NATIONAL COMMISSION ON AIDS

Annual Report to the President and the Congress

August 1990

NATIONAL COMMISSION
ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME

Annual Report

August 1990

MEMBERS OF THE COMMISSION

June E. Osborn, M.D.

Chairman

David E. Rogers, M.D.

Vice Chairman

Diane Ahrens

Scott Allen

The Honorable Richard B. Cheney

Harlon L. Dalton, Esq.

The Honorable Edward J. Derwinski

Don C. Des Jarlais, Ph.D.

Eunice Diaz, M.S., M.P.H.

Donald S. Goldman, Esq.

Larry Kessler

Charles Konigsberg, Jr., M.D., M.P.H.

Belinda A. Mason

The Honorable J. Roy Rowland, M.D.

The Honorable Louis W. Sullivan, M.D.

COMMISSION STAFF

Maureen Byrnes, M.P.A.
Executive Director

Frank Arcari, M.P.A.

Thomas D. Brandt, M.L.S.

Adriana Carmack

LuVerne Hall

Jason Heffner, M.Ed.

Carlton H. Lee, Jr.

Melanie Lott

Lee Marovich

Joan A. Piemme, R.N., F.A.A.N.

Karen Porter, J.D.

Nicole Ryan

Jane Silver, M.P.H.

Patricia Sosa, Esq.

Jeff Stryker

TABLE OF CONTENTS

Appendices

SUMMARY

The National Commission on Acquired Immune Deficiency Syndrome (AIDS) was established under Public Law 100-607 for the purpose of promoting the development of a national consensus on policy concerning AIDS and of studying and making recommendations for a consistent national policy regarding AIDS and the human immunodeficiency virus (HIV) epidemic.

In its first year, the Commission has sought to fulfill its statutory mandate through public hearings, meetings, round table discussions, staff analyses, and interim reports, as well as site visits throughout the nation. These forums have provided a foundation for decision-making by providing an opportunity to consider expert testimony on the increasingly complex policy issues related to HIV infection and AIDS, and by giving the Commission occasion to interact with and learn from care providers and persons living with HIV infection and AIDS in their own communities.

The Commission began its work at the close of a decade in which more than 120,000 persons in the United States had been diagnosed with AIDS and over 70,000 of them had died. It is estimated that approximately 1,000,000 persons in the United States are infected with HIV and will be confronted with premature illness. With the interval between infection with HIV and onset of AIDS commonly up to ten years, at each increment we as a nation are assured that AIDS will continue to be a national concern into the Twenty-first Century.

Confronted with the increasing human toll of the AIDS epidemic, the Commission early in its tenure recognized the need to intensify national efforts to understand and meet the needs of people living with HIV infection and AIDS. Accordingly, the Commission in its work has endeavored to create broad public agreement on the magnitude, scope and urgency of the HIV/AIDS epidemic and to inspire leadership at all levels of both the public and private sectors to put in place effective, cooperative and non-discriminatory systems and resources required for prevention, comprehensive care, and research efforts necessary to halt the epidemic.

Thus far, the Commission has conducted twelve days of full Commission hearings covering HIV/AIDS related issues including health care, treatment, financing, research, regional aspects of the epidemic, correctional facilities, the health care work force, and executive and legislative branch initiatives including the National Drug Control Strategy and the U.S. Bipartisan Commission on Comprehensive Health Care Report.

In addition to full Commission hearings, the Commission has established two working groups to look at specific aspects of the epidemic. The Working Group on Federal, State, and Local Responsibilities convened a hearing in St. Paul, Minnesota to examine the roles of the local, state, and federal governments in the HIV/AIDS epidemic. The Working Group submitted a report on these hearings to the full Commission in March 1990. In its report, the Working Group found that a lack of clear definition of government roles and intergovernmental partnerships have seriously hampered the nation's response to the epidemic. It recommended that an interagency cabinet-level federal task force be established, a forceful, comprehensive national plan for responding to AIDS be developed and that direct emergency relief be provided to states and localities.

The Working Group on Social/Human Issues has held meetings in Boston, Dallas, and Seattle. Its work has focused primarily on the relationship between HIV testing and early intervention, the range of services needed by those affected by the epidemic, and the partnerships needed to deliver these services. A report from this group is expected in the near future.

The Commission has visited many regions around the country in an attempt to gain a better understanding of the diverse challenges confronting us in the HIV/AIDS epidemic. Such site visits have taken place in Washington, D.C., Los Angeles, New York City, Newark, Jersey City, Dallas, Seattle, and Waycross, Macon, and Albany, Georgia. The Commission has visited with persons living with AIDS and HIV infection, their families, loved ones and care providers in such settings as an AIDS hospice, a veteran's hospital, public hospitals, shelters, a drug treatment program, a comprehensive hemophilia care center, clinics, a correctional facility, community based organizations and private homes. To date, the Commission has heard from as many as 500 individuals and organizations from over 50 cities.

Through interim reports, the Commission has brought urgent matters to the attention of the President and the Congress. The Commission has issued three such reports. In December, the first interim report of the Commission called attention to the need for frank recognition of the crisis situation in many cities and the failure of the U.S. health care system to appropriately confront the HIV/AIDS epidemic.

In April, the Commission's second interim report called for a national plan with clearly delineated responsibilities and agreement on the roles of federal, state and local government and the private sector. The Commission recommended that a federal interagency mechanism be established to coordinate a national plan. In the same report, the Commission emphasized the need for federal disaster relief to help states and localities most heavily impacted to provide the HIV prevention, treatment, care and support needed.

In August, the Commission in its third interim report called attention to the rapidly increasing number of new AIDS cases diagnosed in rural communities across the country and the desperate need for resources. In the area of research, the Commission expressed growing concern over the need for clinical trials to be more encompassing, more readily accessible to all, easy to find, well managed and well coordinated. In addition, the Commission urged that greater research efforts be targeted at new drugs and therapies for the management of opportunistic infections. With regard to the health care work force, the Commission addressed the shortage of health care providers capable and willing to care for people living with HIV infection and AIDS.

Through a series of resolutions adopted by the full Commission, the Commission has been proactive in calling upon the Administration and the Congress to reassess some of our existing policies. In the area of immigration, the Commission undertook a review of U.S. immigration and visa policy in light of the 1987 vote by Congress that put HIV infection on the list of dangerous contagious diseases denying entry to the United States. In its review, the Commission found current U.S. immigration policy to be discriminatory and without public health rationale, and issued a resolution calling upon the Administration to conduct a comprehensive review of immigration policies as they regard communicable diseases focusing on public health needs. In issuing its resolution, the Commission held a Washington press conference to define the issues and to alert policymakers to the implications of the current policy. The Commission was joined by the American Bar Association, the American Red Cross, the National Council of La Raza, the World Federation of Hemophilia, and the National Organizations Responding to AIDS. The Commission has also expressed strong support for H.R. 4506, introduced by Representative J. Roy Rowland, which would restore to the Public Health Service the authority to designate diseases to be listed for purposes of barring entry to the United States.

In its statutory role of advising the President and the Congress, the Commission, through hearings, site visits, consultations with Members of Congress and the President, and testimony before Congressional committees, has played an active role in the policy debate around issues such as the Americans with Disabilities Act (ADA), treatment on demand for drug users, the funding of research programs involving the distribution of bleach, as well as legislative initiatives designed to provide critical resources needed to confront the HIV/AIDS epidemic such as the Americans with Disabilities Act (ADA) and the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990.

The Commission continues to monitor the recommendations of the Presidential Commission on the HIV Epidemic issued in July 1988. The Commission has worked closely with the National AIDS Program Office of the Public Health Service and other federal agencies to assess the level of implementation of these recommendations.

Over the coming year, the Commission will continue to conduct its activities through a variety of forums in Washington, D.C. and across the country. Many important and complex issues remain. The role and responsibilities of the public health system, the impact of the epidemic on the African American and Hispanic American communities, financing and delivery of health care, prevention and education, and substance use are among the issues to be given focused attention.

As the second decade of the epidemic begins, the challenges before us are many. It is critical that the public health strategies of the 1990's designed to meet these challenges receive top priority at all levels of government and in the private sector.

CHRONOLOGY

PUBLIC HEARINGS, INITIATIVES AND STATEMENTS

1989

August 3	**Meeting**	Selection of Chairman and Discussion of Future Direction of the Commission - Washington, D.C.
August 17	**Meeting**	Selection of Executive Director - Washington, D.C.
September 6	**Statement**	Support for Passage of the Americans with Disabilities Act
September 18-19	**Hearings**	Overview of the HIV Epidemic - Washington, D.C.
September 19	**Statement**	Support for Increase in AIDS Funding in the FY '90 Appropriations Bill
September 26	**Statement**	Support for the Goal of Treatment on Demand for Drug Users
November 2-3	**Hearings**	Health Care, Treatment, Finance and International Aspects of the HIV Epidemic - Washington, D.C.
November 7	**Statement**	Support for Continued Funding of Research on Effectiveness of Bleach Distribution
December 5	**First Interim Report to President Bush and the Congress**	
		Failure of U.S. Health Care System to Deal with HIV Epidemic
December 12	**Press Conference**	
		Commission Resolution Calls for End to Discriminatory Visa and Immigration Practices and Review of Immigration Policies Regarding Communicable Diseases, Particularly HIV Infection - Washington, D.C.

1990

January 4-5	**Working Group Hearing**	Federal, State and Local Responsibilities. To Examine the Roles and Responsibilities of Different Levels of Government in Responding to the AIDS/HIV Epidemic - St. Paul, Minnesota
January 24-26	**Hearing and Site Visits**	Regional Aspects of the HIV Epidemic in Southern California, Los Angeles Area Community Based Organizations, Clinics, Hospice and Public Hospital - Los Angeles, California
February 15-16	**Working Group Hearing**	Social and Human Issues. To Examine the Relationship of Early Intervention and HIV Testing and Psychosocial Issues and HIV - Boston, Massachusetts
February 26-27	**Site Visits**	To Look at Issues of HIV and AIDS Among the Homeless, Drug Users and Hemophiliacs - New York City, Newark, and Jersey City
March 6	**Testimony**	Chairman June E. Osborn, M.D. Testifies Before the Task Force on Human Resources of the Committee of the Budget of the United States House of Representatives on Meeting the Health Care Needs of People Living with HIV and AIDS
March 6	**Statement**	Commission Endorses Principles and Objectives of Comprehensive AIDS Resources Emergency (CARE) Act of 1990
March 9	**Letter**	Commission Writes President Bush Urging Him to Resolve Visa - HIV Controversy Before International Conferences In the United States in June and August
March 15-16	**Hearings**	Review of Executive and Legislative Branch Initiatives, Including the National Drug Control Strategy and the U.S. Bipartisan Commission on Comprehensive Health Care Report - Washington, D.C.
March 15	**Statement**	Despite Debate Among Epidemiologists, HIV Epidemic Will Have Greater Impact in 1990s than 1980s

March 15	**Working Group Summary Report on Federal, State, and Local Responsibilities**	
		Recommendations from January Meeting in St. Paul, Minnesota on the Roles and Responsibilites of Different Levels of Government
April 16-17	**Site Visits**	To Examine Issues Surrounding AIDS in Rural Communities - Waycross, Albany and Macon, Georgia
April 24	**Second Interim Report to President Bush and the Congress**	
		Leadership, Legislation and Regulation
May 7-8	**Hearings**	Review of Current Research Activities, Particularly Clinical Trials - Washington, D.C.
May 7	**Letters**	Commission Writes Senate Majority Leader, Senator Mitchell, and Senate Minority Leader, Senator Dole, Urging Senate Consideration of the Comprehensive AIDS Resources Emergency (CARE) Act of 1990
May 11	**Statement**	Commission Endorses Principles and Objectives of AIDS Prevention Act (H.R. 4470) and Medicaid AIDS and HIV Amendments Act of 1990 (H.R. 4080)
May 24	**Letter**	Commission Writes Senator Kennedy and Senator Hatch Underscoring Support for the Americans with Disabilities Act, and Declaring the Amendment Concerning Food Handlers Bad Public Health Policy.
June 6	**Letters**	Commission Writes the Speaker of the House, Representative Thomas Foley, and the House Minority Leader, Representative Robert Michel, Urging Congress to Resist Attempts to Impose a Federal Mandate on States for Name Reporting
June 27	**Testimony**	Commissioner Donald S. Goldman Testifies Before the Subcommittee on Health and the Environment of the Committee on Energy and Commerce of the United States House of Representatives Regarding Immigration and Visa Policies, and the Rowland Bill (H.R. 4506)
July 9-10	**Working Group Hearing**	
		Social and Human Issues. To Examine the Relationship of Early Intervention and HIV Testing from the Public

		Health Perspective, and the Range of Social and Human Services Needed by People Affected by the HIV/AIDS Epidemic - Dallas, Texas
July 17-19	**Hearings**	Review of Current Health Care Personnel and Work Force Issues - Washington, DC
July 30-31	**Working Group Hearing and Site Visits**	Social and Human Issues. To Examine the Range of Social and Human Services Needed by People Affected by the HIV/AIDS Epidemic, the Partnerships and Coalitions Necessary to Provide These Services, and the Social/Human Services Programs Established in the Seattle-King County Region - Seattle, Washington
August 16-17	**Site Visits and Hearings**	HIV Infection and AIDS in Correctional Facilities - New York
August 21	**Third Interim Report to President Bush and the Congress**	Research, the Work Force and the HIV Epidemic in Rural America

DOCUMENTS

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

FOR IMMEDIATE RELEASE
September 6, 1989

Contact: Carlton Lee
(202) 254-5125

STATEMENT OF SUPPORT FOR AMERICANS WITH DISABILITIES ACT

We, the Members of the National Commission on Acquired Immune Deficiency Syndrome (AIDS), strongly support passage of the Americans with Disabilities Act, legislation which would implement the key recommendation of the Presidential Commission on the Human Immunodeficiency Virus Epidemic.

People living with AIDS and HIV infection, and those regarded as such, deserve the same discrimination protections as all people with disabilities. Such protections from discrimination are not only necessary to enhance the quality of life for people with AIDS and HIV infection, they are -- as the Presidential Report and the Institute of Medicine have reported -- the linchpin of our nation's efforts to control the HIV epidemic.

Thousands of Americans who should seek voluntary counseling and testing services and many who need life-prolonging medical treatment will not come forward if they believe that doing so could result in the loss of their job or lack of access to public accommodations. Legislation that is based not only on compassion but sound public health principles is a must if we are to reach and assist these individuals.

We are extremely pleased that the majority of the United States Senate and the White House have made a bipartisan commitment to enact the Americans with Disabilities Act. We oppose any efforts to reduce the scope of coverage of the present bill, particularly with respect to HIV, the specific focus of this commission. The ADA will provide a clear and comprehensive mandate to greatly extend discrimination protections for people with disabilities. We are proud to endorse this landmark legislation.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
September 13, 1989

Contact: Thomas Brandt
202-472-9058
(Temporary number)

COMMISSION HOLDS FIRST SUBSTANTIVE HEARING

The National Commission on AIDS, an independent body created by Congress to oversee the national effort against the AIDS epidemic, will hold its first substantive hearing September 18 and 19 in Washington, D.C.

The new Commission, which took office on August 3, includes five voting members appointed by the Senate, five voting members appointed by the House, two voting members appointed by the White House, along with the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs, who are non-voting members.

The new chairman of the Commission, June E. Osborn, M.D., said, "I'm honored to serve on this Commission for which there is no precedent in terms of the blue ribbon expertise of its membership. It represents political diversity, the Black, Hispanic and gay communities, persons with AIDS, and of course many of the nation's top authorities on AIDS."

Dr. David Rogers, the new vice chairman, said, "With this important meeting the Commission will begin laying its base. Our goal is not to reinvent a national strategy for AIDS, which was produced by the former Presidential Commission in 1988, but to focus our authority on select areas

- more -

of greatest need."

The law establishing the Commission calls for it to create a national consensus on major problem areas of the epidemic such as testing new drugs, financing of care and treatment, civil rights, prevention, education and epidemiological issues, among others.

The Monday, September 18 session will open at 9 a.m. in the Caucus Room of the Cannon House Office Building, Capitol Hill, and will run until 5 p.m.
At 10:30 a.m. Tuesday the Commission members will go to the Whitman-Walker Clinic, 1407 S St., NW for briefings on the various programs offered by this community based, non-profit provider of AIDS and HIV services in metropolitan Washington. (News media interested in covering the site visit should go directly to Whitman-Walker).

The Tuesday afternoon Commission meeting will begin at 1:30 p.m. and will be held at the General Services Administration Auditorium, 18th and F Streets, NW.

The Commission will hear from a variety of AIDS and HIV (human immunodeficiency virus) experts. A panel of persons with AIDS will comment on the problems they have seen in the national response to the epidemic. There will be a separate discussion on the implementation of the nearly 600 recommendations in the 1988 report to President Reagan from the Presidential Commission on the HIV Epidemic, which was chaired by Admiral James Watkins.

The Commission will also review pending or proposed legislation or policy recommendations affecting HIV or AIDS.

The Commission first convened on August 3 for an organizational session and elected Dr. Osborn and Dr. Rogers as the chair and vice chair. A list of Commissioners, and an agenda for Sept. 18 and 19, are enclosed.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

SEPTEMBER 18-19, 1989

Monday, September 18, 1989

9:00 a.m.	Opening Remarks, June E. Osborn, M.D., Chairman
9:15 a.m.	Mathilde Krim, Ph.D., American Foundation for AIDS Research
9:45 a.m.	PWA (People With AIDS) Panel Mr. Lou Katoff, Ph.D. Mr. Dave Johnson Ms. Amelia Williams Mr. Willie Bettelyoun
11:00 a.m.	BREAK
11:15 a.m.	C. Everett Koop, M.D., Former U.S. Surgeon General
11:45 a.m.	Jean McGuire, National Organizations Responding to AIDS (NORA)
12:15 p.m.	LUNCH
1:30 p.m.	Robert Newman, M.D., President and CEO, Beth Israel Medical Center
2:00 p.m.	Jim Allen, M.D., National AIDS Program Office (NAPO)
2:30 p.m.	Review of Recommendations by Presidential Commission on HIV Epidemic Identification of Areas of Focus and Attention by the National Commission Discussion of Format for Addressing Priorities (i.e. Working Groups)
3:45 p.m.	BREAK
4:00 p.m.	Discussion of Current Issues
5:00 p.m.	ADJOURN

Tuesday, September 19, 1989

10:30 a.m.	Tour the Whitman Walker Clinic, 1407 S Street
12:00 p.m.	LUNCH
1:30 p.m.	Presentation to Commission by General Services Administration General Counsel
2:30 p.m.	Follow-up to Issues and Plans discussed on Monday, September 18th Staff Briefing on Legislative Action and Commission Administrative Business
3:30 p.m.	ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

FOR IMMEDIATE RELEASE
September 19, 1989

Contact: Thomas Brandt
(202) 755-2446

STATEMENT ON THE FY '90 APPROPRIATIONS

We, the Members of the National Commission on Acquired Immune Deficiency Syndrome (AIDS), strongly support the increase in AIDS funding endorsed by both Houses of Congress and the Administration. While we believe that much work remains to secure adequate funding for the national battle against AIDS, we also recognize the fiscal challenges facing the Congress.

We are particularly pleased that the Senate Committee on Appropriations has increased the total AIDS budget to accommodate humane and cost-effective programs designed to meet the burgeoning care needs resulting from the HIV epidemic. The Congress made clear the priority it places on the health care needs to provide access to lifesaving medical treatment to those who face poverty and death is not only a compassionate response to the crisis but a sound public health strategy for bringing the epidemic under control. The most compelling incentive for individuals to step forward for HIV counseling and testing is the availability of effective treatment and appropriate medical care.

The Commission is most invigorated by the task of advising both the Administration and the Congress. It is a responsibility that we accept with great determination. Given the gravity of the HIV epidemic, we are fortunate to have an abundance of sound data on which to base our public health policy decisions. With this in mind, we urge the Congress to be deliberative in its policy-making processes and to resist fragmented approaches to public policy via amendments to the FY '90 Appropriations bill.

The National Commission on AIDS stands ready to review and comment on proposals under consideration by the Congress for addressing the challenges presented by the HIV epidemic.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

FOR IMMEDIATE RELEASE
September 26, 1989

Contact: Thomas Brandt
(202) 254-5125

STATEMENT OF SUPPORT FOR TREATMENT ON DEMAND FOR DRUG USERS

The new National Commission on AIDS strongly endorses the position taken by the Presidential Commission on the HIV Epidemic in its report of June, 1988 recommending the goal of treatment on demand for all drug users who request it.

The Presidential Commission's position is articulated in the following statement found on page 95 of the report:

> "The Commission believes it is imperative to curb drug abuse, especially intravenous drug abuse, by means of treatment in order to slow the HIV epidemic. Because a clear federal, state, and local government policy is needed, the Commission recommends a national policy of providing treatment on demand for intravenous drug abusers."

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

PRESS RELEASE
October 27, 1989

Contact: Thomas Brandt
202-254-5125

JONATHAN MANN, ANTONIA NOVELLO TO ADDRESS NATIONAL COMMISSION ON AIDS

Dr. Jonathan Mann, Director, World Health Organization Global Programme On AIDS, and Dr. Antonia Novello, who is under White House review to be U.S. Surgeon General, are among the witnesses scheduled to testify before the second set of hearings of the National Commission on AIDS on November 2 and 3.

The Commission will be meeting in hearing room B of the Pan American Health Organization headquarters, 525 23rd St., NW in Washington, D.C. A complete agenda is attached.

The major part of the new Commission's agenda will focus on health care, treatment and finance issues, and will include testimony from a number of national authorities.

"We feel some urgency in turning to health care issues for they are likely to dominate the national agenda of the epidemic for the forseeable future," said Dr. June Osborn, Chairman of the Commission.

Dr. David Rogers, Vice Chairman of the Commission, said, "It is my fond hope that the Commission can swiftly identify the two or three major problems in health care and help move the country towards national

-more-

consensus solutions."

Dr. Mann is expected to tell the Commission that internationally it will be much more difficult to fight the AIDS and HIV epidemic in the 1990s than in the 1980s as the virus accelerates its spread to new regions of the world and into new population groups, such as intravenous drug users, in countries where HIV is already well established.

Dr. Novello, who is a national expert on HIV infection among infants and children, will be speaking on pediatric AIDS.

The National Commission on AIDS, an independent body created by Congress to oversee the national effort against the HIV epidemic, took office on August 3.

The 15-member Commission includes five voting members appointed by the Senate, five by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

NOVEMBER 2-3, 1989

Pan American Health Organization Building
525 Twenty-third Street, Northwest
Washington, D.C.

Thursday, 2 November 1989

9:00 a.m.	Opening Remarks
9:05 a.m.	INTERNATIONAL ASPECTS
	Jonathan M. Mann, M.D., M.P.H. - World Health Organization, Geneva
	Charles J. Carman - World Federation of Hemophilia, Montreal
10:10 a.m.	BREAK
10:20 a.m.	Remarks by Dr. June Osborn, Chair
10:30 a.m.	PUBLIC HOSPITALS
	Dennis P. Andrulis, M.P.H., Ph.D. - National Association of Public Hospitals, National Public Health and Hospital Institute
11:00 a.m.	TREATMENT ISSUES
	Peter Brandon Bayer, J.D., LL.M., M.A. - Hemophiliac with HIV infection, Baltimore Craig Kessler, M.D. - George Washington University Hospital, Washington, D.C.
11:30 a.m.	BREAK
11:40 a.m.	Mark Smith, M.D. - AIDS Services, Johns Hopkins University School of Medicine, Baltimore Ralph Hernandez - Person Living With AIDS Deborah Cotton, M.D., M.P.H. - Beth Israel Hospital, Boston James C. Welch, R.N. - AIDS Program Office, Division of Public Health, State of Delaware
1:00 p.m.	LUNCH

2:00 p.m. TREATMENT ISSUES FOR PRISONERS & DRUG USERS

Theodore M. Hammett, Ph.D. - Abt Associates, Inc., Boston
Nancy N. Dubler, LL.B. - Department of Epidemiology and Social Medicine, Division of Law and Ethics, Montefiore Hospital and Medical Center, NY
Elizabeth Barton, M.P.S. - Samaritan Village, Inc., New York

3:00 p.m. BREAK

3:15 p.m. PEDIATRICS

James M. Oleske, M.D. - Division for Allergy, Immunology and Infectious Diseases, Department of Pediatrics and Preventive Medicine, University of Medicine and Dentistry of New Jersey, Newark
Antonia C. Novello, M.D., M.P.H. - National Institute of Child Health and Human Development, Washington D.C.
Catherine Wilfert, M.D. - Duke University, School of Medicine, Durham

4:15 p.m. ADJOURN

Friday, 3 November 1989

9:00 a.m. Opening Remarks

9:15 a.m. COST AND FINANCING

Philip R. Lee, M.D. - University of California School of Medicine, Institute for Health Policy Studies, San Francisco
Anne A. Scitovsky, M.A. - Health Economics Division, Palo Alto Medical Foundation/Research Institute
Peter Arno, Ph.D. - Department of Epidemiology and Social Medicine, Montefiore Medical Center, New York
Jesse Green, Ph.D. - Department of Health Policy Research, New York University Medical Center, New York

10:45 a.m. BREAK

11:00 a.m. INSURANCE

Mary Ann Baily, Ph.D. - Department of Economics, George Washington University; Department of Health Care Sciences, George Washington Medical School, Washington, D.C.

11:30 a.m. STATE AND COMMUNITY

Robert F. Hummel - New Jersey State Department of Health, Division of AIDS Prevention and Control
Si Hoi Lam, M.D. - Hill Health Center, New Haven
John S. Holloman, Jr., M.D. - National Association of Community Health Centers, Washington, D.C.

12:30 p.m. LUNCH

1:30 p.m. FEDERAL AND FOUNDATION

Paul Jellinek, Ph.D. - Robert Wood Johnson Foundation
Samuel C. Matheny, M.D., M.P.H. - Health Resources and Services Administration, Department of Health and Human Services, Washington, D.C.

2:30 p.m. COMMISSION BUSINESS

Summary of the Hispanic/Latino Teleconference by Eunice Diaz and Patricia Mendoza

3:00 p.m. ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
Tuesday, November 7, 1989

Contact: Thomas Brandt
202-254-5125

NATIONAL COMMISSION ON AIDS TAKES POSITION ON BLEACH AND HIV CONTROL RESEARCH

The National Commission on AIDS today released a statement in support of research projects designed to determine the effectiveness of bleach distribution to intravenous drug users as a means to control the spread of the human immunodeficiency virus (HIV), which causes AIDS. The statement says:

> "The National Commission on AIDS strongly supports the continuation of research and demonstration projects involving the distribution of bleach to reduce the spread of HIV among intravenous drug users until the efficacy of this approach can be determined. This determination should be made by the Assistant Secretary for Health or the Secretary of Health and Human Services."

Dr. June Osborn, Chairman of the Commission, said today that it is important to public health to know whether any of the various methods of distributing bleach to IV drug users can reduce the spread of HIV. Dr. David Rogers, Vice Chairman of the Commission, said, "In the United States

-more-

the conquest of AIDS will be determined by how effectively we can contain the spread of HIV among drug users."

Several experiments are underway in the United States to distribute common household bleach to IV drug users in the hope that it would be used to sterilize shared syringes and hypodermic needles.

Currently there is an increase in the rate of new cases of HIV disease among IV drug users. IV drug users also account for many heterosexually transmitted cases of AIDS. Most infants who contract HIV disease are infected by their mothers who are either IV drug users or the sexual partners of IV drug users.

Congress may deal with the bleach issue during reconsideration of the upcoming FY'90 appropriation bill for the Department of Health and Human Services.

The National Commission on AIDS is an independent body created by Congress to oversee the national efforts against the AIDS epidemic and to make "recommendations for a consistent national policy concerning AIDS."

Five members were appointed by the Senate, five by the House and two by the White House. In addition the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs are non-voting members.

# # # #

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

PRESS RELEASE
December 6, 1989

Contact: Thomas Brandt
202-254-5126

COMMISSION RELEASES REPORT TO PRESIDENT BUSH

The National Commission on AIDS today released its first report to President Bush that calls for urgent action by the White House to deal with an inadequate system of health care delivery and financing for persons with AIDS or HIV.

"In summary, a series of problems have resulted in a health care system singularly unresponsive to the needs of HIV infected people," the report says.

The report also cites national obstacles to providing adequate health care and financing. These impediments include a growing air of complacency towards the epidemic, lack of a national plan for dealing with a health care system that is faltering even without the impact of AIDS, and a national drug strategy that fails to factor in the ominous potential for rapid spread of HIV among intravenous drug users.

Even more alarming, the pattern of HIV infection is evolving and is now "reaching crisis proportions among the young, the poor, women and many minority communities," according to the report to President Bush.

-more-

The Commission also outlined five initial steps to begin solving the problems of health care delivery to the million or more people in the United States with HIV infection.

These include: (1) "recognition that a crisis situation exists in many cities," (2) creation of a "flexible, patient-oriented, comprehensive system of care," (3) possible creation of regional centers of HIV care, perhaps modeled after the regional hemophilia treatment program, (4) creation of units that treat patients who have both HIV and drug addiction, (5) providing comprehensive health care services under one roof.

Dr. June Osborn, Chairman of the Commission, said, "Finding durable solutions to problems identified by the Commission will take much hard work and cooperation. But the solutions also stand to benefit people far beyond the specific arena of HIV, for the health care system itself requires urgent attention."

Dr. David Rogers, Vice Chairman of the Commission, said, "AIDS has spotlighted some of the most serious gaps in our ways of delivering medical care. Many chronic diseases which plague Americans demand more humane responses out of hospital systems of care. Developing such a system for those with HIV related illnesses should do much to improve medical care for all Americans."

Though the Commission is not required to make a report to Congress and the White House until August, 1990, a decision was made to speak now because of the urgency of the health care delivery and financing issues, and because a national voice is essential to solving them.

-more-

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a national consensus on policy" concerning the HIV epidemic.

The Commission took office on August 3 and since then has consulted with dozens of experts, held four days of formal hearings, conducted extensive staff research and reviewed many issues at the full Commission level.

The 15-member Commission includes five voting members appointed by the Senate, five by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

December 5, 1989

President George Bush
The White House
Washington, DC 20500

Dear President Bush:

The official charter for the National Commission on Acquired Immune Deficiency Syndrome (AIDS) was signed on August 2, 1989. Since that time the National Commission has convened a series of hearings to solicit information and recommendations from experts in the field of medicine and public health policy to assist the Commission in meeting its statutory mandate of "promoting the development of a national consensus on policy concerning acquired immune deficiency syndrome."

The testimony we recently heard on health care and financing was so compelling we felt it is vital to write to you now, rather than wait until our statutorily required annual report next August. In fact, the Commission will continue to bring these urgent matters to your attention and to the attention of Congress as we hear from the experts about the Human Immunodeficiency Virus (HIV) epidemic and what is needed to respond to it.

The following represents the first of such reports which we hope will prompt appropriate action.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

cc:

The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of Representatives

The Honorable Robert H. Michel
Minority Leader of the House of Representatives

National Commission
on
Acquired Immune Deficiency Syndrome

Report Number One

OVERVIEW

> "We don't have time to sit around and have this Commission live out its life and issue another report and have another report, another Commission.... We have to act and we have to act swiftly."

This testimony was presented before the National Commission on Acquired Immune Deficiency Syndrome at a hearing held in Washington, D.C., November 2nd and 3rd of this year. The Commission convened a meeting of experts to examine the global, national and local challenges confronting the United States in the HIV epidemic. The message from the experts was clear and alarming:

- There is a dangerous, perhaps even growing, complacency in our country toward an epidemic that many people want to believe is over.
- Far from over, the epidemic is reaching crisis proportions among the young, the poor, women and many minority communities. In fact, the 1990's will be much worse than the 1980's.
- The link between drug use and HIV infection must be acknowledged and addressed in any national drug strategy.
- There is no national plan for helping an already faltering health care system deal with the impact of the HIV epidemic.

Over the coming months, the Commission intends to bring the message of experts who have studied the problems and proposed the solutions to those who have the power to act. The Commission believes it is time to match rhetoric with action.

This letter is intended to outline the first of these messages from experts in the field of health care and financing: the public health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, it may well be the crisis that could pressure responsible national action to correct its serious shortfalls.

SCOPE OF THE PROBLEM

To date, AIDS has claimed more American lives than the Vietnam War. Over the course of the next four years in this country, AIDS will likely claim an additional 200,000 lives. It is estimated that by 1991 AIDS will be among the top ten leading causes of death in the United States. Nearly one-half of all AIDS cases reported to the Centers for Disease Control (CDC) through May 1989 were diagnosed in people 30 to 39 years old. By 1991, ten years after the first AIDS cases were reported, AIDS will far exceed all other causes of death for people between the ages of 25 and 44 years. In testimony before the Commission, it was stated that nine times more adults around the world may develop AIDS during the 1990's than have developed AIDS during the 1980's.

The proportion of AIDS cases with intravenous drug use as a risk behavior has risen from 25 percent prior to 1985, to 30 percent in 1988. In New York City, alone, an estimated 100,000 intravenous drug users are HIV-infected.

The HIV epidemic is not just a New York City or a San Francisco problem as some would like to believe. While it is true that before 1985, 44 percent of all cases of AIDS were diagnosed in the New York City or San Francisco areas, by 1988 this proportion had fallen to 25 percent. By 1991, it is expected that 80 percent of new AIDS cases will come from outside New York City and San Francisco.

In increasing numbers, these new cases will be women and children. As one prominent pediatrician from New Jersey told the Commission, "As a society, we claim to protect and cherish our children, but in fact, we have placed women and children squarely in front of an onrushing HIV epidemic."

The cumulative incidence of AIDS cases is disproportionately higher in Blacks and Hispanics than in whites. Fully 25 percent of all persons with AIDS in the United States are African-American and the number is growing. In fact, there has been, as one witness told the Commission, "a disproportionate impact of HIV on disenfranchised populations, gays, the poor, racial minorities, women, adolescents and drug users--populations having already less than optimal access to quality health care.... The development of a national care and treatment strategy will require a rethinking of our past effort."

ACCESS TO CARE

Recent years have seen considerable advances in the development of new HIV-related drugs, including the prospect of treating HIV infection before symptoms develop. But scientific breakthroughs mean little unless the health care system can incorporate them and make them accessible to people in need.

The belief that Medicaid will pay for the health care needs of the growing number of low income people with HIV infection and AIDS is, as one expert witness told the Commission, a "Medicaid fantasy." According to a 1987 U.S. Hospital AIDS Survey, almost one quarter of all AIDS patients have no form of insurance, private or public. Less than 20 percent of the persons with AIDS treated in southern hospitals were covered by Medicaid, compared with 55 percent in the Northeast and 44 percent nationwide.

