

Mobilizing America's Response to AIDS

Recommendations to
President Clinton



National Commission on AIDS

WASHINGTON, DC • UNITED STATES OF AMERICA



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

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January 22, 1993

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Roy Widdus, Ph.D.

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

Dear Mr. President:

As you know, over the past three years, the National Commission on AIDS has worked intensively to document the nature, extent, and severity of the AIDS epidemic as it has swept relentlessly through our country and the world. In our reports we have made many recommendations which you have already embraced through your campaign positions. We hope through this letter to suggest some actions that we feel should be given urgent priority since they can have important immediate impact on the AIDS epidemic.

The onslaught of this disease has become both a national and a global human horror. Since its 1981 appearance in the United States, more Americans have died of AIDS than have died in all of the military conflicts combined since World War II. It has produced incredible human suffering worldwide and we have witnessed that suffering in all parts of our country.

Despite the magnitude of this tragedy, twelve years into the epidemic we remain without a well-articulated national plan by which to comprehensively address the crisis. We are not caring adequately for many of those who are ill. We live in a climate that still tolerates irrational stigmatization and rejection of those who are infected with the human immunodeficiency virus (HIV), the causative agent of AIDS. Our research and prevention efforts fall disturbingly short of what is needed in scope, direction, and funding.

We believe you have an unparalleled opportunity to forge a new covenant with the nation in addressing this tragic epidemic.

Enclosed are six recommendations for initiatives we believe you could set in motion early in your Presidency. These acts could improve dramatically the American response to AIDS. They are distilled from three years of the National Commission's work including: the thoughtful testimony of many hundreds of Americans, including people living with HIV; careful review of

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the rich literature on HIV and AIDS, and policy proposals from many AIDS and health organizations; the wisdom acquired from experiences of other nations; and the ten published reports produced by the National Commission on AIDS since November 1989.

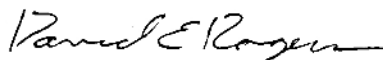
We attach considerable urgency and priority to these suggestions since if they are set in motion very soon, they represent critical opportunities to avert the unnecessary loss of further lives. We have kept the list short since the cost of over-promising is also a concern. We believe all of the recommendations are within Presidential authority to set in motion.


Clearly these Presidential actions alone will not solve the massive problems presented by this disease, nor do they even begin to address the wrenching and complex social conditions in which it is embedded. But they will help and give hope to the many thousands of people struggling to cope with the ravages of the epidemic. They will set the stage for the development of sustained and durable solutions. Above all, they will set a tone of concern and compassion to reinforce the commitment and intent you have articulated so well in recent months.

With such a start from you we believe that many other positive actions will follow, as a deeply concerned nation responds to your leadership.

As you may be aware, the legislative mandate of this Commission expires in September. Therefore, we will review the situation again in the early summer with a view to making further recommendations, as needed, before we cease activities. In the meantime, the Commission stands ready to assist you and your appointees in any way you feel would be helpful.

Sincerely,


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


June E. Osborn, M.D.
Chairman

NATIONAL COMMISSION ON AIDS

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David E. Rogers, M.D., *Vice Chairman*
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The National Commission on Acquired Immune Deficiency Syndrome (AIDS) was established by 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" concerning the HIV epidemic. The Commission is a bipartisan body whose members were appointed by the President, the United States Senate, and the United States House of Representatives.

Further information on the work of the Commission is provided at the end of this document or can be obtained from Roy Widdus, Ph.D., Executive Director, National Commission on AIDS, 1730 K Street, N.W., Suite 815, Washington, D.C. 20006.

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NATIONAL COMMISSION ON AIDS

MOBILIZING AMERICA'S RESPONSE TO AIDS

Recommendations to President Clinton

1. The President should discuss the AIDS crisis with the American people.

As noted in our comprehensive report of September 1991, Americans are accustomed to hearing from the "bully pulpit" in times of national crisis. Americans have heard almost no discussion of AIDS by our Presidents during the first twelve years of the AIDS epidemic. Thus it is not surprising that they seriously underestimate the scale of the AIDS disaster, and the spread of its causative agent, the human immunodeficiency virus (HIV).

The magnitude of the problem deserves Presidential emphasis, for AIDS will soon exceed all other causes of years of working life lost. Moreover, because AIDS has been disproportionately visited upon those whom society has held at a distance, our national resolve to confront the epidemic is exceedingly fragile. In the absence of a cure or vaccine (neither of which is imminent), it is a volatile epidemic which may yet mushroom in communities that have been relatively untouched so far. It is potentially containable by prevention, yet out of control at present. Furthermore, misplaced fear and confusion abound. Both will persist in the absence of your leadership.

