with new drugs?

The options are either that there is funding by the government, private sector, insurance, or the drug isn't available.

10) Could you explain the California drug law regarding more rapid introduction of experimental drugs for AIDS?

California has the authority as most States do to produce, pass and approve for sale within their States products, biologicals or drug products.

11) Have their been any bills passed or considered to change the liability of pharmaceutical companies with respect to AIDS-related drugs or other drugs approved by the FDA?

California has one bill encouraging the Congress to enact legislation related to compensation for injuries resulting from vaccines.

12) Is it conceivable that legislation will protect those who run hospices or care for AIDS patients in their homes in terms of requirements such as number of fire exists?

With respect to reimbursement for home care or hospice care under Medicaid, those standards are substantially set by Federal regulations, leaving States only a little bit of leverage.

EXHIBIT D-I

PRESIDENTIAL COMMISSION ON THE HIV EPIDEMIC

NEW YORK CITY SITE VISIT
Sept. 1-2, 1987

Tuesday, September 1

12 PM	Luncheon Presentation	Memorial Sloan-Kettering Cancer Center 1275 York Avenue
2 - 5:30 PM	Site visit	St. Clare's Hospital 426 West 52nd Street
	Site visit	St. Vincent's Hospital 7th Avenue at 11th Street
	Site visit	Mother Theresa's "Gift of Love" Residence 657 Washington Street
6:30 PM	Dinner	Residence of Cardinal O'Connor 452 Madison Avenue

Wednesday, September 2

8:30 AM	Site visit	Hale House for Infants 154 West 122nd Street
10:30 AM	Site visit-Presentation	Bailey House 180 Christopher Street
12 - 1:30 PM	Luncheon Meeting and Press Brief	Stringfellow's 35 East 21st Street
2 - 4:30 PM	Forum	Gay Men's Health Crisis Center 155 West 23rd Street National Hemophilia Fdn. Urban Resource Institute PWA Coalition Hispanic AIDS Forum Community Health Project Hetrick Martin Institute Women in Crisis Haitian AIDS Coalition

EXHIBIT D-I

NEW YORK CITY SITE VISIT

Co-hosted by:
Dr. Burton J. Lee III, and Dr. William B. Walsh

Notes on the Schedule

Sept. 1, 1987

Memorial Hospital — Luncheon to introduce members and to welcome to New York. Presentation by Infectious Disease and Psychiatric Services.

St. Clare's Hospital — Operated by Archdiocese of New York, St. Clare's has largest dedicated AIDS unit in New York; also has prison unit. Briefing by staff on quality care management, range and cost of services.

St. Vincent's Hosital — Large hospital serving Greenwich Village. Briefing by staff and tour of AIDS unit.

Mother Teresa's "Gift of Love" — Former convent converted by Archdiocese of New York to a hospice for prisoners with AIDS, in Greenwich Village. Many are former IVDA's.

Sept. 2, 1987

Hale House for Infants — Founded by Mother Clara Hale, serves Harlem community. Cares for abandoned infants, many of drug abusing parents, many are HIV-infected.

Bailey House — Former hotel and restaurant, converted to 44 unit, full service residence for homeless PWA's.

Gay Men's Health Crisis (GMHC) — Forum prepared by GMHC, in which leaders of organizations experieinced in dealing with AIDS on a community level briefed the Commission

EXHIBIT D-1

PRESIDENTIAL COMMISSION
ON THE HIV EPIDEMIC

NEW YORK CITY SITE VISIT
Sept. 1-2, 1987

Community-based Organizations: Summary of Recommendations

PWA COALITION
Paul Van Souder
Executive Director

1. Provide greater access to experimental drugs, including full utilization of existing AIDS Treatment Evaluation Units, and the establishment of new ATEU's.

2. Prevent the importation of heroin and cocaine into the United States, in order to prevent I.V. drug addiction.

3. Waive the two-year waiting period for Medicare eligibility.

4. Begin a national public education campaign designed to quell the fear and panic regarding contagion.

5. Expand treatment programs for drug addicts, including risk reduction education, in order to halt further spread of AIDS by shared needle use and sexual contact among or with I.V. drug abusers.

AIDS RESOURCE CENTER (Bailey House)
Joseph McEarthy
Founder

1. Redefine AIDS as a disease entity so that it better fits into existing regulations, and so that patients and care providers can benefit from additional funding from sources already in existence.

2. Encourage additional "Section 2176" waivers, whereby Medicaid funds available at the state level can be used to finance enhanced local services, including hospices, counseling programs, case management work, etc. New Jersey and New Mexico have been granted waivers by Secretary Bowen, and larger, more heavily hit states should follow.

3. Encourage the use of scattered site housing wherever possible, as it maintains autonomy and normal lifestyle, and reduces the cost of provided care to $98.00 per day (in New York City).

EXHIBIT D-I

THE HAITIAN AIDS COALITION
Marie Saint-Cyr Delpe
Program Director

1. Provide appropriate educational materials to recent U.S. arrivals to counsel them about AIDS so that they may reduce risk behavior, thereby slowing the escalation of AIDS. Point of entry is a good point of contact.

2. Counsel and educate the American public that risk behaviors --not being Haitian-- is what transmits AIDS.

WOMEN IN CRISIS
Mari Nobles-daSilva
Program Coordinator

1. AIDS is now the leading cause of death in New York City for women between the ages of 25 and 34. Within the next couple of years, it will be the leading cause of death for women in all childbearing years in New York, and the greatest number of women who will die will be minority women. A specific governmental task force on minority communities should be formed to deal with this problem from within the minority community.

2. Affected families must be assisted to stay together. Funding for home care should be encouraged, and the development of appropriate foster care options should be given high priority.

3. Gender specific information must be developed, along with educational programs specifically targeted to minority cultures.

4. Prevention campaigns, such as promotion of condom use, must not be targeted at women alone. Men must also be strongly encouraged to share the responsibility.

5. Disproportionate numbers of women provide critical health care services to those suffering from AIDS. Adequate training and support must be provided so that these caregivers can function effectively in a high stress environment.

EXHIBIT D-I

THE NATIONAL HEMOPHILIA FOUNDATION
Tom Harrington
Executive Director

1. Improve and continue monitoring for the safety of the blood supply.

2. Expand ongoing AIDS-related research.

3. Enact anti-discrimination legislation which would safeguard confidentiality and include penalties for the breach of confidentiality. Also, we hope that legislation similar to Section 504 of the Rehabilitation Act will be enacted to extend this principle to the private sector.

4. Implement voluntary HIV testing with organized pre- and post-test counseling programs.

5. Provide long-term funding for organized hemophilia HIV counseling programs which need to be in place over a long period of time to assist the HIV-infected person to deal with the potential medical and psychosocial ramifications of this infection. For example, a young hemophilic boy who is infected with HIV will need further age-appropriate information as he moves into adolescence and adulthood. Appropriate educational and counseling programs need to be in place to assist families with their particular situation.

6. It is also important that ongoing training and support be available to the providers of HIV/AIDS care.

7. Provide readily available cost-coverage for health care.
   > There should be immediate access to Medicare once an individual is found to be disabled. An individual who is disabled may receive Social Security, but is not eligible for Medicare for at least two years. Once a person is diagnosed with AIDS, his longevity is less than two years.
   > Access to home care services should be more readily available.
   > Private health care insurance must continue to be available to persons who test HIV antibody positive. This status should not be used as a "pre-existing condition" to bar availability of such coverage. If a person with hemophilia loses access to health insurance, medical care for his primary chronic illness will diminish, putting him in further jeopardy and adding another burden for the taxpayer.

8. It is important that funds be allocated to heighten public awareness regarding HIV/AIDS and lessen fears that frequently lead to discrimination.

EXHIBIT D-I

HETRICK MARTIN INSTITUTE FOR LESBIAN AND GAY YOUTH
A. Damien Martin, Ed. D
Executive Director

1. Building self-esteem is the most potent weapon we have in our efforts to stem the spread of HIV-infection among young people. AIDS education programs must make special efforts to reach out to gay youth and reduce their isolation.

2. Needs assessments of youth-serving personnel including teachers and social workers should be conducted immediately to ascertain levels of knowledge about AIDS and HIV transmission and competency in communicating about these topics and risk reduction. Professional training programs should be designed in response to those needs.

   AIDS education should not be viewed as the job solely of schools. Other youth serving institutions such as settlement houses and community centers should be engaged in this effort.

3. Public education campaigns on AIDS should address youth as a target population. This should include TV, radio, and newspaper ads as well as brochures and posters.

4. Given the realities of current levels of participation in sexual intercourse by teenagers (57% by age 17 nationwide), teens need adequate information about sexual practices that place them at risk for HIV infection and access to protection, including condoms.