For the medically disenfranchised, there is no access to a system of care. For those who have no doctor, no clinic, no means of payment, access to health care services is most often through the emergency room door of one of the few hospitals in the community that treats people with HIV infection and AIDS. Five percent of the nation's hospitals treat fifty percent of the people with AIDS.

For those who are covered by Medicaid, access to care is better than for those who have no insurance at all. However, the obstacles to care under Medicaid funding can be insurmountable for many. One obstacle is the wide variation among states in Medicaid eligibility and scope of benefits. The Food and Drug Administration (FDA), under considerable public pressure, has struggled with mechanisms to speed new drugs to the market. Yet there is no requirement that Medicaid make even life-prolonging drugs such as zidovudine (AZT) available.

Another obstacle to needed care for persons with HIV infection and AIDS who qualify for Medicaid is the low reimbursement rates. Stunning examples of Medicaid physician compensation rates far below those by private insurance or Medicare were illustrated during the Commission hearing. For example, a new patient intermediate office visit in New York City is compensated by Blue Cross at $78, by Medicare at $80, and by Medicaid at $7. One witness indicated that physicians in New York with large AIDS practices were reluctant to refer Medicaid patients for specialty consultations because of low levels of reimbursement--levels so low that several physicians said the few dollars at stake per office visit were not worth the time and paperwork to bill the Medicaid program.

In summary, a series of problems have resulted in a health care system singularly unresponsive to the needs of HIV infected people: the initial appearance of HIV infection and AIDS in groups often shunned by the larger society - gay men, the poor, minorities, and intravenous drug users encouraged a slow response, a gross lack of training support for primary care physicians to treat people with HIV infection and AIDS, and serious disincentives for physicians to take Medicaid patients and perhaps poor people in general.

WHAT IS NEEDED?

FIRST, frank recognition that a crisis situation exists in many cities that will require extraordinary measures to overcome. Significant changes must be made not only in our health care system but in how we think about the system and the people it is designed to serve. As one witness told the Commission, it can no longer be "business as usual."

SECOND, the creation of a flexible, patient-oriented, comprehensive system of care, closely linking hospital, ambulatory, residential, and home care. Primary care physicians must be central to such a system. But if primary care doctors are to care for patients with HIV infection and AIDS, they need the financial, social and institutional support to assist them in managing complicated patients.

THIRD, consideration of the creation of regional centers or networks of care, perhaps using the already existing regionalized hemophilia treatment program as a model. These centers would not serve as a replacement for the care provided by primary care physicians but would provide backup and consultation to help strengthen community based primary care.

It is essential that everyone be afforded early intervention and access to care. In addition, the availability of backup and consultation from appropriate specialists is required to provide the assistance and encouragement primary care doctors need to see more people with HIV infection and AIDS. Regional centers should also provide the appropriate link with the hospital when hospital services are needed.

FOURTH, create units which can treat patients who have both HIV infection and drug addiction. The availability of drug treatment on request is essential for responding to the combined HIV and drug epidemic that imperils not only drug users but also their sexual partners and children.

Given the massive link between drug use and HIV infection, and the fact that there is an alarming increase in the number of new infections among intravenous drug users, the Commission wishes to go on record in expressing its surprise and disappointment that the White House National Drug Control Strategy mentions AIDS only four times in its ninety pages of text and not at all in its recommendations or discussions of how to allocate resources. The President's drug strategy simply must acknowledge and include HIV infection and AIDS.

FIFTH, provide comprehensive health care services under one roof. Fragmented services create additional barriers to needed health care. Often mothers will seek health care services needed for their babies but are not able to then gain access to care for themselves. Health care services for women and children need to be provided in one place. For the homeless, housing and health care need to go hand-in-hand. This is true not only for those who are homeless today but for those who will become homeless tomorrow because of the HIV epidemic.

WHAT WILL IT COST?

Estimates of the national costs of direct medical care for persons with AIDS in 1991 range from $2.5 to 15.1 billion (in 1988 dollars). These estimates represent a small fraction of the total health care costs for the nation - from less than one to slightly more than three percent. We simply must be prepared to make these expenditures.

WHO IS RESPONSIBLE FOR ACTION?

In carrying out its mandate, the National Commission on AIDS will attempt to delineate clearly the roles and responsibilities of various levels of government and the private sector in responding to and managing the HIV epidemic.

To date, there is no national policy or plan, and no national voice. Currently, as one witness testified, without the definition of roles each level of government points a finger at another and says it is their job. Clearly, managing the HIV epidemic is a responsibility which must be shared by all.

Without federal leadership the states have assumed various degrees of responsibility for planning, coordination and the provision of care. Likewise some local governments have played key roles in determining how patient services could be provided and in demonstrating important models for service delivery.

The role of the private sector voluntary and professional AIDS service organizations has been all important in managing the HIV epidemic to date. Foundations and corporations have also been important and their roles need better recognition and definition.

"We must," the Commission was told, "move swiftly to bring the missing players to the table...this includes a greater presence of our federal, state and local governments in terms of leadership, financing and service delivery. It includes the support and cooperation of the insurance industry, employers, physicians and other medical providers, and last but profit-wise not least, the pharmaceutical industry as well."

Responding to the challenge to bring the "missing players to the table," the National Commission on AIDS intends to do just that in hearings, working groups and other forums that can swiftly translate the facts into action and hold us all accountable for the national strategy that is long overdue. The time has come to define exactly what needs to be done, and measure how far we have come, and how much farther we still have to go.

On behalf of all of the members of the National Commission on AIDS, we look forward to being able to continue to bring important information to your attention.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
December 12, 1989

Contact: Thomas Brandt
202-254-5125

COMMISSION CALLS FOR CHANGES IN U.S. VISA AND IMMIGRATION POLICIES

The National Commission on AIDS today called for a comprehensive review of U.S. visa and immigration laws relative to HIV and other communicable diseases, and an immediate end to practices that discriminate against or stigmatize those seeking visitors' visas to the United States.

"Current practices," the Commission said in a resolution released today, "are counterproductive, discriminatory and represent a waste of resources...."

Specifically, the Commission called for the Department of Justice to administratively order an end to the practice of marking passports of those with HIV infection who are granted waivers to enter the country.

The Commission also called for immediate administrative steps to end the questioning of nonimmigrants about their HIV status while applying for visas. This would eliminate the current practice of stopping travelers who are carrying AZT, which is the only licensed anti-HIV drug, and blood products such as clotting factor which is used by hemophiliacs. In some cases travelers have been ejected from the United States because it was revealed, by inference or by direct questioning, that the traveler had HIV infection.

-more-

Dr. June E. Osborn, Chairman of the National Commission, said, "There is no public health justification for current policies, they fly in the face of strong international opinion and practice, they lead to unconscionable infringements of human rights and dignity, and they reinforce a false impression that AIDS and HIV infection are a general threat when in fact they are sharply restricted in their mode of transmission."

A number of scientific, medical and humanitarian organizations have criticized current U.S. visa practices. Sponsors of the VIth International Conference on AIDS scheduled for San Francisco in June, 1990, and the XIXth International Congress on Hemophilia, scheduled for Washington, D.C., in August, 1990, have both said that some expected participants have announced their intention to boycott those meetings unless restrictions are changed.

For the long term, the National Commission today also called for the Department of State, the Department of Justice and the Department of Health and Human Services to "conduct a comprehensive review of immigration policies as they regard communicable diseases, particularly HIV infection, focusing on public health needs."

The review should include a study of the efficacy of the 1987 amendment that added HIV to the Public Health Service list of dangerous and contagious diseases. The list is used under the Immigration and Nationality Act (INA) to determine who can be excluded from the United States on public health grounds.

The Commission has also called for liberal application of HIV waivers to applicants for legalization, refugee status, or permanent residency.

-more-

The Commission has also said that when HIV testing is part of the immigration process, the appropriate Federal agencies must insure that standards are enforced for pre- and post-test counselling, confidentiality, and referrals for follow-up health care.

The National Commission on AIDS, an independent body created by Congress to oversee the national efforts against the HIV epidemic and to make "recommendations for a consistent national policy concerning AIDS," took office on August 3.

Five members were appointed by the U.S. Senate, five by the U.S. House of Representatives, and two by President Bush. In addition the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs are non-voting members.

# # # #

NATIONAL COMMISSION ON AIDS

RESOLUTION ON U.S. VISA AND IMMIGRATION POLICY

December 1989

WHEREAS, policies which govern the medical examination and exclusion of aliens from the United States based upon communicable disease should be determined by sound public health policies alone; and

WHEREAS, these policies need a comprehensive and thorough review based only on public health needs, because other considerations, particularly myth, prejudice and social stigmatization, have been historically but inappropriately considered; and

WHEREAS, the United States Public Health Service has stated that there is no evidence that the Human Immunodeficiency Virus (HIV) is spread through casual social contact; and

WHEREAS, the World Health Organization (WHO) has concluded that screening of international travelers cannot prevent the introduction or spread of HIV infection; and

WHEREAS, in its June 1988 report, the Presidential Commission on the HIV Epidemic concurred with the WHO that "the screening of international travelers for HIV infection would require an unjustified, immense diversion of resources from other critical programs of education, protection of the blood supply, and care"; and

WHEREAS, current practices, particularly as they relate to HIV infection, are counterproductive, discriminatory and represent a waste of resources which could be better used in other ways; and

WHEREAS, these practices, in particular, threaten the attendance of participants from all over the world at the Sixth International Conference on AIDS scheduled for San Francisco and the XIX International Congress of the World Federation of Hemophilia scheduled for Washington, D.C.; and

WHEREAS, the promise of global cooperation on important issues of public health is being jeopardized by current U.S. immigration policy; and

WHEREAS, the Department of Justice has extraordinary power and authority to grant waivers or to take such other action as may be in the best interests of the United States particularly where modification of such practices would cause no danger to the public health and no increased risk of disease spread;

BE IT RESOLVED, that the National Commission on Acquired Immune Deficiency Syndrome recommends and calls upon the Administration to immediately implement the following:

1. The Department of State, the Department of Justice and the Department of Health and Human Services should conduct a comprehensive review of immigration policies as they regard communicable disease, particularly HIV infection, focusing on public health needs.

2. Nonimmigrants, such as conference participants, should not be questioned regarding their HIV status as a condition for entry into the United States or for issuance of a visa. Similarly, persons carrying medications or products associated with HIV infection or hemophilia should not be subject to detention or questioning.

3. The following practices should also be implemented pending the comprehensive overall review of immigration policies recommended above:

A. For applicants who otherwise qualify for legalization asylum, or refugee status and who may be infected with HIV, standards for waivers should be liberally applied and they should be routinely granted particularly where family unity, humanitarian and or public interest grounds may exist.

B. For applicants who otherwise qualify for permanent residency and who may be infected with HIV, similar waiver procedures should be adopted to the extent permitted by law.

C. The Department of State, the Department of Health and Human Services and the Immigration and Naturalization Service should engage in cooperative efforts to institute policies and disseminate information targeted at notifying relevant alien groups of the availability of waivers and the circumstances under which they are granted.

D. To the extent that HIV testing is part of any medical examination of applicants for permanent residency, refugee status or legalization, the Immigration and Naturalization Service and the Centers for Disease Control should carefully monitor training and compliance with their Instructions to Designated Physicians. Particular attention should be paid to pre and post-test counselling, confidentiality and appropriate referrals of persons for medical care and follow-up counselling.

E. Confidentiality should be protected where HIV testing is part of the medical examination of applicants for visas, permanent residency, asylum, refugee status or legalization. Permanent markings in passports (including the use of codes which may become known) which in any way suggest that a person is infected with HIV or any other designated communicable disease should be prohibited. Where medical examinations take place, steps should be taken to safeguard all medical information (including HIV status), particularly from staff recruited locally in foreign countries.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

BACKGROUND PAPER

AIDS AND IMMIGRATION:

An Overview of United States Policy

December 12, 1989

Historical Background[1]

In 1879, in the midst of that century's wave of immigrants, restrictive immigration policies originated with the passage of "An Act to Prevent the Introduction of Infectious or Contagious Diseases into the United States, ..." Section 2 of the Act authorized the President to appoint a medical officer to inspect sanitary conditions on arriving vessels and at foreign ports. Contagious diseases were listed as asiatic cholera, yellow fever, plague, smallpox, typhus fever, and relapsing fever. The crew of an infected vessel was not allowed to come ashore.

The eugenics movement of the late 1800's and early 1900's led to new restrictions. By 1891, medical inspections of immigrants at U.S. ports of entry began. A new law restricting admission of persons "suffering from loathsome or dangerous contagious disease" was passed. The Public Health Service (PHS) interpreted this to include venereal

---

[1] Information for this section was compiled from Staff of House Comm. on the Judiciary, 100th Cong., 2d Sess. Ser. No. 7, Grounds for Exclusion of Aliens Under the Immigration and Nationality Act: Historical Background (Comm. Print 1988); Wolchok, AIDS at the Frontier, 10 J. Legal Med. 127 (1989); Druhot, Immigration Laws Excluding Aliens on the Basis of Health, Va. J. Legal Med. 85 (1986). See also, Musto, Quarantine and the Problem of AIDS, 64 Milbank Q. 97 (1986).

infections. Only those immigrants who showed external signs of infection received full examinations for syphilis and gonorrhea.[2]

In 1952 the federal policy was rewritten as the Immigration and Nationality Act (INA). The INA codified into law the policy of excluding persons from entering the United States on the basis of being suspected of having certain diseases or disabilities. The 1952 Act included a general exclusion for persons with dangerous contagious disease[3], but specifically prescribed exclusions for aliens suffering from tuberculosis and leprosy, two diseases which traditionally subject those afflicted to stigmatization.[4] In 1961 the statute was updated and modified to reflect current medical information, but its focus on diseases associated with social stigmatization persisted. The statute provided for the exclusion of

---

[2] A. Brandt, No Magic Bullet, 20 (1986).

[3] Over 200 communicable diseases are known ranging from AIDS to zygomycosis (a fungal infection). How a given disease is transmitted and the risk that, if transmitted, it will cause harm vary greatly. The American Public Health Association has categorized such diseases into 5 classes with subclasses. They range from Class 1 (e.g. polio and plague) to Class 5 (e.g. the common cold). Tuberculosis, gonorrhea, leprosy and measles are classified as Class 2B diseases which should be reported to local public health authorities by the most practicable means but which need not be forwarded to higher public health authorities on an emergent basis. Control of Communicable Diseases in Man (A. Benenson ed., 14th ed., 1985).

[4] Susan Sontag's Illness as Metaphor (1978) explains how tuberculosis was "a disease regarded as a mysterious malevolency." Pointing out that in Stendahl's Armand (1827), the hero's mother refuses to say 'tuberculosis' for fear that merely uttering the word will hasten her son's death, Sontag shows how "[t]he metaphors attached to TB . . . imply living processes of a particularly resonant and horrid kind."

"TB was -- still is -- thought to produce spells of euphoria, increased appetite, exacerbated sexual desire." Conversely, "TB is often imagined as a disease of poverty and deprivation -- of thin garments, thin bodies, unheated rooms, poor hygiene, inadequate food." Moreover, "people could believe that TB was inherited . . . and also believe that it revealed something singular about the person afflicted." As Kafka wrote to Felice, "Secretly I don't believe this illness to be tuberculosis . . . but rather a sign of my general bankruptcy."

Sontag shows how tuberculosis has been used as a metaphor for all that is "unqualifiedly and unredeemably wicked. It enormously ups the ante. Hitler, in his first political tract, an anti-semitic diatribe . .., accused the Jews of producing 'a racial tuberculosis among nations.'" S. Sontag, supra, at 5-9, 13-19, 38, 44, 61-63.

The irony is, of course, that today tuberculosis is not contagious with current treatment. See, School Bd. of Nassau County, Florida v. Arline, 481 U.S. 1024, 107 S. Ct. 1123, 94 L. Ed.2d 307 (1987) (application of Section 504 of the Rehabilitation Act to communicable diseases).

Likewise, public and institutional responses to persons with leprosy (also known as Hansen's Disease) have subjected those with the disease to social stigmatization, despite the availability and success of treatment.

"aliens who are afflicted with any dangerous contagious disease"[5] by rendering them ineligible to receive visas.[6]

The statute charges the PHS with designating the diseases falling under the purview of the statute and thus used for exclusionary purposes. In 1963, twenty-one diseases were listed in the PHS Manual for the Medical Examination of Aliens. By 1987 the PHS listed only seven diseases, all associated with social stigmatization, for the purposes of INA §212(a)(6). Five were and remain venereal diseases: chancroid, gonorrhea, granuloma inguinale, lymphogranuloma venereum and syphilis (infectious stage). The other two diseases were and remain infectious leprosy and active tuberculosis.

On April 23, 1986, PHS published a proposed rule amending its regulations by adding AIDS to the list of dangerous contagious diseases. The stated rationale for the new rule was that "it would be anomalous to have diseases such as chancroid and lymphogranuloma venereum on such a list and not include AIDS. AIDS is added to the list because it is a recently defined sexually transmitted disease of significant public health importance."[7] It, too, is a disease associated with social stigmatization.

On March 27, 1987, the New York Times reported that PHS was considering a rule which would add the AIDS exclusion under INA §212(a)(7) instead of under INA §212(a)(6). INA §212(a)(7) bars aliens certified as having a "physical defect, disease or disability," which may affect their ability to earn a living.[8] This "more flexible approach

---

[5] The term "alien" refers to a person not a citizen or national of the United States. Under 8 U.S.C. §1101(a)(3) a "national" can be a citizen or a person who owes permanent allegiance to the United States.

[6] I.N.A. §212(a)(6), 8 U.S.C. §1182(a)(6) (1982).

[7] 51 Fed. Reg. at 15,355.

[8] Pear, U.S. to Pursue Proposal to Bar Aliens with AIDS, N.Y. Times, March 27, 1987, at A1.

appeared to reflect the concern expressed by some that characterizing AIDS as a 'dangerous contagious disease' could result in discrimination against high-risk groups, including homosexuals."[9]

On June 8, 1987, the PHS added "acquired immunodeficiency syndrome (AIDS)" to the list of dangerous contagious diseases. Prior to the issuance of PHS final regulations, however, Congress passed the Supplemental Appropriations Act of 1987.[10] Section 518 of the Act, popularly known as the Helms Amendment, directed the President to add the "human immunodeficiency virus (HIV) infection to the INA list of diseases on or before August 31, 1987." Accordingly, the Department of Health and Human Services (HHS) issued new rules substituting HIV infection for AIDS on the list.[11] PHS regulations require that medical examinations of aliens include a chest X-ray examination for tuberculosis and serologic tests for syphilis and HIV infection for all applicants for permanent status. Nonimmigrants are not subject to mandatory tests for the HIV antibody. The Immigration and Naturalization Service (INS) may, however, require a serologic test of a nonimmigrant applying for a visa who is suspected of being HIV seropositive. Similarly, aliens under 15 years of age are not subject to testing unless there is reason to suspect infection. Those who test positive for HIV may be excluded from the United States and must be denied permanent resident status.[12]

---

[9] House Comm. on the Judiciary, <u>supra</u> note 1, at 85.

[10] Pub. L. 100-71, H.R. 1827 (July 11, 1987).

[11] Because of the administrative difficulties, however, the effective date of the new regulations was deferred until December 1, 1987.

[12] 51 Fed. Reg. 32,540-44 (1987); 52 Fed. Reg. 21,607 (effective Dec. 1, 1987). Notably, however, applicants under the Amnesty Program of the Immigration Reform and Control Act of 1986 (IRCA) are not automatically excluded but may apply for a waiver.

Implementation and Current Practice

The Immigration and Naturalization Service's actual implementation of INA §212(a) varies depending on the nature of the status the alien is seeking: i.e. nonimmigrant, permanent resident, legalization, refugee. The practices may also vary with the particular consular officer or immigration inspector.

A. Nonimmigrant

Nonimmigrants who seek to enter the United States as tourists, students or temporary visitors are excludable under INA §212(a)(6) but are not routinely tested for HIV antibodies.[13] At the discretion of a consular officer overseas or an immigration inspector in the U.S., visitors suspected of being HIV positive may be referred for a medical examination and a serologic blood test.[14] Those who test positive for HIV, if overseas, will

---

[13] All visitors to the U.S. are required to fill out an immigration inspection card upon arrival to a U.S. port of entry. One question on this card asks whether the individual has a "dangerous contagious disease." The same question is asked on the Nonimmigrant Visa Application Form. If someone who is HIV positive answers this question "yes" they have admitted their excludability and are subject to exclusion. If someone answers "no" and is later determined to have HIV, this could be considered a "misrepresentation of material fact" which under INA §212(a)(19) is an independent ground for exclusion. Under INA §212(d) an exclusion based on misrepresentation or fraud may be waived, however, in practice such a waiver is virtually unobtainable. There are thirty three separate grounds for exclusion. One of particular concern is INA §212(a)(4). Under this section gay and lesbian aliens have historically been excludable. This section prohibits entry to persons "afflicted with psychopathic personality, or sexual deviation, or a mental defect . . . ." Under current INS policy, an alien may not be questioned regarding his or her sexual preference unless he or she makes some voluntary affirmative statement about being gay or provides information that brings up the issue.

[14] INA §232 authorizes the "Detention of Aliens for Observation and Examination" for the purpose of determining whether they are afflicted with a "dangerous contagious disease." The regulations further state that individuals may be detained for a medical examination whenever there are reasonable grounds for believing" that they are excludable under one of the health related grounds. Conference participants at the meeting of the XIX Congress of the World Federation of Hemophilia (WFH) in Washington, D.C. and at the Sixth International AIDS Conference in San Francisco, both in the summer of 1990, are subject to this provision of the INA. For persons with hemophilia the problem is particularly acute, as many travellers will necessarily be carrying blood products with them and wearing medic-alert bracelets. As with any visitor traveling with AZT or other attention-catching items, persons with hemophilia will quickly be identified as suspect for HIV infection and subject to exclusion. Many members of the hemophilia community, including both patients and physicians, are concerned about the U.S. requirements that obligate persons to declare their HIV status and thereby single them out for discrimination. Such fears have compelled hemophilia organizations of patients and physicians in Canada, the United Kingdom, the Federal Republic of Germany and Greece, among others, to call for a boycott of the WFH Conference and all non-essential travel to the

not be granted a visa. If already at a U.S. port of entry, they will be detained and given the option to return to their place of origin voluntarily or otherwise to pursue their case before an immigration judge in exclusion proceedings.[15] A nonimmigrant visitor may, however, apply for a waiver from the Attorney General.[16] The discretionary authority of the Attorney General will not be used unless the applicant can establish that:

> "(1) the danger to the public health of the United States created by the alien's admission to the U.S. is minimal, (2) the possibility of spread of the disease created by the alien's admission to the U.S. is minimal and (3) there will be no cost incurred by any level of government agency of the U.S. without prior consent of that agency."

Waivers must be applied for at the time of application for a visa at a consulate or in certain circumstances before embarkation to the U.S. or at the port of entry from the INS district director. If a waiver is granted, the alien's passport is stamped with a visa that contains the code "212(d)(3)(a)(6)". This code indicates that a waiver has been granted for the statutory exclusion category corresponding to the dangerous contagious disease

---

U.S. Similar concerns have guided the Scandinavian AIDS and HIV organizations, the League of Red Cross and Red Crescent Societies among others to withdraw from the VI International AIDS Conference.

[15] Besides the well-publicized Hans Verhoef case, in which a citizen and health educator of the Netherlands was detained for six days after admitting to having HIV infection when a Customs luggage check uncovered AZT, several other incidents involving detainment of visitors by INS on the basis of HIV infection have been reported. In June 1989, Knud Jorgensen, a Danish AIDS researcher was detained in Boston after admitting his HIV status to INS officials. According to Jorgensen, officials at Logan Airport asked him if he had HIV infection after he told them he was going to the Montreal Conference. After two hours, Mr. Jorgensen was allowed to continue onto Montreal. On the same day, Henry Wilson, a leader of a British Coalition of PWAs was detained by INS officials in Minneapolis-St. Paul. Wilson's purpose of visiting the U.S. was to participate in a six month study of the drug CD-4. Mr. Wilson returned to London. Knox, INS Policy on Foreigners with AIDS Fuel Outrage as Two are Detained, Boston Globe, June 8, 1989. Other incidents have apparently been more newsworthy in the domestic press of the country of the excluded or detained visitor and have not been the subject of much notoriety in the U.S.

[16] The INS estimates that this procedure takes a minimum of 30 to 60 days (except in urgent circumstances) and therefore suggests that application be made especially early for those with HIV infection.

provision. This information regarding excludability under INA §212(a)(6) is also recorded in the U.S. embassy records in the alien's home country.

In a May 25, 1989 news release and directive issued to consular and immigration officers, the INS asserted that under the so-called balancing test described above, short term (30 days or less) nonimmigrants who are HIV positive should be provided waivers and temporary admission if the applicants establish that their entry into the United States would confer a public benefit which outweighs any risk to the public health. Under that policy a sufficient public benefit included "a showing that the short term nonimmigrant will be attending academic or health related activities (including seeking medical treatment), or conducting temporary business in the U.S." In addition visits to close family members in the U.S. would be considered a sufficient public benefit. However, entry into the United States essentially for tourism reasons alone was not sufficient to be deemed a public benefit.[17]

B. Permanent Resident

At the other end of the spectrum, are those aliens applying for permanent resident status. For these aliens no waivers are available except under the Immigration Reform and Control Act. Every alien applying for permanent resident status is required to undergo a

---

[17] A letter dated September 29, 1989, from the United States Embassy to the President of the Danish Association of Social Workers announced new INS guidelines on the issue of tourism and 30 day stays. According to the letter, the May guidelines referred to above were found "too restrictive" as they "ended up meaning that a child who had contracted AIDS at birth or through a blood transfusion, and who obviously would pose little danger of spreading the infection, would be unable to go with his family on a vacation in the U.S." Apparently in response to complaints about the 30-day limit for waivers, which make extended medical treatment in the U.S. for persons with AIDS impossible, the INS will now allow longer visits if a person with AIDS has a compelling case. The example cited in the letter is one of an "AIDS sufferer who would be staying in a hospital while undergoing treatment or in a clinic while participating in a research program." Such a person would, under the reasoning in the letter, pose a minimal public health risk, while possibly offering a substantial public benefit.

medical examination and serological test for HIV. Aliens who are already in the U.S. and who are denied permanent residence may at the discretion of the INS be classified under the category of "deferred status" which temporarily enables them to remain in the U.S. pending an order of deportation. The informal practice of categorizing persons denied residency under the rubric "deferred status" has been used in some cases to avoid deporting parents, children and spouses of U.S. citizens.

C. Legalization

In 1986, Congress passed the Immigration Reform and Control Act (IRCA) which permits undocumented migrants present in the United States since 1982, to regularize their status to that of permanent residents and imposes penalties on employers who knowingly hire undocumented workers. Applicants for legalization who test positive for HIV are excludable under INA §212 (a)(6). IRCA, however, provides that applicants for legalization may be granted waivers where the applicant can show compelling family unity, humanitarian and/or public interest grounds for waiver.[18] Applicants for legalization must have a medical examination and serologic test. The examination and the test are valid only if conducted by an INS designated civil surgeon. Unlike other immigrants, HIV infection is not in itself a grounds for the deportation of legalization applicants, although it is a ground for excludability. Information submitted in support of legalization applications is confidential and may not be used for any purpose other than determining legalization under IRCA §210(c)(5).

---

[18] I.R.C.A. §245 A(d)(B) and §210(2)(B).

Under the Cuban-Haitian adjustment program,[19] persons from Cuba and Haiti who entered the U.S. before 1980 may adjust their status to that of a permanent resident. However, the IRCA does not contain a waiver provision for these aliens if they test positive for HIV.

D. Refugees

In 1980, Congress amended the INA by adding the Refugee Act. Under this provision, the Attorney General has discretionary authority to waive excludability for refugees who test positive for HIV. Refugee status is granted to persons applying for relief abroad, that is, these individuals are not generally present in the U.S. at the time of application. In general, the refugee population is made up of individuals fleeing economic and political oppression and persecution in their home country. In 1987, there were an estimated 10 million refugees throughout the world.[20] It is estimated that in the current fiscal year some 74,000 refugees will be admitted to the United States.[21] In testimony before the Presidential Commission on the HIV Epidemic, a representative of the Bureau for Refugee Programs expressed his concerns regarding the sensitive status of refugees who exist in tenuous circumstances in their country of first asylum as they flee persecution in their home countries. He pointed out that unlike prospective immigrants, refugees do not

---

[19] I.R.C.A. §202.

[20] In responding to the PHS notice of proposed rule making that would have added AIDS to the list of dangerous contagious diseases, the Department of State declared all refugees of concern to the United States, but identified refugees of particular concern to the U.S. as "among others, those who fought with the United States in Southeast Asia; boat people who have risked victimization by pirates to escape Vietnam; Afghans who fled after the 1979 Russian invasion; Soviet Jews; Cuban political prisoners; refugees from Eastern European totalitarian regimes; refugees escaping civil war-torn Ethiopia; and religious minorities threatened by religious totalitarianism in Iran."

[21] Refugee Reports, May 19, 1989, at 9.

remain citizens of their home countries with recourse to those countries' institutions. Refugees have no home to which to return.[22]

Public Health Perspective

In May of 1987, the 41st World Health Assembly (WHA) adopted resolution WHA 41.24 urging member States to "protect the human rights and dignity of HIV infected people and people with AIDS, and of member population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment and travel." Further, a consultation of experts convened by the World Health Organization's (WHO) Global Programme on AIDS concluded in a March 2-3, 1987 report that HIV screening of international travellers would be ineffective, impractical and wasteful.[23] Specifically, these experts emphasized that "since HIV infection is already present in every region and in virtually every major city in the world, even total exclusion of all travellers (foreigners and citizens travelling abroad) cannot prevent the introduction and spread of HIV." The experts based their opinion in part on the number of persons who cross international borders each year,[24] the natural history of HIV infection,[25] and the

---

[22] See Appendix. Note also that as a matter of policy the United Nations High Commissioner for Refugees and the Department of State have taken as their point of departure the recognition that refugees are not an at risk group for infection with the HIV virus. In its response to the PHS notice of proposed rule making referred to supra note 20, at 8, the Department of State wrote, "It is also important to recognize that epidemiological experts both inside and outside of the Government agree that most of the refugee populations that would be tested under this proposed rule -- i.e., those designated " of special humanitarian concern" to the United States by the President and hence eligible for consideration for admission to the United States-- exhibit a very low incidence of the AIDS virus." See U.N. High Comm. for Ref. Inter-Office Memorandum No. 21/88.

[23] The PHS claims that U.S. policy of screening aliens for HIV does not conflict with the report of the WHO consultation on international travel. According to the PHS the "consultation addressed issues related to international travel and not to decisions individual countries might make with respect to the admission of permanent immigrants" or visa applications. Supplementary Information, 42 CFR 34.

[24] Hundreds of millions of persons cross international borders each year, by boat, air, rail, motor vehicle and foot.

knowledge that tests to determine HIV infection are not perfect and, thus, unlikely to identify persons recently infected and likely to generate a significant number of false positive results in populations with relatively few HIV infected people.[26] Rather than screening international travellers the World Health Organization encourages nations to apply their resources to preventing HIV transmission based on information and education.[27]

According to the International Health Regulations of the World Health Organization,[28] the only health document that can be required from international travellers

---

[25] The term "natural history of HIV infection" is used here to refer to two separate phenomenon: 1) the clinical manifestations of the disease which are relatively non-specific, including research evidence that indicates that antibodies to HIV do not commonly appear before six weeks post-infection; and 2) the modes of transmission: sexual contact with an infected person, exposure to infected blood products (through transfusion or sharing of needles with IV-drug user), and perinatal transmission from an infected woman to her fetus.

[26] The basis for this objection is clearly explained in Allin, <u>The AIDS Pandemic: International Restrictions and the World Health Organization's Response,</u> 28 Va. J. Int'l L. 1043, 1058 (1988). "The first . . . (ELISA) test was designed for large scale screening of blood donated to blood banks and hospitals. Cut-points on ELISA tests are set quite low to eliminate any possibly infected blood from the donor pool. When the same test is used to test the presence of antibodies in individuals, the low cut-points result in a high rate of false positives. To eliminate false positives, individuals who test positive usually undergo the second type of test, called the Western Blot. The Western Blot test is very expensive and labor-intensive; it is not designed for large scale screening programs." The number of false positives varies with the level of risk of the population tested. With a low risk population, the false positive rate is likely to be much higher than with a middle or high risk population. Critics add that it is hard to control for the accuracy of foreign labs in the case of travellers applying for visas at an embassy abroad and that the more expensive Western Blot test may not be available.

[27] Report of the Consultation on International Travel and HIV Infection, 2-3 March 1987 World Health Organization WHO/GLO/87.1. Apparently, in 1987 in response to an announcement by a European country to screen travellers for HIV, the WHO announced that it would not hold meetings in any country that required an HIV screening for meeting participants. The WHO did not, however, issue a resolution declaring this policy, thus the practice has never been institutionalized. <u>See</u> Cong. Res. Serv., Issue Brief Update 6 (April 5,1989). In 1987, the 99th meeting of the Executive Committee of the Pan American Health Organization (PAHO) adopted a resolution recommending that PAHO urge member countries "to continue permitting freedom of international travel, without restrictions based on human immunodeficiency virus (HIV) infection status."

[28] The International Health Regulations adopted by the WHA in 1951 addressed four communicable diseases: plague, cholera, yellow fever, and small pox. In 1969 this list was expanded to include louse-borne typhus, louse-borne relapsing fever, influenza, poliomyelitis and malaria. As a primary means of controlling disease and encouraging cooperation between countries, the Regulations instituted an elaborate notification system which obligated member states to make detailed reports to WHO on the incidence of these diseases. In keeping with the goal of minimizing restrictions on international traffic the Regulations forbade requirements of health documents in international travel, with an exception in the case of yellow fever. <u>See</u>

is a valid vaccination certificate against yellow fever. Under this regulation no country may refuse entry into its territory a person who fails to provide a medical certificate stating that he or she is not carrying the HIV virus. Thus an international travel policy that detains suspected carriers of the virus, refers them to medical evaluation and refuses them entrance into a country based on HIV status or failure to submit to a medical examination violates this agreement.[29]

In the United States, the PHS has explicitly stated, "There is no evidence that the virus is spread through casual social contact (shaking hands, social kissing, coughing, sneezing, sharing swimming pools, bed linens, eating utensils, office equipment, being next to or served by an infected person)."[30] And, further, that "HIV has three main modes of transmission: sexual contact with an infected person, exposure to infected blood or blood products (mainly through needle-sharing among IV-drug users), and perinatal transmission from an infected woman to her fetus or infant."[31]

As early as 1987, when the first proposed rule to add AIDS to the list under INA §212(a)(6) was announced, public health experts have questioned the efficacy of screening international travellers and immigrants. Public health experts predicted the plan to test about 400,000 immigrants a year to be "unlikely to stem the spread of acquired immune

---

Allin, supra note 24, at 1049-1050.

