

MEMORANDUM
OF CALL

Previous editions usable

TO:

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YOU WERE CALLED BY YOU WERE VISITED BY

Roy Widdus/Carlton Lee
OF (Organization)

PLEASE PHONE FTS AUTOVON

P6(b)(6)

WILL CALL AGAIN IS WAITING TO SEE YOU

RETURNED YOUR CALL WISHES AN APPOINTMENT

MESSAGE

*What's meeting - Nat'l Committee
on Aids
Did memo
to scheduling*

RECEIVED BY <i>103</i>	DATE <i>2/9</i>	TIME <i>4:15</i>
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NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815
 Washington, D.C. 20006
 (202) 254-5125 FAX 254-3060 TDD 254-3816

February 3, 1993

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Roy Widdus, Ph.D.

Carol Rascoe
 Special Assistant to the
 President for Domestic Policy
 The White House
 West Wing - 2nd floor
 1600 Pennsylvania Ave., N.W.
 Washington, D.C. 20500

Dear Ms. Rascoe:

I write regarding the request of the National Commission on AIDS to meet with President Clinton to discuss its recent recommendations. The attached materials were sent to Mr. Magaziner on January 22, as we were informed that he was the only person handling health issues actually in the White House at that time.

However, this morning I spoke with Patsy Fleming, Special Assistant to Secretary Shalala, she informed me you had now taken up your position and might be more likely to handle the Commission's request for a meeting with President Clinton (Mr. Magaziner's focus apparently being health care reform).

If after reviewing the enclosed materials you have any question please do not hesitate to call me.

Any assistance you could render in bringing these issues to the President's attention or in clarifying with whom to communicate about a possible meeting with him would be most appreciated.

Yours sincerely,

Roy Widdus, Ph.D.
 Executive Director

THE NATIONAL COMMISSION ON AIDS

*1730 K Street, N.W.
Suite 815
Washington, D.C. 20006
202/254-5125*

*Fax Transmittal Sheet
Sending Fax Phone: 202/254-3060*

DATE: FEBRUARY 3, 1993

TO: CAROL RASCOE

fax: (202) 456-2878

voice: _____

FROM: ROY WIDDUS, Ph.D.

DOCUMENT NAME AND DESCRIPTION:

MESSAGE:

PLEASE SEE ATTACHED. ORIGINAL LETTER and ATTACHMENTS TO FOLLOW via COURIER.

NUMBER OF PAGES INCLUDING TRANSMITTAL SHEET: 2

THE NATIONAL COMMISSION ON AIDS

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Washington, D.C. 20006
202/254-5125

Fax Transmittal Sheet
Sending Fax Phone: 202/254-3060

(initials) Dry: C/Rasco
KC: Marcia

Hale: Can
you let me
know what

I should
tell him if
he calls me?

I don't believe
the Pres. is
ready to
meet with
them.
CHR

DATE: Feb. 8, 1993

TO: Carol Rascoe

fax: _____

voice: _____

FROM: Roy Widdow

DOCUMENT NAME AND DESCRIPTION:

MESSAGE:

NUMBER OF PAGES INCLUDING TRANSMITTAL SHEET:

3



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Carol Rascoe
 Special Assistant to the
 President for Domestic Policy
 The White House
 West Wing--2nd floor
 1600 Pennsylvania Ave., N.W.
 Washington, D.C. 20500

Dear Ms. Rascoe:

The National Commission on AIDS meets on Friday, February 12th, 1993 to discuss its activities for the remainder of FY 1993 (agenda attached).

As I previously indicated the Commission would very much like to meet with President Clinton in the near future, to discuss with him its recent recommendations (sent to you on February 3, 1993).

Any information you could provide prior to Friday, as to the prospect for such a meeting would be greatly appreciated.