5. Any testing program for HIV antibodies for youth or any other age group must be accompanied by pre- and post-test counseling and long term follow-up for those who test positive.

6. Public risk-reduction campaigns for youth and other age groups should be sex-positive. Kids say no to "Just say no" campaigns.

7. Drug rehabilitation programs need to be expanded manifold.

8. A national effort to destigmatize AIDS and reduce fear of casual contagion must be conducted.

9. The Surgeon General's Report on AIDS should be distributed to every household in the nation, not just to disseminate information about AIDS, but to help create a national climate of concern.

10. An effort comparable to the national effort to mass produce penicillin must be mounted to develop, test, and deploy treatments for AIDS and HIV-infection, and to produce a vaccine.

EXHIBIT D-I

PRESIDENTIAL COMMISSION
ON THE HIV EPIDEMIC

NEW YORK CITY SITE VISIT
SEPT. 1-2, 1987

LIST OF PARTICIPANTS

Institutions

Memorial Sloan-Kettering Cancer Center
1275 York Avenue
New York, NY 10021

Dr. Burton J. Lee	Attending Physician, Lymphoma Service	(212) 794-7092
Ms. Peggy Dufour	Lymphoma research, Assistant to Dr. Lee	-7093
Dr. Donald Armstrong	Chief, Infectious Disease Service	-7809
Dr. John Gold	Assoc. Attending, Infectious Disease Service	-7813
Mrs. Grace Christ	Chief, Department of Social Work	-7017
Sr. Rosemary Moynihan	Ass't. Dir., Dept. of Social Work	-7018
Dr. Karolynn Siegel	Dir. of Research, Dept. of Social Work	-7017
Dr. Mary Jane Massie	Ass't. Attending Physician, Psychiatry Dept.	-8010
Dr. Bijan Safai	Chief, Dermatology Dept.	-5806

St. Clare's Hospital
426 West 52nd Street
New York, NY 10019 (212) 586-1500

Dr. Richard Yezzo	President, St. Clare's Hospital
Dr. Debbie Spicehandler	Chief, Dept. of Social Work

St. Vincent's Hospital
and Medical Center of New York (212) 790-7000
153 West 11th Street
New York, NY 10011

Sr. Margaret Sweeney	President, St. Vincent's Hospital
Theodore J. Druhot	Executive Vice President
Dr. Lambert King	Medical Director, V.P. for Professional Affairs
Sr. Karen Helfenstein	V.P. Community Health Services
Margaret Seery, R.N.	Assistant V.P. of Nursing
Ellen Brady	Nursing Care Coordinator AIDS Unit
Philip W. Brickner	Dir., Dept. of Community Medicine
Michelle Cohen	Social Worker, AIDS Unit
Dr. Edith Chanin	Attending Physician, Dept. of Community Medicine
Gaetana Manuele	Social Work Supervisor

(continued)

St. Vincent's Hospital

(continued)

Dr. James Mazarra	Director, Department of Medicine
Victoria Morris, R.N.	Clinical Director of Nursing
Sr. Patrice Murphy	Director of Supportive Care Department
Dr. Jill Nord	Chief of Inpatient AIDS Unit
Patricia O'Neil	Assistant Nursing Care Coordinator, AIDS Unit
Marguerite Oerlemans	Nurse Epidemiologist, Infection Control, Quality Assurance Dept.
Dr. Barbara Starrett	Attending Physician, Department of Medicine (community AIDS physician)
Dr. Ramon A. Torres	Resident, Department of Community Medicine
Dr. Joyce Wallace	Attending Physician, Department of Medicine (community AIDS physician, studies STD's, prostitutes)
Dr. Ira Wagner	Associate Chief of Critical Care Medicine
Mr. Mark Ackermann	Director of Development

Mother Teresa's "Gift of Love" (IVDA's and prisoners with AIDS)
657 Washington Street
New York, NY 10014 (212) 645-0587

Sr. Sabita Sister Superior
Sr. Rochelle, Sr. Thomas Moore, Sr. Dobrilla

Hale House for Infants
154 West 122nd Street
New York, NY 10027

The Hale Foundation
68 Edgecombe Avenue
New York, NY 10031 (212)690-5623

Mother Clara Hale Founder, Hale House
Dr. Lorraine Hale Director, Hale Foundation

Bailey House (multi-service residence for homeless PWA's)
180 Christopher Street
New York, NY 10014 (212) 206-1001

Mr. Douglas Dorman Executive Director
Mr. Gordon Hough Administrator

Additional Institutions (not visited)

The Stuyvesant Polyclinic
137 Second Avenue
New York, NY 10003 (212) 674-0220

Dr. Richard Elian Director, AIDS Clinic

Organizations and Individuals

Mr. Joseph McEarthy (founder)
AIDS Resource Center
24 West 30th Street
New York, NY 10001

(212) 481-1270

ARC started and supports Bailey House and operates scattered site apartments for homeless PWA's.

Monsignor James Cassidy
Director of Health and Hospitals
Archdiocese of New York
1011 First Avenue
New York, NY 10022

(212) 371-1000

The Archdiocese operates St. Vincent's Hospital, St. Clare's Hospital, The Gift of Love, and many other health institutions in the City.

The Anti-Violence Project
208 West 13th Street
New York, NY 10011

(212) 807-0197
Begun in 1980 in response to AIDS related violence against gays and lesbians.

Community Health Project
Bellevue Satellite Clinic
208 West 13th Street
New York, NY 10011

(212) 675-3559

Rona Affoumado, Director
Mulit-service clinic for people at risk for AIDS

Deaf AIDS Task Force
Mr. Aaron Rudner

(212) 473-4197
Communication network for deaf PWA's

Ms. Ann Silver
The Silent News
112 East 19th Street
New York, NY 10003

(212) 598-4739

Newspaper for deaf persons, carrying information on AIDS prevention and care.

Foundation for Research on
Sexually Transmitted Diseases (STD's)
266 West 12th Street
New York, NY 10014

(212) 929-2530

Dr. Joyce Wallace, President
Dr. Wallace is a Greenwich Village physician who has published research papers on AIDS in prostitutes in New York City.

Gay Men's Health Crisis (GMHC)
Box 124, 132 West 24th Street
New York, NY 10011

(212) 807-6664
Richard Dunne, Executive Director
Tim Sweeney, Dep. Director of Policy
Lewis Katoff, Director of Client Services
Dr. Charles McKinney, Director of Education
Mr. Mark Fenak, Director of Legal Services

GMHC is the largest and most diversified AIDS-related organization in the country. Its many services include a telephone hotline, publications, legal and other client services, and facilities including a recreation center for client use. Serving all people.

Organizations and Individuals
(continued)

Haitian Coalition on AIDS
Haitian Centers Council, Inc.
50 Court Street, Suite 605
Brooklyn, NY 11201

(718) 855-7275 855-7276

Marie Saint-Cyr Delpe, Program Director
Organized to educate Haitians and general public about AIDS and relation to Haitians, and to serve as information and communication network among Haitian Americans.

Hetrick Martin Institute
Youth Aid and Education Services
110 East 23rd Street, 10th Floor
New York, NY 10010

(212) 473-1113

A. Damien Martin, Ed.D., Executive Director

Serves all youth, but primarily gays and lesbians. Helps kids get off streets and out of risk.

National Hemophilia Foundation
104 East 40th Street, Suite 506
New York, NY 10016

(212) 682-5510

Mr. Tom Harrington, Executive Director
Information and assistance organization for hemophiliacs and (info. to) general public.

Hispanic AIDS Forum
Ms. Ruth Rodriguez, Exec. Director

(212) 463-8244
Hispanic network for information and referrals
140 West 22nd Street, New York, NY 10011

New York City Parents and Friends
of Lesbians and Gays, Inc.
P.O. Box 553, Lenox Hill Station
New York, NY 10021

(914) 793-5198
Mrs. Amy Ashforth, spokesperson, mother of a son who died of AIDS in June.
Information and support network; publications.

People With AIDS Coalition (PWA Coalition)
263 West 19th Street
Room 125
New York, NY 10011

(212) 627-1810
Paul Van Souder, Executive Director
Created by PWA's to help each other. Advocacy, housing, forums, speakers bureau. Community Research Initiative (CRI) with its own IRB, runs clinical trials of experimental AIDS/ARC treatments in a community setting with qualified physician management.

Urban Resource Institute
Addiction Research and Treatment Corp.
22 Chapel Street
Brooklyn, NY 11201

(718) 834-5332,3,4

Lawrence S. Brown, M.D., M.P.H., V.P. Research and Medical Affairs
Extensive programs for IVDA's.

Women in Crisis
133 West 21st Street
New York, NY 10011

(212) 242-4880
Mari Nobles-daSilva, Program Coordinator.
Black women's service organization, under auspices of Project Return Foundation, Inc.