[29] Chin,"HIV and International Travel" in Global Impact of AIDS, 63 (1988).

[30] U.S. Department of Health and Human Services, Public Health Service, Information/Education Plan to Prevent and Control AIDS in the United States, 9 (March 1987). The Institute of Medicine has stated further that,"Finally, additional data from studies of health care workers (CDC,1988d), nonsexual household contacts (Friedland and Klein, 1987), and insect bites (CDC,1986) all support the conclusion that HIV is not transmitted by casual contact or insect bites. A change in HIV transmission modes would be biologically unprecedented in a virus. There is no evidence that HIV is capable of such a change." Confronting AIDS Update 1988, 39 (1988).

[31] C.D.C., 38 Morbidity and Mortality Weekly Report, May 12, 1989, No. S-4 at 2.

deficiency syndrome."[32] The State Department's own estimate that only 250 immigrants would test positive for HIV infection annually paled in comparison to the PHS estimate that 1 million to 1.5 million Americans are infected.[33] That the United States has more reported cases of AIDS than any other country seemed to belie any thoughtful belief that screening immigrants and visitors would affect the spread of AIDS in the United States.[34]

Just recently, the American Bar Association (ABA), adopted the following resolution:[35]

> Legalization pursuant to the Immigration Reform and Control Act should not be denied to otherwise-qualified aliens solely because of HIV status.[36]
>
> Non-immigrant visitors to the United States should not be barred solely because of HIV status.[37]
>
> Otherwise-qualified political asylees and refugees should not be barred from the United States solely because of HIV status.

---

[32] Okie, Public Health Experts Raise Doubts on Plan to Test Immigrants for AIDS, Washington Post, July 15, 1987, at A14.

[33] 103 J. of U.S. Pub. Health Serv. 3 (1988).

[34] See Comments of Allan Brandt, Lincoln Chen, Donald Henderson, Joyce Lashof, June Osborn, and Sheldon Wolff on Proposed Regulation for Adding HIV Infection to the List of Dangerous Contagious Diseases of the INA.

[35] Adopted at the August, 1989 annual meeting of the ABA.

[36] The ABA pointed out that not only would the humanitarian and economic intent of IRCA be frustrated by exclusion but also that "rejected applicants would probably be driven underground with their disease and would continue to live in fear of seeking help from public authorities."

[37] The ABA pointed out that as to non-immigrant visitors, exclusionary practices would invite retaliation from other countries and would be virtually unenforceable. Just as the United States initially categorized travel to and from Haiti as a "high risk behavior," much of the rest of the world views travel to the United States as a form of "high risk behavior."

> The Attorney General should have the authority to waive exclusions based on HIV status for immigrants on a case-by-case basis.[38]

In its June 1988 report, the Presidential Commission on the HIV Epidemic concurred with the World Health Organization that "the screening of International travelers for HIV infection would require an unjustified, immense diversion of resources from other critical programs of education, protection of the blood supply, and care." "At best," the Commission concluded, "border screening programs would only briefly retard the spread of HIV." In its recommendations the Commission warned against the implementation of ineffective and cumbersome regulations.[39]

Resolution

WHEREAS, policies which govern the medical examination and exclusion of aliens from the United States based upon communicable disease should be determined by sound public health policies alone; and

WHEREAS, these policies need a comprehensive and thorough review based only on public health needs, because other considerations, particularly myth, prejudice and social stigmatization, have been historically but inappropriately considered; and

WHEREAS, the United States Public Health Service has stated that there is no evidence that the Human Immunodeficiency Virus (HIV) is spread through casual social contact; and

---

[38] The ABA suggestion of case-by-case determination does not apply to non-immigrant visitors because under their recommendation such visitors should not be subject to exclusion in any event based on HIV status.

[39] The Presidential Commission also recommended that the Center for Disease Control expand its booklet, "Health Information for International Travel," to include information on HIV and called for the State Department, Health and Human Services and the Immigration and Naturalization Service to reevaluate the screening policy as it relates to refugees twelve months after implementation.

WHEREAS, the World Health Organization (WHO) has concluded that screening of international travelers cannot prevent the introduction or spread of HIV infection; and

WHEREAS, in its June 1988 report, the Presidential Commission on the HIV Epidemic concurred with the WHO that "the screening of international travelers for HIV infection would require an unjustified, immense diversion of resources from other critical programs of education, protection of the blood supply, and care"; and

WHEREAS, current practices, particularly as they relate to HIV infection, are counterproductive, discriminatory and represent a waste of resources which could be better used in other ways; and

WHEREAS, these practices, in particular, threaten the attendance of participants from all over the world at the Sixth International Conference on AIDS scheduled for San Francisco and the XIX International Congress of the World Federation of Hemophilia scheduled for Washington, D.C.; and

WHEREAS, the promise of global cooperation on important issues of public health is being jeopardized by current U.S. immigration policy; and

WHEREAS, the Department of Justice has extraordinary power and authority to grant waivers or to take such other action as may be in the best interests of the United States particularly where modification of such practices would cause no danger to the public health and no increased risk of disease spread;

BE IT RESOLVED, that the National Commission on Acquired Immune Deficiency Syndrome recommends and calls upon the Administration to immediately implement the following:

1. The Department of State, the Department of Justice and the Department of Health and Human Services should conduct a comprehensive review of immigration policies as they regard communicable disease, particularly HIV infection, focusing on public health needs.

2. Nonimmigrants, such as conference participants, should not be questioned regarding their HIV status as a condition for entry into the United States or for issuance of a visa. Similarly, persons carrying medications or products associated with HIV infection or hemophilia should not be subject to detention or questioning.

3. The following practices should also be implemented pending the comprehensive overall review of immigration policies recommended above:

A. For applicants who otherwise qualify for legalization, asylum, or refugee status and who may be infected with HIV, standards for waivers should be liberally applied and they should be routinely granted particularly where family unity, humanitarian and or public interest grounds may exist.

B. For applicants who otherwise qualify for permanent residency and who may be infected with HIV, similar waiver procedures should be adopted to the extent permitted by law.

C. The Department of State, the Department of Health and Human Services and the Immigration and Naturalization Service should engage in cooperative efforts to institute policies and disseminate information targeted at notifying relevant alien groups of the availability of waivers and the circumstances under which they are granted.

D. To the extent that HIV testing is part of any medical examination of applicants for permanent residency, refugee status or legalization, the Immigration and Naturalization Service and the Centers for Disease Control should carefully monitor training and compliance with their Instructions to Designated Physicians. Particular attention should be paid to pre and post-test counselling, confidentiality and appropriate referrals of persons for medical care and follow-up counselling.

E. Confidentiality should be protected where HIV testing is part of the medical examination of applicants for visas, permanent residency, asylum, refugee status or legalization. Permanent marking in passports or on visas (including the use of codes which may become known) which in any way suggest that a person is infected with HIV or any other designated communicable disease should be prohibited. Where medical examinations take place, steps should be taken to safeguard all medical information (including HIV status), particularly from staff recruited locally in foreign countries.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
December 27, 1989

Contact: Thomas Brandt
202-254-5125

COMMISSION HOLDS JANUARY SESSIONS IN ST. PAUL AND LOS ANGELES

The National Commission on AIDS will hold a working group meeting in St. Paul, Minnesota on January 4 and 5, then the entire Commission will meet in Los Angeles on Jan. 24, 25 and 26 for formal hearings and site visits.

The St. Paul working group will study the responsibilities of federal, state and local governments in responding to the human immunodeficiency virus (HIV) epidemic, and will report on their work to the full Commission.

The Commissioners on the working group are Diane Ahrens, who is also a Ramsey County (St. Paul) Commissioner, Dr. Charles Konigsberg, who is Director of the Division of Health of the Kansas Department of Health and the Environment, and Larry Kessler, who is Executive Director of the AIDS Action Committee in Boston.

The groups who will testify before the commissioners in St. Paul include the U.S. Conference of Mayors, the National Association of Counties and the National Conference of State Legislatures, among others. (A copy of the St. Paul agenda is attached).

The Commission will also hear from officials from Dallas, Minneapolis, New York, North Carolina, Philadelphia, and San Francisco, as well as the Director of the National AIDS Program Office of the U.S. Department of

Health and Human Services.

A copy of the agenda for the Los Angeles hearing will follow by separate mailing in January.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a national consensus on policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs.

(For your background please find enclosed a fact sheet on the Commission).

# # # #

NATIONAL COMMISSION ON AIDS

Working Group on Federal, State and Local Responsibilities

AGENDA

ST. PAUL, MINNESOTA

JANUARY 4 - 5, 1990

Thursday, January 4, 1990

9:00 a.m.	Opening Remarks County Commissioner Diane Ahrens, National Commission on AIDS
9:15 a.m.	Dr. James Allen, Department of Health and Human Services
9:45 a.m.	Ms. Ann Klinger, National Association of Counties
10:05 a.m.	Mayor Donald Fraser, U.S. Conference of Mayors
10:25 a.m.	BREAK
10:40 a.m.	Councilmember Brian Coyle, National League of Cities
11:00 a.m.	State Senator Linda Berglin, National Conference of State Legislatures
11:20 a.m.	LUNCH
12:45 p.m.	Councilmember Angel Ortiz, Philadelphia City Council
1:15 p.m.	Mr. James E. Smith, National Association of People with AIDS
1:45 p.m.	Mr. A. Billy S. Jones, National AIDS Network

2:15 p.m.	Councilmember Lori Palmer, Dallas City Council
2:45 p.m.	Mr. Herb Stout, North Carolina County Commissioner
3:15 p.m.	Sister Mary Madonna Ashton, Minnesota Health Commissioner
3:45 p.m.	Mr. James Bulger, New York State AIDS Institute
4:15 p.m.	Mr. Tim Wolfred, San Francisco Mayor's Task Force
4:45 p.m.	ADJOURN

Friday, January 5, 1990

8:30 a.m.	Working Group Meeting on Federal, State and Local Government Roles
12:30 p.m.	LUNCH
1:30 p.m.	Commission and Staff Wrap-Up
1:45 p.m.	ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
January 12, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION'S LOS ANGELES HEARINGS AND SITE VISITS TO FOCUS ON REGIONAL RESPONSE TO HIV EPIDEMIC

The National Commission on AIDS will hold three days of hearings and site visits in Los Angeles January 24, 25 and 26 to study the special characteristics of the HIV (human immunodeficiency virus) epidemic in Southern California and the local response from the public and private sectors.

Metropolitan Los Angeles has the second highest number of reported cases of AIDS in the country. The National Commission decided to hold hearings in Los Angeles because the epidemiology of the epidemic, the community response and the regional population differ from cities such as New York, which has the highest number of reported cases, or San Francisco, which is third.

June Osborn, M.D., Chairman of the Commission, said, "The extensive experience in Los Angeles and Southern California epitomizes some of the variation of AIDS and HIV epidemic patterns in different regions of the country. It is very important to appreciate that such variety exists as we strive to develop comprehensive preventive and health care strategies."

- more -

David Rogers, M.D., Vice Chairman of the Commission, said, "Because of the heavy burden of HIV in Los Angeles, and some of the innovative responses taken by local groups, the National Commission wants to know how some of these solutions might be applied in a national policy context."

More than 30 witnesses will appear before the Commission during a full day of hearings on Thursday, Jan. 25 which will be held from 9 a.m. to 5:30 p.m. in the Oscar Room of the Hollywood Roosevelt Hotel, 7000 Hollywood Blvd., Hollywood.

On Wednesday afternoon, Jan. 24 and all day Friday, Jan. 26 the Commission will visit various HIV and AIDS service organizations in the private and public sectors, including community-based organizations, hospitals and a hospice.

Eunice Diaz, a member of the Commission from Los Angeles and Assistant Clinical Professor of Family Medicine at the University of Southern California School of Medicine, played a major role in planning the Commission's agenda for Los Angeles.

A complete hearing agenda and schedule of the Commission's site visits is attached.

Questions about the Commission in general and the Thursday hearings should be directed to Thomas Brandt at 202-254-5125. Journalists wishing to cover any of the site visits should contact the organization directly. Not all sites have provisions for full press coverage. Media contact names and telephone numbers for the site visits are listed on the attached schedule.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a consistent national policy" concerning the AIDS epidemic.

- more -

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

LOS ANGELES, CALIFORNIA

JANUARY 24 -26, 1990

Wednesday, January 24, 1990

2:00 p.m. Optional Site Visits - Departure from Hollywood Roosevelt Hotel

Thursday, January 25, 1990

9:00 a.m. OPENING REMARKS

Chairman June E. Osborn, M.D.

WELCOME

The Honorable Tom Bradley, Mayor, City of Los Angeles
Supervisor Edmund D. Edelman, County of Los Angeles
The Honorable Rand Schrader, Chair, Los Angeles County AIDS Commission

9:15 a.m. OVERVIEW OF SOUTHERN CALIFORNIA

Area Demographics: Viviane Doche-Boulos, Ph.D., Southern California Association of Governments

Epidemiology: Martin Finn, M.D., Los Angeles County Department Of Health Services

Tom Prendergast, M.D., M.P.H., Orange County Health Care Agency

9:45 a.m. SYSTEMS OF CARE

Alex Taylor, M.P.H., San Bernadino County AIDS/STD Programs
Dave Johnson, City of Los Angeles AIDS Coordinator
Penny Weismuller, Dr.P.H., Orange County Health Care Agency
Dale Fleishman, San Diego County Department of Health Services

10:05 a.m. BREAK

10:15 a.m. ACCESS TO CARE

Robert Gates, M.P.A., Los Angeles County Department of Health
Wilbert Jordan, M.D., M.P.H., King/Drew Medical Center
Bisher Akil, M.D., Kenneth Norris Hospital
Mario Solis-Marich, Neighborhood AIDS Consortium
Phill Wilson, Black Gay and Lesbian Leadership Forum
J. Craig Fong, J.D., Asian Pacific Legal Center of So. California
Donald Hagan, M.D., AIDS Services Foundation, Orange County
Fred Wietersen, Being Alive
Paul Rothman, D.O., Pacific Oaks Medical Group

12:00 p.m. ALTERNATIVES TO INPATIENT CARE

Michael Weinstein, AIDS Hospice Foundation
Pam Anderson, AIDS Project Los Angeles
Sharon Grigsby, M.B.A., Visiting Nurses Association
Bessie Hughes, R.N., King/Drew Medical Center

12:40 p.m. LUNCH

1:40 p.m. COMMISSION BUSINESS

2:40 p.m. SUBSTANCE ABUSE AND AIDS ISSUES

Irma Strantz, Dr.PH., Los Angeles County Drug Abuse Program Office
Connie Norman, AIDS Activist
Henry Alonzo, El Centro Human Services Corporation
William Edelman, L.C.S.W., A.C.S.W., Orange County Drug Abuse Services
Xylina D. Bean, M.D., King/Drew Medical Center
Danny Jenkins, Tarzana Treatment Center

3:15 p.m. BREAK

3:30 p.m. YOUTH, STREET YOUTH, PROSTITUTION AND HOMELESSNESS

Gabe Kruks, Gay and Lesbian Community Service Center
Ruth Slaughter, Project Warn
Michael Cousineau, Dr.P.H., Los Angeles Homeless Health Care Project
Jackie Goldberg, M.A.T., Los Angeles Board of Education

4:10 p.m. ISSUES AFFECTING GAY AND BISEXUAL PEOPLE OF COLOR

Juan Ledesma, AIDS Project Los Angeles
Raul Magana, Ph.D., Orange County Health Care Agency
Gil Gerald, Minority AIDS Project
Dean Goishi, Asian/Pacific Lesbians and Gays
Lydia Otero, Gays & Lesbians Latinos Unidos (GLLU)

5:00 p.m. ADJOURN

NATIONAL COMMISSION ON AIDS

SITE VISITS

LOS ANGELES, CALIFORNIA

<u>Friday, January 26, 1990</u>

7:00 a.m.	Board Bus at Hollywood Roosevelt Hotel
7:30 a.m.	Breakfast at Chris Brownlie AIDS Hospice
9:00 a.m.	Los Angeles County - University of Southern California Medical Center
11:30 a.m.	Lunch with Latino Community Leaders at Tamayo's Restaurant
2:00 p.m.	King/Drew Medical Center
4:00 p.m.	West Los Angeles Veterans Administration Medical Center
6:30 p.m.	Ecumenical/Interfaith Presentation at Santa Monica Hospital

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
February 7, 1990

Contact: Thomas Brandt
Washington 202-254-5125
Boston (Feb. 15 and 16 only,
Westin Hotel) 617-262-9600

COMMISSION REVIEWS ISSUES SURROUNDING HIV TESTING

A working group of the National Commission on AIDS will meet in Boston February 15 and 16 to begin the Commission's study of early intervention and the psychosocial aspects of testing for HIV (human immunodeficiency virus).

"HIV testing is one of the more sensitive and complicated issues of the AIDS epidemic," said Commissioner Scott Allen, who will chair the two-day meeting.

The sessions will be held in the Westin Hotel Copley Place, 10 Huntington Avenue, Boston. The Thursday session will run from 10 a.m. to 5:15 p.m. and Friday's session will run from 9 a.m. to 4:30 p.m.

The meeting format will include formal presentations followed by round table discussions, led by a professional facilitator, and including approximately 30 meeting participants. The participants will include government public health officials, health care professionals, representatives of community based organizations, academics, the Defense Department and the American Civil Liberties Union.

-more-

A summary report from the meeting will be presented at the next full Commission meeting, to be held in Washington in March.

A copy of the Boston meeting agenda and a list of participants is attached.

Members of the National Commission Working Group on Social/Human Issues are: Harlon Dalton, who is Professor of Law at Yale; Eunice Diaz, who is an authority on AIDS among Hispanics and Assistant Professor of Family Medicine at the University of Southern California; Don Goldman, who is an attorney and former president of the National Hemophilia Foundation; and Larry Kessler, who is co-founder and Executive Director of the AIDS Action Committee in Boston. Other members of the Commission may attend.

The Chairman of the Working Group, Scott Allen, is a Dallas minister who has done extensive work on the spiritual, ethical and psychological aspects of AIDS.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a consistent national policy concerning AIDS" and the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

Working Group on Social/Human Issues

AGENDA

BOSTON, MASSACHUSETTS

FEBRUARY 15-16, 1990

Thursday, February 15, 1990

10:00 a.m.	Introductions	Scott Allen, Chair Marc J. Roberts, Ph.D., Facilitator
10:15 a.m.	SESSION I:	State of the Art in Trends and Issues * Presentations * Overview of Testing Issues - Paul Cleary, M.D. Types and Standards of Tests - John W. Ward, M.D. State Legislative Trends - Kate Cauley, Ph.D. The Challenge of Testing in Different Populations - Marie St. Cyr
11:30 a.m.	BREAK	
11:45 p.m.	SESSION II:	Programs of the Public Health Service * Presentations * The Centers for Disease Control Health Resources and Services Administration
12:45 p.m.	LUNCH	
1:45 p.m.	SESSION III:	The Role of HIV Testing in Early Intervention * Roundtable Discussion *
4:45 p.m.	Wrap Up	
5:15 p.m.	ADJOURN	

Friday, February 16, 1990

9:00 a.m.	Introductions	Scott Allen, Chair Marc J. Roberts, Ph.D., Facilitator
9:15 a.m.	SESSION IV:The Continuum of Psychosocial Needs	
		* Presentation *
		Dr. Marshall Forstein
		* Roundtable Discussion *
12:15 p.m.	LUNCH	
1:15 p.m.	SESSION V: Summary	
		* Roundtable Discussion *
2:15 p.m.	BREAK	
2:30 p.m.	Working Group Business	
4:30 p.m.	ADJOURN	

NATIONAL COMMISSION ON AIDS

Working Group on Social/Human Issues

February 15 & 16, 1990
Boston, Massachusetts

Commission Working Group

Scott Allen
Harlon L. Dalton, Esq.
Eunice Diaz, M.S., M.P.H
Donald S. Goldman, Esq.
Larry Kessler

Meeting Facilitator

Marc J. Roberts, Ph.D. - Professor of Political Economy and Health Policy, Harvard School of Public Health

Participants

Rona N. Affoumado - Executive Director, Community Health Project, New York
Hortensia Amaro, Ph.D. - Assistant Professor, School of Public Health, Boston University
Walter F. Batchelor - Director of Research, John Snow, Inc., Research and Training Institute; Member, American Psychological Association
Kate Cauley, Ph.D. - Deputy Director for the AIDS Policy Project, Intergovernmental Health Policy Project
Paul Cleary, M.D. - Associate Professor of Medical Sociology, Harvard School of Public Health
Deborah Cotton, M.D., M.P.H.- Clinical Director for AIDS, Beth Israel Hospital, Boston, MA
Mindy Domb - AIDS/HIV Educator, Pittsfield, MA
Eric L. Engstrom - Executive Director, National AIDS Network, Washington, DC
William F. Flanagan - Director of Public Policy, AmFAR, New York
Marshall Forstein, M.D. - Outpatient Psychiatry, Cambridge Hospital
Jackie Gelfand, M.A., M.F.C.C.- ATS Project Manager, Los Angeles Gay & Lesbian Community Services Center
Alan Hinman, M.D., M.P.H. - Director of Centers for Prevention Services, Centers for Disease Control
Wayne Johnson, Jr., M.S.P.H. - School of Public Health, University of South Carolina, Columbia
Jeff Levi - Consultant, Washington, DC
Harvey Makadon, M.D. - Executive Director, Boston AIDS Consortium; Asst. Professor, Harvard Medical School
John F. Mazzuchi, Ph.D. - Office of Assistant Secretary for Health Affairs, Department of Defense, Washington, DC
Jim McEvoy - Representative from the National Association of People With AIDS
Alvin Novick, M.D. - Professor of Biology, Yale University; Mayor's Task Force on AIDS, New Haven, CT
Joseph O'Neill, M.D., M.P.H. - Chief Medical Director, Division of HIV Services, Health Resources and Services Administration
Alonza Plough, Ph.D. - Deputy Commissioner for Public Health, City of Boston
Marie St. Cyr - Executive Director, Women and AIDS Resource Network, Brooklyn
Ronald St. John, M.D., M.P.H.- National AIDS Program Office, Department of Health and Human Services

Romeo Sanchez - Human Rights Specialist, New York City Commission on Human Rights

H. Denman Scott, M.D. - Director of Health, Rhode Island Department of Health; President, Association of State & Territorial Health Officials

Peter Smith, M.D. - Department of Pediatrics, Rhode Island Hospital, Providence

Jill Strawn, R.N., M.S.N. - Director of Agency Outreach, Community Health Education Project, New Haven, CT

John W. Ward, M.D. - Special Assistant for Science (HIV), Centers for Disease Control, Atlanta

Bob White - Deputy Director, BEBASHI (Blacks Educating Blacks About Sexual Health Issues), Philadelphia

Wayne S. Wright - Executive Director, Multicultural AIDS Coalition, Boston

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
February 20, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION VISIT FOCUSES ON HIV AMONG NEW YORK HOMELESS AND NEW JERSEY DRUG USERS, HEMOPHILIACS AND CHILDREN

On February 26 the National Commission on AIDS will visit facilities for the homeless in New York City including the Bowery Resident's Committee, Bellevue Men's Shelter, Fort Washington Armory Shelter, Hetrick-Martin Institute, and the Minority Task Force on AIDS to learn more about the prevalence of HIV infection among the homeless and their access to health care.

On February 27 the Commission will go to New Jersey for briefings by state health officials followed by tours of two hospitals, a drug treatment center, and a regional hemophilia treatment center.

Many experts believe that 30 percent or more of New York City's homeless are already infected with HIV, which is the virus that causes AIDS. In several New York shelters the HIV incidence is thought to be 60 percent or more. Government officials say there are more than 30,000 homeless persons in New York City, though advocates for the homeless say there may be two to three times that number.

The Commission will also tour Children's Hospital in Newark and the Regional Hemophilia Treatment Center at St. Michael's Hospital in Newark.

-more-

"The tragedies of homelessness, of drug addiction, and of HIV disease are each devastating," said June E. Osborn, M.D., Chairman of the National Commission.

"When they are combined the affect is debilitating to society itself and underscores our need to deal aggressively with fundamental inequities in access to health care which have been enhanced by the pressures of the AIDS epidemic," Dr. Osborn added.

David E. Rogers, M.D., who is Vice Chairman of the National Commission and also chairman of the AIDS advisory panels to the state of New York and to New York City, said, "New York City remains the epicenter of AIDS. Nowhere are the heartrending problems created by this dreadful disease more evident.

"Many places the Commission is visiting, where they do daily battle against poverty, drug abuse and homelessness, were on mere subsistence budgets even before the HIV epidemic. Now they must try to survive while facing the enormous new burdens of HIV. The Commission wishes to witness this struggle first hand as it develops recommendations for Presidential and Congressional action," Dr. Rogers added.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the AIDS epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

SITE VISITS

NEW YORK CITY

FEBRUARY 26, 1990

7:30 a.m. Presentations

Ernest Drucker, Ph. D., Albert Einstein College of Medicine
Topic: Epidemiology of homelessness and AIDS

Kim Hopper, Ph. D., New School
Topic: Sociological impact of the AIDS epidemic and homelessness

8:45 a.m. Bellevue Men's Shelter - 400 East 30th Street

Presentation

Gail Gordon, Executive Director, Adult Services Agency, Human Resources Administration, City of New York

Tour of facilities

9:45 a.m. Bowery Resident's Committee - 191 Chrystie Street

Tour of subway station, public housing for single individuals and other facilities

11:30 a.m. Hetrick-Martin Institute - 24 Horatio Street

Meeting with service providers and runaway youth

- Hetrick-Martin, First Step Project
- Street Work, A Project of Victims Services
- Street Beat, Planned Parenthood South Bronx Project

1:00 p.m. LUNCH

Citizens Commission on AIDS - 121 Avenue of the Americas

3:00 p.m. Minority Task Force on AIDS - 92 Saint Nicholas Avenue

Presentation

Homeless women living with HIV

Meeting with Minority Community Based Organizations

Minority Task Force on AIDS
Hispanic AIDS Forum

4:30 p.m. Fort Washington Armory Shelter - 219 Fort Washington Avenue

Tour of facilities

NATIONAL COMMISSION ON AIDS

SITE VISITS

NEW JERSEY

FEBRUARY 27, 1990

8:30 a.m. Jersey City Medical Center - 50 Baldwin Avenue, Jersey City

Welcoming Remarks

Jonathan Metsch, Ph. D., Chief Executive Officer, Jersey City Medical Center

Presentations

Robert Hummel, Assistant Commissioner, Division of AIDS Prevention and Control, New Jersey Department of Health.
Topic: Overview of AIDS/HIV in New Jersey

Christine M. Grant, Deputy Commissioner of Health, New Jersey Health Department
Topic: Health Care Delivery System and Reimbursement in New Jersey

Jonathan Metsch, Ph.D. Chief Executive Officer, Jersey City Medical Center
Topic: The Jersey City Experience

Case conference/Program issues

Other providers attending

- Christ Hospital
- Jersey City AIDS Task Force
- Hudson County AIDS Consortia
- FAITH Services
- Hyacinth Foundation
- Health Care for the Homeless

11:00 a.m. Spectrum Health Care - 461 Frelinghuysen Avenue, Newark

Welcoming Remarks

Richard Russo, Assistant Commissioner of Health, Division of Narcotics and Drug Abuse Control, New Jersey Health Department

Presentation

Edward Cox, Executive Director, Spectrum Health Care
John Cox, Director, AIDS Programs

Joyce Jackson, Chief, Division of Alcoholism and Drug Abuse Control, N.J. Department of Health

Dialogue

James Cowan, M.D. Spectrum Health Care
Fr. Norman O'Connor, Straight and Narrow, Inc.
Anita Vaughn, M.D., Newark Community Health Center
Christine Grant, New Jersey Department of Health

1:00 LUNCH

Children's Hospital, Newark, New Jersey

2:00 p.m. Children's Hospital - South 9th Street, Newark

Roundtable discussion

The Commission members will be divided into four groups. The groups will discuss the following issues:

Women and AIDS

AIDS and Public Policy

Community Based Organizations in the AIDS Epidemic

New Jersey Service Delivery System for Families with AIDS

Tour of facilities

3:15 p.m. St. Michael's Hospital - 268 Martin Luther King. Blvd., Newark
Comprehensive Hemophilia Care Center

Tour of facilities

Presentations

Franklin Desposito, M.D. & Yale Arkel, M.D., Directors
Parvin Saidi, M.D., Director, Comprehensive Hemophilia Treatment Center, Robert Wood Johnson University Hospital

Meeting with patients and families

4:15 p.m. CLOSING REMARKS

Leah Zisken, M.D., Acting Health Commissioner, New Jersey Health Department

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

TESTIMONY

before the

TASK FORCE ON HUMAN RESOURCES

COMMITTEE OF THE BUDGET
U.S. HOUSE OF REPRESENTATIVES

March 6, 1990

by

JUNE E. OSBORN, M.D.
Chairman

Good afternoon, Congresswoman Boxer and members of the Committee. I am Dr. June Osborn, Dean of the School of Public Health at the University of Michigan and Chairman of the National Commission on AIDS. I want to tell you about some experiences the Commissioners have had recently that intensify our sense of urgency about meeting health care needs of people living with HIV and AIDS. All these impressions lead to the same conclusion: that over the past decade the U.S. has suffered the accelerating emergence of a **human** disaster that is unequally distributed across the country, that dwarfs in scale the physical disasters of recent times, and that begs for an urgent federal response such as that embodied in "Impact Aid".

Since the beginning of January, the Commission has visited some of the areas most severely affected by the first decade of AIDS, including southern California, New York and New Jersey. Furthermore, as chairman, I joined Mayor Agnos of San Francisco in January to help make public the product of a year's work by his AIDS Task Force -- an event I will mention at the close of my remarks.

Let me share with you some impressions of the New York-New Jersey visit of last week, since they are indelibly etched in my mind. [Parenthetically, a number of the Commissioners have told me that they, too, have found it impossible to shake the effects of what we saw when we visited there, and have barely been able to sleep since our visits with the homeless of New York.]

The anguish we witnessed -- the destitution, the unthinkable daily jeopardy of persons who lack homes and food and health care, whose families have been decimated by poverty and chemical dependency, and whose lives are now under threat from HIV and AIDS -- all those abstract components of tragedy took human shape in the narratives of personal experience, and were made all the more real to us by the poignant pleas for understanding by the homeless people we talked with. The brave advocates and outreach workers who facilitated our meetings left me in awe of the courage they display just in returning, day after day, to a battle where they have no ammunition and, indeed, no battlefield on which to stand.

Images of our visit to the Fort Washington shelter are burned as indelibly on my retinae as if I had stared into the cruel winter sun. Nine hundred thirty-three men sleep there nightly (a slightly different group each night, depending on who is lucky enough to line up in time for a cot). The very great likelihood is that a majority of those huddled there -- when we visited on the coldest night of the year -- were infected with the human immunodeficiency virus. As a physician, I found that almost beyond contemplation! That should definitely be against medical advice!!

But even in that unthinkable place, humanity shone through from what seemed the least likely of directions. A couple of destitute homeless men, showing their positive tuberculin skin tests to the Commissioners, voiced their concern that -- and I quote -- "people who are extra-susceptible to infections should never be sleeping in a place like this!"

Fort Washington was not the only horror. During our travels we heard about families not only broken but **kept** asunder by rigid visitation rules for addicted mothers -- even those under treatment. We heard from people who had at least staked out a specific shelter site, who were suddenly being shuttled from one remote cot to another, coincident with authorities learning of their HIV-positive status. Outreach workers told us of the extraordinarily brisk response of addicts to take up the hope offered by new drug treatment slots -- and of the anxiety of the conscientious health professionals at drug treatment clinics about how they would cope when the one-year-only funding wore out and freshly recruited addicts in treatment could no longer be accommodated. We heard tales of health care denied unless it required acute hospitalization, and we heard desperate pleas in New Jersey that something be done to ensure that all hospitals participate equally in provision of under-reimbursed AIDS care, rather than continue the grossly disproportionate distribution resulting from the subtle "patient dumping" now practiced.

All this would have been troubling enough; but one could not escape the nagging awareness that if we are so far behind now, what will we do as the case numbers double within the next two years? and how can we be urging that people come forward for HIV testing using the lure of early interventive evaluation and treatment, when health systems are collapsing with one-tenth their number and when discrimination seems a far more likely result than compassionate care? The mere word "disaster" is not strong enough to describe what we have seen, for in a very real sense, the "human" has been leached from "human services" in a way that should shame us all!

I am a member, also, of the Global Commission on AIDS of the World Health Organization, and in November we met in central Africa, undertaking similar visits in an effort to appreciate the impact of the HIV epidemic there. I came back much shaken, for in Kinshasa I had seen hospitals where the beds were lined up 30 in a row with only enough space between them for family to stand and tend to their loved ones themselves since there were no nurses; and half those beds were filled with people with AIDS. There was no pharmacy, no food service, no laundry; and the doctors had not been paid for several weeks -- but at least there were families, and they were doing their best. I thought, after that, that I had seen it all, but after last week I realized that even central Africa paled in comparison to some of what is happening in the shadow of the Statue of Liberty! We are seeing drugs and poverty and hopelessness -- and now HIV and AIDS -- threaten to complete the investiture of an "underclass" in our once-proudly classless land of opportunity.

By inattention we have let our cities slide into a silent social disaster. There are more homeless in New York in 1990 than there were at the depths of the Great Depression, and now their ranks are being swollen further by AIDS. The despairing people in New York, in Jersey City and Los Angeles, in Newark and San Diego must find it harsh and bitter to hear about the wonderful biomedical research progress against HIV, about increasingly effective treatment for AIDS, and about the promise of early intervention -- when they cannot even get access to **primary** care! Even the emergency rooms on which they depend in times of crisis are closing their doors, as public hospitals teeter on the brink of collapse. It is indeed a disaster! There were no carefully engineered steel rods in the health care edifice that was so casually erected over the past several decades, and the crumbling has begun in earnest!

It is often said these days that AIDS is "just one disease" -- that we have focussed enough resources on it and should now move on to other diseases and issues. I could not disagree more strongly! In a very important sense, AIDS is a metaphor -- the only really new things about the HIV epidemic are the virus itself and the pressure of burgeoning numbers of young adults needing sustained care. All the rest of the problems we face are old ones that we have ignored or patched or minimized beyond all common sense.

There is a ghastly public complacency in this country right now about the AIDS epidemic, stemming (I fear) from the sense that it is happening to "others." Soon we will get over that, for we will all know someone caught in the sad web of blighted lives and premature death. We might have the help of that universal awareness even now, were not so many people grieving **in secret** for fear of discrimination or perceived disgrace. We have had over 120,000 cumulative cases of AIDS in America, and over 70,000 have died. Those awful numbers will double and double again during this decade, even if we could stop further virus spread tomorrow! We must recognize this for the disaster it is and respond humanely. And we must, at the same time that we take urgent action, proceed to make amends for the heartless omissions of past decades and plan carefully for the compassionate care of all our citizens. If we do so thoughtfully, our efforts will have benefits far beyond the range of the HIV epidemic.