Yours sincerely,

Roy Widdus

Roy Widdus, Ph.D.
 Executive Director

COMMISSION BUSINESS MEETING

**Embassy Suites Hotel
1250 22nd Street, N.W.
Washington, D.C.
February 12, 1993
9:00a.m.-4:00p.m.**

Tentative Agenda

1. Update on request for meeting with President Clinton and response to Commission recommendations
2. Discussion of future activities
3. Discussion of status of Haitian refugees with HIV infection held at Guantanamo Bay, Cuba
4. Recommendations to Congress—Distribution of penultimate draft
5. Other Business
 - Congressional and Administration liaison
 - Update on plans for Austin Hearing
 - Sexual Orientation, Military Service and HIV/AIDS
 - Statement on NIH Office of AIDS Research



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However, this morning I spoke with Patsy Fleming, Special Assistant to Secretary Shalala, she informed me you had now taken up your position and might be more likely to handle the Commission's request for a meeting with President Clinton (Mr. Magaziner's focus apparently being health care reform).

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Yours sincerely,

Roy Widdus, Ph.D.
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January 22, 1993

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Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

Roy Widdus, Ph.D.

Ira Magaziner
Senior Advisor for Policy
Development
Old Executive Office Building
Room 216
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500-0001

Dear Mr. Magaziner:

I attach for your information and consideration a letter, proposing a meeting between the National Commission on AIDS and President Clinton which I understand was forwarded to Chief of Staff, Mr. McLarty.

The Commission's recommendations for President Clinton's early actions on AIDS referred to in the letter are now ready for transmittal. I will send these to you at the White House today so that you can review them and communicate them to President Clinton. (No press conference is scheduled for the release of this document, but it will be available to interested parties next week.)

The Commission hopes President Clinton will consider these suggestions carefully and also hopes to meet with him soon to discuss them. I would be grateful for any assistance you can provide in regard to arranging such a meeting.

May I also take this opportunity to congratulate you on your appointment.

Yours sincerely,

Roy Widdus

Roy Widdus, Ph.D.
Executive Director



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January 4, 1993

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Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

Roy Widdus, Ph.D.

**Judith Feder
Director of Health Policy
Clinton-Gore Transition Board
1120 Vermont Avenue, N.W.
Washington, D.C. 20270**

Dear Ms. Feder:

The National Commission on AIDS has been developing for President-elect Clinton a succinct set of recommendations on immediate actions by which he can rapidly set the national response to the HIV/AIDS epidemic on a more appropriate course.

We are encouraged by President-elect Clinton's intention, stated during the campaign, to be guided by the Commission's previous recommendations. In keeping with the Commission's desire to work collaboratively with his new administration, we would like to convey our recommendations for his early actions on AIDS directly to President Clinton as soon after January 20th, 1993 as is possible, prior to any public release of our suggestions.

I look forward to hearing if you feel a meeting with President Clinton will be possible and suggestions as to its timing.

Your sincerely,

**Roy Widdus, Ph.D.
Executive Director**

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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Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

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

The President
January 22, 1993
Page 2

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.

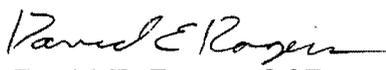
We attach considerable urgency and priority to these suggestions since if they are set in motion very soon, they represent critical opportunities to avert the unnecessary loss of further lives. We have kept the list short since the cost of over-promising is also a concern. We believe all of the recommendations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

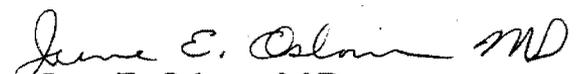
Clearly these Presidential actions alone will not solve the massive problems presented by this disease, nor do they even begin to address the wrenching and complex social conditions in which it is embedded. But they will help and give hope to the many thousands of people struggling to cope with the ravages 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

June E. Osborn, M.D., *Chairman*
David E. Rogers, M.D., *Vice Chairman*
The Honorable Diane Ahrens
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The Honorable J. Roy Rowland, M.D.

Ex Officio

The Secretary of Defense
The Secretary of Health and Human Services
The Secretary of Veterans Affairs

Former Members

Earvin Johnson, Jr.
Belinda Mason

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.