Individuals and Organizations
(continued)

N.Y. State Senator John R. Dunne
RIVKIN, RADLER, DUNNE & BAYH
EAB Plaza
Uniondale, NY 11556-0111
(516) 357-3252

Office: Roberta Glaros
(Exec. Director of Task Force)
505 State Capitol
Albany, NY 12247
(518) 455-2831

N.Y. State Senator Tarky Lombardi, Jr.
723 Hiawatha Blvd. West
Syracuse, NY 13204

Office: Harriet Morse Stephen Boese
(518) 455-3511

Senator Dunne and Senator Lombardi co-chaired the New York State Task Force on AIDS, which published its report in July, 1987.

Congressman Charles Rangel
U.S. House of Representatives
House Office Building, Annex 2, R. 234
Washington, D.C. 20515

(212) 225-4365 Secretary: Pat Bradley

Rep. Rangel has been very active in programs relating to AIDS and IVDA.

Mr. Ed Jurith
Staff Director
House Select Committee on Narcotics
Abuse and Control
2330 Rayburn H.O.B.
Washington, D.C. 20515

(202) 226-3040

Dr. David Axelrod
New York State Commissioner of Health
New York State Department of Health
Empire State Plaza
Corning Tower Bldg., Room 1408
Albany, NY 12237

Office: (518) 474-2121

Dr. Stephen Joseph
Commissioner of Health
New York City
125 Worth Street, Rm. 331
New York, NY 10013

Office: (212) 566-7150

Dr. Jo Ivey Boufford
President
New York City Health and
Hospitals Corporation
125 Worth Street, Rm. 514
New York, NY 10013

Office: (212) 566-8650

EXHIBIT D-2

SAN FRANCISCO SITE VISIT

Sept. 2-3, 1987

S C H E D U L E

Wednesday, Sept. 2, 1987

9 AM	Presentations and Press Briefing	Dept. of Public Health 101 Grove Street San Francisco, CA
12 - 1:30 PM	Luncheon Meeting	
2 PM	Site visit	Bayview Hunter's Point Foundation 6025 3rd Street
4 PM	Site visit	Coming Home Hospice 18th and Diamond Streets

Thursday, Sept. 3, 1987

7:30 AM	Breakfast Meeting	S.F. General Hospital 1001 Potrero Avenue
12:30 PM	Press Briefing	S.F. General Hospital 1001 Potrero Avenue

EXHIBIT D-3

SOUTH FLORIDA HEARINGS AND SITE VISITS
Nov. 10-12, 1987

S C H E D U L E

Tuesday, November 10, 1987

12 PM	Presentations	Palm Beach County Health Department 826 Evernia Street Palm Beach, FL
	Site visit	PBCHD AIDS Clinic 3701 N. Broadway Avenue
	Site visit	County Home and General Care Facility 1200 45th Street
	Briefing	C.L. Brumbach Community Health Center 38754 State Road 80 Belle Glade, FL

Wednesday, November 11, 1987

9:15 - 10 AM	Site visit	A.I.D. Center One 370 E. Prospect Road Fort Lauderdale, FL
10:15 - 10:45	Site visit	Our House
12:30 - 1:30	Luncheon	Palms Restaurant
1:30 - 2:30	Site visit	Mt. Sinai Medical Center 4300 Alton Road Miami Beach, FL
2:45 - 3:15	Site visit	Cure AIDS Now 2240 S. Dixie Highway Miami, FL
3:30 - 4:00	Site visit	Health Crisis Network 1351 NW 20th Street
4 - 5 PM	Site visit	Jackson Memorial Regional Medical Center 1611 NW 12th Avenue

Thursday, November 12, 1987

8:30 AM - 5 PM	Public Meeting	University of Miami, Mailman Center 1601 NW 12th Avenue

APPENDIX D-3

ACTIVITIES AND RECOMMENDATIONS

12 NOVEMBER 1987

Dr. John Witte (Assistant State Health Officer, State of Florida)

OVERVIEW OF AIDS IN FLORIDA

1) The Florida Department of Health and Rehabilitative Services maintains a good surveillance program.

2) Current projections on the incidence of the disease in Florida:
   a) The number of cases is doubling every 12-15 months;
   b) The cumulative number of expected cases is:
      4000 in 1988
      8000 in 1989
      16000 in 1990
      32000 in 1991
   c) In Florida, 15% of the cases were spread heterosexually as opposed to the 4% national average.

3) Current funding for AIDS activities is $4 million from the Federal Government. For this fiscal year, the State has appropriated $12.5 million.

4) A waiver for adult congregate living facilities (ALCF's) is being processed. Those persons infected with HIV will probably be admitted soon. This waiver would include nursing homes.

Ms. Linda Quick (Executive Director, Health Council of South Florida)

1) The Health Council of South Florida is a voluntary, non-profit corporation serving Dade and Monroe Counties.

2) The Council's purpose is to provide effective health planning, and to promote the development of health services, manpower, and facilities which meet identified health needs in a cost-effective manner.

3) In October 1985, the Health Council began a massive effort to assist Florida in addressing the impact of AIDS:
   a) Initially, the Board of Directors authorized the establishment of an Ad Hoc Committee to develop a plan;
   b) The Committee represented affected parties, political and social leadership, and segments of the health care

community already actively involved in South Florida AIDS efforts;

4) Four work groups were established in the areas of public education and information, care and treatment, legal and ethical dilemmas and research and prevention.

5) Thus far, the care and treatment plan has been implemented. The South Florida AIDS network has been established which consists of service providers centered and administered by University of Miami Medical School and Jackson Memorial Hospital. Specifically, the Visiting Nurses Association, Health Crisis Network, Hospice, Dade County Human Resources Health Center, Florida Department of Health and Rehabilitative Services. There is an ever-widening circle of others as well.
   a) The network is funded by a combination of Federal, State and private money.
   b) Similar, but smaller treatment networks have also begun in Broward and Monroe Counties, as well as West Palm Beach.

6) The goal is to link all of southeast Florida with a sophisticated and accessible care and treatment system.

7) New funds and programs are being developed for residential facilities for adults and children, specialized care of addicts (IV and other drugs), programs addressing the interface of mental health and AIDS care; efforts to reach minorities at risk of AIDS.

8) Part of this implementation process was the creation of the South Florida AIDS Advisory Committee. This was formed and funded in part by the Robert Wood Johnson Foundation and the Health Resources and Services Administration.

9) This Committee was organized by the Health Council as a standing committee. This will coordinate the whole community to address and resolve non-treatment issues, as well as provide advice and coordinated assistance to Dade, Broward and Monroe Counties' care and treatment networks.

10) The Committees goals include:
   a) Continued dialogue, undertaking additional plans and projects and fulfill a leadership role;
   b) Encourage and nurture plan implementation, serve as community-wide advisory board to the Trust and its foundation funds;
   c) Provide requested advice and information and to seek additional financial resources.

11) The Committee has developed a policy statement on HIV testing and submitted it to the Florida legislature.

12) Citicorp Savings of Florida donated $10,,000 to the Health Crisis Network.

13) Advisory Committee has begun conducting an objective data collection and analysis effort to help the state evaluate its expenditure of resources.

14) The Committee is also examining the best way to include Palm Beach County for an even broader regional plan.

15) In the past nine months, the Statewide Health Council (consortium of Florida's eleven local health councils) has published two extensive policy reports addressing public schools, AIDS and insurance, and related discrimination issues.

16) Health Council of South Florida is very concerned with State and Federal legislation. Policy statements have been attached.

Questions and Answers

Attitudes within communities towards location of hospices and nursing homes is a general zoning problem and not just because of AIDS. Education is more than cognitive information. It requires a change in attitude. As leaders in the community change their attitudes they can lead the way.

All of the efforts involve both the leadership and grassroots people, all segments of the community. Minority based community groups are competing for funds to better target and reach out with educational and care and treatment programs.

CARE AND TREATMENT CONCERNS

Joyner Sims, Ph.D. (State AIDS Program Administrator)

1) The premier patient care network in Florida is in Dade County.

2) The patient care networks have one objective: to provide a continuum of quality care for persons with AIDS and persons with ARC at a minimum cost.

3) The State role in this effort has been to channel $6.5 million of State general revenues into Dade County. The community effort there has made the process easy.

4) The State has also provided $1.7 million in general revenue funds to eleven other counties.

5) The networks to be developed by these funds are in various stages of development.

6) A lot of counties use the money to round out services not available elsewhere by other health care providers, such as in Broward County they established a patient care clinic with a very popular dental clinic.

7) In Palm Beach County the money is used to round out the network process as well. They are in the process of planning for a dental clinic.

8) The State has established or assisted in establishing networks in counties where more than 90% of all AIDS cases have been reported.