I mentioned at the beginning that I had been to San Francisco in January, and it was a gleam of light in this dark time. There is no question **there** about whether AIDS is a disaster. And the Task Force report I helped to "launch" gave inspiring testimony to what a community can do when it pulls together to face the problems squarely, uniting business and health care and religion and minority and community activist groups with government in a common and coordinated response. There is no doubt that the San Francisco plan will be demanding -- in fact, I strongly suspect that emergency federal relief through Impact Aid may constitute the marginal difference between success and failure. But the example of a united front against this awful disease reminds me again of the power of family -- of just how powerful we can be in the face of disaster when we remember that we are all one **human** family!

Note: The text of a full address delivered on December 1, 1990 to the Harvard AIDS Institute by Dr. Osborn at their World AIDS Day observance was introduced by Congressman Louis Stokes into the Congressional Record of January 31, 1990 (see pages E141-144).

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

FOR IMMEDIATE RELEASE
March 6, 1990

Contact: Thomas Brandt
(202) 254-5125

STATEMENT ON THE "CARE" ACT OF 1990

The National Commission on AIDS endorses the principles and objectives of the Comprehensive AIDS Resources Emergency (CARE) Act of 1990. This legislation is responsive to many of the recommendations in the report issued by the National Commission on AIDS in December, 1989, as well as to recommendations of the Presidential Commission Report on the HIV Epidemic of June, 1988.

There must be frank recognition that a health care crisis exists in many of our cities that will require extraordinary measures to overcome. The HIV epidemic of the 1990's will be far worse than what we have seen thus far. Our nation simply must be prepared to invest adequate resources now or pay dearly later.

The CARE Act of 1990 will provide emergency funds to those areas hardest hit by the epidemic. It will provide critical support for services in hospitals, clinics, other health facilities, and in the home. The CARE Act will prompt the development of more effective systems for the delivery of health and support services, including early intervention. It will develop and fund mechanisms to assure continuity of health insurance coverage for people with HIV disease and will also create community-based consortia capable of delivering a comprehensive continuum of care.

The Commission's recent hearings and site visits in the Los Angeles, New York City, and northern New Jersey areas impressed upon us the serious need for increased coordination between the various levels of government. Managing the HIV epidemic is a responsibility that must be shared by all. This legislation would stimulate further planning and coordination between all levels of government and the private sector.

The health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, it's epidemic nature has accelerated the urgent need for responsible national action to correct the system's serious shortfalls.

The Commission is extremely pleased that a strong bipartisan commitment has been made to enact this bill and looks forward to the passage and funding of comprehensive AIDS care legislation by the 101st Congress.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN
June E. Osborn, M.D.

MEMBERS
Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR
Maureen Byrnes

March 9, 1990

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

Dear President Bush:

We are writing to summarize some of the recent events concerning international travel restrictions and HIV infection, in hope that you may be able to accelerate a resolution of problems of intense concern to scientists and to travelers.

As you may know, the constraint on visa applicants and international travelers arose through a Congressional amendment to the Supplemental Appropriations Act of 1987, which directed the President to add HIV infection to the list of "dangerous contagious diseases" that included a number of other infections. Many experts in the U.S. Public Health Service and in the scientific and infectious disease communities felt that the list, as then constituted, was out of date and failed to take into account recent advances in our understanding of the limited transmissibility of most of the diseases listed. We are delighted by the recent thorough review conducted by the Public Health Service which concluded that, in this day and age, only active tuberculosis should be on such a list, and that there was no modern justification for continuing to list the others, including HIV infection.

Legislation is currently being introduced to assert that the authority for such a conclusion properly lies with the Public Health Service; however, that will clearly take some time to make its way through Congress. In the meanwhile, as you know, there is increasingly intense international unrest about the present travel policies which are considered to be onerous and discriminatory, even as amended. The important scientific and service contributions of the Sixth International Conference on AIDS and the XIX International Congress of the World Federation of Hemophilia are in jeopardy. The sentiment of the international community is clearly articulated in a motion passed by the European Parliament calling for the relocation of the Sixth International Conference on AIDS -- currently scheduled for San Francisco, June 20-24, 1990 -- "to a country that does not practice discrimination."

We respectively suggest, since all the background work has been conducted diligently by the health component of the Executive Branch and since the remaining difficulties relate to domestic issues of clarification of jurisdiction, that you could make a major contribution to early resolution of this sensitive problem by calling for a blanket waiver of HIV infection restrictions in all visa considerations.

Many international groups have deferred definitive boycott as long as possible, but we fear that deadlines are fast approaching. Therefore, we respectfully suggest that time is of the essence. We would be glad to provide further documentation, and of course we would be pleased to discuss these matters with you if you so desired.

Sincerely,

David E. Rogers

David E. Rogers, M.D.
Vice Chairman

June E. Osborn

June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
March 9, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION REVIEWS THE 'DRUG WAR' AND THE PEPPER COMMISSION REPORT FOR HIV IMPACT

The National Commission on AIDS will hold hearings March 15 and 16 to review the HIV elements of the National Drug Control Strategy and to examine the issues in the Pepper Commission report concerning care for those with HIV disease.

Dr. Herbert D. Kleber, a deputy director of the White House Office of National Drug Control Strategy, will discuss the President's drug control plan with the Commission, while the Pepper Commission will be represented by a member, U.S. Representative Henry Waxman, and Judith Feder, the executive director.

June E. Osborn, M.D., Chairman of the National Commission on AIDS, said, "Experience has been a harsh teacher regarding the intimate connection between drug use and the HIV/AIDS epidemic. In New York and New Jersey, Edinburgh and most recently in Thailand, we have seen awesome demonstrations of the flashfire potential for HIV spread associated with illicit drug use. The Commission is concerned that present Administration plans for drug control strategy appear to minimize the critical issue of availability of drug treatment for addicted persons who see the dangers and want out."

-more-

On March 3 the Pepper Commission released recommendations on providing health care coverage to 31 million uninsured Americans and long term care to the disabled.

David E. Rogers, M.D., Vice Chairman of the National Commission on AIDS, said, "A rapidly growing problem of the HIV epidemic is the lack of funds to care for those who are ill or dying with AIDS, and the problem is intensified as the epidemic grows worse among the poor and homeless who often have no health insurance, and little contact with providers of medical care. It is our hope that many of the solutions suggested by the Pepper Commission will be helpful in dealing with the AIDS crisis."

At the two-day hearing there will also be discussions of issues currently under review by working groups of the AIDS Commission dealing with intergovernmental responsibilities and social and human issues, along with other Commission business.

The sessions will be held in meeting room B of the Pan American Health Organization Building, 525 23rd St., NW, Washington, D.C. (Foggy Bottom is the closest Metro stop). An agenda for the two day meeting is attached.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

MARCH 15-16, 1990

Pan American Health Organization
525 23rd Street, N.W.
Meeting Room B
Washington, D.C.

Thursday, March 15, 1990

8:30 a.m. REPORT OF THE PEPPER COMMISSION
U.S. Bipartisan Commission on Comprehensive Health Care Recommendations To The Congress

Honorable Henry A. Waxman
U.S. Representative

Judith Feder
Executive Director, The Pepper Commission

9:00 a.m. DRUG USE AND THE HIV EPIDEMIC

Herbert D. Kleber, M.D.
Deputy Director for Demand Reduction
Office of National Drug Control Policy

Representative
Alcohol, Drug Abuse, and Mental Health Administration

Representative
National Institute on Drug Abuse

Don C. Des Jarlais, Ph.D.
National Commission on AIDS

12:00 p.m. LUNCH

1:00 p.m. PEPPER COMMISSION REPORT - Further Discussion

2:00 p.m. HOUSING AND THE HIV EPIDEMIC

3:00 p.m.	BREAK
3:15 p.m.	COMMISSION BUSINESS WORKING GROUP REPORTS 1. Social/Human Issues 2. Federal, State, and Local Responsibilities
4:30 p.m.	ADJOURN

Friday, March 16, 1990

9:00 a.m.	COMMISSION BUSINESS Chairman's Overview
9:30 a.m.	Commission Initiatives and Legislative Update
10:15 a.m.	BREAK
11:30 a.m.	General Discussion
12:30 p.m.	LUNCH
1:30 p.m.	General Discussion
3:00 p.m.	ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN
June E. Osborn, M.D.

MEMBERS
Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR
Maureen Byrnes

FOR IMMEDIATE RELEASE
March 15, 1990

Contact: Thomas Brandt
202/254-5125

STATEMENT BY NATIONAL COMMISSION ON AIDS THAT EPIDEMIC MAY HAVE PEAKED IN 1988

There is an ongoing debate among epidemiologists as to whether or when the HIV epidemic may "peak." We do not wish to enter that debate. What we wish to emphasize is the universal agreement on an absolutely key point: that the load of new cases of AIDS and the human suffering in the 1990s will far surpass the 1980s. It is estimated that there are roughly one million people in the United States who are infected with HIV. To date only a little more than 10 percent of them have developed full blown AIDS, but there is every indication that many more will do so. Indeed, in many parts of the country the AIDS epidemic is only getting started.

The National Commission on AIDS feels we simply must move much more aggressively than we did in the 1980s to provide care and treatment for those who will inevitably become sick, to continue an intensive effort to find a cure, a vaccine, and to promote preventive education to stop the spread of infection to new individuals. Clearly we will continue to have morally and economically unacceptable numbers of people falling ill with AIDS during the decade to come.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN

June E. Osborn, M.D.

MEMBERS

Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR

Maureen Byrnes

WORKING GROUP SUMMARY REPORT

on

Federal, State, and Local Responsibilities

January 4-5, 1990
St. Paul, Minnesota

March 15, 1990

INTRODUCTION

The lack of clear definition of government roles and intergovernmental partnerships in responding to the Human Immunodeficiency Virus (HIV) epidemic has seriously hampered efforts to end discrimination, to finance health care, to organize and deliver health and social services, to recruit and train health care workers, to provide housing for the sick, to provide effective AIDS education and prevention programs, and to provide substance abuse treatment and prevention programs. This is one of the major findings of the Working Group of the National Commission on AIDS looking at the roles and responsibilities of different levels of government in responding to the HIV epidemic. Given the testimony received from representatives of all levels of government, the Working Group strongly recommends that the federal government adopt a greater leadership role in helping to delineate government responsibilities and to create effective partnerships between the various levels of government as well as with the private sector.

The Working Group was told "The responsibility for addressing AIDS-related issues and services and care that are provided for us [persons with HIV] is, for the most part, haphazard, inconsistent, isolated and not integrated." We were also told "Governments must assume leadership in this crisis" and "Leaders often must take unpopular stances and try that which has not been tried." And, we were reminded that Thomas Jefferson once said, "The care of human life and happiness is the first and only legitimate object of good government."

With this report to the Full Commission, we hope to highlight the different roles of government, the problems confronting all levels of government in responding to the HIV epidemic, and recommendations for how we might better respond to the epidemic and forge the partnerships so desperately needed in this country.

This report by no means contains all the answers or even covers all the issues. What it does is take the first step toward answering the question "Who is responsible for action?" Although we do not have all the answers, we are confident that the most effective response to the HIV epidemic will be one that reflects a partnership between all levels of government and the private sector; and the driving force, the leadership needed to establish these partnerships, we believe, should come from the federal government.

BACKGROUND

The National Commission on AIDS held a working group meeting on federal, state, and local responsibilities in St. Paul, Minnesota on January 4-5, 1990.

The first day of the meeting was devoted to formal testimony. At the morning session, oral and written testimony was presented by representatives from the U.S. Department of Health and Human Services; the National Governors' Association; the National Conference of State Legislatures; the National Association of Counties; the National League of Cities; and the U.S. Conference of Mayors.

At the afternoon session, elected and appointed officials of municipal, county, and state government presented testimony, as well as representatives of national AIDS service organizations. Public officials represented Philadelphia; Dallas; San Francisco; Wake County (Raleigh), North Carolina; New York State; and the State of Minnesota. Testimony was heard from representatives of the National Association of People with AIDS and the National AIDS Network.

The second day of the meeting was a roundtable discussion of policy, program and service areas for government related to the HIV epidemic, and specific roles and responsibilities of federal, state, and local governments. Participants in the roundtable discussion included federal, state, and local officials, as well as national AIDS service organization representatives, who had testified earlier, three members of the National Commission on AIDS, staff to the Commission, and a group facilitator. A copy of the agenda and the presenters for the two-day meeting is attached to this summary report.

Diane Ahrens, a member of the National Commission on AIDS and also Commissioner of Ramsey County (St. Paul), Minnesota, chaired the two-day meeting. Commissioner Ahrens is Chair of the National Association of Counties' Task Force on HIV Infection and AIDS. Other members of the National Commission on AIDS participating in the working meeting included Larry Kessler, Executive Director of the AIDS Action Committee in Boston and Dr. Charles Konigsberg, Director of the Kansas Division on Health, Kansas Department of Health and Environment.

OVERVIEW

Three goals were set for the working group meeting:

1. to establish policy, program, and service areas related to the HIV epidemic for different levels of government (federal, state, county, and municipal) to answer the question, "Who is doing what?"

2. to delineate major problem areas related to government roles and responsibilities in responding to the HIV epidemic to answer the question, "What isn't working?"

3. to hear the views of municipal, county, state, and federal officials, as well as the views of a national AIDS service organization, about appropriate roles and responsibilities for different levels of government in specific areas to answer the question, "What would work better?"

The two major themes to emerge from the testimony and discussion about government roles and responsibilities in responding to the HIV epidemic were leadership and partnership.

Leadership at all levels of government was defined as "taking hold of an issue, providing an idea of the extent of a problem and the ramifications of action and inaction, inspiring people and calling forth the best from them to deal with the problem, mobilizing their compassion and talents."

Local

Examples of leadership at the community level included: city council members' involvement in Philadelphia in calling for the first public hearings on the impact of the HIV epidemic on the city's residents; a city sponsored AIDS awareness program in Dallas; and in Minneapolis "putting early money" into the first AIDS education efforts of the Minnesota AIDS Project. The U.S. Conference of Mayors, which has monitored activities of communities since 1984 in planning and coordinating local responses to AIDS and developing AIDS policies, pointed to San Francisco's Mayor's HIV Task Force, Seattle-King County's five-year HIV plan, and Austin-Travis County (Texas) HIV Commission as examples of leadership and partnership involving cities, counties, and private sector groups.

The U.S. Conference of Mayors described a leadership role for cities in the following areas: (1) assessing the incidence of HIV infection and affected populations and the need for prevention, treatment, and support services; (2) planning, program development, and coordination; (3) establishing policies; (4) assuring or providing services within the resource capabilities of cities (e.g., early intervention services, health care and supportive services, substance abuse services); (5) providing and encouraging education and prevention services (e.g., city employees, elementary and secondary schools, local employers); (6) financing services; (7) passing anti-discrimination ordinances in employment, housing, and public accommodations; (8) advocacy for state and federal resources to address the disproportionate need in cities; and (9) advocacy for support and funding for research, which is essential in combating the HIV epidemic.

At the county level, the National Association of Counties' Task Force on HIV Infection and AIDS has both provided leadership and encouraged county officials to provide leadership through its Task Force Report, *County Government and HIV Infection*, through peer-education, technical assistance efforts, and developing community based, participatory strategic plans at the county level.

The Task Force report also defines four broad policy goals for counties and lays out roles for counties in planning, education (e.g., employees, schools, emergency services workers, hospital personnel, and correctional facility staff), health care services, human rights financing, and county advocacy of appropriate federal and state roles.

State

Leadership at the state level, in the view of the National Governors' Association, can be exercised in a number of ways including: (1) establishing priorities and allocating resources for AIDS within the context of competing demands on the state's domestic policy agenda; (2) defining the state's mission and objectives in managing the AIDS epidemic; (3) enunciating a policy of caring for those with HIV disease; (4) mobilizing the citizenry and the private sector to address the AIDS crisis; (5) assigning responsibility for the state response to AIDS to a lead agency; (6) ensuring that consistent and coherent policies are developed and coordinated across state agencies having administrative purview over programs relating to AIDS (e.g., public health, education, medical treatment, and insurance regulation); (7) planning for the future and being aware of emerging issues and trends by ensuring that accurate and timely data are collected to provide a sound basis for public policy; and (8) establishing policies related to state employees and institutions that will set a standard for other employers in the state. The National Governors' Association has recently issued *A Governor's Policy Guide on AIDS*.

States' key roles in public health, the organization, delivery, and financing of health care, and in other program and service areas shape their roles in response to the HIV epidemic. States play a critical role in several areas: (1) establishing policies related to Medicaid eligibility, scope of benefits, and provider reimbursement, and paying the state share of Medicaid; (2) regulating the activities of insurers and health maintenance organizations; (3) developing strategies to provide care for the medically indigent, or the uninsured; (4) administering public health programs; (5) administering social services programs; (6) administering substance abuse and mental health programs; (7) administering in some states a public hospital system; (8) licensing health care facilities and other residential facilities; and (9) licensing health care providers.

Federal

Despite a lack of overall leadership at the federal level, certain examples of federal leadership include the early and pivotal role of the Centers for Disease Control in epidemiologic studies to determine the modes of transmission of HIV infection and populations at risk of infection. Another example of federal leadership is the primary role of the National Institutes of Health in supporting intramural and extramural biomedical and clinical research leading to the discovery of the causative agent in HIV disease, the development of the HIV antibody test, and the development of drugs, such as AZT and aerosolized pentamidine. The federal government also has played a leadership role in the development of guidelines for infection control and risk reduction, in protecting the blood and tissue supply, and in regulating the testing, licensure, and production of drugs, vaccines, diagnostic reagents, and medical devices.

Partnership was another major theme emerging during the working group meeting. Clarity and agreement on the roles and responsibilities of different levels of government in responding to the HIV epidemic allow partnerships to be formed. Confusion and disagreement about these roles and responsibilities, on the other hand, lead to what was described as "haphazard, inconsistent, isolated" efforts. Implicit in the concept of a collaborative partnership among federal, state and local government is the obligation of each to participate in the partnership. The effectiveness of the partnership is enhanced by the material contribution of all members. Equally important is the essential role of the private sector, especially foundations and community based organization in these partnerships.

It was also noted that here is no driving force forging these partnerships. Where there are functional partnerships among different levels of government, they were viewed as reinforcing, supportive, and enhancing, and leading to coordinated and integrated approaches to the development of policies, programs, and services.

Ineffective partnerships were viewed as adversarial, competitive, duplicative, and depleting, and leading to uncoordinated and fragmentary approaches.

In an effort to delineate government roles and responsibilities the Working Group participants identified the following policy, program, and service areas:

1. Anti-discrimination/civil rights
    - education
    - employment
    - housing
    - public accommodations
    - health and life insurance

2. Health care financing, public and private
    - Medicaid & Medicare
    - private insurance
    - uninsured

3. Health care and social service organization and delivery

4. Recruitment, retention, and training of human services personnel

5. Housing

6. Prevention, education, and information

7. Substance abuse prevention and treatment

8. Research
    - biomedical
    - clinical
    - epidemiologic
    - behavioral and other social sciences
    - health services research

9. Epidemiologic surveillance

10. Drug and medical device regulation

11. Blood and tissue supply protection

The Working Group also identified the following roles and functions of government:

1. Assessment

2. Policy setting

3. Planning

4. Program development

5. Program administration

6. Organization of services

7. Delivery of services

8. Regulation

9. Monitoring and evaluation

10. Technical assistance and capacity building

11. Financing

These roles and functions served as a guide to the Working Group in considering traditional responsibilities of government in policy program and service areas related to the epidemic.

Areas of research, epidemiologic surveillance, drug and medical device regulation and blood and tissue supply protection were set aside for purposes of the meeting, as government roles in these areas are more clearly defined. Roles and responsibilities of federal, state, and local levels of government were often unclear or confusing in the remaining areas. The Working Group attempted to define the different roles of government in these areas. While it did not define the specific roles of federal, state, and local governments for all of the issues, the Working Group did agree on recommendations to be submitted for consideration by the Full Commission.

RECOMMENDATIONS

1. Efforts in the public sector at all levels of government should be guided by broad policy goals.

The Working Group suggested that the policy goals identified by the National Association of Counties Task Force on HIV Infection and AIDS could serve as a model for all levels of government. These goals are:

1. to end the HIV epidemic through prevention, education and research;
2. to assure access to treatment, care and support services for all persons with HIV infection;
3. to protect the civil rights of all citizens; and
4. to assure adequate funding for a continuum of HIV prevention, treatment, care and support services and HIV research through effective public sector-federal, state, and local government and private sector leadership and partnership.

2. Federal, state and local governments should develop comprehensive plans for implementing identified goals. These plans should be developed in response to the policy recommendations of the National Commission on AIDS with interagency government representation and private sector involvement, including community-based organizations and persons with HIV disease.

The Working Group strongly recommended that the federal government should immediately develop a forceful comprehensive national HIV plan addressing prevention, education, treatment, care, support services, civil rights, research, and funding for these activities. The President should designate a cabinet level task force to develop such a plan.

While the National Commission on AIDS fully intends to recommend policy goals for a national plan, the Commission believes it is essential that a mechanism be in place to coordinate government-wide implementation of such a plan. In this way, those who are ultimately responsible for the implementation will have had an active role in its development, thus enhancing the likelihood of implementation. The task force should include each department in the federal government.

3. The U.S. House of Representatives should, like the United States Senate, pass the Americans with Disabilities Act and state and local governments should pass laws forbidding discrimination in areas not covered by the Americans with Disabilities Act or other federal statutes.

4. Immediate action is necessary at the federal level to assist states, counties, and cities disproportionately impacted by the HIV epidemic. "Impact Aid" - disaster relief or direct emergency relief - is needed to assist states and localities in developing a continuum of HIV prevention, treatment, care, and support services.

5. The issues of Health Care Financing and Health Care and Social Service Organization and Delivery require a level of expertise and commitment of time that was not provided for

in this working group session. The Working Group believes these issues would be best addressed by the Full Commission.

6. Incentives at the federal, state and local level need to be created to recruit, retain and train human services personnel. The Working Group recommends that the federal government should support a National Health Service Corps approach to involving more primary care providers in the care of persons with HIV. Medicaid reimbursement rates for outpatient care should be augmented and all universities (public and private) should include HIV education in health professional education and training.

7. Federal, state and local government should have in place policies to encourage the development of housing programs that meet emergency, short-term and long-term needs of persons with HIV. Congress should support legislation to establish housing programs that provide short-term and long-term housing with necessary support services. State legislation should encourage flexibility in developing alternative housing and residential settings. Localities need to address the "not-in-my-backyard" syndrome related to shelters and residencies, and work closely with neighborhood groups.

8. Federal, state and local governments and community-based agencies need to develop more effective partnerships in HIV prevention, education and information. The Working Group believes that federal restrictions on the use of education and prevention funds is counterproductive and prolongs the HIV epidemic. Restrictive legislative language appears to hinder states and localities and community-based agencies in providing the prevention message in ways that would reduce individual risk and limit the spread of HIV infection. Therefore, while state and localities should be accountable for the federal funds they receive, the use of these dollars for education and prevention programs should be flexible. Evaluation of these programs to determine what approaches work best is essential and these programs should be innovative, creative, and culturally respectful. Finally, since community-based organizations are at the heart of HIV education efforts, these agencies should be supported by all levels of government, including the provision of support for education and training of agency staff and organizational development assistance.

9. The Working Group identified substance abuse prevention and treatment as a priority area but time did not permit specific recommendations to be made. The Working Group recommends that the Full Commission address this issue.

In conclusion, the working group meeting on federal, state, and local responsibilities of the National Commission on AIDS found significant problems in government response to the HIV epidemic and has proposed initial recommendations to address some of these problems.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
April 3, 1990

Contact: Thomas Brandt
202-254-5126

COMMISSION REVIEWS "RURALIZATION" OF HIV EPIDEMIC

The National Commission on AIDS will make site visits to Waycross, Albany and Macon, Georgia on April 16 and 17 to study the upsurge of the HIV epidemic in towns and rural communities.

The rate of increase of new cases of HIV (human immunodeficiency virus) in major metropolitan areas such as New York and Los Angeles is now being matched by many small towns and rural communities in what the Centers for Disease Control calls the "ruralization of AIDS."

Dr. June Osborn, Chairman of the National Commission, said, "The rapid increase in HIV infection in the rural heart of America is an unwelcome fact of life, and the drug associated virus spread in that context comes as a surprise to many people. We need to understand these dynamics if we are ever to put a stop to the further expansion of HIV infection and AIDS."

Congressman J. Roy Rowland, a Georgia physician who is a member of the National Commission on AIDS, said, "Most of our national planning for AIDS has focused on the media intensive major cities. Yet the virus is infiltrating even our small towns and farm communities, often linked to

-more-

substance abuse and heterosexual transmission, where HIV prevention programs and health care are often scarce or non-existent."

The patterns of HIV transmission in rural areas were discussed in a recent report by the Georgia Department of Human Resources that said "crack use is as prevalent in rural Georgia as it is in the major metropolitan areas," and that "syphilis cases, once largely confined to the state's seven major urban areas, have shifted significantly to rural areas."

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

A copy of the Commission agenda is attached.

# # # #

NATIONAL COMMISSION ON AIDS

SITE VISITS

GEORGIA

APRIL 15 - 17, 1990

<u>Sunday, April 15, 1990</u>

Arrive Atlanta Hartsfield International Airport

Check in

Stouffer Waverly Hotel
2450 Galleria Parkway
Atlanta, Georgia

<u>Monday, April 16, 1990</u>

7:15 a.m. Meet in Main Lobby of Stouffer Waverly Hotel

7:30 a.m. Depart Stouffer Waverly Hotel for Dobbins Airforce Base

8:00 a.m. Depart Dobbins Airforce Base

<u>Waycross</u>

9:00 a.m. Arrive Brunswick, Georgia
Depart for Waycross, Georgia

Briefing

Dr. Ted Holloway
District Health Director
Southeast Health Unit
Georgia Department of Human Resources

10:00 a.m. Community Site Visits

12:00 p.m.	Lunch Community and Civic Leaders St. Joseph's Catholic Church 2011 Darling Avenue Waycross, Georgia
1:15 p.m.	Depart for Airport Brunswick, Georgia
2:30 p.m.	Depart for Albany
	Albany
3:30 p.m.	Site Visit Phoebe Putney Memorial Hospital 417 Third Avenue Albany, Georgia
5:30 p.m.	Depart for Airport Albany, Georgia
	Macon
7:30 p.m.	Reception and Dinner Hosted by Georgia Department of Human Services Holiday Inn Arkwright Road at Riverside Drive Macon, Georgia

Tuesday, April 17, 1990

8:00 a.m.	Meet in Main Lobby of Holiday Inn Depart for Downtown Macon
8:30 a.m.	Site Visit Bibb County Department of Health HIV Ambulatory Clinic 770 Hemlock Street Macon, Georgia
12:00 p.m.	Lunch
2:00 p.m.	Depart Holiday Inn for Atlanta Airport

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
April 24, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION RELEASES SECOND REPORT TO PRESIDENT BUSH

In its second Report to President Bush, the National Commission on AIDS today made five major recommendations for swift action, including creation of a "federal interagency mechanism" to coordinate a national plan for the human immunodeficiency virus (HIV) epidemic.

The Commission also called for support of "disaster relief" legislation for cities and states heavily impacted by the HIV epidemic; federal housing aid to address the multiple problems faced by persons with HIV infection and AIDS, including many homeless people; support of anti-discrimination legislation; lifting of federal constraints that impede HIV education and prevention programs.

Dr. June E. Osborn, chairman of the Commission, said, "Throughout the nine long years of the epidemic many people in various roles in the Federal government have worked desperately to keep pace with the expanding demands of the epidemic as it pervades society.

"But a much more flexible and responsive mechanism is needed to coordinate the many components of governmental action. The President can be most helpful in creating such a coordinating body to provide focus at the top," she added.

-more-

In commenting on the proposal for a new federal interagency mechanism, Dr. David E. Rogers, Vice Chairman of the Commission, said, "What mechanism would best serve the national needs, be it a Cabinet Officers' Task Force or a coordinating council, is obviously for the President to determine.

"What is all too evident to the Commission is a critical lack of any top level federal group - clearly accountable and capable of swift, authoritative action - to coordinate efforts among HHS, HUD, Social Security, the VA and other government and private entities to deal with the AIDS crisis," he added.

The report is the second sent to the President and Congress by the Commission which took office last August 3. Congress created the Commission as an independent body to advise the Executive and Legislative branches of government on development of "a national consensus on policy" concerning the HIV epidemic.

The first report on December 5, 1989 cited a national health care system that was "singularly unresponsive to the needs of HIV-infected people" and called for a major federal effort to "begin solving the problems of health care delivery."

Today's report goes beyond those issues to say that failures in health care and many other HIV epidemic related matters can only be corrected with federal leadership and a "clear definition of government roles at all levels...." The report's summary said that such lack of definition "has hampered our national ability to organize health care services, to recruit and train human services personnel, to provide housing for the sick, to provide effective AIDS education and prevention programs, to provide coordinated, comprehensive substance abuse treatment and prevention and to develop sufficient monies to finance all of these efforts."

-more-

The Commission's four other recommendations to the President and Congress are:

- "Disaster relief" funds for those cities and states that are the most heavily impacted by the HIV epidemic.
- Federal housing aid to address the multiple problems posed by HIV infection and AIDS.
- Passage of the Americans with Disabilities Act (ADA) to provide protection against discrimination for those with HIV infection and AIDS. State and local governments should also pass laws forbidding discrimination in areas not covered by the ADA or other federal statutes.
- Lifting of federal restrictions that are impeding the effective use of funds for HIV prevention and education programs.

Since August, 1989 the Commission has held nine days of hearings in Washington and Los Angeles plus four additional days of working group meetings in Boston and St. Paul. The Commission has also made site visits to Los Angeles, Newark, Jersey City, New York City and rural areas of Georgia where it has focused on a number of issues including the impact of the HIV epidemic on the homeless, substance users, women, children, Hispanics, Afro-Americans and other minorities.

The report also congratulated President Bush for his "important and historic" speech on the HIV epidemic on March 29.

"His call for more preventive education, vaccines and new therapies to improve the care for the increasing number of Americans who will fall ill with this disease moves this

- more -

nation in the proper direction. Now the President's commitment needs translation into action," the Commission report said.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House and two appointed by President Bush. The three non-voting members are the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN
June E. Osborn, M.D.

MEMBERS
Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR
Maureen Byrnes

April 24, 1990

President George Bush
The White House
Washington D.C. 20500

Dear President Bush:

We much appreciated your meeting with us on March 29 and your historic speech that same day.

In our continuing effort to bring important and urgent matters to your attention, and to the attention of Congress, enclosed is a second report on the HIV epidemic from the National Commission on Acquired Immune Deficiency Syndrome (AIDS). Again, it contains a short series of recommendations for swift action.

Sincerely,

David E. Rogers   June E. Osborn

David E. Rogers, M.D.
Vice Chairman

June E. Osborn, M.D.
Chairman

cc: The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of Representatives

The Honorable Robert H. Michel
Minority Leader of the House of Representatives

National Commission
on
Acquired Immune Deficiency Syndrome

Report Number Two

INTRODUCTION

On December 5, 1989, the National Commission on AIDS wrote to President Bush indicating that "significant changes must be made not only in our health care system but in how we think about the system and the people it is designed to serve." It was also the Commission's belief that a clear statement from the President indicating that in this crisis, care must be dispensed equitably, non-judgmentally, and without discrimination to all who had AIDS and HIV infection would do much to improve the climate and permit swifter progress in combatting this tragic epidemic.

On March 29, 1990, in a speech to a national meeting of business leaders the President responded to the Commission's call. In it he said:

> "And for those who are living with HIV and AIDS, our response is clear: They deserve our compassion. They deserve our care. And they deserve more than a chance--they deserve a cure.... In this Nation, in this decade, there is only one way to deal with an individual who is sick. With dignity, compassion, care, confidentiality, and without discrimination."

In addition to establishing a national standard for caring for people living with HIV infection and AIDS, the President outlined the challenges confronting all of us in the HIV epidemic.

> "It is our duty to make certain that every American has the essential information needed to prevent the spread of HIV and AIDS. Because while the ignorant may discriminate against AIDS, AIDS won't discriminate among the ignorant."
>
> "Once disease strikes--we don't blame those who are suffering. We don't spurn the accident victim who didn't wear a seatbelt. We don't reject the cancer patient who didn't quit smoking. We try to love them and care for them and comfort them. We do not fire them, or evict them, or cancel their insurance."

We congratulate the President on his important and historic statement. It sets the stage for expansion of efforts of critical importance if we are to genuinely contain the spread of the HIV epidemic. His call for more preventive education, vaccines and new therapies to improve the care for the increasing number of Americans who will fall ill with this disease moves this nation in the proper direction. Now the President's commitment needs translation into action.

Since 1981, more than 75,000 people have died of AIDS and the 1990's will be much worse than the 1980's. This second report from the National Commission on AIDS to the President and the Congress highlights another set of critical issues and focuses on the particular needs of communities most heavily impacted by the epidemic. It contains an additional five recommendations for swift action.

OVERVIEW

> "Much in AIDS care is happening all over this nation. But like an orchestra without a conductor, we are all playing our own tune. Sometimes we harmonize, sometimes we don't.... It's pretty tough without a conductor."

The above quote is from National Commission Member Diane Ahrens summarizing the testimony the Commission received at a Working Group Meeting in St. Paul, Minnesota. The call for leadership in response to the Human Immunodeficiency Virus (HIV) epidemic was heard repeatedly during the Commission's hearing in Southern California and again during our visit to New York City's homeless shelters and New Jersey's hospital and drug treatment programs.

We were told, "Governments must assume leadership in this crisis," and, "Leaders often must take unpopular stances and try that which has not been tried." And, we were reminded that Thomas Jefferson once said, "The care of human life and happiness is the first and only legitimate object of good government." The President's speech was an important initial step in this direction.

COMMISSION FINDINGS

Nowhere was it more evident that the care of human life must be a priority for our government than in the streets of New York City. Here the estimates of the numbers of homeless vary from 20,000 to as many as 70,000. It is further estimated that 20 to 30 percent of the overall number of homeless individuals are HIV positive. Perhaps 10,000 have AIDS or HIV-related illness. They live in places that are beyond belief in their horror. We heard that the number of homeless in New York City now exceeds the number seen at the height of the great depression. "The new Calcutta" is a term now often applied to this, our premier city.