Your strong voice can bring home awareness of how widespread the potential risk is; you can quiet diffuse anxiety; you can outline the scope of problems to come; and you can articulate the need for compassion, care, investment in research and preventive measures that are carefully tailored to the subpopulations most at risk. Your discussions with the American people must begin early and be repeated periodically.

2. The President should establish an AIDS Coordinator's Office reporting to the President.

The range of problems presented by a human disaster of this scale cuts across many cabinet jurisdictions and requires effective horizontal coordination among HHS, HUD, Defense, Veterans Affairs, Justice, State, Education, and others. Because of a decade of silence by the Executive there is great need, in addition to your efforts, for a spokesperson to be seen and heard around the country expressing your concerns about HIV/AIDS and your commitment to deal squarely with the problem. Much has been learned throughout the first decade of AIDS that can be used to reduce the cost of the response while enhancing the quality of care and efforts toward prevention.

We recommend that your AIDS Coordinator have sufficient authority to deal with the numerous cabinet officers whose jurisdictions are affected by AIDS (HHS, HUD, Defense, Veterans Affairs, Justice, State, Education, and others). Such a coordinator should have adequate resources and staff to fulfill the complex coordinating roles required. Most important, such a

coordinator must have ready access to you and report directly to you. We recognize that, in the past, such extra-structural positions have frequently not succeeded. Only with your unequivocal personal commitment to this office can it operate effectively.

3. The President should instruct the Secretary of HHS, in cooperation with the AIDS Coordinator, and other Cabinet Secretaries as necessary to immediately develop a National Strategic Plan to confront the epidemic.

The plan should include:

a. Steps to implement a comprehensive, effective initiative for prevention of HIV infection, which build on the knowledge already developed in many communities.

Experience has shown that the spread of HIV infection can be prevented through frank, culturally-appropriate, sustained interventions that deal realistically with sex and drugs, particularly those developed through community-based efforts by and for the people the messages are intended to reach. A comprehensive national HIV prevention initiative should integrate the approaches of federal, state, county, and municipal governments; community-based organizations; the private sector; and affected populations.

b. Steps to ensure access to health care and supportive services for those who are HIV infected.

Medical care *per se* is a very small part of what is needed for people living with HIV/AIDS. Counselling, nursing care, housing, nutritional guidance, treatment for drug users, long-term care, and many other social and human support services play vital roles. They can markedly improve the quality of life and reduce the need for costly high technology services for HIV-infected Americans.

c. Steps for education and legal action that will diminish unwarranted fears, stigmatization and discrimination against people with HIV infection.

At present these attitudinal mind sets threaten and limit access of people with HIV infection to employment, to education, to health care, to social services, and to equal participation in society generally.

d. Steps to ensure a broadly based, better directed research approach to HIV/AIDS problems.

The scope, direction and funding of our research effort need enhancing. While some areas of enormous importance—particularly biomedical problems—have received considerable (but not necessarily optimal) attention, there has been far less emphasis given to crucial facets of behavioral and social science research that are clearly critical to an effective response to the epidemic. Similarly, health services research has also been underfunded. For example, the effectiveness of a multiprofessional "one-stop shopping" approach to the care of HIV/AIDS patients was explored in a few early research/demonstration projects that have not, in general, been broadened or pursued. Their promising findings could have relevance far beyond the realm of AIDS to other chronic diseases and the multisystem problems of the elderly. Such approaches should be explored in the context of general health care reform.

e. Steps to enhance U.S. involvement in the international response to HIV.

The HIV/AIDS pandemic is devastating many developing nations. They are rapidly losing productive citizens and will be predictably overwhelmed—socially and economically—by the burdens of AIDS. We ignore their plight at our peril. A global U.S. perspective and response is required.

4. The President should request full funding for the Ryan White CARE Act.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was intended as a disaster relief measure to help our hardest hit cities care for people with AIDS, and to

provide assistance to communities and less heavily populated areas which had not yet felt the full impact of the epidemic to plan services before they too were overwhelmed. The law made bold promises (including the linking of testing with early treatment services) which its implementors have been unable to fulfill. Gross underfunding has allowed the disaster to grow.

Full funding is urgently needed and should be seen as essential to support the upcoming health care reform process. Further legislation of a similar sort is also needed to meet the burgeoning needs of cities, rural communities, and the health care facilities which care for the most impoverished members of our society. Some institutions are in imminent danger of collapse under the pressure of the escalating health care crisis exacerbated by the HIV/AIDS epidemic.