Dr. Arthur Fournier (AHEC Program Director, University of Miami)

CARE AND TREATMENT CONCERNS

Dr. Fournier is an Associate Professor in the Department of Medicine, University of Miami, with nine years experience teaching and eight years experience in treating patients with HIV infection.

Impact of AIDS on Medical Education and the Health Care Delivery System:

1) A generation of physicians were trained in an atmosphere of complacency. With the discovery of penicillin and other vaccines, the assumption was that the major infectious diseases could be cured or eliminated through vaccination programs.

2) With the HIV epidemic, physicians were shocked back to the historical mainstream -- they can diagnose, counsel and comfort patients and their families, but seldom can cure.

3) The epidemic has challenged the profession to deal with previously tolerated inadequacies particularly in education and delivery systems:
   a) continuing medical education;

b) maldistribution of physicians (both geographical/specialty);
c) medical ethics;
d) medical economics.

4) Since the epidemic first surfaced in 1979, physicians have witnessed the delineation of clinical syndromes associated with immunodeficiency. They have:
   a) worked through the basic immunology;
   b) conceptualized risk behavior;
   c) identified the virus;
   d) developed screening tests/partially effective treatment;

5) The currently existent system for continuing education of practicing physicians is inadequate.

6) Recently developed programs at HRSA and NIMH should be encouraged and expanded.

7) Primary care physicians should be encouraged to be the principal providers of care to HIV infected individuals for the following reasons:
   a) Patients with AIDS represent a minority of those exposed to HIV infection.
   b) Those in need of screening and counseling are usually asymptomatic and should be dealt with in an ambulatory setting.
   c) The epidemic is spreading into every region of the country and if current projections are met, tertiary centers will soon be overwhelmed. In some instances, they may not be available to infected or at risk individuals.
   d) Many patients that are counted for statistical purposes in major cities, return to their families in other parts of the country once resources are exhausted. This is the phenomenon of going home to die.
   e) Tertiary care is discontinuous, costly and frequently more impersonal than primary care.
   f) Modern primary care physicians receive special training in skills that are especially germane for the care of HIV infected patients.
   g) The full-blown illness is multi-system and patient management requires a broad base of general knowledge that transcends some specialty concerns.
   h) An optimum health care system should foster already existent programs designed to redress the mal-distribution of physicians, and encourage primary care trainees to become knowledgeable about AIDS-related matters.

i) There is a glaring deficiency in the current system of knowledgeable primary care physicians in inner cities.
j) Federal programs designed to address mal-distribution--should be fully supported and encouraged to develop the training.

8) Impact on career choices:
a) Negative impact on training in internal medicine.
b) Accurate information and an appeal to professional responsibility towards patients can reverse trend.

9) Ethics:
a) Need for ethical training.
b) Need for a consensus among the profession on issues such as confidentiality, refusal to treat and equal access.

Dr. Paula Sparti (Community physician, Miami)

CARE AND TREATMENT CONCERNS

1) Mandatory testing is frightening and implies abandoning the principles of informed consent and the protection of individual rights.

2) Recommend that mandatory testing and reporting not be done prior to confidentiality and anti-discrimination laws being passed and made enforceable.

3) Recommend State legislators confer with State medical associations and AIDS task force groups regarding intended outcomes of proposed legislation.

4) Priorities must be education, access to health care, terminal care facilities and research.

5) Intensify efforts to reach those who continue to expose themselves, and those who are not already infected. This requires a concerted effort on the part of educational and psychological experts.

6) Access to medical care:
a) Public health care system is overwhelmed and unable to accommodate the uninsured.
b) Recommends a decrease in the Medicare eligibility waiting time to no more than 6 months for those individuals who have paid into the system.

7) Research:
Eliminate barriers to sound research.

Questions and Answers

Often one hospital bears the burden of patients who are unable to pay. Patients are often taken to another hospital initially and then transferred to the Jackson Memorial Hospital--primarily because of money.

Payments by Medicaid are inadequate. Referrals to specialist is a problem both because of financing and fear or lack of information--some legitimate fear of exposure.

Dr. Daniel Seckinger (Chairman, Florida Medical Association Task Force on AIDS)

CARE AND TREATMENT CONCERNS

The Florida Medical Association has 16,000 members.

1) Created a most functional and successful model for a statewide organization--it is a private sector organization with committees on substance abuse, corrections, public health and education and involves physicians in infectious diseases, family medicine, pathology, oncology and hematology. The have included other medical professional associations and input of

   faculty at the major educational institutions. It transcends the spectrum of care from patient interface to research to policy.

2) Education:
   a) Need for comprehensive broad based educational program that brings in the lay community, the professional community, and paraprofessionals.
   b) They are developing an AIDS manual for the 16,000 physicians in Florida; Florida Medical Association has contributed $25,000.

3) Major area to look at is access to care.
   a) Negative physician and other professionals bias towards AIDS patients exists with adequate safety in the workplace as a concern.
   b) The cost of caring for AIDS patients (perhaps $18 billion in 1991) could topple the private insurance industry in an already stressed area and the public sector is not prepared to handle this.

4) Due to a finite amount of funding, education is a must, particularly in low prevalence areas where misunderstanding seems to be more apparent.

Reverend Hugh Westbrook (President, Hospice Care, Inc.)

CARE AND TREATMENT CONCERNS

Hospice Care operates comprehensive in-patient and home care hospices in Miami and other cities.

1) Culturally we have a problem in dealing with terminally ill people; confronting the notion of dying.

2) A hospice deals with management and delivery of all in-patient and out-patient, home care that relates to a person's terminal illness.

3) Hospice care is paid for separately and is cost accountable thus, the public or private payor save money. It is, however, underutilized in the care of AIDS patients.

4) Three ways to provide care for AIDS patients:
   a) Unmanaged care--this is simply the lack of a system.
   b) Network care--this is a brokerage system where one entity acts as a broker finding other agencies to provide slices of the needed care.
   c) Managed care--the manager of the care is also accountable and responsible for the delivery of that care in this system.

Patrick Haney

PERSONS WITH AIDS CONCERNS

Patrick Haney was diagnosed with ARC in 1984, and AIDS in 1987.

1) The disease affects us all because of the impact on medical care and cost, social services, loss of productivity and loss of human potential.

2) HIV infection is a daily struggle--24 hours a day.

3) The epidemic of the AFRAIDS is leading to incredibly reactionary responses.

4) Violence has sharply increased. Oppressive laws are being proposed and passed. Repressive social controls are being called for.

5) Many believe that AIDS is some kind of punishment, and it carries a stigma, shame and a pointed finger of blame.

6) Massive education campaigns are vital--with a goal of acceptance of all people and recognition of our common humanity.

Jim Merriam

PERSONS WITH AIDS CONCERNS

Jim Merriam was diagnosed eleven months ago with AIDS.

1) A lot of good work is being done--but also there are a lot of holes in the system.

2) Important for Persons With AIDS (PWA) to be involved in the Commission work as volunteers and as paid staff.

3) Free education brochures distributed by the government are needed similar to those on cancer and chemotherapy on how to take care of yourself for people with AIDS.

4) Need for the Library of Congress, or a similar group, to provide for taped material for people who are blind or too sick to read.

5) The Center for Disease Control has put restrictions on the number of educational brochures that are available.

6) The Public Health Services videos are boring making it difficult for people to get information.

7) The Federal Government needs to be involved in health care worker training. The two-year waiting period for Medicare should be waived.

8) Millions of dollars are paid locally to pay for care of foreigners who come to Miami for treatment. This should be a Federal responsibility.

9) Insurance companies, both health and homeowners, are beginning to add riders, or exclusions and limitations because of AIDS.

10) AIDS treatment evaluation systems which do initial testing to enable people to get experimental drugs require payment in cash, they will not accept Medicaid or Medicare, private insurance or checks.

11) There are problems of coordination and communication between groups. There is not adequate follow-up after a patients release from the hospital.

Doug Segal

Doug Segal is a hemophiliac and considers himself one of the more fortunate AIDS victims.

1) Mr. Segal has a large circle of friends, family and business associates who support, care and understand his circumstances.

2) He feels that education and research are vital to erasing this deadly disease that attacks all parts of your body--makes you totally dependent.

3) Money for medical care, medication and counseling should be allocated directly to the persons with AIDS and their families. All should receive the same financial consideration.

Ellen Bucksteil-Segal

Ellen Bucksteil-Segal and her children do not have AIDS, nor have they tested positive for the virus.

1) They are not consumed with fear of transmission in their household. They share towels, shower together, kiss and hug all the time. She does fear the intolerance that someone might display toward her children because of lack of proper knowledge and information

2) She feels that as the first of many generations of AIDS victims, their legacy must be to encourage programs of research and education.

3) It is ironic that now for her and her husband an act of love that consummates their feelings for each other can be the same act that could kill them.