On February 26th, the Commission visited a variety of homeless "shelters"-- ranging from subway tunnels to flophouses to an aging armory. At the armory, which can really best be described as a human warehouse, we stood on a balcony and saw stretched out below us nearly 900 tightly packed cots in a gloomy, cavernous old building. Each night the cots are filled with homeless men. The very great likelihood is that many of those huddled there (we visited on the coldest night of the year) were infected with HIV. While we were there two homeless men, showing their positive tuberculin skin tests to us, voiced their concern that--"people who are extra-susceptible to infections should never be sleeping in a place like this!"

Fort Washington Armory was not the only human catastrophe we witnessed. During our travels we heard about families not only broken but kept asunder by rigid visitation rules for addicted mothers--even those under treatment. We met women with HIV infection who sleep in shelters during the night and struggle to maintain their health (and their children) on the streets and in the shelters during the days. We heard about a supportive housing program that funds only 140 units when at least 2,400 could be filled immediately. We talked to teenagers who trade sex for drugs and money, putting themselves at risk for HIV infection everyday. Now referred to as "throwaway kids," these teenagers seek shelter not only from the cold but from the Hudson River piers and neighborhood streets where adults visiting from out of town, out of state, and, in some cases, out of the country, seek sex for $15 without a condom and $10 with one.

We met with outreach workers who go down into the subway tunnels day after day fighting a battle where they have no ammunition and, indeed, no battlefield on which to stand. The outreach workers hope that one day the "down under" people will come to one of the day programs offered in the Bowery where they can receive medical assessment, treatment and referrals. "Many homeless people are suspicious of promises made for better lives," staff of the Bowery Residence Committee (BRC) told the Commission. "Too often these promises have been broken." In fact, the promise of health care for many of the homeless HIV-infected population in New York's Bowery will be further delayed if, as we were told, the federal dollars are terminated.

In California, New York and New Jersey, we heard repeatedly about the "disaster relief" needed from the federal government for those cities hardest hit by the epidemic.

In Los Angeles, the Commission was deeply troubled by the hamstringing restrictions on the use of public dollars imposed by the elected local officials. Here local decision makers are prohibited from initiating the very efforts that could prevent further spread of the epidemic in a county with the second highest number of reported cases of AIDS in the United States.

In some areas of California there is absolutely no outpatient care available to people with HIV infection and AIDS. In yet other areas, there are six to eight week waits for outpatient services. "Outrage," the Commission was told, "is the only morally credible response."

In February of 1990, the Commission visited a drug treatment program in Northern New Jersey. We were told that, this year, New Jersey received in excess of $6 million in federal funds to reduce its waiting list for drug treatment services. New Jersey created more than 1,000 new treatment slots with the funds, but the Commission was told these funds will run out at the end of September. When we asked what drug treatment programs would do when the one-year-only federal dollars run out the response was, "Serve more with less - just like we always do." New Jersey ranks fifth among the states in its reported number of AIDS cases and first in its proportions of cases among intravenous drug users, minorities, women and children.

Across the country, the Commission also heard tales of health care denied unless it required acute hospitalization, and we heard desperate pleas that something be done to insure that all hospitals participate equally in provision of under-reimbursed AIDS care, rather than continue the grossly disproportionate distribution resulting from the subtle "patient dumping" now apparently practiced all too frequently in too many parts of the country.

SUMMARY

A lack of clear definition of government roles at all levels has hampered our national ability to organize health care services, to recruit and train human services personnel, to provide housing for the sick, to provide effective AIDS education and prevention programs, to provide coordinated, comprehensive substance abuse treatment and prevention and to develop sufficient monies to finance all of these efforts. All across the country there is a cry for leadership from the federal government and partnership between the different levels of government. There is no question that there have been creative and often heroic efforts at every level of government to address the HIV epidemic, but coordination of these efforts is the missing link to an effective national strategy.

We are increasingly convinced that one set of actions recommended in our first report must be swiftly implemented. A national plan, with clearly delineated responsibilities and agreement on the roles of federal, state and local government and the private sector is essential and long overdue. If we are to respond effectively to the HIV epidemic we must have a clear cooperative plan and make responsible use of the limited dollars available.

The National Commission on AIDS, therefore, makes the following recommendations:

1. The National Commission on AIDS will continue to recommend policy goals for a national plan. However, the Commission believes it is essential that a federal interagency mechanism be in place to coordinate a national plan. In this way, those who are ultimately responsible for the implementation will have an active role in its development.

2. Federal disaster relief or direct emergency relief is urgently needed to help states and localities most seriously impacted to provide the HIV prevention, treatment, care and support services now in short supply. The Commission strongly supports the efforts in Congress, now embodied in S.2240, to address this need. The resources simply must be provided now or we will pay dearly later.

3. Housing is an absolutely vital component of any comprehensive effort to address the multiple problems posed by HIV infection and AIDS. While the Commission recognizes that coordination between the state and local government, with input from community based organizations, is essential to effectively respond to the homeless crisis, we also believe the federal government must take the lead in providing the dollars needed to respond to this overwhelming, indeed catastrophic, problem.

4. Government restrictions imposed on the use of education and prevention funds are seriously impeding HIV control. They are clearly serving to prolong the HIV epidemic and should be removed.

5. Because the Americans with Disabilities Act (ADA) guarantees protection against discrimination for people with HIV infection and AIDS, the National Commission on AIDS strongly urges the U.S. House of Representatives to pass the ADA in a swift and timely manner. State and local governments should pass laws forbidding discrimination in areas not covered by the ADA or other federal statutes.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN
June E. Osborn, M.D.

MEMBERS
Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR
Maureen Byrnes

Press Release
May 1, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION TO REVIEW RESEARCH INITIATIVES

The National Commission on AIDS will hold hearings in Washington on May 7 and 8 to review current research initiatives related to HIV infection and AIDS.

On both days Commissioners will hear from representatives from a number of groups, including the Institute of Medicine, the Food and Drug Administration, ACT UP, the National Institutes of Health, Project Inform, the Pharmaceutical Manufacturers Association, community research projects, the American Association of Physicians for Human Rights, and persons living with AIDS.

The hearings both days will start at 8 a.m. and will be held at the Pan American Health Organization, 525 23rd St. NW, Washington, D.C. (Foggy Bottom Metro stop). A copy of the agenda is attached.

Dr. June E. Osborn, Chairman of the National Commission on AIDS, said, "What the Commission seeks to do is update our understanding of the progress in biomedical and therapeutic sciences, particularly as they relate to active care strategies for persons with HIV disease and AIDS."

-more-

Another member of the Commission, Dr. Don C. Des Jarlais, said, "Biomedical research in AIDS has been among the most productive and controversial in the history of medicine. The nation needs a systematic understanding of where we have been and where we are going in AIDS research.

"It is changing the way we think about research on fatal illnesses. However right now we don't even have a good method for setting priorities," he added. Dr. Des Jarlais is also Director of Research at the Chemical Dependency Institute of Beth Israel Medical Center in New York City.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members of the Commission are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

MAY 7-8, 1990

Pan American Health Organization Building
525 23rd Street N.W.
Meeting Room B
Washington, D.C.

Monday, May 7, 1990

8:00 a.m. NATIONAL ACADEMY OF SCIENCES OVERVIEW

Samuel O. Thier, M.D., President, Institute of Medicine
Robin Weiss, M.D, Director, AIDS Activities, Institute of Medicine
Charles Turner, Ph.D, Director, Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences, National Research Council

9:00 a.m. DRUG DEVELOPMENT AND APPROVAL OVERVIEW

Ellen C. Cooper, M.D., M.P.H., Director, Division of Antiviral Drug Products, Food and Drug Administration
Gerald Quinnan, M.D., Deputy Director, Center for Biologics Evaluation and Research, Food and Drug Administration
Joel Solomon, Ph.D., Director, Division of Blood and Blood Products, Center for Biologics Evaluation and Research, Food and Drug Administration
John C. Petricciani, M.D., Vice President, Medical and Regulatory Affairs, Pharmaceutical Manufacturers Association

9:45 a.m. BREAK

10:15 a.m. NATIONAL INSTITUTES OF HEALTH OVERVIEW

Anthony S. Fauci, M.D., Director, Office of AIDS Research, National Institutes of Health
Philip A. Pizzo, M.D., Chief of Pediatrics, Head, Infectious Disease Section, National Cancer Institute
Janet Heinrick, Dr.P.H., R.N., Director, Division of Extramural Programs, National Center for Nursing Research

11:30 a.m. COMMUNITY NEEDS AND PERSPECTIVES

Sonia Singleton, Community Outreach Education and Prevention Inc., Miami, Florida
Jim Eigo, M.F.A., ACT UP

Neil Schram, M.D., Chair, AIDS Task Force, American Association of Physicians for Human Rights
John Caldwell, Project Inform
Luis Hernandez, Outreach Assistant Coordinator, Community Research Initiative, New York
Rosa Martinez, Pediatric AIDS Advocate, Tampa, Florida

1:00 p.m. LUNCH

2:00 p.m. COMMISSION BUSINESS

4:00 p.m. ADJOURN

Tuesday, May 8, 1990

8:00 a.m. SCIENTIFIC AND CARE COMMUNITY

Panel I

Gerald Friedland, M.D., Professor of Medicine, Epidemiology and Social Medicine, Albert Einstein College of Medicine
Donald I. Abrams, M.D., Chair and Principal Investigator, Community Consortium, San Francisco General Hospital
Melanie Thompson, M.D., President, AIDS Research Consortium of Atlanta
George Perez, M.D., Medical Director, North Jersey Community Research Initiative

Panel II

Cecelia Hutto, M.D., Assistant Professor of Infectious Diseases and Immunology, Department of Pediatrics, University of Miami School of Medicine
Janet L. Mitchell, M.D., M.P.H., Chief of Perinatology, Department OB-GYN, Harlem Hospital Center
Amy Simon-Kramer, R.N., M.P.A., National Hemophilia Foundation
Mathilde Krim, Ph.D., Co-Chair, Committee on Research, National Organization Responding to AIDS
Ronald Sable, M.D., Co-founder, AIDS Program, Cook County Hospital

10:15 a.m. BREAK

10:45 a.m. RESEARCH AND DEMONSTRATION PROJECTS

John K. Watters, Ph.D., Assistant Adjunct Professor, Department of Epidemiology and Biostatistics, University of California, San Francisco

Patricia McInturff, M.P.A., Director, Regional Division, Seattle-King County Comprehensive AIDS Services Program, Seattle-King County Department of Public Health

Anita Vaughn, M.D., Medical Director, Newark Community Health Centers, Inc.

12:30 p.m. LUNCH

1:30 p.m. COMMISSION BUSINESS

3:30 p.m. ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN

June E. Osborn, M.D.

MEMBERS

Diane Ahrens

Scott Allen

Hon. Dick Cheney

Harlon L. Dalton, Esq.

Hon. Edward J. Derwinski

Eunice Diaz, M.S., M.P.H.

Donald S. Goldman, Esq.

Don C. DesJarlais, Ph. D.

Larry Kessler

Charles Konigsberg, M.D., M.P.H.

Belinda Mason

David E. Rogers, M.D.

Hon. J. Roy Rowland, M.D.

Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR

Maureen Byrnes

May 7, 1990

The Honorable George J. Mitchell
Majority Leader
U. S. Senate
S-221 Capitol Building
Washington, D. C. 20510

Dear Mr. Majority Leader:

As you know, the National Commission on AIDS recently issued the second in a series of reports on the HIV epidemic. A copy of the report, dated April 24, 1990, was sent to you. We will continue to bring urgent matters to the attention of Congress and the President.

In our latest report, we urged the President and the Congress to provide federal disaster relief to help states and localities most seriously impacted by the HIV epidemic. We indicated support for efforts in Congress, now embodied in S. 2240, the Comprehensive AIDS Resources Emergency (CARE) Act of 1990, to address this need.

In a statement issued by the Commission upon the introduction of S. 2240, we noted that the health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, its epidemic nature has accelerated the urgent need for responsible national action to correct the system's serious shortfalls.

The Commission is extremely pleased that over 60 Senators, including you, have joined Senators Kennedy and Hatch in support of this legislation. With the FY'91 appropriation process now underway, we urge the leadership to move the bill with all deliberate speed. The resources simply must be provided now or we will pay dearly later.

Given the gravity of the HIV epidemic, we are fortunate to have an abundance of sound data on which to base our public health policy decisions. With this in mind, the National Commission on AIDS stands ready to review and comment on any proposals under consideration by the Congress.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice-Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

May 7, 1990

The Honorable Bob Dole
Minority Leader
U. S. Senate
S-230 Capitol Building
Washington, D. C. 20510

Dear Mr. Minority Leader:

As you know, the National Commission on AIDS recently issued the second in a series of reports on the HIV epidemic. A copy of the report, dated April 24, 1990, was sent to you. We will continue to bring urgent matters to the attention of Congress and the President.

In our latest report, we urged the President and the Congress to provide federal disaster relief to help states and localities most seriously impacted by the HIV epidemic. We indicated support for efforts in Congress, now embodied in S. 2240, the Comprehensive AIDS Resources Emergency (CARE) Act of 1990, to address this need.

In a statement issued by the Commission upon the introduction of S. 2240, we noted that the health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, its epidemic nature has accelerated the urgent need for responsible national action to correct the system's serious shortfalls.

The Commission is extremely pleased that over 60 Senators, including you, have joined Senators Kennedy and Hatch in support of this legislation. With the FY'91 appropriation process now underway, we urge the leadership to move the bill with all deliberate speed. The resources simply must be provided now or we will pay dearly later.

Given the gravity of the HIV epidemic, we are fortunate to have an abundance of sound data on which to base our public health policy decisions. With this in mind, the National Commission on AIDS stands ready to review and comment on any proposals under consideration by the Congress.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice-Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

FOR IMMEDIATE RELEASE
May 11, 1990

Contact: Thomas Brandt
(202) 254-5125

STATEMENT ON THE AIDS PREVENTION ACT (H.R.4470) & THE MEDICAID AIDS AND HIV AMENDMENTS ACT (H.R.4080)

The National Commission on AIDS endorses the principles and objectives of the AIDS Prevention Act of 1990 (H.R.4470) and the Medicaid AIDS and HIV Amendments Act of 1990 (H.R.4080). This legislation is responsive to many of the recommendations of the National Commission on AIDS and the Presidential Commission on the HIV Epidemic.

There must be frank recognition that a health care crisis exists in many of our cities that will require extraordinary measures to overcome. The HIV epidemic of the 1990's will be far worse than what we have seen thus far. Our Nation simply must be prepared to invest adequate resources now or pay dearly later.

The AIDS Prevention Act of 1990 will provide emergency funds to those areas hardest hit by the epidemic. It will expand the availability of HIV testing and counseling and the accessibility of early intervention drugs which have been found to prolong life and prevent serious deterioration of health for those with HIV infection and AIDS. This legislation will also authorize demonstration projects that will provide comprehensive treatment services for HIV infection and AIDS.

The Medicaid AIDS and HIV Amendments Act of 1990 will provide states with the option to expand Medicaid services to provide home and community based services for children with AIDS, to assure continuity of private insurance coverage for people with HIV infection and AIDS, and to expand availability of early intervention drugs under Medicaid for income eligible individuals with compromised immune systems. This legislation also recognizes the financial problems now facing hospitals treating individuals with AIDS and HIV infection.

The health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, its epidemic nature has accelerated the urgent need for responsible national action to correct the system's serious shortfalls.

The Commission is pleased that these bills are moving forth in the legislative process and looks forward to the passage and funding of comprehensive AIDS care legislation by the 101st Congress.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN
June E. Osborn, M.D.

MEMBERS
Diane Ahrens
Scott Allen
Hon. Dick Cheney
Harlon L. Dalton, Esq.
Hon. Edward J. Derwinski
Eunice Diaz, M.S., M.P.H.
Donald S. Goldman, Esq.
Don C. DesJarlais, Ph. D.
Larry Kessler
Charles Konigsberg, M.D., M.P.H.
Belinda Mason
David E. Rogers, M.D.
Hon. J. Roy Rowland, M.D.
Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR
Maureen Byrnes

May 24, 1990

The Honorable Edward M. Kennedy
The Honorable Orrin G. Hatch
Committee on Labor & Human Resources
U.S. Senate
Washington, DC 20510

Dear Senators Kennedy and Hatch:

We are writing to underscore our support for the Americans with Disabilities Act and to reiterate our concern about any amendment reducing its scope of coverage for persons with HIV infection. As you may recall, the National Commission on AIDS issued a statement to that effect at the outset of its work in September, 1989, a copy of which is attached.

As Secretary of HHS, Dr. Louis Sullivan has stated, "Any policy based on fears and misconceptions about HIV will only complicate and confuse disease control efforts without adding any protection to the public health." The amendment concerning food handlers narrowly adopted by the House only reinforces unwarranted fear and perpetuates the discrimination that the ADA is designed to end. All evidence indicates that bloodborne and sexually transmitted diseases such as HIV are <u>not</u> transmitted through food-handling processes. Simply put, this amendment is bad public health policy.

We hope that the conference deliberations can yield a bill that fully protects persons with HIV infection from fear and discrimination, without exception.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice-Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

/enclosure

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

CHAIRMAN

June E. Osborn, M.D.

MEMBERS

Diane Ahrens

Scott Allen

Hon. Dick Cheney

Harlon L. Dalton, Esq.

Hon. Edward J. Derwinski

Eunice Diaz, M.S., M.P.H.

Donald S. Goldman, Esq.

Don C. DesJarlais, Ph. D.

Larry Kessler

Charles Konigsberg, M.D., M.P.H.

Belinda Mason

David E. Rogers, M.D.

Hon. J. Roy Rowland, M.D.

Hon. Louis W. Sullivan, M.D.

EXECUTIVE DIRECTOR

Maureen Byrnes

June 6, 1990

The Honorable Thomas S. Foley
Office of the Speaker
H-204 Capitol Building
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Speaker:

We are writing to express our concern about any amendment to the AIDS Prevention Act, H.R.4785, which would federally mandate the reporting of names of HIV infected individuals to state health authorities.

As you may know, the National Commission on AIDS issued a statement on May 11, 1990 in support of the principles and objectives of the AIDS Prevention Act as reported out of the Subcommittee on Health and the Environment. A copy of the statement is attached.

With respect to partner notification programs, the Commission believes that the current language in H.R. 4785 is sufficient, as it orders the State to provide assurances that it will require that the State public health officer, "to the extent appropriate in the determination of the officer, carry out a program of partner notification regarding cases of infection with the etiologic agent for acquired immune deficiency syndrome." To go further with a federal mandate would be counterproductive.

The need for reporting of names or other identifying information of individuals who test positive for HIV is a decision best left to the departments of health in each state. While numerous states have chosen to adopt some kind of name reporting system, many of these same states have continued to provide anonymous testing services and have allowed for locally generated approaches to counseling and testing for HIV infection. Appropriately, these systems were developed by the state health officials based on such factors as level of incidence, demographic data, and the availability of resources within the state.

We urge the Congress to resist attempts to impose a federal mandate on the states for name reporting.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice-Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

June 6, 1990

The Honorable Robert H. Michel
Office of the Minority Leader
H-230 Capitol Building
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Minority Leader:

We are writing to express our concern about any amendment to the AIDS Prevention Act, H.R.4785, which would federally mandate the reporting of names of HIV infected individuals to state health authorities.

As you may know, the National Commission on AIDS issued a statement on May 11, 1990 in support of the principles and objectives of the AIDS Prevention Act as reported out of the Subcommittee on Health and the Environment. A copy of the statement is attached.

With respect to partner notification programs, the Commission believes that the current language in H.R. 4785 is sufficient, as it orders the State to provide assurances that it will require that the State public health officer, "to the extent appropriate in the determination of the officer, carry out a program of partner notification regarding cases of infection with the etiologic agent for acquired immune deficiency syndrome." To go further with a federal mandate would be counterproductive.

The need for reporting of names or other identifying information of individuals who test positive for HIV is a decision best left to the departments of health in each state. While numerous states have chosen to adopt some kind of name reporting system, many of these same states have continued to provide anonymous testing services and have allowed for locally generated approaches to counseling and testing for HIV infection. Appropriately, these systems were developed by the state health officials based on such factors as level of incidence, demographic data, and the availability of resources within the state.

We urge the Congress to resist attempts to impose a federal mandate on the states for name reporting.

Sincerely,

David E. Rogers
David E. Rogers, M.D.
Vice-Chairman

June E. Osborn
June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

TESTIMONY

before the

SUBCOMMITTEE ON HEALTH & THE ENVIRONMENT

COMMITTEE ON ENERGY & COMMERCE
U.S. HOUSE OF REPRESENTATIVES

June 27, 1990

by

DONALD S. GOLDMAN, ESQ.
Commissioner

Good afternoon, Mr. Chairman and Members of the Committee. My name is Donald S. Goldman. I am an attorney in the private practice of law in West Orange, New Jersey, former President and Chairman of The National Hemophilia Foundation, the United States delegate to the World Federation of Hemophilia, and a Vice President of the National Health Council. I appear before you as a member of and on behalf of the National Commission on Acquired Immune Deficiency Syndrome which was created to advise the Congress and the President on issues relating to AIDS and HIV infection. Today my comments relate to U.S. immigration and visa policies.

Many of us on the Commission were long aware of U.S. immigration and visa policies. Our distinguished chair, Dr. June Osborn, sits on the World Health Organization's Global Commission on AIDS. Concern regarding U.S. immigration and visa policies was brought to the Commission's attention by a number of individuals and organizations. Among them was Charles J. Carman, President of the World Federation of Hemophilia, who asked us to do something about a U.S. visa policy threatening vital global cooperation by restricting entry to vital international conferences such as the World Federation of Hemophilia's XIX Congress scheduled for August here in our nation's capitol. I understand Mr. Carman will also be testifying before you this afternoon.

The Commission launched a study of the issues and prepared a documented working paper for the Commission's consideration. Following its review, the Commission issued a Resolution on December 12, 1989 calling upon the Administration to rectify the many problems created by current policy. I have included a copy of the Commission's Resolution with my formal testimony. The Commission was joined in a resounding chorus of other responsible organizations and agencies including the World Health Organization, the Red Cross, the American Bar Association, the National Association of Persons with AIDS and many others.

The Commission's basic message was simple. Our nation's public health is too important to be trusted to anyone but our nation's leading public health officials. Public health policy in this area should not be based upon myth, prejudice nor social stigmatization as it has often been in the past. Public health officials should decide which of hundreds of contagious diseases should bar entry. They should be free to add or subtract from that list as new diseases are discovered or new treatments and cures are found.

What must not happen is the process surrounding the amendment offered by Senator Helms which was attached to the 1987 Appropriations Bill from the floor and without benefit of a single committee hearing. This amendment, the Administration now claims, ties the hands of the Public Health Service and the Secretary of Health and Human Services from achieving a rational public health policy.

What is the impact of having allowed politics to interfere with public health? The impact was made all too vivid during last week's Sixth International Conference on AIDS. U.S. travel policy restrained thousands from participation, whether through conscience or fear. It made those who were there poorer for the absence of their international colleagues and those living with HIV. It was embarrassing to our country, which should serve as a proud beacon for emerging democracies and instead was a model of misguided and irrational policy-making.

26

There is a special irony to U.S. travel restrictions. The U.S., an area with a high and early incidence of AIDS, has long been viewed as a source of HIV infection. This makes U.S. policy particularly anomalous and inflammatory because it is directed to parts of the world with far lower rates of HIV infection. The message sent by these restrictions runs against everything we know about HIV since the best protection against it is a knowledgeable citizenry not legal barriers.

U.S. travel policy also has symbolic meaning. While the President and this Congress have stood so strongly behind the principle that, to quote President Bush, "We won't tolerate discrimination," U.S. travel policy undermines that effort. Allowing such restrictions to stand when public health officials say they are senseless merely validates discrimination. This Commission, President Reagan's Presidential Commission, and virtually every panel of experts ever convened are unanimous that abolishing discrimination is the most critical element in the war against HIV.

The Administration's response, a special 10 day visa, is not an answer. The European Parliament gave unanimous voice to its inadequacy by passing a resolution stating, "The exemption procedures introduced by the American Government undermine the principles of confidentiality for persons affected by HIV." The Parliament went on to urge that the conference be transferred to countries which do not practice such unjustified discrimination.

I can assure you that international attendance at the World Hemophilia meeting has already been decimated. I can assure you that under present circumstances, many international congresses will no longer grace our shores. I can assure you that the laudable efforts of this Administration to demonstrate that we are at war with a disease and not the people who suffer from it will be undermined.

At present, however, the Administration will not move further without a congressional mandate, yet its own public health officials have reviewed and underscored that there is no public health justification for having HIV infection on the list of dangerous contagious diseases. The Congress will have to act if we are to end the discriminatory effect of our policy towards people with HIV who wish to travel or immigrate to the U.S.

A major step forward would be the passage of H.R. 4506, sponsored by my esteemed colleague on the Commission Representative J. Roy Rowland. His legislation would give clear authority to those best qualified to make public health determinations, the Secretary of Health and Human Services and the Public Health Service. It would and should be only they who determine which contagious diseases bar entry to our country. The Commission urges the Committee and the Congress to move swiftly in passing the Rowland bill.

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
July 2, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION PANEL REVIEWS EARLY INTERVENTION ISSUES AND BARRIERS TO SERVICES

A working group of the National Commission on AIDS will meet in Dallas July 9 to continue its review of the relationship between HIV testing and early intervention with particular attention to the views of public health officials.

On the second day of the Dallas meeting, July 10, the Commission's Working Group on Social/Human Issues will take testimony on the range of human and social services needed by people affected by the HIV/AIDS epidemic with an emphasis on barriers to these services.

Rev. Scott Allen of Dallas, a member of the National Commission who is chairman of the Working Group, said, "The unique dynamics of the South as it confronts the HIV epidemic will hopefully provide us an understanding of the magnitude of the obstacles along with insight into the solutions for early intervention strategies to work."

The format of the Monday, July 9 session will be a facilitator-led, roundtable discussion among nearly 20 invited participants and Commissioners, along with additional time set aside for comments from members of the public in attendance. The meeting will take place in the

-more-

auditorium of Parkland Memorial Hospital, 5201 Harry Hines Boulevard, Dallas. (Broadcast media should contact Esther Bauer, Director of Community Relations for Parkland, for coverage arrangements. Phone: 214-590-8048).

On Monday afternoon individual Commissioners, accompanied by case managers from the AIDS Arms Network of Dallas, will visit with persons living with AIDS. These are private meetings not open to the press or public.

On Tuesday, July 10 the Working Group will follow a hearing format where more than 20 public health officials, care providers and educators from primarily the South and Southwest will present testimony and answer questions from the Commissioners. This session, which will also include time for comments from the public, will be held in the auditorium of the Dallas Public Library, 1515 Young Street at Ervay in Dallas.

A copy of the agenda and a list of participants for both days is attached.

Members of the National Commission on AIDS Working Group on Social/Human Issues are: Rev. Allen, chairman, who is a Dallas minister with extensive experience in the spiritual, ethical and psychological aspects of HIV disease; Harlon Dalton, who is Professor of Law at Yale and author of the book *AIDS and the Law: A Guide for the Public*; Eunice Diaz, M.S., M.P.H., who is an authority on AIDS among Hispanics and Assistant Professor of Family Medicine at the University of Southern California; Donald S. Goldman, who is an attorney and former President of the National Hemophilia Foundation; Larry Kessler, who is co-founder and Executive Director of the AIDS Action Committee in Boston; and Charles Konigsberg, M.D., M.P.H., who is the Director, Division of Health, Kansas Department of Health and the Environment.

-more-

June Osborn, M.D., who is Chairman of the National Commission on AIDS and Dean of the School of Public Health of the University of Michigan, will also attend the Dallas meetings.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a consistent national policy concerning AIDS" and the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

Working Group on Social/Human Issues

AGENDA

JULY 9-10, 1990

Parkland Memorial Hospital
5201 Harry Hines Boulevard
Dallas, Texas

Monday, July 9, 1990

8:30 a.m. Arrive at Hospital

Ron Anderson, M.D., President - Parkland Memorial Hospital

9:00 a.m. Introductions

Scott Allen, Chair - Working Group on Social/Human Issues
June E. Osborn, M.D., Chair - National Commission on AIDS

9:15 a.m. Roundtable Discussion

"The Relationship of HIV Testing and Early Intervention:
The Public Health Perspective"

Facilitator: Nancy Love, Ph.D.

10:45 a.m. BREAK

11:00 a.m. Roundtable Discussion Continued

1:30 p.m. Comments from the Public

2:00 p.m. LUNCH

3:00 p.m. Commissioners to Accompany Care Coordinators

5:00 p.m. Return to Hotel

6:00 p.m. Reception - Hosted by the AIDS ARMS Network

Tuesday, July 10, 1990

8:30 a.m. Introduction

Scott Allen, National Commission on AIDS

8:45 a.m. Overview of the Social and Human Needs of People Affected by the HIV/AIDS Epidemic

Warren Buckingham, Executive Director, AIDS ARMS Network

Examining the Range of Social and Human Services Needed by People Affected by the HIV/AIDS Epidemic with an Emphasis on the Barriers to these Services

9:00 a.m.

Eileen Carr - Dallas Urban League, Dallas, Texas
Deliana Garcia - National Migrant Resources Project, Austin, Texas
John Hannan - Positive AIDS in Recovery, Dallas, Texas
Don Schmidt - Board Member, AIDS Action Council, Person Living With AIDS, New Mexico

10:00 a.m.

Barbara Aranda-Naranjo, R.N. - South Texas Children's AIDS Center, San Antonio, Texas
Robert Dickson - Texas Commission on Alcohol and Drug Addiction, Austin, Texas
Timothy Panzer - Valley AIDS Council, Harlingen, Texas
William Waybourn - Dallas Gay Alliance, Dallas, Texas

11:00 a.m. BREAK

11:15 a.m.

Donna Antoine-Perkins - HIV Services Planning Project, Mississippi State Department of Health
Rebecca Lomax, M.S.W., M.P.H. - Associated Catholic Charities of New Orleans, Louisiana
Janet Voorhees, M.P.H. - New Mexico HIV Services Planning Grant Director

12:15 p.m.	LUNCH
1:30 p.m.	
	Roslyn Cropper, M.D. - Desire Narcotics and Rehabilitation Center, New Orleans, Louisiana Jean Derry, M.S.W. - Field Operations Division, Oklahoma Department of Human Services Paula Elerick Espinosa - Southwest AIDS Committee, El Paso, Texas Steve Hummel - Good Samaritan Project, Kansas City, Missouri
2:30 p.m.	
	George Buchanan, M.D. - Director, North Texas Comprehensive Hemophilia Center, Dallas, Texas Luis Fuentes - AVES (Amigos Volunteers in Education & Services), Houston, Texas Don Maison - AIDS Services of Dallas, Texas Henry L. Masters, III, M.D. - AIDS/STD Division, Arkansas Department of Health Ted Wisniewski, M.D. - HIV Outpatient Program, Charity Hospital, New Orleans, Louisiana
3:30 p.m.	BREAK
3:45 p.m.	Comments from the Public
4:15 p.m.	Summary of the Day's Proceedings by Jeff Stryker - Policy Analyst, National Commission on AIDS
4:30 p.m.	Working Group Business
5:30 p.m.	ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
July 12, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION REVIEWS RECRUITMENT, TRAINING AND ETHICAL ISSUES FACING THE HIV/AIDS WORK FORCE

The National Commission on AIDS will hold hearings in Washington, D.C. on July 18 and 19 to review work force and personnel issues in the HIV/AIDS epidemic.

The issues before the Commission will include recruitment and retention, education and training, and ethical issues. Specific attention will be paid to minority recruitment, geographic distribution, the availability and adequacy of specialized training for doctors, nurses, dentists, social workers and allied health care workers. The Commission will also review military health care, workplace safety and ethical issues such as duty to treat.

June E. Osborn, M.D., Chairman of the National Commission, said, "The ongoing availability of well trained health care professionals is absolutely crucial to the nation's long term ability to deal with the epidemic. There is a haunting analogy between the long, silent interval before HIV causes recognizable disease and the long interval of training needed to create new, key health personnel. In each case the failure to intervene early promises to intensify the crisis.

"Even at present there is a real crisis in the shortage of nurses, and a somewhat artificial crisis created by the worrisome number of physicians and

- more -

dentists who try to avoid the epidemic rather than seek the continuing education needed to meet it square on," Dr. Osborn added.

David E. Rogers, M.D., Vice Chairman of the Commission, said, "A serious problem of mounting proportion that hampers our ability to care for persons living with AIDS is a lack of trained professionals at all levels. What we don't have, but what we vitally need, is a cadre of professionals with the knowledge of how to care for persons with HIV infection or AIDS."

The hearing will run from 9 a.m. to 5 p.m. on both days in hearing room B, Interstate Commerce Commission (ICC) Building, 12th and Constitution Ave., N.W., Washington, D. C. (Use Constitution Ave. entrance. Federal Triangle Metro stop). A copy of the agenda and a list of witnesses is enclosed.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

AGENDA

JULY 18-19, 1990

Interstate Commerce Commission
Hearing Room B
12th and Constitution Avenues, N.W.
Washington, D.C.