5. The President should remove unwarranted restrictions relating to HIV Infection.

HIV-infected individuals do not constitute a threat to an informed citizenry. Yet the federal government requires mandatory testing in a variety of situations—which sends a false message of alarm, suggesting that HIV-infected individuals pose a risk—and imposes certain restrictions upon people with HIV infection, which may be unnecessary since these restrictions are not supportable on scientific or public health grounds. Such mandatory testing invades personal privacy and perpetuates discriminatory attitudes.¹

In this regard we urge the rapid elimination of HIV-related immigration restrictions. They remain despite HHS findings that neither medical standards nor epidemiologic principles require such restrictions. The President should also order reevaluation of other federal restrictions relating to HIV infection with a view to removing those that are unwarranted or counter-productive.

6. The President should request a plan to make immediate treatment a reality for all drug users who seek it.

Injection drug use poses a significant threat of HIV transmission to those who inject drugs, their sexual partners, and their offspring. Every major assessment of the epidemic has identified the urgent need to make treatment for addiction the highest priority in an effective public health effort to curtail further spread of HIV. Despite these recommendations, it remains the rare exception that such treatment is readily available. Thus, addicted persons who need help to overcome their addiction are denied care, and left at great risk for unconscionable periods of time. For those drug users not receiving treatment, other programs to prevent further spread of this fatal infection are urgently needed, including education and legal access to sterile injection equipment.

¹ Voluntary HIV antibody testing, confidential or anonymous, with counselling should be available to all wishing to avail themselves of it, as part of comprehensive health services.

COMMISSION DOCUMENTS

For any of the information about reports and proceedings of the National Commission on AIDS please contact:

The National Commission on Acquired Immune Deficiency Syndrome
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125
TDD (202) 254-3816

Records are kept of all Commission proceedings and are available for public inspection at the above address.

For copies of all reports please contact:

National AIDS Clearinghouse
P. O. Box 6003
Rockville, Maryland 20849-6003
1-800-458-5231
TDD 1-800-243-7012

Reports

First Interim Report to the President and the Congress: "Failure of U.S. Health Care System to Deal with HIV Epidemic." December 1989.

Second Interim Report to the President and the Congress: "Leadership, Legislation, and Regulation." April 1990.

Third Interim Report to the President and Congress: "Research, the Work Force, and the HIV Epidemic in Rural America." August 1990.

Fourth Interim Report to the President and the Congress: "HIV Disease in Correctional Facilities." March 1991.

Fifth Interim Report to the President and the Congress: "The Twin Epidemics of Substance Use and HIV." August 1991.

Second Annual Report to the President and the Congress: "America Living With AIDS." September 1991.

Sixth Interim Report to the President and the Congress: "The HIV/AIDS Epidemic in Puerto Rico." June 1992.

Seventh Interim Report to the President and the Congress: "Housing and the HIV/AIDS Epidemic, Recommendations for Action." July 1992.

Eighth Interim Report to the President and the Congress: "Preventing HIV Transmission in Health Care Settings." July 1992.

Ninth Interim Report to the President and the Congress: "The Challenge of HIV/AIDS in Communities of Color." December 1992.

Additional Materials

Working Group Summary Report on Federal, State, and Local Responsibilities. March 1990.

Annual Report to the President and the Congress. August 1990.

Report of the Working Group on Social and Human Issues to the National Commission on AIDS. April 1991.

Technical Report Prepared for the National Commission on AIDS. "Financing Health Care for Persons with HIV Disease: Policy Options." August 1991.

Statements

Support for Passage of the Americans with Disabilities Act. September 6, 1989.

Support for Increase in AIDS Funding in the FY '90 Appropriations Bill. September 19, 1989.

Support for the Goal of Treatment on Demand for Drug Users. September 26, 1989.

Support for Continued Funding of Research on Effectiveness of Bleach Distribution. November 7, 1989.

Resolution on U.S. Visa and Immigration Policy. December 1989.

Endorsement of Principles and Objectives of Comprehensive AIDS Resources Emergency (CARE) Act of 1990. March 6, 1990.

Despite Debate Among Epidemiologists, HIV Epidemic Will Have Greater Impact in 1990s than 1980s. March 15, 1990.

Endorsement of Principles and Objectives of AIDS Prevention Act (H.R. 4470) and Medicaid AIDS and HIV Amendments Act of 1990 (H.R. 4080). May 11, 1990.

Endorsement of Principles and Objectives of the Ryan White CARE Act of 1990. March 6, 1991.

Statement on Immigration. July 1991.

Statement on the Meeting Between the National Commission on AIDS and the Secretary of Health and Human Services. June 25, 1992.

Statement by David E. Rogers, M.D., Vice Chairman, National Commission on AIDS, on the Resignation of Magic Johnson from the NBA. November 2, 1992.

Information on the Commission

Commission Fact Sheet

Individual Commissioner Biographies

Public Law 100-607 (Creation of the National Commission on AIDS)