Michele Rigaud, M.D., M.P.H. (Haitian Task Force)

Dr. Rigaud represents Haitians nationwide and worldwide.

1) Haitian people will never recover from the stigma imposed on them through their identification as a risk group for HIV infection--an ethnic misclassification.

2) Policies used by American institutions have been detrimental to Haitian patients who are routinely subjected to testing for HIV infection solely on the basis of nationality.

3) It is an overwhelming challenge to provide education and counseling to the Haitian people given existing insensitivities and stigmatizing policies.

4) The Haitian Caucus submitted a resolution to the CDC which laid out basic guidelines that should be followed in addressing the needs of Haitians. They include:
   a) Involving Haitian professionals in AIDS program development and risk reduction activities;.
   b) Intensive training by the CDC for Haitian professionals.
   c) Providing financial and technical support for Haitian community service organizations.

Manuel Laureano, M.S., M.D. (Hispanic Task Force)

1) Hope gives individuals control and motivation for decisive action in facing the AIDS crisis.

2) Hispanics are overrepresented as a percentage of the total AIDS cases nationally.

3) The areas with the largest Hispanic populations coincide with the areas where AIDS has the highest incidence.

4) In Hispanic communities, there is a high value on the family, retention of traditional values and special meaning and use of the spanish language.

5) Hispanics are a resourceful community where 24% of the heads of households have college educations.

6) AIDS is visualized by the Hispanic community as a disease of white, gay men. There is great difficulty identifying with AIDS or effectively communicating about the nature and risk of the disease within the community.

7) There is reluctance among key influential leaders and elected officials to be associated with AIDS, which reinforces denial.

8) The greatest need is for access to accurate information about AIDS.

9) Mass media educational programs delivered directly into the privacy of the home are more effective than special forums or community conferences.

10) There is a need for a Spanish hotline on AIDS to provide an opportunity to inquire about AIDS confidentially.

11) Among Hispanic families there is a genuine and culturally rooted desire to take care of AIDS patients within the family structure.

12) These families need assistance from established community based agencies to deal with AIDS-related problems.

Question: There is an indication that the high level of Hispanic population was the reason for high heterosexual transmission rates in South Florida?

Answer: This is probably due to high-risk sexual behavior, particularly bisexual behavior and denial of such -- so those people get statistically labeled as heterosexual.

SUBSTANCE ABUSE

Bruce Hayden (Substance Abuse Task Force)

(Submitted written testimony)

1) There are two aspects to addressing residential treatment program issues -- clinical and administrative.

2) Clinical issues include:
   a) Substance abuse rehabilitation is based on recovery, and staff training is geared to that.
   b) Staff training is needed on death and dying issues.
   c) Training for staff and clients on personal attitudes toward treating and interacting with people with AIDS, dealing with family members and those who reside with AIDS victims is also needed.

d) Important to distinguish when treatment protocol for a chemically dependent person ends and when medical needs of the AIDS client becomes priority.

3) Administrative issues include:
   a) Due to lack of policy and direction programs are generating policy statements that are widely different from program to program.
   b) There are many questions about testing, confidentiality, funding of treatment programs, insurance coverage and liability.

PEDIATRICS AND FAMILY

Ana Garcia (LCSW, Social Worker Pediatric Immunology, University of Miami)

Ana Garcia is a Pediatric Social Worker working with children who have AIDS and their families for the past 5 years.

1) Families are often unaware of AIDS, or that they are infected, consequently children are born infected with the virus.

2) These are not isolated incidents, and we are seeing the destruction of families and children being abandoned.

3) Education and counseling to encourage change of behavior, safer sex practices and, for infected women, encouragement not to continue to have children.

4) Foster care implications are incredible. Currently there is no waiting for placement but there is a continuous need for placement. There are no special licensing procedures for families who take AIDS children beyond a suitable home environment and meeting State guidelines with a sincere interest to have these children.

5) There is full coverage of medical expenses for children who are followed in the pediatric clinic.

6) Professionally there is a shortage of AIDS social workers.

LESBIAN AND GAY COMMUNITY

Cliff O'Neill (TWN Weekly News)

Cliff O'Neill is the news editor of the Weekly News, the State's gay and lesbian newspaper.

1) One in ten high school students is a lesbian or gay man.

2) There has been much debate about how to educate youth about the dangers of unsafe sexual activity. Not informing teenagers on the verge of sexual awakening about risk-reduced sex is dangerous.

3) Many young people are confused as to how to explore their sexuality without coming in contact with the HIV virus. They have come to the gay community and have asked questions, read literature and explored their sexuality safely.

4) Many other youths have gotten the message through the media, their families and schools that homosexual sex is inherently fatal.

5) Some youths are practicing promiscuously unsafe sex and others have committed suicide.

6) Restrictions on explicit education material "which would promote or encourage homosexual sex" is tantamount to banning Federal funding for most of the gay and lesbian community AIDS service organizations wiping out AIDS education programs which would allow for the education of these people.

Joseph McQuay (President, Dade Advocates for Rights and Equality)

1) The Surgeon General has said that AIDS is not transmitted in places of employment; by houses; by food-handlers and that some doctors are shirking their ethical responsibility.

2) AIDS discrimination ravages South Florida as much as the disease. Elected officials must be an example, the guardians of the public good.

3) Where is the national leadership? The Secretary of Health and Human Services believes the States should take the lead to protect against discrimination.

4) Education needs to reach every corner of this country. A treatment must be found, not just a vaccine for this disease.

5) We need Federal legislation banning discrimination against those who are AIDS infected or those who have the disease.

6) There is no legal precedent--only one case that threatened to go to court--but was settled out of court.

7) The rights of employees to have a chance to maintain employment has been upheld by the state Civil Rights Division.

8) Education and legislation must go hand in hand.

NOTE: Chairman Watkins committed to hold hearings specifically on discrimination and confidentiality.

Bill Bahlman (ACT-UP)

ACT-UP is the AIDS Coalition to Unleash Power.

1) There is a lot of anger among the people with AIDS due to the lack of abilities, as individuals and collectively, on the Commission.

2) It is a symptom of how inadequate the Federal Government has been in responding to AIDS.

3) FDA's passive approach to drug approval is another means of genocide; 87% of patients are in AZT studies. When are other promising treatment to be tested?

4) Specific information, and data on drug testing will be provided to the Commission for special hearings to be held in January.

5) Currently there is no national clearinghouse of data on AIDS-related drugs that is full and all encompassing.

6) Project Inform in California is a clearinghouse of data.

INCARCERATED POPULATION

Harry Shuman (M.D., State Health Services)

Dr. Shuman is the Regional Health Services Director for the Florida Department of Corrections.

1) Fiscal responsibility to taxpayers is considered in utilizing available health services funding in ways that will be most beneficial to the health and safety of the inmates, a well as protecting the public health upon the patients return to society.

2) Pressure from the outside is being felt to institute mandatory testing for HIV on all inmates.

3) That policy is irrational, fiscally irresponsible and medically unsound.

4) The ELISA screening test is suitable for screening the blood supply, but it cannot predict which of those infected will go on to disease.

5) Segregation of individuals who are HIV positive, yet are not engaging in high risk behavior is medically unwarranted.

6) Confidentiality with a correctional setting, in reality, often cannot be completely achieved because of security concerns.

7) Targeted education programs are the only viable way to contain the epidemic within special populations.

8) Medical developments must not be withheld on the basis of the incarcerated state of the patient.

9) Mandatory testing does not advance the ends of public health. Currently, those states which do mandatory testing do not have a firm plan to follow after identification.

10) Follow-up and linkages are supposed to be arranged for patients with AIDS making transition from incarceration to release.

Marilyn Volker (Women's Task Force)

Ms. Volker coordinates education for the community at Health Crisis Network, the AIDS project in Miami.

1) The Health Crisis Network has support groups for women.

2) HIV infected women are mostly in the category of IV drug users or heterosexual contact.

3) Brochures are the least effective method of education, but are probably what we do best.

4) Many women do not trust the organizations that provide the information, education, counselling and related services.

5) Models and images must be clear in communicating to certain women about AIDS. Many of these women do not know their own bodies.

6) If their survival is based on the use of their bodies to maintain money for their children. Saying use protected sex may not work.

7) Women in drug programs come with enormous needs in terms of self esteem, lack of communication skills, lack of support systems and lack of networking.

8) We are faced with enormous challenges in terms of intervention and prevention. Non-traditional ways of presenting information must be considered.

9) Similarly situated peers should be used to reach women on the streets, in drug rehabilitation programs and women who are infected.

WOMEN'S CONCERNS

Fran Bohnsack-Lee (Dade County N.O.W.)

Ms. Bohnsack-Lee is the President of the National Organization for Women in Dade County.