Wednesday, July 18, 1990

9:00 a.m. PERSONNEL AND WORK FORCE OVERVIEW

Eli Ginzberg, Ph.D., Director, Conservation of Human Resources, Columbia University
Connie R. Curran, R.N., Ed.D., FAAN, Health Care Consultant, The Curran Group
Molly Cooke, M.D., Assistant Professor of Clinical Medicine, University of California, San Francisco

10:00 a.m. RECRUITMENT AND RETENTION

Joyce V. Kelly, Ph.D., Associate Vice President for Clinical Services, Association of American Medical Colleges
Caroline Bagley Burnett, Sc.D., R.N., Senior Consultant, Commission on the National Nursing Shortage
Brigadier General Clara L. Adams-Ender, R.N., Chief, Army Nurse Corps

10:45 a.m. BREAK

11:00 a.m. Nicholas A. Rango, M.D., Director, New York AIDS Institute
Carolyn H. Smeltzer, Ed.D., R.N., FAAN, Vice President for Nursing, University of Chicago Hospital
Rene Rodriguez, M.D., President, Interamerican College of Physicians and Surgeons
Floyd J. Malveaux, M.D., Ph.D., Professor of Medicine and Microbiology, Howard University College of Medicine; Board of Trustees, National Medical Association
Charles Helms, M.D., Ph.D., Associate Dean, University of Iowa College of Medicine
Caitlin Ryan, M.S.W., ACSW, Director, AIDS Policy Center, IHPP, George Washington University; National Association of Social Workers

12:30 p.m. EDUCATION AND TRAINING

Harvey J. Makadon, M.D., Executive Director, Boston AIDS Constorium
Rose Walton, Ed.D., Chair, Allied Health Resources, SUNY at Stony Brook
Ronald L. Jerrell, President, National Association of People With AIDS
David Henderson, M.D., Associate Director for Quality Assurance, Clinical Center, NIH

1:30 p.m. LUNCH

2:30 p.m. COMMISSION BUSINESS

5:00 p.m. ADJOURN

Thursday, July 19, 1990

9:00 a.m. MINORITY RECRUITMENT AND RETENTION (H.R. 3240)

THE DISADVANTAGED MINORITY HEALTH IMPROVEMENT ACT OF 1989

Honorable Louis Stokes, U.S. Representative, 21st District, Ohio

9:30 a.m. FEDERAL PERSONNEL AND WORK FORCE OVERVIEW

Fitzhugh Mullan, M.D., Director, Bureau of Health Professions, HRSA
Marilyn H. Gaston, M.D., Director, Division of Medicine, Bureau of Health Professions, HRSA

10:15 a.m. EDUCATION AND TRAINING

Carol Raphael, CEO, Visiting Nurse Service of New York
Raymond Scalettar, M.D., F.A.C.P., Member, Board of Trustees, American Medical Association
John Molinari, Ph.D., Chair, Curriculum Advisory Committee on Blood-Borne Infectious Diseases, American Association of Dental Schools
Enid A. Neidle, Ph.D., Associate Executive Director for Scientific Affairs, American Dental Association

11:00 a.m. BREAK

11:15 a.m. VOLUNTEERS AND THE WORK FORCE

Jim Graham, J.D., L.L.M., Administrator, Whitman-Walker Clinic, Inc., Washington, D.C.
Laurie Sherman, Speakers Bureau Coordinator, AIDS Action Committee, Boston
Eric E. Rofes, Executive Director, Shanti Project, San Francisco

12:15 p.m. ETHICAL DILEMMAS FOR THE WORK FORCE

Lawrence O. Gostin, J.D., Executive Director, American Society of Law and Medicine
Christine Grady, R.N., M.S.N., Nurse Consultant, National Center for Nursing Research, NIH
Vincent Rogers, D.D.S., M.P.H., Chair, Department of Community Dentistry, Temple University
Alvin Novick, M.D., Professor of Biology, Yale University

1:30 p.m. LUNCH

2:30 p.m. COMMISSION BUSINESS

5:00 p.m. ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
July 23, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION PANEL REVIEWS SEATTLE 'PARTNERSHIP' MODEL, BARRIERS TO CARE, DRUG PROGRAMS AND OTHER ISSUES

A working group of the National Commission on AIDS will meet in Seattle on July 30 and 31 for local site visits at HIV care and housing facilities, and also to take testimony on national issues relating to the provision of services for persons with HIV infection or AIDS.

On Monday, July 30 the Commission's Working Group on Social/Human Issues will take testimony in three areas: the barriers to the human and social services needed by people affected by the HIV/AIDS epidemic; the successful aspects of the Seattle-King County programs and their community wide partnerships in care; improving or creating partnerships and coalitions in other areas of the country.

Partnership in care refers to successful, cooperative program arrangements among local, state and federal government entities, community based organizations, volunteer groups, businesses, foundations and organizations representing specific communities heavily impacted by the HIV epidemic. Rev. Scott Allen of Dallas, a member of the National Commission who is chairman of the working group, said, "In Seattle we want to examine

- more -

how the many public and private organizations have worked, hand in hand, to build partnerships that have significantly improved the quality of life, and level of service, for people living with HIV disease. The partnerships have created strong, flexible structures that can grow as we know that the demand for their services will grow."

The working group will take testimony from 9 a.m. to 6:30 p.m. on Monday, July 30. The session will be held in the south conference room, fourth floor, of the Henry M. Jackson Federal Building, 915 Second Ave. Time has been set aside for public comment at 6 p.m.

On Tuesday the working group will visit an AIDS support group, a housing program and a drug treatment program that are part of the region's successful partnership concept. However these will be small private meetings with persons living with AIDS, and will not be open to the news media.

Members of the National Commission on AIDS Working Group on Social/Human Issues who will meet in Seattle are: Rev. Allen, chairman, who has extensive experience in the spiritual, ethical and psychological aspects of HIV disease; Harlon Dalton, who is Professor of Law at Yale and author of the book *AIDS and the Law: A Guide for the Public*; Eunice Diaz, M.S., M.P.H., who is an authority on AIDS among Hispanics and an Assistant Professor of Family Medicine at the University of Southern California; Donald S. Goldman, who is a New Jersey attorney and former President of the National Hemophilia Foundation; and Larry Kessler, who is co-founder and Executive Director of the AIDS Action Committee in Boston.

June Osborn, M.D., who is Chairman of the National Commission on AIDS and Dean of the School of Public Health at the University of Michigan, will also attend the

- more -

Seattle meeting.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of "a consistent national policy concerning AIDS" and the HIV epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

Working Group on Social/Human Issues

AGENDA

JULY 30-31, 1990

The Henry M. Jackson Federal Building
915 Second Avenue
Seattle, Washington

Monday, July 30, 1990

9:00 a.m. Introductions

Scott Allen, Chair, Working Group on Social/Human Issues
June E. Osborn, M.D., Chair, National Commission on AIDS

Examining the Range of Social and Human Services Needed by People Affected by the HIV/AIDS Epidemic

9:15 a.m. Gail Barouh - Long Island Association for AIDS Care, Huntington, New York
Jon Fuller, S.J., M.D. - Jesuit Urban Center, Boston, Massachusetts
Linda Meredith - ACT UP Women's Committee, Washington, DC
David Woodring (Osage) - National Native American AIDS Prevention Center

10:00 a.m. Sean Duque - PWA, Member of the Board of Life Foundation, Honolulu, Hawaii
Robert Greenwald, Esq. - AIDS Action Committee, Boston, Massachusetts
Veneita Porter - Planned Parenthood, Alameda/San Francisco, California
David Schulman, Esq. - AIDS/HIV Discrimination Unit, City of Los Angeles

Partnerships in Care: Examining the Seattle-King County Model

10:45 a.m. Lead Agency Model

Nancy Campbell - Executive Director, Northwest AIDS Foundation
Catlin Fullwood - Executive Director, People of Color Against AIDS Network

11:15 a.m. BREAK

11:30 a.m. Case Management Systems

Margo Bykonen, R.N. - AIDS Outpatient Coordinator, Swedish Hospital Medical Center
Jeffrey Sakuma, M.S.W. - Coordinator, Community Health Services, Group Health Cooperative

12:00 p.m. AIDS Intervention Programs for Substance Users

Charlton Clay - Assistant Coordinator, Seattle Needle Exchange, Community AIDS Services Unit
Dave Purchase - Point Defiance AIDS Project, Tacoma, Washington
Robert Wood, M.D. - Director, AIDS Control Program, Seattle-King County Department of Public Health

12:45 p.m. LUNCH

1:45 p.m. Housing Programs

Harris Hoffman - Project Manager, AIDS Housing of Washington
Patricia McInturff, M.P.A. - Director, Regional Division, Seattle-King County Department of Public Health

Partnerships in Care: Improving and Creating Partnerships in the Delivery of Social and Human Services

2:15 p.m. Rene Durazzo - San Francisco AIDS Foundation, California
Randall Gorbette - Phoenix Shanti Group, Phoenix, Arizona
Ronald Johnson - Minority Task Force on AIDS, New York City
John Pacheco - Minnesota Hispanic AIDS Partnership, St. Paul, Minnesota
Lorraine Teel - Minnesota AIDS Project, Minneapolis

3:15 p.m. BREAK

3:30 p.m. Maribel Clements, R.N., M.A. - Hemophilia Program, Puget Sound Blood Center
Deborah Lee - Association of Asian Pacific Community Health Organizations, Oakland, California

Cliff Morrison, R.N. - Robert Wood Johnson Foundation, AIDS Health Services Program, University of California, San Francisco
Elizabeth Valdez, M.D. - Concilio Latino de Salud, Phoenix, Arizona

Responsibilities and Roles of Government Agencies in the Development of Social and Human Services Networks

4:30 p.m. Kristine M. Gebbie, R.N. - Washington Department of Health
King Holmes, M.D. - University of Washington
Adam Myers, M.D. - Denver Department of Health and Hopsitals, Denver, Colorado
Joseph O'Neill, M.D., M.P.H. - Bureau of Health Care Delivery and Assistance, Division of Special Populations, Health Resources and Services Administration

5:30 p.m. Comments from the Public

6:00 p.m. ADJOURN

Tuesday, July 31, 1990

9:00 a.m. Commission Working Group Business

11:30 a.m. Commission Site Visits and Meetings with Persons Living With AIDS

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
August 8, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION REVIEWS HIV INFECTION ISSUES IN CORRECTIONAL FACILITIES

The National Commission on AIDS will tour New York prison and jail sites, followed by a full day of formal hearings in Manhattan, as part of its review of HIV infection issues in the nation's correctional facilities.

On Thursday, August 16 the Commission will tour Rikers Island Correctional Facility, which is a New York City jail, and the Fishkill Correctional Facility, which is a New York state prison. Rikers only will be open to the press.

The hearings will be held Friday, August 17, in room 342 at 5 Penn Plaza, Manhattan. Witnesses will include officials from the Federal Bureau of Prisons, the National Prison Project of the ACLU, authorities on correctional issues from Alabama, California, New Jersey, Pennsylvania, New York and other states, the Centers for Disease Control, the National Women's Law Center and other organizations. A copy of the agenda for both days is attached.

June Osborn, M.D., Chairman of the National Commission, said, "The convergence of the twin epidemics of HIV infection and illicit drug use make prisons a particularly sensitive setting. On the one hand they can serve as an

- more -

exceptionally good place for HIV education for prevention, and at the other extreme they can focus the worst societal forces such as discrimination and lack of access to health care."

Dr. Osborn also said, "There is a long standing argument about the ethics of doing clinical research in captive populations. And yet since much of AIDS therapy is experimental, that raises perplexing issues of appropriate opportunity to participate in available therapeutic options."

Harlon Dalton, a member of the Commission and a Yale law professor, said, "Often prison officials are reluctant to acknowledge that sex and drug use occur behind prison bars, which makes it extremely difficult to design programs to promote safer behaviors."

Mr. Dalton, who is also editor of *AIDS and the Law: A Guide for the Public*, added, "Problems of the outside are magnified in prison, particularly the challenge of providing quality health care, and the problem of insuring confidentiality."

Other issues before the Commission will include the epidemiology of HIV in correctional facilities, prisoners' access to health care, HIV segregation, the ethics and history of medical experimentation on prisoners, and family issues.

The National Commission on AIDS is an independent body created by Congress to advise Congress and the President on development of a "consistent national policy" concerning the HIV epidemic.

The 15-member commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense, and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON AIDS

SITE VISITS

AUGUST 16, 1990

8:00 a.m. Rikers Island Correctional Facility

Briefing and Tour:

Charles A. Braslow, M.D.
Project Director
Montefiore Rikers Island Health Services

Leslie Keenan
Associate Commissioner
New York City Department of Corrections

2:00 p.m. Fishkill Correctional Facility

Briefing and Tour:

Robert B. Greifinger, M.D.
Deputy Commissioner
Chief Medical Officer
State of New York
Department of Correctional Services

NATIONAL COMMISSION ON AIDS

AGENDA

AUGUST 17, 1990

5 Penn Plaza
8th Avenue
33rd & 34th Streets
Room 342
New York, New York

9:00 a.m. Welcome

June E. Osborn, M.D.
Chairman

An Introduction to Corrections

Mark Lopez, Esq.
Staff Attorney
National Prison Project of the ACLU Foundation

Epidemiological Perspective

Kenneth G. Castro, M.D.
Special Assistant to the Director for Science
Division of HIV/AIDS
Centers for Disease Control

9:30 a.m. Health Care in the Correctional Setting

Robert Cohen, M.D.
Inpatient AIDS Services
St. Vincent Hospital

9:50 a.m. Federal System

Kenneth P. Moritsugu M.D., M.P.H.
Assistant Surgeon General
Medical Director
Federal Bureau of Prisons

10:15 a.m. BREAK

10:30 a.m. Issues in Correction: State Experiences

Alabama

Alexa Freeman, Esq.
Staff Attorney
National Prison Project of the ACLU Foundation

California

German V. Maisonet, M.D.
Chief, HIV Services
California Medical Facility -- Vacaville

New Jersey

Catherine Hanssens, Esq.
State of New Jersey Department of the Public Advocate
Office of Inmate Advocacy

New York

Michael Wiseman, Esq.
Staff Attorney
Prisoners Rights Project of the Legal Aid Society

11:30 a.m. Women and HIV Infection

Brenda Smith, Esq.
National Women's Law Center

Marilyn Rivera
Founding Member ACE Program
Bedford Hills Correctional Facility

12:00 p.m. LUNCH

1:30 p.m. Presentation of Inmate Statements and Affidavits

Judy Greenspan
AIDS Information Coordinator
National Prison Project of the ACLU Foundation

1:45 p.m. Inmate Access to Clinical Trials

Robert J. Levine, M.D.
Professor of Medicine
Yale University School of Medicine

Victoria Sharp, M.D.
Medical Director
Spellman Center
St. Clairs Hospital

Ann Graham, C.R.N.A., M.P.H.
Executive Director
Research Involving Human Subjects Committee
Federal Drug Administration

A. Billy S. Jones
Macro Systems Inc.

2:30 p.m. HIV/AIDS Education

Lewis Tanner Moore, M. Ed.
HIV/AIDS Educator
Philadelphia Prison AIDS Project

Sharon A. Letts
Deputy Director
Delaware Council on Crime and Justice

Edward A. Harrison
Director of Planning
National Commission on Correctional Health Care

Jose C. Hernandez, Jr.
Executive Director
Project HACER

3:30 p.m. BREAK

3:45 p.m. Courts, Inmates and HIV/AIDS Policy Making through Litigation

Honorable Richard T. Andrias
Justice of the New York State Supreme Court

Scott Burris, Esq.
Staff Attorney
AIDS and Civil Liberties Project
ACLU of Pennsylvania

J. L. Pottenger, Jr., Esq.
Clinical Professor of Law
Jerome N. Frank Legal Services Organization
Yale Law School

4:30 p.m. <u>HIV/AIDS and Release Policies</u>

Cathy Potler, Esq.
Director, AIDS in Prison Project
Correctional Association of New York

Romeo Sanchez
Supervisor of Advocacy Issues
City Commission on Human Rights
AIDS Discrimination Division

5:15 p.m. Public Comment

5:30 p.m. ADJOURN

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

Press Release
August 21, 1990

Contact: Thomas Brandt
202-254-5125

COMMISSION REPORTS ON PROBLEMS IN AIDS CLINICAL RESEARCH PROGRAM; THE HIDDEN EPIDEMIC IN RURAL AMERICA; AND THE HEALTH CARE WORKER CRISIS

The National Commission on AIDS today released a report to President Bush and Congress that cites serious problems in three major areas of the HIV epidemic including the AIDS clinical trial program, rural America, and the nation's health care work force.

In research, the Commission found that too few people of color, women and children are included in clinical trials; that research has expanded too slowly on the management of opportunistic infections even though they are usually the cause of death for people with AIDS; and that federal officials need to respond to the perception of possible conflict of interest, and the call for full disclosure of pharmaceutical company consulting relationships, by researchers who also advise the National Institutes of Health on AIDS matters.

In rural America, the Commission found a volatile mix of discrimination, lack of knowledge and education about HIV infection, and minimal health care systems unable to serve their community's even basic needs, let alone the increase in HIV infection. The Commission is alarmed that many rural areas and small towns are currently unable, and often

-more-

unaware, of their need to deal with the three epidemics of HIV infection, drug addiction and sexually transmitted diseases.

The Commission's third issue is concern over the crisis shortage of health care providers willing to care for people living with HIV infection and AIDS. The Commission found that among health care workers, many refuse to treat people with HIV or AIDS out of fear of infection on the job, others claim lack of training, and some simply discriminate against people with HIV infection or AIDS. "The Commission's findings should give all of us -- the White House, Congress and the American people -- a sense of urgency," said Dr. June Osborn, Chairman of the National Commission on AIDS.

"Many infected people aren't getting the care and access to clinical trials at the levels they need; many parts of rural America are about to be blind sided by the epidemic; and perhaps least excusable, many health care workers still refuse to fulfill their obligations to the sick if the disease is HIV," she added.

"These issues are at the cutting edge of the epidemic which is certain to become much worse in the 1990s than the 1980s, even if we were somehow able to stop all further infections tomorrow," Dr. Osborn said.

The Commission's report includes the following six recommendations:

1. A comprehensive community-based primary health care system, supported by adequate funding and reimbursement rates, is essential for the care and treatment of all people, including people living with HIV infection and AIDS. The Commission highlighted this need in its first report and continues to believe that lack of access to primary care services provided by adequately trained primary care providers is undermining current efforts in HIV/AIDS research, prevention and treatment. The development of a comprehensive system with linkages to research protocols, existing community-based services, hospitals, drug treatment programs, local health departments, and longterm care facilities, based on a foundation of adequate support, is long overdue and should be a top priority for the federal government.

-more-

2. AIDS education and outreach services in rural communities should be expanded and designed to provide clear and direct messages about how HIV is and is not transmitted, and the kinds of behaviors that may place an individual at risk for HIV and other sexually transmitted diseases. Expansion of programs, resources and health care providers is also needed to respond to rural America's need for prevention and treatment programs that address the three epidemics of HIV infection, drug addiction and sexually transmitted diseases.

3. The NIH clinical trials program is in serious trouble. The limited number of enrollees in trials and the lack of demographic and geographic diversity of the participants threatens the success of the program and denies many people living with HIV infection and AIDS the opportunity to participate in experimental drug therapies. The academic health centers involved have not been as vigorous as one would hope in advancing these trials, nor has the NIH been vigorous in monitoring their performance. Aggressive efforts must be made to overcome the obstacles to participation for many who are under-represented. Success in this area can only be measured by increased participation in trials.

4. There is a desperate need for more research on the management of opportunistic infections, usually the cause of death for people with AIDS. The NIH simply must expand the level of research in this area. This expansion must not come at the expense of other research efforts and should be an integral part of a comprehensive AIDS research plan. This plan should outline the AIDS research priorities and goals for the entire NIH, and the resources needed to achieve them. The plan should be widely disseminated and should incorporate the views of persons living with HIV infection and AIDS.

5. There is a shortage of crisis proportions of health care providers capable and willing to care for people living with HIV infection and AIDS. This crisis will only get worse as the HIV epidemic continues into the 1990's. Action must be taken now to increase and improve the effectiveness of all programs designed to educate and retain practicing health care professionals, and to create incentives for providers to care for people in underserved areas. Existing programs such as the National Health Service Corps should be expanded. New programs such as those outlined in the Disadvantaged Minority Health Improvement Act (H.R. 3240) should be created. And, specific HIV/AIDS fellowships and training programs should be established and supported to prevent a crisis of greater magnitude.

6. Volunteers should be publicly recognized not only for the invaluable contribution they have made to people living with HIV infection and AIDS, but also for the way in which they fight fear and bigotry by fostering compassion and caring. The cost effective dollars needed to recruit, train, support and manage volunteers must be provided by the government and the private sector, and recognized as essential to our national response to the HIV epidemic.

-more-

The report released today to the President and Congress is the third interim report from the National Commission. The first, released Dec. 6, 1989, dealt with the failures of the health care delivery system to deal with HIV, among other issues. The second report, released on April 24, 1990, called for several actions including new federal leadership for the epidemic and additional funds targeted for cities and states that are most heavily impacted by the epidemic.

The National Commission on AIDS is an independent body created by Congress to advise the Congress and the President on development of "a national consensus on policy" concerning the HIV epidemic.

The Commission took office on August 3, 1989 and since then has held nearly 30 days of hearings, working group meetings and site visits in various regions of the country. In addition the Commission has consulted with dozens of experts and conducted extensive staff research and review of major issues in the AIDS epidemic.

The 15-member Commission includes five voting members appointed by the Senate, five appointed by the House, and two appointed by President Bush. The three non-voting members are the Secretary of Health and Human Services, the Secretary of Defense and the Secretary of Veterans Affairs.

# # # #

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

August 21, 1990

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

Dear Mr. President:

Since our last report to you, the National Commission on AIDS has traveled to rural Georgia to better understand the impact of the HIV epidemic in rural communities across the country. Two formal hearings have examined the current status of HIV research and drug development and looked at the mounting hardships which shortages in health care personnel are imposing on people with HIV infection and AIDS. A working group of the Commission also met with public health officials and others from the Southwest region of the country in Dallas and heard poignant testimony about the lack of many basic publicly supported services needed by people affected by the HIV epidemic. The enclosed report highlights the National Commission's most recent findings. Again it contains a short series of recommendations for swift action.

Sincerely,

June E. Osborn
June E. Osborn, M.D.
Chairman

David E. Rogers
David E. Rogers, M.D.
Vice Chairman

cc: The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of Representatives

The Honorable Robert H. Michel
Minority Leader of the House of Representatives

National Commission
on
Acquired Immune Deficiency Syndrome

Report Number Three

AIDS IN RURAL AMERICA

Overview

The number of new AIDS cases diagnosed in rural communities across the country is growing at an alarming rate. Although the epidemic continues to be most severe in urban areas, there has been a 37 percent increase in diagnosed AIDS cases in rural areas compared to a 5 percent increase in metropolitan areas with populations of over 500,000 in just a one year period. In Georgia the number of AIDS cases has tripled in the past two years. For the first time, the spread of disease in rural Georgia and small cities has equalled the growth of HIV infection in metropolitan Atlanta.

This is happening all across the country. The Commission was told of alarming rates of increase in HIV infection in Arkansas, Mississippi and rural communities in Texas. It is happening tragically and secretly without adequate health care services or human support in these rural areas.

Findings

- In rural America, there is an epidemic of fear and bigotry, fanned by the absence of education and knowledge, surrounding HIV infection and AIDS. Like much of urban America, rural communities are just beginning to confront the realities of HIV infection and AIDS. The fear of being "found out," we were told, is almost as great as the fear of the disease itself. As one Commission member, Belinda Mason, noted, "I have seen rural America at its warm, supportive best and at its close-minded, bigoted worst."

  In one community we learned of a young man who sneaks out to his mother's car at night, covers himself with a blanket and waits for his mother to come out at dawn to drive him many miles to another county where he can receive treatment anonymously. When he returns home he remains in the car covered by the blanket until sundown when he creeps back into his mother's trailer home. All this, to prevent others from knowing that his mother is housing and caring for a son who has AIDS. Little will be known of his life -- only that he died of AIDS.

  One man told us of being "thrown out of my church and told not to come back." A local doctor told us, "We've had people lose their jobs and get kicked out of their apartments." Another told us, "President Bush talks about those thousand points of light, but whenever people hear that I have HIV, the lights go out and I am in the dark."

In Texas we were told that the isolation and stigmatization of people with AIDS in rural areas is similarly severe. "Even a family is apt to reject the patient because of fear that the neighborhood or community will respond hatefully."

- AIDS education is virtually non-existent and desperately needed in rural communities. This includes even the simplest of education about HIV infection for health care providers. Ignorance and misinformation are seriously hampering if not crippling efforts to treat those who are sick; clearly contributing to the rapid increase in rates of HIV infection in rural America; and contributing greatly to the discrimination against and ostracism of people living with HIV infection and AIDS.

  Drug education, prevention, and treatment programs range from grossly inadequate to non-existent. If there is to be any hope of stemming the tide of what one health official described as "three epidemics - AIDS, drugs and STD (sexually transmitted diseases)" - services for all of these disease problems and educational programs designed to contain them must be dramatically expanded.

  One infectious disease specialist from Macon, Georgia expressed great concern about the spread of AIDS into families, noting that he was currently seeing five families in which both parents are infected with HIV. The growth in the number of heterosexual cases of AIDS, in rural communities, particularly among women, (many in their teens), is often attributed to the combination of crack cocaine, trading sex with multiple partners for drugs or money, and rising rates of syphilitic infections which seem to increase transmission of HIV infection. In the last five years, the number of new cases of syphilis has increased tenfold in Southeast Georgia.

- The singular lack of access to primary health care services in rural America was shocking and heartrending. The Commission's firsthand look at rural communities made graphic and personal reports of "a rural health care crisis evidenced by rising rural maternal and infant mortality rates, lower health status of rural Americans compared to those living in cities, [and] a greater proportion of rural Americans lacking any health insurance" (Senate Report 101-127). AIDS is dramatically accentuating the problem.

  In Macon, Georgia, the Commission visited the Bibb County HIV Ambulatory Clinic where health care providers were virtually overwhelmed with the increasing number of people with HIV infection and AIDS needing treatment and support services. As the need for services increases, the dollars decrease. The Bibb County HIV Ambulatory Clinic, operated by the Bibb County Health Department, receives no direct financial assistance whatsoever from the federal government. Given the rising demand for services, this can no longer continue. Federal assistance is essential for this clinic and other similar clinics who are serving the growing numbers of people living with HIV infection and AIDS.

HIV RESEARCH AND DRUG DEVELOPMENT

Overview

On May 7 and 8, the Commission convened hearings to review the current status of HIV-related biomedical research efforts and the status of new clinical drug trials. Representatives from the National Institutes of Health (NIH), Institute of Medicine, ACT UP, the American Foundation for AIDS Research, Project Inform, American Association of Physicians for Human Rights, and others were invited to report to the Commission on their ongoing efforts to support and monitor private and public HIV-related research efforts. The Commission will continue to rely on these organizations, with expertise to carefully examine many complex scientific issues, to keep us apprised of research efforts and findings.

While the investment of public and private funds into HIV-related research is impressive, and the fundamental biomedical knowledge about HIV infection acquired over a very short time remarkable, the transfer of knowledge and treatment to those who are HIV infected falls far short of the mark. To put it bluntly, the number of people involved in clinical trials (12,000) versus the number of people eligible for clinical trials is pitifully small. The ground rules for trials seem often too rigid to permit many (such as drug users) from being included. People of color, women, and children are grossly under-represented in federally financed trials. This limits access to experimental therapies as well as basic health care services many receive only through participation in trials. Communication between researchers, people living with HIV infection and AIDS, and the public is not being done well, accentuating all the problems noted above. Much of the blame for many of these problems rests with academic health centers. These centers and the federal government must do better. A clear, crisp, well articulated clinical research strategy is simply not in evidence.

Also grossly apparent is that many people seeking access to experimental therapies are simply not getting basic health care services for HIV-infection and AIDS. Clinical trials cannot exist or be productive in a health care vacuum. They must be part of a comprehensive health care system which ensures adequate access and reimbursement for all kinds of care needed, including experimental therapies for HIV-infection and AIDS.

Findings

- Opportunistic infections are usually the cause of death for people with AIDS, yet the NIH has been slow in expanding its AIDS-related research activities to include research on drugs to manage opportunistic infections. The Commission agrees with all those who have called for a greater priority to be given to research related to these infections without slackening research on drugs to treat HIV infection and AIDS. Clearly, both are vitally needed and the dollars to ensure both are essential.

- Severe criticism was repeatedly expressed about the lack of results from the sizable investment (to date, approximately $428 million) in the AIDS Clinical Trials Group Program (ACTG). It was pointed out that the majority of FDA approved drugs for AIDS and AIDS-related opportunistic infections have all been developed outside the

ACTG program.

Heated criticism about the limited number of participants in ACTG trials continues. Barriers contributing to the low level of participation in clinical trials, in addition to those already mentioned, include lack of adequate transportation, day care needs, exclusion of persons with hemophilia, and lack of access to basic medical services and clinical trial information. These barriers all demand aggressive attention and solutions, not more discussion.

- People of color are grossly under-represented in clinical trials. Approximately forty-three percent of all AIDS cases are seen in men and women of color. Yet only approximately 23 percent of the participants in clinical trials are men and women of color.

  The Commission was told that this under-representation was of concern to the NIAID and that efforts were underway to increase minority participation in clinical trials. The Commission strongly supports these efforts and believes these efforts should be swift and carefully monitored to assure their success, with the results promptly reported to the public.

- Women, particularly women of color, have traditionally experienced difficulty qualifying for clinical trials. One witness told the Commission she has attempted to qualify for a research protocol for two years. "In this country," she said, "women have been secondary to men with AIDS, and most recently are secondary to babies."

  According to the Chief of Perinatology at Harlem Hospital, "This historical precedent for excluding women of childbearing age from treatment trials can no longer be allowed. On the other hand, including women, especially pregnant women, only for the sake of improving the outcome of the child, is also intolerable. Women have a right to be included simply because they are infected and are dying. No other reason is needed." The Commission emphatically agrees.

- For a parent whose child is diagnosed with AIDS and whose only hope lies in the child's participation in an AIDS-related clinical trial, the exclusion of children from trials certainly highlights one of the gross inequities in our research programs. Since the early days of the epidemic, parents have been demanding that children be included in AIDS-related clinical trials and that parents and patient advocates be included in decisions about the care of their child.

  Traditionally, children have been denied access to experimental drugs because of the unresolved ethical dilemma of whether or not to include children in trials. In fact, the Director of Pediatric AIDS Research at the National Cancer Institute told the Commission how efforts to increase participation of children in clinical trials were hampered by the lack of a national consensus on this major ethical question. Clearly, science has moved forward to where the inclusion of children in experimental therapies is essential.

  The location of clinical trial sites and the availability of affordable transportation to them are crucial factors in making clinical trials accessible to children. We heard from one mother who traveled from Florida, to North Carolina and finally to Maryland before she could get her daughter into a clinical trial. We were also told that unless transportation is available and affordable it can be impossible for many people to travel even 45 minutes away from home. These are problems we can address and must address quickly.

- The Commission believes the NIH Community Program for Clinical Research on AIDS (CPCRA) is an imaginative and positive step. Because of a different philosophy and an aggressive grassroots impetus, these trials should help include people of color, women, intravenous drug users, children and other under-represented communities in clinical trials. The Commission heard testimony from three physicians participating in the CPCRA program. All testified that the program would enable greater participation of people in trials at the places where they receive primary health care. "Clinical trials conducted in the primary care setting," according to one physician, "have access to large numbers of patients and are likely to fill quickly and finish as rapidly as possible." We also heard testimony from the National Hemophilia Foundation (NHF) about an ACTG-without-walls concept that demonstrates community programs do not sacrifice scientific value and integrity. The Commission strongly encourages continuation and expansion of the CPCRA program in parallel with the steps necessary to strengthen the ACTG's.

- Complaints were expressed about delays in the publication of clinical trial information. One witness urged all agencies sponsoring clinical trials in HIV/AIDS "to be more accountable to an anxious public, and that they actively and expeditiously release specific data concerning the results of their clinical trials."

- One impression needs swift settlement. We were told that there currently exists a perception of conflict of interest for some investigators who play an advisory role with the NIH in setting national AIDS research priorities. One witness called on the Secretary of Health and Human Services "to mandate the full disclosure of all consulting relationships these investigators maintain with pharmaceutical companies." This deserves a prompt response from the Department of Health and Human Services.

Summary

As is apparent, the Commission is worried about the status of clinical treatment trials. We are vividly aware of the enormous challenge confronting all scientists in developing new drugs and therapies for HIV and opportunistic infections. The obstacles are many and the successes, still sadly enough, are all too few. But the hope for thousands of people still rests with our clinical trial programs. Clearly these must be made more encompassing, more readily accessible to all, easy to find, well managed and well coordinated. There are many problems which need attention. We know they are being addressed but we can and must do better, swiftly and visibly.

PERSONNEL AND WORKFORCE

Overview

On July 18 and 19, the Commission convened a hearing to examine the personnel shortages which are hampering our response to the HIV epidemic. Physicians, nurses, dentists, social workers, allied health workers, volunteers, and representatives from the federal government and professional organizations presented the Commission with a picture of a national health care workforce confronted with increasing demands and decreasing support and re-enforcements. We were also reminded that unrealistically low health care reimbursement rates, especially rates for outpatient services, continue to serve as institutional disincentives for many health care providers to care for people with HIV infection and AIDS.

Findings

DENTISTS

While there does not appear to be a national shortage of dentists, we heard repeatedly about a serious shortage of dentists willing to treat people with HIV infection and AIDS. We were told that since the early days of the epidemic many dentists did not treat people with AIDS because they were afraid and because they felt dentists had a traditional right to choose their own patients and refuse to see those who were suspected of or who openly admitted to being infected. "Happily," we were told by the American Dental Association, "not all dentists chose this avenue of escape, and the avenue has been closing as understanding of the disease has grown, as courts have declared this kind of behavior unacceptable, as dentists have become more comfortable with the disease and as their sense of moral and professional responsibility has replaced their initial fears."

While the Commission believes more dentists are willing to treat people with HIV infection and AIDS than in the early days of the epidemic, the number remains grossly inadequate and unacceptable. The difficulty, and in many cases complete inability, of obtaining dental services is still an all too common problem for people living with HIV infection and AIDS. One witness told us of only two dentists in his community who would accept Medicaid, neither of whom would see him due to his HIV infection. One dentist's excuse was that his office was carpeted and he would not be able to sterilize the room after the visit. The other dentist said she had plants and could not take the risk of him infecting her plants and her plants then infecting her other patients. That particular witness did find an oral surgeon who was willing to see him, but only if he would come after hours, come in the back door, and not tell anyone he had been there.

As one Commissioner put it, "Whether it is in rural communties or big cities, when it comes to dentists, I just keep hearing people with HIV infection and AIDS saying, 'I can't get help.'"

NURSES

The current nursing shortage continues to be of crisis proportions. The Commission heard testimony from experts who have studied the overall nursing shortage. It is clear to us the shortage promises to get worse in the future unless it is addressed now. We were told the Department of Health and Human Services and Department of Labor are predicting that the need for Registered Nurses will increase by 60 percent in the next 10 years. And, contrary to popular opinion, there is no untapped resource of trained nurses. One witness told us that only 4 percent of licensed Registered Nurses are working outside of nursing.

While efforts are underway to address the overall nursing shortage, special efforts are needed to better understand and address how the shortage is compounded by the HIV epidemic. Misinformation and fear about caring for people with HIV infection and AIDS and the considerable emotional strain that often comes with caring for people with HIV infection and AIDS are issues which must be confronted if we are to prevent nurses from avoiding the field.

PHYSICIANS

A shocking number of physicians are reluctant to take care of people living with HIV infection and AIDS. The New York Times recently reported that "with an estimated 200,000 people infected with the virus, New York City has more AIDS cases than any other city in the world. Still, the city's Health Department records show that 78 percent of local physicians and dentists have never done a single AIDS test. Although the city has about 25,000 physicians, the Gay Men's Health Crisis, the largest volunteer AIDS agency, has a referral list of just 45 qualified private AIDS specialists in Manhattan who are willing to take patients. There are only one or two for each of the city's other four boroughs which have half of the city's cases." Nationally, the Physicians Association for AIDS Care has a referral list of only 2,000 physicians, a tiny fraction of the country's total of 600,000.