1) AIDS is the leading cause of death among women ages 25 to 29 in New York City.

2) In discussing AIDS, it is helpful to reflect upon the past, to learn about the social construction of disease.

3) Government policy is confused. The Surgeon General says one thing, the Secretary of Education says another.

4) The Army's efforts to deal with syphilis during World War II parallels the AIDS policy today.

5) AIDS is a medical issue and should not become the fodder for ideology.

6) We debate about using billboards for AIDS education, while a person with AIDS is engulfed in flames in a hospital bed.

7) Certainly the nation that went to the moon can do more when 25,000 of its citizens have died.

8) We triumphed in the Manhattan project during World War II, so must we triumph against AIDS.

EDUCATION ISSUES

Patrick Gray (Ph.D., Executive Assistant Superintendent, Dade County Schools)

1) Dade County is the nation's fourth largest school system.

2) 255,000 students, 25,000 employees and in excess of 300,000 parents are clients of the system.

3) A task force of medical and legal experts and labor union representatives put together state-of-the-art information and accordingly adopted an aggregate of procedures which constitute a policy.

4) The policy constitutes the review of a child's medical status and the acceptance of a child in the school under certain conditions.

5) 60% of the teachers at the school where children with AIDS were enrolled volunteered to teach these children.

6) Some other teachers, do not associate in the lounge or cafeteria with these teachers. They are experiencing isolation.

7) The school system is successfully implementing a comprehensive AIDS education program with the children, parents and employees.
   a) Contrary to the Surgeon General's opinion to begin teaching children about AIDS at grade 3, we are teaching grades 5 through 10.
   b) Above grade 10, they are educated through presentations of the Public Health Department.
   c) Employees are educated through material, telecasts, video tapes and information.
   d) Parents are reached through the PTA and a Florida-based Advisory Committee network.
   e) Public school systems depend upon their public health resources for education about AIDS.
   f) Very little appropriate curriculum material is fully appropriate for the various different learning levels of children.

8) Collaboration with the nation's Public Health Department and the nation's schools could expand individual school system resources.

Ms. Ruth Shack (Executive Director, The Dade Foundation)

1) It is time to reexamine and evaluate the educational programs and the way to reach effectively the diverse components of the community on AIDS related issues and prevention.

2) Problems in educating the community can best be surmounted by developing programs specially targeted and delivered by members of their own ethnic groups.

3) There is a need for a well-trained staff hired from the communities themselves.

4) To avoid duplication of administration, support, and service systems, a central organization, such as the Miami Health Crisis Network could function as the home base for small neighborhood outreach programs. These programs should educate, do initial counseling, and channel those in need to central service providers.

5) In the development of the educational programs, special attention needs to be focused on the following:
   a) Materials must be developed by each community with relevant language and graphics.
   b) Materials should not simply be translated from English but must represent meaningful issues to each of the communities.
   c) There needs to be clear graphic materials tastefully presented by the facilitators who are comfortable with a discussion of all aspects of human sexual behavior and drug use.
   d) Educational materials need to be updated and evaluated for accuracy and effectiveness.
   e) There must be inclusion of AIDS educational materials for persons already infected with the virus.
   f) For persons who do not know that they are infected, materials need to include basic immunology information, resources for support, and the most current information about intervention protocols.

6) We need to provide educational programs for training the trainers. They should not only include facts and examination of attitudes, but also incorporate skill development into presentations.

Mr. Spencer Lieb (AIDS Program Supervisor, State AIDS Education Office)

1) The CDC funds projects collectively known as Health Education, Risk Reduction (HERR). These projects include:
   a) programs in South Florida, in the regional four county area, and in Belle Glade;
   b) a statewide AIDS public information project;
   c) an upcoming minority AIDS education initiative.

2) The AIDS risk reduction message must often be tailored to a given culture and lifestyle. The messenger must be credible to the audience.

3) It is critical to convey a sense of vulnerability to those at risk.

4) To those not at risk, we must convey information that will reduce fear so that rational problem solving can take place.

5) Non-judgmental, one-on-one counseling has been provided in pre- and post-testing settings to 20,000 individuals.

6) Counselors trained by the AIDS Program staff carefully avoid stereotyping by emphasizing the factors and behaviors that incur risk, rather than the personal characteristics of the infected individual.

7) Confidential testing and counseling sites are now being established in all county health departments.

8) AIDS information, education, testing and counseling is being offered in STD clinics, family planning clinics, and maternity clinics around the State.

9) In the past two years, the AIDS Program has contracted services with several AIDS service organizations.

10) This year, contracts will be developed with as many as ten minority community groups.

11) The successful development and distribution of a survey instrument on AIDS would not have been possible without the contractual involvement of four major community-based or AIDS service organizations.

12) Printed materials are ineffective when dealing with groups having high illiteracy rates. The Dade County staff are pursuing the development of audio cassettes

with a 15-minute AIDS educational program in Haitian Creole on one side and English on the other.

13) Women with AIDS and female sex partners of men with AIDS were presented with vital preventative information during a regularly scheduled sewing circle in Belle Glade.

14) In South Florida, a billboard and bus placard campaign was conducted aimed at the general public.

15) An original "music and laugh advertisement" was also developed and air time was purchased on three popular Black-oriented radio stations.

16) This past spring, a non-random survey of AIDS knowledge, attitudes, and behaviors was conducted among 2,300 persons who were predominantly at risk.

17) It is not lack of knowledge, but subjective assessment and the perceived inconvenience that prevent wider use of condoms.

18) The only way to prevent new infections is through effective, sensitive education and intervention. Systematic and ongoing evaluation is essential to insure that several years from now we have not missed the boat and that we make necessary mid-course corrections.

Pastor Wisler Marcelus (Haitian Lutheran Services Protestant Voice, Broward and Dade Counties)

1) Lutheran Haitian services cares for the Haitian people, providing child care, health services, education, and referral services.

2) The Haitian Community Center has decided to provide education concerning AIDS in Creole as well as English. They are working for better understanding and research in Haitian care.

3) His group is concerned about the unequal treatment of the poor.

4) The language barrier is a problem facing the Haitian community in trying to joining the AIDS network.

Dr. Carl Eisdorfor (Director, Center for Biopsychosocial Studies of AIDS, University of Miami)

1) AIDS is not simply an infectious disease. It has profound psychological and social consequences.

2) We need intensive efforts to understand how to maximize the impact on those behaviors which are acting to transmit and exacerbate the disease.

3) The virus affects the central nervous system. It can produce dementia before any other symptoms of AIDS are present. In fact, it can affect HIV infected individuals, not just AIDS patients.

4) We need much more in the way of mental health intervention, including psychiatric care in inpatient and outpatient settings as well as community care systems.

5) The biological, cultural, and social families of AIDS victims need psychological help as well.

6) Help for staff is also necessary. Staff burnout is common in these situations.

7) We also need to concentrate more on IV drug users and minorities.

8) More attention needs to be paid to the area of psychoneuroimmunology. There are cofactors such as depression, anxiety, and stress which lead to alterations of the immune system.

9) There is a need to stress mental health research and practice.

10) One way of helping is to establish support groups for HIV infected individuals. The mental health professional could act as a counsel to these groups.

11) There should be more funding for psychiatrically trained nurses. In terms of numbers, they are the one most involved in work in this area.

12) Some suggestions for training professionals:
    a) A lot of psychiatric education is supported by NIMH. An initiative on their part would enable people to establish programs for continuing professional education.
    b) You should reach out directly to the American Psychiatric Association and ask what they are doing.

c) Medical societies around the country, through the State and national medical associations are currently educating their members.

Dr. Dale Chitwood

1) We are currently determining the prevalence of HIV infection of IV drug users, both in treatment center sample and street sample.

2) We are also working on incidence to determine the number of new cases among IV drug users who initially test negative.

3) We are beginning to implement a program to change the behavior of IV drug users on the street and are evaluating that approach by accessing emergency rooms, criminal justice systems, and street networks.
   a) We need to take a careful look at the adequacy of treatment.
   b) We have to take a very active role in going out and enrolling people in the treatment. A central assessment center is being developed to do this.

4) We need an aggressive indigenous worker outreach program.

5) We are looking at the relation of IV drug abuse with other drug use.

6) We are looking carefully at the relationship between prostitution and drug use.

7) One major problem in delivering care is the whole process of the way in which IV drug users seek and receive care. They show up in the emergency room only when they need drastic care.

8) All these efforts need to be coordinated across the country. This could be one of the Commission's recommendations.

9) If we really want to impact IV drug use, we are going to have to talk about stopping all drug use. For those who use drugs, we should teach them to stop shooting. For those who shoot, we should teach them to use new needles or how to clean their needles.

NOTE: There are definitely waiting lists in Florida for drug treatment programs.

Dr. Gwen Scott (Pediatric Infectious Disease Specialist, Jackson Memorial Hospital)

1) The 13 to 18 year old age group of those with AIDS tends to be a forgotten group.

2) The networking program is extremely important because many AIDS children must go home on oxygen or respiratory therapy. The Visiting Nurses Association has been invaluable in keeping these patients as out-patients.

3) Research efforts need to be directed towards:
   a) the development of lab tests which will simplify diagnosis in infants;
   b) studies of the mechanism of transmission from mother to infant;
   c) further understanding of the natural history of the disease in infants;
   d) a better understanding of the physiology of the disease in the various organ systems;
   e) determining the risk of infection to an infant born to an HIV positive mother.

4) Drug studies need to be instituted early in children.

5) Real hope lies in the development of effective antiviral drugs and a vaccine.

6) Treatment programs should be targeted to the neonate by treatment of the mother during pregnancy or of the newborn infant.

7) Model programs of patient care need to be developed. Children with HIV are particularly work-intensive.

8) Development of peer groups to go out and educate their peers is one way to reach teenagers.

9) We also need more education for physicians.

Dr. Mary Jo O'Sullivan (Director of Obstetrics, Jackson Memorial Hospital)

1) We need to understand the population we are dealing with--how they think and why they behave the way they do.

2) We need good studies to determine incidence in the various population groups.

3) We also need studies to examine:
   a) what increases the risk of transmission during pregnancy;
   b) development of techniques to make the diagnosis in utero;
   c) the risks of breast feeding;
   d) impact of this infection on women:
      I) Is a pregnant woman more susceptible to infection?
      II) Is progression of infection more rapid in pregnant women?
      III) Is a woman's survival rate decreased by a pregnancy when she is HIV positive?

Dr. Lisa Marchette (Associate Professor, University of Miami School of Nursing, Nursing Research Coordinator at Mt. Sinai Medical Center)

1) The nursing shortage in general is causing problems. Adding to this problem are nurses who feel very strongly about caring for people with AIDS, and others who feel very strongly about mandatory testing for all patients.

2) Education and support groups are needed for nurses.

3) Strong leadership is needed from the CDC, OSHA, and JCAH to continue to protect health care providers. Health care administrators need to insist that nurses continue to care for people with HIV infection and that confidentiality is maintained and that testing is voluntary.

4) Research is needed for the non-medical therapies that are used by people with AIDS.

5) More funding incentives and financial support are needed for the education of nurses at all levels. Continuing education programs are needed as well.

6) Financial incentives would help nursing generally, but feeling comfortable in their work is probably more important.

Mr. Leon Kelner (U.S. Attorney, Southern District of Florida)

Law enforcement agencies deal with the drug abuse problem from the other side, the supply side.

Dr. Terrence Collins (Chairman, Working Group on AIDS and Florida Statewide Health Council)

1) The State Health Council was established by Florida law to be an advisory council on health planning. They have recommended actions in the areas of public education, testing, confidentiality, concerns in schools, insurance, discrimination, and workplace issues.

2) Access to quality health care is contingent on access to some component of the health care financing system.

3) The insurance industry is seeking ways to better screen applicants in order to assess risk and price premiums accordingly, or to refuse insurance to high risk applicants.

4) At the same time, state legislatures and insurance departments are considering regulatory methods to insure continued access to health care through private insurance.

5) The Council recommends the following policy components:
   a) Determination of HIV seropositivity should not be used as the basis for adverse underwriting decisions for insurance of any type, including health and disability for conditions that are not related to the HIV infection.
   b) Involuntary termination of coverage for persons diagnosed with AIDS or ARC under the context of a pre-existing condition should be prohibited.
   c) Testing for the purpose of obtaining individual life, health, and disability insurance should not be prohibited by law. This testing should be restricted to the most accurate series of tests available.
   d) Guidelines should be developed so that the industry's use of the tests is applied in a non-discriminatory fashion, that informed written consent be given, that appropriate counseling is offered, that results remain confidential, that results are delivered to the person individually and in person, and that results are not included in the industry data banks.
   e) Testing for the purpose of group insurance should not be permitted.
   f) Inquiry into prior AIDS testing history should be prohibited.
   g) Legislation should be enacted to insure that any information concerning HIV infection held by the insurance companies remains confidential. This

includes subpoena or any other form of access, except under rare, well defined circumstances.

h) Federal legislation should be enacted to prevent discrimination in housing, employment, school admission, public accommodation, and procurement of goods and services.

i) The establishment of risk pools should be encouraged through Federal legislation and funding.

j) Eligibility requirements should be structured so that any HIV-infected individual is immediately eligible for enrollment.

k) Federal incentives should be developed to encourage studies by the states to determine the feasibility of implementing a program of subsidies for premiums and/or deductibles for persons participating in such risk pools.

l) Losses to State risk pools should be shared by all health insurance providers, including those who are self-insured who are currently exempt from participation.

6) We must decide whether areas with the highest incidence should bear the greater burden or whether the cost should be more evenly spread.

Father James McCartney (System Ethicist, Allegany Health System, Director of Bioethics Institute at St. Francis Hospital)

1) There are seven areas in which the Federal Government has the responsibility to provide leadership and funding:

a) Research:

I) NIH should provide funds for basic research in virology with a special focus on retroviruses.

II) NIH should be empowered to conduct clinical trials as expeditiously as possible on new antiviral agents.

b) Education:

I) The Federal Government should continue to provide information under the direction of the Surgeon General in cooperation with State and local governments.

II) The information campaign should also include advertisements shown during widely watched shows. The advertising the military has done could be a model here.

c) Compiling epidemiological information:

I) The Federal Government should require the reporting of all HIV positive individuals anonymously to the CDC.

II) The CDC should come up with relevant statistics to help understand the spread of the disease.

d) Assisting other governments:
   I) The United States has a moral responsibility to assist other governments in coping with this disease. This can be done by sending other governments the latest research information to other government-based health agencies.
   II) The United States should build into its foreign aid budget funds which will help foster basic care for people in those countries most afflicted.

e) Care:
The Federal Government through grants and contracts, must ensure the possibility of treatment for all HIV positive persons and not allow the market to allocate resources as is done in other areas of health care.

f) Housing:
In-patient hospice care facilities are primarily the responsibility of State and local governments but the Federal Government could help by providing funds through HUD to initiate some model projects.

g) Balancing privacy rights and protection of public health:
   I) The Federal Government should regulate insurance companies so that they cannot refuse insurance for persons who are HIV positive.
   II) The Federal Government must enforce legislation which prevents job discrimination on the basis of HIV positivity alone.
   III) The Federal Government should enact legislation to protect doctors from liability when they communicate HIV positivity information to an at-risk sexual partner.
   IV) The Federal Government should ensure privacy and confidentiality when screening for military service.

Mr. John Sforza (Executive Director, Florida Health Coalition)

1) The direct costs to an employer's health plan is in the range of $60,000 to $100,000 for every AIDS patient according to a recent publication of "Medical Benefits."

2) Other costs include:
   a) increased health care insurance premiums;
   b) impact on group life insurance costs;
   c) disability benefits;

d) temporary replacement;
e) productivity losses.

3) Indirect costs include:
a) employee education on AIDS prevention;
b) costs of providing safety information on AIDS in the workplace;
c) public relations costs regarding the safety of the product especially for food providers;
d) increased marketing costs of products;
e) advertising costs;
f) the uncollected health care costs associated with uninsured AIDS patients which will be passed on to the insured population in treatment fees.

4) The assessment, development, and implementation of a comprehensive service delivery system for the care of AIDS patients in a cost-effective manner must be achieved.

5) Insurers and employers who are hit hard by AIDS claims must be able to protect their solvency through an AIDS insurance pool.

6) Government should sponsor large-scale preventative programs and businesses should sponsor localized programs. An extra tax incentive should be offered to corporations that provide AIDS prevention programs.

Mr. David Berger (President, South Florida Chapter, American Immigration Lawyers Association)

1) AILA is engaged in the representation and assistance of aliens and corporate entities who appear before the Immigration Service and related Federal agencies.

2) Since July 8, 1987, all aliens have had to undergo a clinical examination for symptoms of AIDS. On December 1, 1987, all aliens must take a blood test for AIDS. A positive test makes the immigrant inadmissible to the United States.

3) For legalization applicants (i.e., those applying under the amnesty program of the Immigration Reform and Control Act of 1986) any person who tests positive would be arrested and removed from the country. This causes conflicts with the confidentiality provisions of the act which state that the information cannot be given to any other Federal agency and those who come forward and are denied legalization cannot be deported.

4) A similar problem occurs in the adjustment of status cases. The person can be denied his application, but is not taken into custody.