One witness told us of a recent study that estimated only "10 percent of internal medicine residents have a strong commitment to the care of HIV infected people and are likely to include them in their post-training practice. About 25 to 30 percent have a definite aversion to HIV work and are planning their professional lives to avoid contact with these patients. The remaining 65 percent are neutral or uncommitted in their stance towards the AIDS epidemic."

Unwillingness or reluctance to care for people with HIV infection and AIDS is often attributed to fear of occupational risk and lack of adequate training and expertise in treating HIV infection and AIDS. The Commission believes both of these concerns should be acknowledged and addressed. Support at every institutional level is needed for education about occupational risks, training in the use of universal precautions, and the provision of adequate equipment. Support is also needed to develop a comprehensive HIV/AIDS educational strategy that effectively meets the needs of all physicians, particularly primary care physicians. After all, as one witness reminded us, if you consider that we have one million or more cases of persons infected with HIV across the country, it can no longer be acceptable for a physician or dentist to offer as an excuse, "I don't have expertise in relation to this particular disease." They simply must acquire the expertise.

Finally, we were told that "physicians who do not intend to work with HIV infected patients are characterized by negative attitudes toward people from predominant HIV risk groups, dislike working with an incurable disease which produces progressive loss of function and decreasing dependency, and a weak sense of professional responsibility." These findings certainly have important implications as we attempt to increase the willingness of physicians to work with people with HIV infection and AIDS, and to ensure access to care.

SOCIAL WORKERS

Many people living with HIV infection and AIDS have relied on social workers for much of their care. Social workers have developed many of the early models of AIDS services and community care and provided all levels of service for patients and families. The number of social workers across the country (500,000 in total) falls far short of the growing need. Social workers have long gone unsupported and unrewarded. It is time that changed.

ALLIED HEALTH

Clearly, physicians, nurses, dentists, and social workers are not the only care providers in the HIV epidemic. Indeed, allied health workers do much of the hands-on care provided to people with HIV infection and AIDS. One witness pointed out there are 85 allied health professions, representing one-to two-thirds of the entire health workforce. These professionals are the hundreds of thousands across the country who draw blood, process HIV antibody tests, provide respiratory therapy, physical therapy, nutritional therapy and countless other health care services so many of us take for granted. There is a shortage of allied health professionals and, we were told, the shortage will be greater than the current physician and nursing shortage.

PUBLIC HEALTH

The Commission also recognizes that there is an increasing need for public health specialists such as epidemiologists and biostatisticians. Nurses, physicians, dentists and others trained specifically in public health and often serving in community settings need support and re-enforcement. Schools of public health must expand and enrich HIV/AIDS specific programs in their curricula and training opportunities.

VOLUNTEERS

Volunteers are now and always have been at the heart of our response to the HIV/AIDS epidemic. They provide many of the services traditionally provided by paid professionals. "It is the volunteers," we were told, "who do the job, and most important in some ways it is the volunteers who save all of us millions of dollars every single year in this epidemic."

But all too often volunteers are viewed as a free resource, when in fact volunteers require financial and management support for recruitment, training and coordination. The cost effective dollars to train and support one of our most valuable resources in the HIV/AIDS epidemic simply must be given priority in government grants and agency operating budgets. In addition, one witness told us, something as simple and inexpensive as the President inviting AIDS volunteers to the White House would not only honor AIDS volunteers but would also send the message that our country is still in the midst of an HIV/AIDS epidemic and volunteers are key to the country's response.

Summary

Finally, the Commission heard from experts about the ethical dilemmas confronting health care workers in the HIV/AIDS epidemic. Concerns about occupational risk, duty to treat, the right to know a patient's HIV antibody status, emotional stress and strain, and assisting patients to make treatment decisions were all raised as difficult, sensitive issues that we must begin to confront and to assist health care workers to resolve. Caring for people with HIV infection and AIDS will challenge health care providers to overcome their fears, ignorance and prejudices. For many this will not be easy. But, as one witness reminded us, "We have taken on difficult tasks before." What we must do, he said, "is teach people a set of skills that we have largely ignored: how to relate to patients, how to understand their frame of reference.... We are defined by our patients and by the depth and breadth of care that we provide for them...we must encompass that when we become a professional."

It is clear to the Commission that effective AIDS education programs are needed for all health care workers. This includes those who are currently practicing, as well as those in training. We must support and re-enforce those who have chosen to provide the care and services needed over the last decade to people living with HIV infection and AIDS. We can no longer rely on what one witness called "people with a calling." By a personal demonstration of tolerant, less judgmental, more accepting, more compassionate, and more constructive attitudes toward all people living with HIV infection and AIDS, each of us could help this nation move more swiftly toward the changes that must come if we are to truly care for all people and control the HIV epidemic.

The Commission makes the following recommendations:

1. A comprehensive community-based primary health care system, supported by adequate funding and reimbursement rates, is essential for the care and treatment of all people, including people living with HIV infection and AIDS. The Commission highlighted this need in its first report and continues to believe that lack of access to primary care services provided by adequately trained primary care providers is undermining current efforts in HIV/AIDS research, prevention and treatment. The development of a comprehensive system with linkages to research protocols, existing community-based services, hospitals, drug treatment programs, local health departments, and longterm care facilities, based on a foundation of adequate support, is long overdue and should be a top priority for the federal government.

2. AIDS education and outreach services in rural communities should be expanded and designed to provide clear and direct messages about how HIV is and is not transmitted, and the kinds of behaviors that may place an individual at risk for HIV and other sexually transmitted diseases. Expansion of programs, resources and health care providers is also needed to respond to rural America's need for prevention and treatment programs that address the three epidemics of HIV infection, drug addiction and sexually transmitted diseases.

3. The NIH clinical trials program is in serious trouble. The limited number of enrollees in trials and the lack of demographic and geographic diversity of the participants threatens the success of the program and denies many people living with HIV infection and AIDS the opportunity to participate in experimental drug therapies. The academic health centers involved have not been as vigorous as one would hope in advancing these trials, nor has the NIH been vigorous in monitoring their performance. Aggressive efforts must be made to overcome the obstacles to participation for many who are under-represented. Success in this area can only be measured by increased participation in trials.

4. There is a desperate need for more research on the management of opportunistic infections, usually the cause of death for people with AIDS. The NIH simply must expand the level of research in this area. This expansion must not come at the expense of other research efforts and should be an integral part of a comprehensive AIDS research plan. This plan should outline the AIDS research priorities and goals for the entire NIH, and the resources needed to achieve them. The plan should be widely disseminated and should incorporate the views of persons living with HIV infection and AIDS.

5. There is a shortage of crisis proportions of health care providers capable and willing to care for people living with HIV infection and AIDS. This crisis will only get worse as the HIV epidemic continues into the 1990's. Action must be taken now to increase and improve the effectiveness of all programs designed to educate and retain practicing health care professionals, and to create incentives for providers to care for people in underserved areas. Existing programs such as the National Health Service Corps should be expanded. New programs such as those outlined in the

Disadvantaged Minority Health Improvement Act (H.R. 3240) should be created. And, specific HIV/AIDS fellowships and training programs should be established and supported to prevent a crisis of greater magnitude.

6. Volunteers should be publicly recognized not only for the invaluable contribution they have made to people living with HIV infection and AIDS, but also for the way in which they fight fear and bigotry by fostering compassion and caring. The cost effective dollars needed to recruit, train, support and manage volunteers must be provided by the government and the private sector, and recognized as essential to our national response to the HIV epidemic.

APPENDICES

Appendix A

PUBLIC LAW 100-607

National Commission on Acquired Immune Deficiency Syndrome Act. 42 USC 300cc note.

Subtitle D—National Commission on Acquired Immune Deficiency Syndrome

SEC. 241. SHORT TITLE.

This subtitle may be cited as the "National Commission on Acquired Immune Deficiency Syndrome Act".

SEC. 242. ESTABLISHMENT.

There is established a commission to be known as the "National Commission on Acquired Immune Deficiency Syndrome" (hereinafter in this Act referred to as the "Commission").

SEC. 243. DUTIES OF COMMISSION.

(a) General Purpose of the Commission.—The Commission shall carry out activities for the purpose of promoting the development of a national consensus on policy concerning acquired immune deficiency syndrome (hereinafter in this subtitle referred to as "AIDS") and of studying and making recommendations for a consistent national policy concerning AIDS.

(b) Succession.—The Commission shall succeed the Presidential Commission on the Human Immunodeficiency Virus Epidemic, established by Executive Order 12601, dated June 24, 1987.

(c) Functions.—The Commission shall perform the following functions:

(1) Monitor the implementation of the recommendations of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, modifying those recommendations as the Commission considers appropriate.

Research and development. State and local governments.

(2) Evaluate the adequacy of, and make recommendations regarding, the financing of health care and research needs relating to AIDS, including the allocation of resources to various Federal agencies and State and local governments and the roles for and activities of private and public financing.

(3) Evaluate the adequacy of, and make recommendations regarding, the dissemination of information that is essential to the prevention of the spread of AIDS, and that recognizes the special needs of minorities and the important role of the family, educational institutions, religion, and community organizations in education and prevention efforts.

(4) Address any necessary behavioral changes needed to combat AIDS, taking into consideration the multiple moral, ethical, and legal concerns involved, and make recommendations regarding testing and counseling concerning AIDS, particularly with respect to maintaining confidentiality.

Civil rights.

(5) Evaluate the adequacy of, and make recommendations regarding, Federal and State laws on civil rights relating to AIDS.

(6) Evaluate the adequacy of, and make recommendations, regarding the capability of the Federal Government to make and implement policy concerning AIDS (and, to the extent feasible to do so, other diseases, known and unknown, in the future), including research and treatment, the availability of clinical trials, education and the financing thereof, and including specifically—

(A) the streamlining of rules, regulations, and administrative procedures relating to the approval by the Food and Drug Administration of new drugs and medical devices, including procedures for the release of experimental drugs; and

(B) the advancement of administrative consideration by the Health Care Financing Administration relating to reimbursement for new drugs and medical devices approved by the Food and Drug Administration.

(7) Evaluate the adequacy of, and make recommendations regarding, international coordination and cooperation concerning data collection, treatment modalities, and research concerning AIDS.

SEC. 244. MEMBERSHIP.

(a) NUMBER AND APPOINTMENT.—

(1) APPOINTMENT.—The Commission shall be composed of 15 members as follows:

(A) Five members shall be appointed by the President—

President of U.S.

(i) three of whom shall be—

(I) the Secretary of Health and Human Services;

(II) the Administrator of Veterans' Affairs; and

(III) the Secretary of Defense;

who shall be nonvoting members, except that, in the case of a tie vote by the Commission, the Secretary of Health and Human Services shall be a voting member; and

(ii) two of whom shall be selected from the general public on the basis of such individuals being specially qualified to serve on the Commission by reason of their education, training, or experience.

(B) Five members shall be appointed by the Speaker of the House of Representatives on the joint recommendation of the Majority and Minority Leaders of the House of Representatives.

(C) Five members shall be appointed by the President pro tempore of the Senate on the joint recommendation of the Majority and Minority Leaders of the Senate.

(2) CONGRESSIONAL COMMITTEE RECOMMENDATIONS.—In making appointments under subparagraphs (B) and (C) of paragraph (1), the Majority and Minority Leaders of the House of Representatives and the Senate shall duly consider the recommendations of the Chairmen and Ranking Minority Members of committees with jurisdiction over laws contained in chapter 17 of title 38, United States Code (relating to veterans' health care), title XIX of the Social Security Act (42 U.S.C. 1901 et seq.) (relating to Medicaid), and the Public Health Service Act (42 U.S.C. 201 et seq.) (relating to the Public Health Service).

(3) REQUIREMENTS OF APPOINTMENTS.—The Majority and Minority Leaders of the Senate and the House of Representatives shall—

(A) select individuals who are specially qualified to serve on the Commission by reason of their education, training, or experience; and

(B) engage in consultations for the purpose of ensuring that the expertise of the 10 members appointed by the Speaker of the House of Representatives and the President pro tempore of the Senate shall provide as much of a balance as possible and, to the greatest extent possible, cover the fields of medicine, science, law, ethics, health-care economics, and health-care and social services.

(4) TERM OF MEMBERS.—Members of the Commission (other than members appointed under paragraph (1)(A)(i)) shall serve for the life of the Commission.

(5) VACANCY.—A vacancy on the Commission shall be filled in the manner in which the original appointment was made.

(b) CHAIRMAN.—Not later than 15 days after the members of the Commission are appointed, such members shall select a Chairman from among the members of the Commission.

(c) QUORUM.—Seven members of the Commission shall constitute a quorum, but a lesser number may be authorized by the Commission to conduct hearings.

(d) MEETINGS.—The Commission shall hold its first meeting on a date specified by the Chairman, but such date shall not be earlier than September 1, 1988, and not be later than 60 days after the date of the enactment of this Act, or September 30, 1988, whichever is later. After the initial meeting, the Commission shall meet at the call of the Chairman or a majority of its members, but shall meet at least three times each year during the life of the Commission.

(e) PAY.—Members of the Commission who are officers or employees or elected officials of a government entity shall receive no additional compensation by reason of their service on the Commission.

(f) PER DIEM.—While away from their homes or regular places of business in the performance of duties for the Commission, members of the Commission shall be allowed travel expenses, including per diem in lieu of subsistence, at rates authorized for employees of agencies under sections 5702 and 5703 of title 5, United States Code.

(g) DEADLINE FOR APPOINTMENT.—Not earlier than July 11, 1988, and not later than 45 days after the date of the enactment of this Act, or August 1, 1988, whichever is later, the members of the Commission shall be appointed.

SEC. 245. REPORTS.

(a) INTERIM REPORTS.—

(1) IN GENERAL.—Not later than 1 year after the date on which the Commission is fully constituted under section 244(a), the Commission shall prepare and submit to the President and to the appropriate committees of Congress a comprehensive report on the activities of the Commission to that date.

(2) CONTENTS.—The report submitted under paragraph (1) shall include such findings, and such recommendations for legislation and administrative action, as the Commission considers appropriate based on its activities to that date.

(3) OTHER REPORTS.—The Commission shall transmit such other reports as it considers appropriate.

(b) FINAL REPORT.—

(1) IN GENERAL.—Not later than 2 years after the date on which the Commission is fully constituted under section 244(a), the Commission shall prepare and submit a final report to the President and to the appropriate committees of Congress.

(2) CONTENTS.—The final report submitted under paragraph (1) shall contain a detailed statement of the activities of the Commission and of the findings and conclusions of the Commis-

sion, including such recommendations for legislation and administrative action as the Commission considers appropriate.

SEC. 246. EXECUTIVE DIRECTOR AND STAFF.

(a) EXECUTIVE DIRECTOR.—

(1) APPOINTMENT.—The Commission shall have an Executive Director who shall be appointed by the Chairman, with the approval of the Commission, not later than 30 days after the Chairman is selected.

(2) COMPENSATION.—The Executive Director shall be compensated at a rate not to exceed the maximum rate of basic pay payable under GS-18 of the General Schedule as contained in title 5, United States Code.

(b) STAFF.—With the approval of the Commission, the Executive Director may appoint and fix the compensation of such additional personnel as the Executive Director considers necessary to carry out the duties of the Commission.

(c) APPLICABILITY OF CIVIL SERVICE LAWS.—The Executive Director and the additional personnel of the Commission appointed under subsection (b) may be appointed without regard to the provisions of title 5, United States Code, governing appointments in the competitive service, and may be paid without regard to the provisions of chapter 51 and subchapter III of chapter 53 of such title relating to classification and General Schedule pay rates.

(d) CONSULTANTS.—Subject to such rules as may be prescribed by the Commission, the Executive Director may procure temporary or intermittent services under section 3109(b) of title 5, United States Code, at rates for individuals not to exceed $200 per day.

(e) DETAILED PERSONNEL AND SUPPORT SERVICES.—Upon the request of the Commission for the detail of personnel, or for administrative and support services, to assist the Commission in carrying out its duties under this Act, the Secretary of Health and Human Services and the Administrator of Veterans' Affairs, either jointly or separately, may on a reimbursable basis (1) detail to the Commission personnel of the Department of Health and Human Services or the Veterans' Administration, respectively, or (2) provide to the Commission administrative and support services. The Secretary and the Administrator shall consult for the purpose of determining and implementing an appropriate method for jointly or separately detailing such personnel and providing such services.

SEC. 247. POWERS OF COMMISSION.

(a) HEARINGS.—For the purpose of carrying out this Act, the Commission may conduct such hearings, sit and act at such times and places, take such testimony, and receive such evidence, as the Commission considers appropriate. The Commission may administer oaths or affirmations to witnesses appearing before the Commission.

(b) DELEGATION.—Any member or employee of the Commission may, if authorized by the Commission, take any action that the Commission is authorized to take under this Act.

(c) ACCESS TO INFORMATION.—The Commission may secure directly from any executive department or agency such information as may be necessary to enable the Commission to carry out this Act, except to the extent that the department or agency is expressly prohibited by law from furnishing such information. On the request of the Chairman of the Commission, the head of such department or agency shall furnish nonprohibited information to the Commission.

(d) MAILS.—The Commission may use the United States mails in the same manner and under the same conditions as other departments and agencies of the United States.

SEC. 248. AUTHORIZATION OF APPROPRIATIONS.

There is authorized to be appropriated for fiscal year 1989 $2,000,000, and such sums as may be necessary in any subsequent fiscal year, to carry out the purposes of this Act. Amounts appropriated pursuant to such authorization shall remain available until expended.

SEC. 249. TERMINATION.

The Commission shall cease to exist 30 days after the date on which its final report is submitted under section 245(b). The President may extend the life of the Commission for a period of not to exceed 2 years.

Appendix B

SUPPORTING DOCUMENTS FOR BACKGROUND PAPER ON IMMIGRATION

SIXTH INTERNATIONAL CONFERENCE ON AIDS
SAN FRANCISCO, CALIFORNIA USA • 20–24 JUNE 1990

Sponsor
University of California San Francisco

Co-Sponsors
World Health Organization
City and County of San Francisco
American Foundation for AIDS Research
International AIDS Society

Local Program Office
University of California San Francisco
Box 1505
San Francisco
California
94143-1505
USA
Telephone
415-550-0880
Telefax
415-550-0886

November 17, 1989

June E. Osborn, M.D.
Chair
National Commission on AIDS
1730 K Street N.W. Suite 815
Washington, D.C. 20006

Dear Dr. Osborn,

As you are aware, the Sixth International Conference on AIDS has been deeply involved in attempts to eliminate all federal regulations restricting travel of HIV infected individuals to the United States.

The government took a positive first step when, on May 25, the Justice Department issued directives establishing a procedure by which HIV infected individuals may obtain waivers to enter the United States. We wish to make clear, however, that federal policy on this issue remains medically unsound and counter-productive to global efforts to control the AIDS epidemic.

We write to urge the National Commission on AIDS to use its influence with all appropriate agencies of the federal government to achieve the elimination of restrictions on travel of HIV infected individuals to the United States.

AIDS is not a casually contagious disease, and is spread only by engaging in certain high risk behaviors. HIV infected foreigners pose no greater health risk to residents of the United States who practice safe sexual behaviors than any other individuals. Suggesting that they are a threat does nothing to assist the government's own efforts to reduce unwarranted fear of HIV.

Given the medical facts about the risks of AIDS transmission, the federal government is not assisting in control of the AIDS epidemic through its policies on travel of HIV infected people. The government may, in fact, be doing harm to the global effort to control AIDS.

An important goal of eliminating barriers to travel of HIV infected individuals is assuring participation of HIV infected AIDS researchers, educators and service providers in meetings directed at controlling the epidemic globally. The May 25 directives have not resolved the threat posed to free exchange of knowledge and information required to control AIDS.

HIV infected individuals take many unacceptable risks in applying for and obtaining a waiver to travel to the United States.

We share the concern of many of our delegates that they may suffer severe discrimination if the government of their country of residency is allowed to access information concerning their HIV status obtained through the HIV waiver process. We are also concerned that documentation in passports and visas that in any way suggests an individual may be HIV infected could result in the limitation of international travel over which the United States should have no control.

Additionally, we take strong exception to the power of government officials to require travellers to submit to HIV antibody tests. The World Health Organization has stated that such policies will do little or nothing to control the spread of AIDS. The United States has carefully avoided taking these highly intrusive steps with its own citizens. We can think of no medical justification for doing so with travellers to this country.

The May 25 directives were intended in part to protect the leadership of the United States in AIDS research, treatment, education and social services by assuring that HIV infected scientists and service providers can participate in AIDS related meetings here. Given the many problems with the directives, however, there appears to be increased international refusal to attend AIDS related meetings in this country. We know the Commission understands how significant a threat this poses to the goal of controlling AIDS, and to the image of the United States among all people of the world anxious for a response to the epidemic.

Finally, we concur with Members of Congress, including Senator Wilson and Representative Pelosi, that it was not the intent of the Senate in adopting legislation restricting immigration of HIV infected people to also restrict the travel of HIV infected individuals. It is also clear from comments by the Secretary of Health and Human Services in the Federal Register on June 8, 1987 that the proposed rules governing immigration of HIV infected individuals were not intended to control travel.

Enclosed is a Resolution of the delegates to the Vth International Conference on AIDS in Montreal calling on all governments to permit unrestricted entry of HIV infected travellers.

We appreciate the leadership of the National Commission on AIDS on this critical issue which threatens discrimination against many individuals important to the effort to identify solutions to the AIDS epidemic.

Please contact us if we can provide further information as the Commission deliberates this issue and considers its approach to the administration to correct this unsound policy.

Sincerely,

John L. Ziegler, MD

John Ziegler, M.D.
Co-Chair

Paul Volberding, M.D.
Co-Chair

cc: James Mason, M.D.

A RESOLUTION OF
THE DELEGATES TO THE VTH INTERNATIONAL CONFERENCE ON AIDS CALLING ON ALL GOVERNMENTS TO PERMIT ENTRY OF HIV INFECTED TRAVELERS

WHEREAS, AIDS and HIV infection are not casually transmitted and travelers infected with HIV do not pose a health risk to others; and

WHEREAS, Restrictions on travel of HIV infected people are not medically or scientifically justified and will not play a significant role in preventing the spread of the AIDS epidemic; and

WHEREAS, People with AIDS and HIV infection have taken leadership roles in altering the course of the AIDS epidemic throughout the world as physicians, researchers, care providers and patients; and

WHEREAS, Several nations now deny or limit the entry of HIV infected people for purposes of travel; and

WHEREAS, Such restrictions inhibit the free exchange of critical research and information upon which all nations depend to respond to the AIDS epidemic; and

WHEREAS, The World Health Organization opposes the "stigmatization" of persons with AIDS and HIV infection and supports an open border policy in all nations with regard to persons with HIV infection; and

WHEREAS, The government of the United States has recently taken steps that will permit HIV infected individuals to seek waivers to enter the country solely for the purposes of attending conferences, visiting relatives, obtaining medical treatment and conducting business;

BE IT RESOLVED, That the delegates to the Fifth International Conference on AIDS condemn the policies of nations which restrict the entry of HIV infected travelers; and

BE IT FURTHER RESOLVED, That the delegates to the Fifth International Conference on AIDS call on the governments of all nations to adopt policies permitting entry of HIV infected travelers; and

BE IT FURTHER RESOLVED, That the delegates to the Fifth International Conference on AIDS seek assurances from the Government of the United States that all persons wishing to attend the Sixth International Conference on AIDS in San Francisco will be assured entry into the United States regardless of HIV status; and

Approved at Closing Ceremonies
June 9, 1989

UK NGO AIDS CONSORTIUM FOR THE THIRD WORLD

Martin Whiteside, Chairperson
Sue Lucas, Co-ordinator

Professor June Osborn
Chairman, National Commission on AIDS
University of Michigan

November 16, 1989

Dear Professor Osborn,

RE: US ENTRY RESTRICTIONS AND VIth INTERNATIONAL CONFERENCE ON AIDS IN SAN FRANCISCO, JUNE 1989

We have recently become aware of the full implications of the US entry restrictions for people who are HIV positive or have AIDS, and we are writing to you in the belief that you will not only appreciate how serious these are, but also will be able to influence the thinking in the US on this matter. Dr Tony Pinching of St Mary's Hospital in London suggested your name.

I am sure that you are only too well aware of the current restrictions, and the fact that a person who is HIV positive or who has AIDS must apply for a waiver if he or she wishes to enter the States. The visa is then for a maximum period of 30 days, and only if the purpose of the visit is business, a conference, medical treatment or to visit relatives.

I have just received further information about this from Barbara Wallace of the League of Red Cross and Red Crescent Societies in Geneva, who recently visited the Department of State in Washington DC and spoke to the Associate Director of Visa Services about how the waiver works in practice.

The procedure is as follows:
Anyone wishing to enter the States must fill out a form obtained from the American Embassy in their own country. If they are HIV positive or have any other sexually transmitted or contagious disease, they are supposed to tick the relevant section on the form. An interview with Embassy staff is then arranged, to find out further details. If the person has a treatable disease, (eg syphilis) they are told to go and get treatment and then re-apply. If, however, they state that they have HIV, and request a waiver, the decision becomes a matter for the Attorney General. An unclassified cable is sent to the Attorney General's Office (which for African countries is in Rome) giving details of the person's name, serostatus and request for a waiver. The decision is taken in about a week to ten days. If a waiver is granted, the person's passport is stamped with a visa with a number 6 at the bottom. This number refers to 2286 - the number for dangerous and contagious diseases - and indicates to the Immigration and Naturalisation Service (INS) officials that a waiver has been granted for one of these conditions. In theory this could mean a number of conditions, but in practice this nearly always means HIV, since anyone with a treatable disease will be encouraged to return after seeking treatment. The meaning of the number 6 is not confidential information.

Three Castles House, 1, London Bridge Street, London SE1 9SG Tel: 01-378 1403 Fax: 01-403 6003

Not only is the information that a person is HIV positive permanently marked in his or her passport, but it is also recorded in the US Embassy records in his or her home country. Although these records are not open to the public, they are not kept confidential from embassy staff, who include those recruited locally.

This procedure clearly compromises the confidentiality of HIV positive people and people with AIDS and could be particularly serious for nationals of countries where the government suppresses the rights of people who are HIV positive.

There are also implications for agencies who wish to sponsor individuals to conferences in the States, in particular the VIth International Conference on AIDS. By offering sponsorship, the agency may be putting an individual into the position of either identifying him or herself as HIV positive or breaking the law. In addition, if a sponsored individual who was HIV positive entered without a waiver and was then found to be or suspected of being HIV positive, this could involve considerable legal and repatriation fees - which sponsors would presumably have to meet. Several Consortium members feel that they cannot sponsor conference attendance in the US, especially for the VIth International AIDS Conference in San Francisco, while the current regulations are in force.

We hope very much that your influence - and that of others who realise the serious and permanent consequences of the US policy to individuals - can bring about some change before the Conference. If not, and if it is impossible to change the venue, then several Consortium members feel that they will have to boycott the Conference. This position has already been taken by the Scandinavian AIDS and HIV organisations, and some British organisations. The League of Red Cross and Red Crescent Societies has also just withdrawn from the conference. No-one wants to take this step, because we believe that there is value in meeting annually and of having the widest possible representation, including people who are HIV positive and have AIDS, and people from the worst affected countries. But we cannot recommend that anyone should be put in a position in which they must reveal their serostatus to officials who will both mark their passports and keep a permanent record.

Yours sincerely

Sue Lucas

Sue Lucas
For Consortium Steering Group

cc Prof LO Kallings, President IAS, Sweden
Prof. P Volberding, President Elect IAS, Joint Chairman, VIth International Conference on AIDS, USA
Prof F Deinhardt Executive Secretary, IAS, Germany
Prof June Osborn, Chairman Presidential AIDS Commission, USA
Norbert Gilmore, Royal Victoria Hospital, Canada
Justice Michael Kirby, President of the Court of Appeal, Supreme Court, Australia
Senator Edward Kennedy

Your Ref.
Our Ref. HD/BWS

LEAGUE OF RED CROSS
AND RED CRESCENT SOCIETIES
International Federation of
National Red Cross and Red Crescent Societies

RECEIVED
DEC - 5 1989

Dr. June Osborne
National Commission on AIDS
1730 K St. N.W.
Washington, D.C. 20006
USA

29 November 1989

Dear Dr. Osborne,

I am writing to inform you of the League of Red Cross and Red Crescent Society's decision to withdraw from participation in the VIth International Conference on AIDS in San Francisco, and of the reasons for that decision. We hope that by taking a stand on this issue at an early date, it may still be possible for changes in the U.S. visa regulations or their application to be made prior to the Conference. The League and our National Societies have participated actively in the two previous International Conferences, and very much regret the situation which makes it necessary for us to withdraw from the Conference in San Francisco.

I have attached a copy of a statement which we released on November 21, explaining our position. The decision was not taken lightly. Concern about the visa policy had first been expressed during a meeting of the Red Cross European and North American Task Force on AIDS in Stockholm in October. We wrote to the American Embassy in Switzerland asking for clarification on a number of points, and they referred us to the State Department. I travelled to Washington in November, and met with Richard H. Williams, Associate Director for Visa Services, on November 8.

As you are aware, a number of countries have experienced active discrimination against people with HIV/AIDS, so we were particularly concerned about the waiver procedure. Any process which exposes HIV status could put people at risk in their home country. We were also concerned about entry procedures in the U.S., which have already caused problems for a number of HIV positive people, and the potential liability (both financial and ethical) of the League should we sponsor delegates who are later detained and deported.

Mr. Williams informed me that everyone who applies for a visa at the American Embassy in their home country, and who has HIV or certain other sexually-transmitted or contagious diseases, is supposed to tick the appropriate category of Section 35. They are then interviewed by

Address:
17, chemin des Crêts
Petit-Saconnex
Geneva

Postal address:
P. O. Box 372
CH - 1211 Geneva 19
Switzerland

Bank address:
Postal cheque
account
Geneva 12-8020-2

Telephone (022) 734 55 80
Telegramme LICROSS-GENEVA
Telex 22555 LRCS CH
Telefax (022) 733 03 95

Embassy staff and asked to explain why they ticked this section. If they state that they have HIV, and request a waiver, an unclassified cable is sent to the Attorney General's office giving details of the person's name, serostatus and request for a waiver. The decision is taken in about a week. If the waiver is granted, the person's passport is stamped with a visa with the number "6" at the bottom. This number refers to 2286 - dangerous and contagious diseases - and indicates to Immigration and Naturalisation Service officials that the person has received a waiver for one of these conditions. In theory this could mean a number of conditions; in practice, according to Mr. Williams, it will nearly always mean HIV, since anyone with a treatable disease will be encouraged to return after seeking treatment. The meaning of the number 6 is not confidential, and a permanent record of the person's HIV status is kept in the Embassy records of the person's home country, where according to Mr. Williams it could be seen by Embassy staff.

This procedure clearly compromises the confidentiality of HIV positive people at several points, and could be particularly serious for nationals of countries where discrimination against people with HIV is common and/or condoned by the government.

This issue is extremely worrying for us because we have Red Cross or Red Crescent Societies in 149 countries, including those most affected by AIDS and those in which discrimination is a problem. We know that among our own staff a number of people are seropositive; these people may be some of our best workers, and would thus be likely to be offered sponsorship to San Francisco. For example, in one East African country where adult seropositivity rates are very high, the field staff of the National Society who gave blood during an AIDS training seminar were later found to have a seropositivity rate of nearly 30%. We have a humanitarian mandate to do everything in our power to prevent discrimination against people with HIV and AIDS; in addition, we have a personal stake in the visa issue because it will affect our Red Cross and Red Crescent staff.

We felt we had no alternative but to withdraw from the Conference, since we could not continue our planning while such visa regulations are in force. If we were to encourage our National Society staff to apply for sponsorship to the Conference, we would be faced with three options: encourage people not to declare their HIV status, which would mean we were encouraging them to break the law; encourage them to declare, which would mean that through our sponsorship they would be subjected to loss of confidentiality and possible discrimination (both in their home country and at entry into the U.S., where INS officials' behaviour is unpredictable); or encourage seropositives not to apply for sponsorship, which would mean we were participating in discrimination. All these options are untenable, since they are in clear violation of the stand taken against discrimination by the League General Assembly and contrary to the humanitarian mandate of the Red Cross Movement.

We have already received strong statements of support for the League position from European and North American Red Cross Societies, and expect further support from other regions when they have had time to receive and respond to our position paper.

We urge you to bring this matter before the National Commission on AIDS, and trust that the Commission will do everything in its power to effect a change in the visa requirements or their application. It would be regrettable if the visa requirements prevented the VIth International Conference from being the same type of international gathering which took place in Stockholm and Montreal. It would be tragic if the voices of people with HIV and AIDS from all parts of the world were not heard in San Francisco, or heard under conditions which violate human dignity and personal safety.

Yours sincerely,

Barbara Wallace

Barbara Wallace
AIDS Coordinator

cc. American Red Cross

STATEMENT BY THE LEAGUE OF RED CROSS AND RED CRESCENT SOCIETIES REGARDING PARTICIPATION IN THE SIXTH INTERNATIONAL CONFERENCE ON AIDS IN SAN FRANCISCO

The League of Red Cross and Red Crescent Societies has decided to withdraw from participation in the VIth International Conference on AIDS which will be held in San Francisco from June 20-24, 1990.

Pär Stenbäck, the Secretary General of the League in announcing this decision referred to the apparent conflict between U.S. visa policy regarding HIV positive individuals who might wish to attend the Conference and the Red Cross and Red Crescent principles of humanitarian support for and prevention of discrimination against people with HIV infection or AIDS.

The League will reconsider its position should there be changes in the U.S. visa regulations or their application.

Current U.S. regulations prohibit the granting of a visa to people with HIV infection or AIDS who wish to visit the U.S. It is possible for those who declare that they are HIV positive to apply for a waiver for up to 30 days if they are going for business, medical or family reasons. However, the procedure of granting this waiver and marking the visa does not provide satisfactory guarantees of confidentiality for the person in his or her home country or in other countries.

Decision 24 of the League of Red Cross and Red Crescent Societies' VIth General Assembly in 1987, which called all National Societies to action against AIDS, urged "all National Societies to do everything in their power to prevent discrimination against and offer humanitarian support to people who are carriers of HIV, people with AIDS and their families." To sponsor delegates or otherwise participate in the Conference would be in conflict with this mandate, as the League would appear to condone discriminatory visa policies. Should delegates from Red Cross or Red Crescent Societies who are seropositive be sponsored to attend, they would be put at risk from discriminatory policies and breaches in confidentiality. Conversely, if seropositive staff members were advised not to apply for sponsorship, the League would be participating in discrimination.

In addition to the League decision regarding discrimination, the 41st World Health Assembly (May 1988) resolved that member states should "protect the human rights and dignity of HIV infected people and people with AIDS...and avoid discriminatory action against and stigmatisation of them in the provision of services, employment and travel".