5) The AILA has submitted a proposal for dealing with legalization, adjustment and some immigrant visa cases. Those who test positive would be required to receive counseling and education and would be allowed to enter or stay in the United States under the humanitarian provisions of the law. Deporting these people would simply increase the global nature of the disease and would be an affront to the world community.

Mr. James Sammone (President, AIDS Coalition Endowment)

1) It is of paramount importance that the Commission make the statement that this disease is not transmitted through casual contact.

2) The Commission needs to recommend to the President and to Congress that a state of national health emergency exists and that extraordinary measures need to be taken.

3) The Commission should endorse the New Manhattan Project on AIDS. The project would have one leader, an AIDS expert from the health care community to develop and initiate a national strategy with government agencies responsible to that person.

4) Research should be done on rendering the HIV virus non-infectious as can be done with other retroviruses.

5) Studies on new drugs, like Ampligen, should be measured against control groups of people on AZT, not victims on placebos.

6) Data should be collected from people who are using all the underground pharmaceuticals. For this purpose, a corporation is underwriting the cost of information data sheets (Scantron sheets) to be sent to people nationwide who are using other pharmaceuticals and food supplements. This corporation is also funding the distribution of AIDS Coalition Endowment brochures.

Mr. Gary Jacobs (President, Health Management)

1) Health Management works in the innovation and design of cost containment programs for the Federal Government, the State government, and the private sector.

2) In corporate America, the initial steps taken are education, training, and strategic planning. Effective case management is also necessary to build strength.

3) The insurance industry must implement programs and benefit plans in conjunction with the employers' response at the workplace, as well as with government at all levels.

4) Florida has hundreds of health plans. In this competition there are restrictions: there are retroactive denials of coverage and pre-existing clauses designed to contain cost and lower risk.

5) Risk management, through carefully developed treatment protocols and payment policies, must be implemented in order to contain the cost of AIDS care.

6) Insurers of all kinds must enact case management methods, consistent with current medical protocols in order to provide humane care in the most cost-efficient way.

7) Effective case management may cause political and insuring institutions to change the laws and policies which presently restrict care for AIDS to more costly settings under Medicaid and major medical policies.

8) Without a Federal waiver, Florida AIDS victims who qualify for Medicaid can only gain access to providers and services currently covered under the state's Medicare program. This prohibits reimbursement for less costly alternatives.

9) Zoning at the local level must also be reexamined to foster the development of group living environments for AIDS patients. These must be so designed that they can receive payment from the payer systems.

10) Coordination through community-based networks of licensed facilities must be implemented so that on a county by county basis all residents will be assured availability of treatment.

11) Counseling must be an integral part of care from the point of pretesting on.

Representative Elaine Gordon (Member, Florida House of Representatives, Legislative Task Force on AIDS)

1) Regarding Florida's State legislation:
   a) in 1985 Florida established statutory authority for alternative testing sites;

b) in 1986 a comprehensive rewrite of the venereal disease statute was passed. This law strengthened provisions relating to confidentiality, reporting, investigating, examining, and treating STD's.
c) in 1986 a law was passed requiring those who have been arrested for prostitution to be offered an antibody test, and for those who have been convicted to be given the test.
d) in 1987, the House formed the Legislative Task Force on AIDS to have a thorough discussion of the AIDS related proposals.

2) The Task Force has three functions:
a) to receive and evaluate testimony on AIDS-related issues;
b) to act on various individual member bills, which have been referred to the full committee;
c) to draft legislation as a proposed committee bill on AIDS.

3) Some of the issues the Task Force is looking at:
a) the need for further implementation of a comprehensive and coordinated statewide education effort;
b) encouraging voluntary and anonymous testing;
c) requiring that anyone who receives an antibody test be offered counseling and follow-up services;
d) guarantees of confidentiality;
e) strong non-discrimination laws.

3) Florida has authorized substantial expenditures for AIDS. For FY '87/'88 FY, the State appropriated $12.5 million for AIDS.

4) The Federal Government must show stronger leadership and a greater financial commitment. Specifically:
a) providing education in a frank, open manner. This education should involve community-based groups.
b) establishing a national position and policy on testing which underscores the limited and counter-productive value of compulsory testing;
c) The Federal Government must address the widespread discrimination faced by people with AIDS. There should be minimum Federal standards set.

5) The States should allow some creativity and innovation in AIDS research.

6) Florida needs more money if it is to implement all its projects.

Ms. Sylviane Kaufman (Acting Director, Metropolitan Dade County Health Services)

1) The county has been involved with AIDS issues since 1982. It began with the initial planning efforts of the Health Council of South Florida and the development of the AIDS Network of South Florida.

2) The Human Resources Health Center pioneered the provision of skilled nursing care to AIDS patients in 1982 when no other nursing home in the country would accept AIDS patients.

3) The Health Center developed a treatment and staff education program that has been used as a model throughout the country.

4) A 30-bed AIDS unit will be completed at the Center probably in July, 1989. The state provided the funds for building but the operating costs will be paid by the county.

5) The Department of Human Resources also provides home health care, including skilled nursing and homemaker services, medical management of diagnosed AIDS cases in the correctional system, counseling, community education, social services, inservice education for care providers, and advocacy.

6) The Department's Office of Rehabilitative Services provides medical detoxification, assessment, referral, and residential care to substance abusers with AIDS.

7) The Office of Emergency Assistance provides emergency financial assistance and independent living arrangements as part of the AIDS Network's residential care component.

8) The county is involved in CDC-funded research projects. They have been involved in a study on the transmission of HIV among prostitutes in Miami. Project staff have been supported by the county with no state assistance.

9) The Community Action Agency provides 20 meals a day to AIDS victims through a private sector agency, Cure AIDS Now.

10) The County has mandated that all its employees receive AIDS education. To this end:
    a) The county formed the Metro-Dade AIDS Task Force which has developed a Train the Trainers Program on AIDS. Selected staff from all departments will

receive AIDS education and these will in turn train all department employees.

b) Printed brochures on AIDS will be provided in English and Spanish to 22,000 employees.

c) Posters have been designed and will be distributed.

d) Continued information will be provided through the county publication.

Dr. Larry Capp (Executive Director, Metro Miami Action Plan)

1) This organization was developed as a catalyst through which a broad range of activities could become directed towards improvement in the quality of life of the Black community in Dade County.

2) There is a lack of sufficient educational outreach efforts directed towards the Black community. Currently, only two brochures have been found which specifically target the Black community.

a) The information must be targeted and the language understandable.

b) Presenters must have credibility within the Black community.

c) There is a problem with reaching those who don't read pamphlets or newspapers or watch television.

3) We need to look at the psychological barriers that prevent people from acquiring the necessary information, that cause people to deny and avoid access to the information.

4) There are Black community-based organizations that have delinquency units that are called street workers who go out and work with the dropouts under the trees and on the street corners. These are the kinds of organizations that have credibility and are respected.

6) One of the goals of the organization is to pull together all the local volunteer groups in a coalition.

EXHIBIT E

Presidential Commission
on the HIV Epidemic

REPORT FORMAT

--W O R K I N G D R A F T--

ACKNOWLEDGMENTS to all organizations and individuals who have contributed.

LITERARY FOREWORD

PROLOGUE
Charter and goals
Organization of report and rationale for structure
Description of Commission activities

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counseling and testing, diagnosis, outpatient care, hospital care, supportive care, home health care, alternative care settings, psychiatric care, terminal care.

Biodynamics of HIV infection and need for new care delivery strategies:
case management, team care,

Needs of special populations, e.g.:
pediatric AIDS patients, intravenous drug abusers, patients with psycho-sexual problems, asymptomatic immunosuppressed patients, hemophiliacs, patients in prison, families and friends of patients, etc.

Need for specialized training:
Retraining existing personnel, e.g.:
counselors, emergency room physicians and nurses, pediatricians, IVDA clinic workers, paremedics, law enforcement officers, teachers, (new diagnostic information, care alternatives, psychiatric concerns)

EXHIBIT E

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EXHIBIT E

Preventive education of those not yet sexually active or not using drugs:
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- > private sector approaches, including community groups working with children
- > role of the family
- > innovative approaches, including teens teaching teens, advertising and marketing strategies, and media use

Behavior modification to prevent or reduce transmission:
- > target general population as well as special population sub-groups, i.e., gay men, women, teenagers, minorities
- > look for model risk reduction programs that have been successful with special populations, especially gay men and IVDA's, as well as successful in other fields
- > utilize both traditional and innovative techniques, and include program evaluation
- > testing as an adjunct to thorough and appropriate counseling
- > the benefits of testing, counseling and early diagnosis for behavior change that can influence duration and quality of life
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EXHIBIT E

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BIBLIOGRAPHY

APPENDICES

APPENDIX F

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This team will remain available to the Commission to assist in providing access to accurate medical data on a continuous basis.

APPENDIX G-1

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