In the IV International Conference in Stockholm and the Vth International Conference in Montreal, the League of Red Cross and Red Crescent Societies played a very active role. In Stockholm, the

Swedish Red Cross organised a day-long meeting on the psychosocial aspects of the AIDS pandemic, ran a rest centre for people with AIDS, and organised a meeting for delegates from National Societies in 30 countries. There was also a League booth and display. A member of the Uganda Red Cross gave a moving address at the closing ceremony in which she asked all delegates to stand for a moment of silence to remember those who had died of AIDS around the world.

During the Montreal Conference, the League's exhibition of children's posters drawn by Red Cross and Red Crescent youth on themes of care, hope and compassion formed a key display. The League sponsored 15 delegates from developing countries, who also took part in the pre-conference meeting for non-governmental organisations. The League organised a series of international meetings for National Society delegates from 40 countries, covering topics such as "Working with youth at risk and street children", "Working with other non-governmental organisations including seropositive groups", "Blood donor education and counselling", and "Working at the grassroots - branches and chapters". The Canadian Red Cross provided all First Aid services to the Conference, and ran a rest centre and shuttle service for people with AIDS in cooperation with a Canadian seropositive group.

Similar activities had been planned for San Francisco before the visa issue arose. The League position does not imply a lack of support for the Conference organisers, or a failure to recognise the importance of such international gatherings.

21 November 1989

WORLD FEDERATION OF HEMOPHILIA
FEDERATION MONDIALE DE L'HEMOPHILIE
FEDERACION MUNDIAL DE HEMOFILIA

Suite 830 - 1450 City Councillors Street, Montreal, Canada H3A 2E6
Telephone: (514) 848-0315 Cable: WORHEMO Telex: 055-61764
Fax: (514) 848-0337

Founder
Frank Schnabel

Honorary Patron
Martha Schnabel

EXECUTIVE & COUNCIL

President
Charles J. Carman

Chairman
Reverend Alan Tanner

Vice President & Treasurer
Johannes Michels

Vice President - Medical
Pier Mannuccio Mannucci, M.D.

Vice President
José Alonso Gomez

Executive Members
Roberto Carcaro, M.D.
Klaus Schimpf, M.D.

Medical Secretaries
Shelby L. Dietrich, M.D.
Bruce L. Evatt, M.D.
Peter H. Levine, M.D.
Kevin A. Rickard, M.D.

Council Members
Takashi Abe, M.D.
William Mindak
Jennifer Ross
Cees Th. Smit Sibinga, M.D.

Medical Board Chairman
Elizabeth Berry, M.D.

Executive Director
Declan Murphy

Administrative Assistant
Sheila Brading

Official Relations

World Health Organization

International Committee on Thrombosis & Haemostasis

International Society of Blood Transfusion

International Society of Haematology

October 12, 1989

President George Bush
The White House
1600 Pennsylvania Avenue N.W.
Washington, D.C.. 20015, U.S.A.

Dear Mr. President:

In the name of the World Federation of Hemophilia, which has National Member Organizations in sixty-eight countries, and whose purpose is to strive to improve the quality of life for people afflicted with hemophilia, we wish to bring to your attention a situation which is particularly painful to this group of people. As well as having to learn to live with a life long physical disorder, recently they have been struck with a new drama: The very blood product which gave them hope has now condemned them to disaster. Many have contracted HIV because of contaminated blood products.

In August 1990, the World Federation of Hemophilia will hold its XIX International Congress in Washington, D.C. Recently it has been brought to our attention that as of 1987 the U.S. Congress approved an immigration policy whereby any person with HIV must declare their status and subsequently request an exemption in order to enter the United States. We feel that this truly is a discriminatory act, especially coming from a country which forged its very existence on the principle of freedom and respect for individual rights. People with hemophilia who have contracted HIV are innocent victims of the terrible leprosy of AIDS.

It has become so internationally sensitive that a few weeks ago, the Haemophilia Society of the United Kingdom called for a global boycott to protest the U.S. Immigration policy. Other member countries are now debating whether they should follow up with a similar call for a boycott.

We beg your immediate intervention on this delicate issue and bring this to your personal attention because there is no time for Congress to change the policy before the World Federation's meeting. The participants need to know immediately whether they will be subjected to this interrogation or whether they may plan their trip. People from many countries who live in constant pain and anguish and need support and encouragement are hoping that they may attend the World Federation's Congress without being forced to disclose their status, an infringement of their human rights. As you can understand, Mr. President, the benefits these people derive from such a Congress are vitally important to their lives. Yet unless there is sufficient participation we may see ourselves in the unfortunate position of being forced to cancel the event.

National Member Organizations: Algeria Arab Republic of Egypt Argentina Australia Austria Belgium Brazil Bulgaria Canada Chile Colombia Costa Rica Cuba Cyprus Denmark Dominican Republic El Salvador Federal Republic of Germany Finland France German Democratic Republic Greece Honduras Hungary Iceland India Indonesia Iran Ireland Israel Italy Jamaica Japan Kenya Korea Kuwait Luxembourg Malaysia Malta Mexico Netherlands New Zealand Nicaragua Nigeria Norway Pakistan Panama Paraguay Peru Philippines Poland Portugal Singapore Somali Republic South Africa Spain Sweden Switzerland Thailand Trinidad/Tobago Tunisia Turkey United Kingdom United States of America Uruguay Venezuela Yugoslavia Zimbabwe

Our request, in the name of those who suffer from hemophilia worldwide, is that you grant them the possibility to enter the United States of America next August without undergoing the humiliation of having to disclose publicly their health condition. On an international level, this will truly demonstrate to the world the humanitarian hand of the American people.

Thank you for your concern and help.

Gratefully yours,

Charles J Carman

Charles J. Carman
President

Declan Murphy

Declan Murphy
Executive Director

CJC/DM:an

THE WHITE HOUSE
WASHINGTON

November 15, 1989

Dear Mr. Carman:

Thanks for your recent letter on behalf of the World Federation of Hemophilia. It is indeed a cruel misfortune that many who suffer from hemophilia have now through transfusion contracted the HIV virus.

I asked my new INS Commissioner, Gene McNary, to review the immigration issue you've raised and have now received his reply. In 1987, the Congress passed a law adding HIV to the list of dangerous diseases that render aliens excludable from the United States. The INS is, of course, enforcing this law.

There is, as your letter notes, an exemption process that allows individuals infected with the HIV virus to enter the United States. I have been assured that the INS is sensitive to preventing any possible embarrassment connected with making such an application.

Special instructions regarding enforcement of this law have been sent to INS field offices. The application for a waiver may be made at any American consulate abroad at the time of application for a visa. In humanitarian cases involving medical problems such as hemophilia, the waiver process can be expedited. Medical information provided in the exemption application is held confidential and is not subject to public disclosure.

Gene McNary is also writing you and will supply additional information about our enforcement of this statute.

Sincerely,

Mr. Charles J. Carman
President
World Federation of Hemophilia
Suite 830
1450 City Councillors Street
Montreal H3A 2E6
CANADA

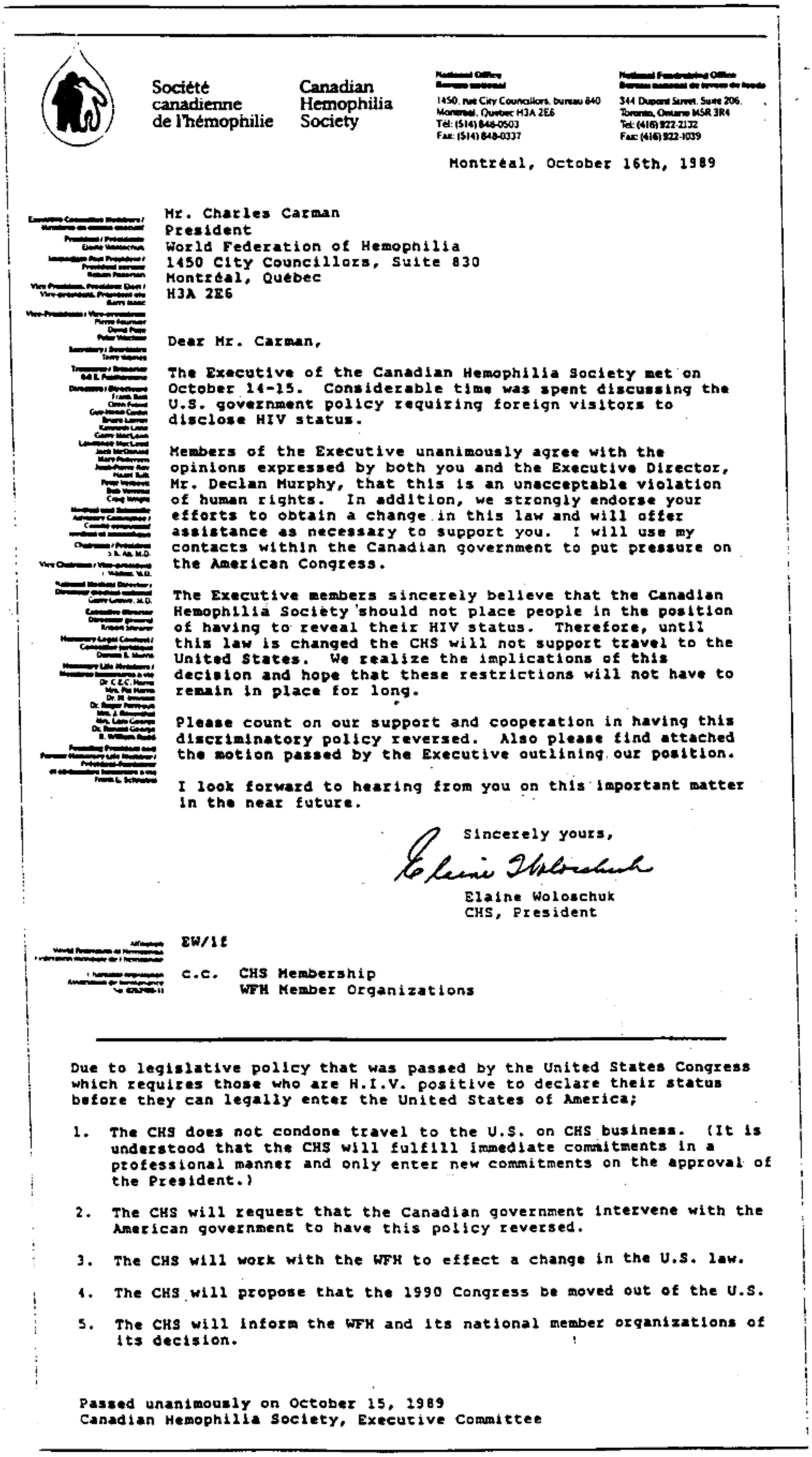
US Travel Restrictions

The Executive Committee of the Canadian Hemophilia Society held their fall meeting in Montreal on October 14 & 15. One very important issue that was raised, was the concern regarding the legislation policy that was passed by the United States Congress that requires those who are HIV positive to declare their status before they can legally enter the US.

The CHS Executive Committee unanimously agreed that this is an unacceptable violation of human rights and spent considerable time discussing what action they would take.

The following letter to Mr. Charles Carman, President of the World Federation of Hemophilia, with the attached motion clearly states the position of the Canadian Hemophilia Society with regards to the US legislation and the necessity not to condone travel to the United States.

We will endeavour to keep you informed of this very important issue through updates in *Hemophilia Today*.



Société canadienne de l'hémophilie
Canadian Hemophilia Society

National Office
Bureau national
1450, rue City Councillors, bureau 840
Montreal, Quebec H3A 2E6
Tél: (514) 848-0503
Fax: (514) 848-0337

National Fundraising Office
Bureau national de levée de fonds
344 Dupont Street, Suite 206,
Toronto, Ontario M5R 3R4
Tel: (416) 922-2132
Fax: (416) 922-1039

Montréal, October 16th, 1989

Mr. Charles Carman
President
World Federation of Hemophilia
1450 City Councillors, Suite 830
Montréal, Québec
H3A 2E6

Dear Mr. Carman,

The Executive of the Canadian Hemophilia Society met on October 14-15. Considerable time was spent discussing the U.S. government policy requiring foreign visitors to disclose HIV status.

Members of the Executive unanimously agree with the opinions expressed by both you and the Executive Director, Mr. Declan Murphy, that this is an unacceptable violation of human rights. In addition, we strongly endorse your efforts to obtain a change in this law and will offer assistance as necessary to support you. I will use my contacts within the Canadian government to put pressure on the American Congress.

The Executive members sincerely believe that the Canadian Hemophilia Society should not place people in the position of having to reveal their HIV status. Therefore, until this law is changed the CHS will not support travel to the United States. We realize the implications of this decision and hope that these restrictions will not have to remain in place for long.

Please count on our support and cooperation in having this discriminatory policy reversed. Also please find attached the motion passed by the Executive outlining our position.

I look forward to hearing from you on this important matter in the near future.

Sincerely yours,

Elaine Woloschuk

Elaine Woloschuk
CHS, President

EW/lf

c.c. CHS Membership
WFH Member Organizations

Due to legislative policy that was passed by the United States Congress which requires those who are H.I.V. positive to declare their status before they can legally enter the United States of America;

1. The CHS does not condone travel to the U.S. on CHS business. (It is understood that the CHS will fulfill immediate commitments in a professional manner and only enter new commitments on the approval of the President.)
2. The CHS will request that the Canadian government intervene with the American government to have this policy reversed.
3. The CHS will work with the WFH to effect a change in the U.S. law.
4. The CHS will propose that the 1990 Congress be moved out of the U.S.
5. The CHS will inform the WFH and its national member organizations of its decision.

Passed unanimously on October 15, 1989
Canadian Hemophilia Society, Executive Committee

EMBASSY OF THE
UNITED STATES OF AMERICA

September 29, 1989

35 [illegible]
Modt. - 2 OKT 1989
KOPI VZ ✓

Kurt Eriksen
President
Dansk Socialrådgiverforening
Toldbodgade 19A
1253 Kobenhavn K

Dear Mr. Eriksen:

I have good news from the United States regarding travel of HIV-positive persons. The guidance provided in May, which I sent to you, has been found too restrictive. New guidelines on this subject make it easier for HIV carriers to visit the U.S.

In evaluating any HIV-positive waiver request, the Immigration and Naturalization Service (INS) will weigh the risk of harm to society if the applicant is admitted and the nature of the applicant's reasons for wanting to enter the U.S. Also considered are: Danger to public health, possibility of spread of the infection, and cost which might be incurred by our government. The risk to public health must be balanced against the public benefit which would be realized if the waiver were granted.

The May 1989 INS guidance that "entry into the United States...for tourism...alone does not constitute the requisite public benefit to overcome the risk" ended up meaning that a child who had contracted AIDS at birth or through a blood transfusion, and who obviously would pose little danger of spreading the infection, would be unable to go with his family on a vacation in the U.S. Such waivers will now be granted.

There were also complaints received regarding the 30-day limit for waivers, which make extended medical treatment in the U.S. for AIDS victims impossible. There are undoubtedly cases in which longer stays in the U.S. would increase the public health risk posed by a visiting AIDS victim.

On the other hand, an AIDS sufferer who would be staying in a hospital while undergoing treatment, or in a clinic while participating in a research program, would pose a minimal public health risk, while possibly offering a substantial public benefit.

So, our policy has now changed: HIV carriers who wish to visit the U.S. for tourism, or who wish to stay for more than 30 days, whose presence in the U.S. would confer a public benefit outweighing the risk to public health, will be able to obtain visas. In such cases, we must still forward the case to the INS in Frankfurt for their final decision.

If you have further questions, please do not hesitate to contact us.

Sincerely,

Robert Fretz

Robert Fretz
Consul

COALITION FOR IMMIGRANT AND REFUGEE RIGHTS AND SERVICES

2111 Mission Street, Room 401 • San Francisco, California 94110 • (415) 626-2360

November 8, 1989

Dr. June E. Osborne
National AIDS Commission
1730 K Street N.W.
Washington, D.C. 20006

Dear Dr. Osborne:

We enjoyed meeting you and having the opportunity to discuss the issue of the HIV antibody testing of immigrants with you while you were here in San Francisco last month at the National AIDS Update. We have enclosed a comprehensive packet of background information for your staff and hope that the National AIDS Commission will examine this issue and make some public policy recommendations in this area. This letter outlines some of our most urgent concerns.

Of the most immediate concern are the several hundred applicants nationwide for legalization or so-called "amnesty" under the Immigration Reform and Control Act of 1986 (IRCA) that face denials of legalization without "waivers" of exclusion based on their HIV antibody seropositivity. There would be a direct and significant impact on these waiver decisions now pending at the Immigration and Naturalization Service (INS) if the National AIDS Commission would join other health officials and public policy makers in urging the generous granting of these waivers. The denial of these waivers by the INS would create a group of HIV seropositve persons living in the United States who would be afraid and unable to access adequate health care.

At the same time, we are alarmed at the lack of pre- and post-testing counselling of immigrants who receive the HIV antibody test from the INS-"designated civil surgeons." Although the Centers for Disease Control (CDC) has issued instructions regarding such counselling, there has been no training of these INS civil surgeons and there is no monitoring of whether such counselling takes place. It has been our experience that, in fact, many INS civil surgeons either provide no counselling or actually provide incorrect information and even have made erroneous diagnoses. The INS has also provided incorrect information about HIV to immigrants being tested. Both the CDC and the INS seem to place the responsibility for counselling on the other agency with the result that no training or monitoring is done. Moreover, neither agency has accepted any responsibility for notifying persons who do test seropositive that waivers might be available. The National AIDS Commission would be an ideal forum to raise some of these issues of inter-agency responsibility.

We are also extremely concerned about the various other

ACLU of N. Cal. • AFSC • AGUILA • American Immigration Lawyers Assn. • Asian Immigrant Women Advocates • Asian Law Caucus • AYUDA • Bar Association of SF - Volunteer Legal Services Program • CRLA Foundation • CARECEN • Central American Refugee Services Project - CMHS • Catholic Charities - San Mateo • Catholic Charities - SF • Catholic Charities - Marin • Catholic Charities - Oakland • Committee to Defend Immigrant and Refugee Rights • Chinese Progressive Association • CHRICA • Coastside Opportunity Center • Comite en Defensa de los Inmigrantes of Redwood City - Comité de Refugiados Salvadoreños • CRECE • CUCAM • East Bay Sanctuary Covenant - Refugee Rights Program • Legal Aid of SF - Employment Law Center • Father Moriarty Central American Refugee Program • Filipino Immigrant Services • Good Samaritan Community Center • Immigrant Legal Resource Center • Instituto Laboral de la Raza • International Institute of SF • International Institute of the East Bay • Jewish Vocational Services • La Raza Centro Legal • Legal Aid of San Mateo • LULAC - Council 2055 • Lutheran Social Services of N. Cal. • MALDEF • MultiService Center for Koreans • National Lawyers Guild Immigration Committee • Options for Women Over 40 • Pacific News Service • Plant Closures Project • SF Lawyers Committee for Urban Affairs • SF Sanctuary Covenant • State Bar of Cal. - Office of Legal Services • Union y Progreso • United Way of the Bay Area Information & Referral • World Relief of SF • YMCA Literacy School

categories of immigrants who are subject to the HIV antibody testing requirement but who cannot apply for waivers under current law. These immigrants include hundreds of HIV antibody seropositive Haitians and Cubans applying through a special IRCA legalization program and potentially hundreds of persons seeking to obtain lawful permanent residence in the United States through visa petitions filed by close family members or employers. Representative Barney Frank (D-MA) has introduced legislation (H.R. 1280) that would restructure all the grounds of exclusion and would allow certain lawful permanent residence applicants to apply for waivers. However, until such legislation is passed, these hundreds of HIV antibody seropositive immigrants have no protection from deportation. Their continued underground presence in the United States without any legal status also raises serious public health concerns.

Another issue that has received much more media attention is the exclusion of nonimmigrants, or visitors, to the United States, based on HIV antibody status. This concern has not been addressed fully by the INS' new policy of granting waivers for stays of no longer than thirty days to visitors found to be HIV antibody seropositive. The international implications of our exclusion policy will be heightened as we approach next June's Sixth International AIDS Conference.

Finally, we note that the Presidential Commission on the HIV Epidemic did recommend that the HIV antibody testing of refugees abroad seeking admission to the United States should be reevaluated twelve months after the implementation of the policy. Recommendation 11-47. That policy has now been in effect for almost two years and has resulted in the exclusion of at least two refugees (one from Zaire being processed in Kenya and one from Laos being processed in Thailand). Both those refugees have applied for waivers but the INS has yet to respond to the waiver applications.

Our HIV and Immigration Task Force has developed considerable experience and expertise on this issue and we are eager to provide any additional information or materials that your staff or the Commission may need to examine this issue. Please do not hesitate to call us if you have any questions. We thank you again for your interest and your personal commitment to responding to the HIV epidemic and look forward to hearing from your staff in the near future.

Sincerely,

Ignatius Bau

Ignatius Bau (415) 543-9444
Jorge Cortinas (415) 626-2360
Monica Hernandez (415) 554-2444
for the HIV and Immigration
Task Force

AMERICAN BAR ASSOCIATION

POLICY ON AIDS

Adopted August, 1989

BE IT RESOLVED, That the American Bar Association urges that federal, state, and local law, and the policies of private entities concerning the Human Immunodeficiency Virus (HIV) should be consistent with the following principles.

IMMIGRATION

Legalization pursuant to the Immigration Reform and Control Act should not be denied to otherwise-qualified aliens solely because of HIV status.

Non-immigrant visitors to the United States should not be barred solely because of HIV status.

Otherwise-qualified political asylees and refugees should not be barred from the United States solely because of HIV status.

The Attorney General should have the authority to waive exclusions based on HIV status for immigrants on a case-by-case basis.

Resolution XII

The 99th Meeting of the Executive Committee,

Having reviewed Document CE99/7 and Add. I on acquired immunodeficiency syndrome (AIDS) in the Americas; and

Considering the threat that the AIDS epidemic poses to public health in the Region of the Americas,

Resolves:

To recommend to the XXXII Meeting of the Directing Council the adoption of a resolution along the following lines:

The XXXII Meeting of the Directing Council,

Having reviewed Document CD32/____ on acquired immunodeficiency syndrome (AIDS) in the Americas and Resolution WHA40.26[14] of the World Health Assembly;

Recognizing that the AIDS epidemic presents an unprecedented immediate and long-term threat to public health in the Region of the Americas, requiring urgent, coordinated action;

Aware that, under these conditions, special efforts must be made to prevent and control the spread of the disease, yet concerned that these efforts reaffirm human dignity; protect human rights while stressing the social responsibilities of individuals; foster political commitment to health; strengthen health systems based on the primary care approach; and protect freedom of travel, interpersonal communication, and international commerce;

Fully supporting the global response to this problem which is being implemented through the WHO Special Program on AIDS, and recognizing its responsibilities as WHO Regional Committee for the Americas to review annually the situation in the Americas, to monitor the use of regional resources, and to report annually to the Director-General of WHO; and

Aware of the impact AIDS has on health services,

Resolves:

1. To urge Member Countries:
    - a) To develop, implement, and sustain strong national AIDS prevention and control programs along the model recommended by the WHO Special Program on AIDS, adapted to individual national contexts;
    - b) To strengthen national epidemiologic surveillance activities in order to improve national programs;
    - c) To mobilize and coordinate the use of national and international resources for the prevention and control of AIDS while assuring that national health systems are maintained and strengthened in order to combat this epidemic;
    - d) To provide accurate information to their citizens about AIDS, strengthening health information through all mass media and health promotion activities, and promoting responsible, appropriate public action to reduce the transmission of the virus and to provide compassionate responses to those with the disease;
    - e) To continue permitting freedom of international travel, without restrictions based on human immunodeficiency virus (HIV) infection status; *
    - f) To provide periodic situation and progress reports to PAHO/WHO, as requested;
    - g) To make every effort to develop the Special Program on AIDS within the framework of the policy for health system development and strengthening, making use of the AIDS crisis to promote the needed changes in health services.
2. To request the Director, within available resources:
    - a) To coordinate regional AIDS prevention and control activities with the global program in the establishment of a PAHO/WHO Special Program on AIDS;
    - b) To provide urgently needed technical support to national AIDS prevention and control programs, including support for implementing, strengthening, and maintaining surveillance systems with appropriate laboratory support services; transmission prevention and control programs; health professional training programs; and research activities needed to define the epidemiology of AIDS;
    - c) To develop AIDS control activities, especially those related to health care, together with the development and strengthening of health systems;

---

[14] Document WHA40/1987/REC/1, 21-23.

Appendix C

BIOGRAPHICAL INFORMATION

BIOGRAPHICAL INFORMATION

Chairman June E. Osborn, M.D. is the Dean of the School of Public Health at the University of Michigan and Professor of Pediatrics and Communicable Diseases at the University of Michigan Medical School. She also serves on numerous federal and non-federal committees, including the AIDS Research Advisory Committee of the National Institute of Mental Health; the Ad Hoc Working Group on AIDS and the Nation's Blood Supply (Chair) for the National Heart, Lung and Blood Institute; the WHO Global Commission on AIDS; and the Robert Wood Johnson Foundation National Advisory Committee for AIDS Health Services Program (Chair). Dr. Osborn has researched and published extensively in the field of virology. She earned her M.D. at Case Western Reserve University School of Medicine.

Vice Chairman David E. Rogers, M.D. has had an interesting and varied career since he completed his M.D. in 1948 at Cornell University and served an internship and residency at Johns Hopkins. Among his important appointments are those of Dean of Medicine and Vice President for Medical Affairs at Johns Hopkins University, and Medical Director of the Johns Hopkins Hospital. Dr. Rogers was appointed as the first Walsh McDermott University Professor of Medicine at the NYH-CUMC in November 1986. For the 15 years preceding this appointment, Dr. Rogers was the President of the Robert Wood Johnson Foundation in Princeton, N.J., the largest philanthropy devoting its resources to alleviating problems in the health care of Americans. Dr. Rogers has been very involved in the problems of AIDS, holding appointments as Chairman of the Advisory Council of the AIDS Institute of New York State, as a member of the Citizens Commission on AIDS of New York and New Jersey, Chair of the Scientific Advisory Committee, NYH Partnership Advisory Committee, and Chair of the New York City Mayoral Task Force on AIDS.

Diane Ahrens is presently serving her fourth term as Commissioner of Ramsey County Minnesota. In 1987, she convened the Tri-County Task Force on AIDS to develop an AIDS Implementation Plan, which was passed unanimously by the Ramsey County Board in the Fall of 1988. In addition, as Chair of the National Association of Counties' Task Force on HIV and AIDS, Commissioner Ahrens has overseen the formulation of recommendations regarding the appropriate responsibilities of the county, state, and the federal governments in our nation's response to the AIDS epidemic. She earned her Masters Degree in Theology and Religious Education at Yale University.

Scott Allen has done extensive research on the spiritual, ethical, and psychological dimensions of AIDS as a consultant to the Christian Life Commission of the Baptist General Convention of Texas. He also provides direct pastoral care for people with AIDS, and is often called upon to act as a liaison between PWA's and their religious community and/or family. In addition, Reverend Allen is the founder and Co-Coordinator of the AIDS

Interfaith Network of Dallas, Chairperson of the Subcommittee on State Responsibility of the Special Texas Legislative Task Force on AIDS, and Board Member of AIDS ARMS, a program to meet the special human needs of PWA's. Reverend Allen earned his Masters in Divinity from the Golden Gate Theological Seminary, and served as pastor of the Pacific Baptist Church in California and a Minister of Education and Youth for the First Christian Church in Colorado Springs before joining the Christian Life Commission in 1985.

Honarable Richard B. Cheney was nominated by President Bush to be Secretary of Defense on March 10, 1989, was confirmed by the United States Senate on March 17, 1989, and took the oath of office on March 21, 1989. In August 1974, when Gerald R. Ford assumed the Presidency, Mr. Cheney served on the Ford transition team and, and beginning in September 1974, as a Deputy Assistant to the President. In November 1975, be was named Assistant to the President and White House Chief of Staff, a position he held through the remainder of the Ford Administration, until January 1977. He returned to his home state of Wyoming in May 1977 to resume private life. Mr. Cheney was elected to Congress in November 1978. He was re-elected in 1980, 1982, 1984, 1986, and 1988.

Harlon L. Dalton, Esq. is a Professor at Yale Law School and a leading authority on legal issues generated by the AIDS epidemic. His publications include, AIDS and the Law: A Guide for the Public, "AIDS: A Drama in Blackface" in Daedalus and "Thinking AIDS, Rethinking Law: An Ongoing Lesson in the Regulation of Human Behavior". Mr. Dalton serves on the Board of Directors of AIDS Project New Haven, the Advisory Board of the Connecticut Consortium of AIDS, and the Editorial Board of the AIDS Alert. He earned his J.D. from Yale Law School, and is a member of the Bar of New York, Connecticut, the Supreme Court of the United States, the United States District Court, and the United States Court of Appeals, Second Circuit.

Honorable Edward J. Derwinski, President Bush's choice to become the first Secretary of the newly created Cabinet-level Department of Veterans Affairs, was confirmed by the Senate on March 2, 1989 and sworn in on March 15, 1989. Secretary Derwinski directs the activities of the federal government's second largest department, responsible for a nationwide system of health-care services and benefits programs for America's 27.3 million veterans. A member of the U.S. House of Representatives from 1959 to 1983, representing Illinois' Fourth Congressional District, he was senior minority member of the House Foreign Affairs Committee and the House Post Office and Civil Service Committee. He played a major role in the passage of landmark Civil Service Reform, Postal Service Reorganization, and Foreign Service Reform legislation.

Don C. Des Jarlais, Ph.D. is currently the Director of Research for the Chemical Dependency Institute of Beth Israel Medical Center and Deputy Director for AIDS Research with Narcotic and Drug Research, Inc. He is an international leader in the fields of AIDS and intravenous drug use and during the last six years, Dr. Des Jarlais has published over 50 articles on the topics. He was the plenary speaker on intravenous drug use and AIDS at the 3rd and 4th International Conferences on AIDS and serves as consultant to various institutions, including the Centers for Disease Control, the National

Institute on Drug Abuse, the National Academy of Sciences and the World Health Organization. He is a Guest Investigator at Rockefeller University and a Visiting Professor of Psychology with Columbia University. Dr. Des Jarlais earned his Doctorate of Philosophy in Social Psychology from the University of Michigan.

Eunice Diaz, M.S., M.P.H. is currently an Assistant Clinical Professor of Family Medicine at the University of Southern California School of Medicine. She is a nationally acclaimed authority and speaker on the subject of AIDS in the Hispanic community, and a former board member of AIDS Project Los Angeles. In addition, Ms. Diaz has served on numerous AIDS-related committees and panels, including the Los Angeles County Commission on AIDS, the Planning Committee for the Surgeon General's Conference on Pediatric AIDS, and most recently, the Task Force on AIDS of the Society for Hospital Marketing and Public Relations, American Hospital Association. Ms. Diaz earned a Master of Science in Public Health and a Master of Public Health at the Loma Linda University.

Donald S. Goldman is an attorney in private practice as a partner in the West Orange, New Jersey law firm of Harkavy, Goldman, Goldman & Caprio. Active in The National Hemophilia Foundation and its chapters for over 25 years, he served as its Chairman from 1983 to 1984 and its President from 1984 to 1986. Mr. Goldman coordinated the National Hemophilia Foundation's efforts to improve the safety of our nation's blood supply, started many of its efforts in HIV risk reduction and introduced initiatives to improve hemophilia and HIV service delivery to minorities. Currently he is also Vice-President of the National Health Council, Inc. Mr. Goldman earned his J.D. from Rutgers University, and has published and lectured widely on legal aspects of hemophilia, HIV infection, and other medical and ethical issues. He is a member of the Bar of New Jersey, the United States Court of Appeals for the Third Circuit, and the United States Supreme Court.

Larry Kessler is the Co-Founder and Executive Director of AIDS Action Committee in Boston, a community-based service organization staffed by 75 full-time employees and over 1,500 volunteers. In addition, he serves on the Massachusetts Governor's Task Force on AIDS and the Boston Mayor's Task Force on AIDS, under appointments by Governor Dukakis and Mayor Flynn, respectively. Kessler is also a longtime Catholic activist and a member of the Board of Directors of both the National Catholic AIDS Ministry in New York and the AIDS Action Council in Washington, D.C. In 1987, Simmons College in Boston awarded him an Honorary Degree of Doctor of Human Services.

Charles Konigsberg, M.D., M.P.H. has been Director of the Division of Health of the Kansas Department of Health and the Environment since October of 1988. Previously, he was the District Health Program Supervisor and Broward County Public Health Unit Director for the Department of Health and Rehabilitative Services in Fort Lauderdale. In Florida, Dr. Konigsberg represented the county health official perspective on the Governor's AIDS Advisory Task Force. Dr. Konigsberg has also served as a consultant to the Centers for Disease Control and the U.S. Public Health Service in the development of HIV prevention and control strategies. He earned his M.D. from the University of Tennessee

Center for the Health Sciences and his Master of Public Health in Community Health Administration from the University of North Carolina School of Public Health.

Belinda Mason is a 31 year old mother of two children, who acquired AIDS through a blood transfusion. She was diagnosed with AIDS in January, 1987 and lived with the disease in an isolated, rural area, with no contact with other people with AIDS. In August 1988, she founded the first organization in Kentucky and Indiana for people with HIV disease. She has traveled around the country speaking about the human side of the AIDS epidemic and providing education and perspective to groups of all sizes and interests from college students, to health care professionals and national policy makers. Mrs. Mason is now the president of the National Association of People with AIDS.

Honorable J. Roy Rowland, M.D. is now serving his fourth term in the United States House of Representatives (Democrat, Georgia's Eighth Congressional District). As the only physician in Congress from 1985 to 1988, Congressman Rowland has provided leadership and insight on a number of health issues, such as infant mortality, rural health, the veterans' health system, and AIDS. His efforts on behalf of the AIDS community include sponsoring the legislation which authorized creation of the National Commission on AIDS and introducing a bill mandating study of AIDS among college students -- an idea which was adopted administratively by the Centers for Disease Control. Congressman Rowland earned his M.D. from the Medical College of Georgia, and maintained a family practice in middle Georgia for three decades before pursuing a political career.

Honorable Louis W. Sullivan, M.D. was sworn in as Secretary of Health and Human Services March 10, 1989. As head of the Department of Health and Human Services, Dr. Sullivan oversees the federal agency responsible for the major health, welfare, food and drug safety, medical research and income security programs serving the American people. Dr. Sullivan came to HHS from the Morehouse School of Medicine in Atlanta, Georgia. In July 1975, Dr. Sullivan had become founding dean and director of the medical education program at Morehouse College. Since July 1, 1981 when the School of Medicine became independent from Morehouse College, he had served as its first dean and president. In April 1985, the Morehouse School of Medicine was fully accredited and on May 17, 1985, the school awarded the M.D. degree to its first 16 graduates.

☆ U.S. GOVERNMENT PRINTING OFFICE: 1990 - 274-550 - 814/20762