January 22, 1993

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)



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815

Washington, D.C. 20006

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January 22, 1993

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May I also take this opportunity to congratulate you on your appointment.

Yours sincerely,

Roy Widdus

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Executive Director



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Larry Kessler

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

Hon. J. Roy Rowland, M.D.

Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

Roy Widdus, Ph.D.

**Judith Feder
Director of Health Policy
Clinton-Gore Transition Board
1120 Vermont Avenue, N.W.
Washington, D.C. 20270**

Dear Ms. Feder:

The National Commission on AIDS has been developing for President-elect Clinton a succinct set of recommendations on immediate actions by which he can rapidly set the national response to the HIV/AIDS epidemic on a more appropriate course.

We are encouraged by President-elect Clinton's intention, stated during the campaign, to be guided by the Commission's previous recommendations. In keeping with the Commission's desire to work collaboratively with his new administration, we would like to convey our recommendations for his early actions on AIDS directly to President Clinton as soon after January 20th, 1993 as is possible, prior to any public release of our suggestions.

I look forward to hearing if you feel a meeting with President Clinton will be possible and suggestions as to its timing.

Your sincerely,

**Roy Widdus, Ph.D.
Executive Director**

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

1730 K Street, N.W., Suite 815

Washington, D.C. 20006

(202) 254-5125 FAX 254-3060 TDD 254-3816

January 22, 1993

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June E. Osborn, M.D.

VICE CHAIRMAN

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Hon. Diane Ahrens

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Hon. J. Roy Rowland, M.D.

Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

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

The President
January 22, 1993
Page 2

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.

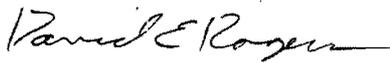
We attach considerable urgency and priority to these suggestions since if they are set in motion very soon, they represent critical opportunities to avert the unnecessary loss of further lives. We have kept the list short since the cost of over-promising is also a concern. We believe all of the recommendations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

June E. Osborn, M.D., *Chairman*
David E. Rogers, M.D., *Vice Chairman*
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Ex Officio

The Secretary of Defense
The Secretary of Health and Human Services
The Secretary of Veterans Affairs

Former Members

Earvin Johnson, Jr.
Belinda Mason

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.

January 22, 1993

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)



JUN 23 1993

Washington, D.C. 20201

TO: Carol Rasco
Special Assistant to the President
for Domestic Policy

FROM: Kevin Thurm
Chief of Staff
Department of Health
and Human Services

SUBJECT: Background information and upcoming activities on the
National Commission on AIDS (NCOA)

PURPOSE

To provide you with information on the National Commission on AIDS including activities planned for June 28, 1993 and issues of concern to the Commission.

*AIDS
6/24/93 file*

NCOA MEMBERSHIP

Dr. June Osborn, Chair, National Commission on AIDS
Dr. David Rogers, Vice-Chair, National Commission on AIDS
Dr. Roy Widdus, Executive Director, National Commission
on AIDS
(Attached at TAB A is a list of NCOA members)

BACKGROUND

The Commission is scheduled to hold a press conference to release their final report, **AIDS: An Expanding Tragedy** on June 28, 1993 at the National Press Club. A copy of the final report along with summary is attached at TAB B. On June 24, Secretary Shalala will also be meeting with Drs. Osborn and Rogers. It is anticipated that they will want to discuss with the Secretary the recommendations contained in their final report.

As you may know, the Commission is scheduled to officially terminate its operations on September 3, 1993.

ISSUES OF CONCERN

- The Commission has tried unsuccessfully on numerous occasions to get a meeting with the President to discuss recommendations contained in their major reports. At TAB C is a copy of their letter to the President and a summary of the six recommendations they believed he could act upon early in his Administration to address the HIV epidemic.

Page 2

- At TAB D are copies of correspondence to you, from Roy Widdus, requesting to meet with the President. To date, the Commission has not received any written acknowledgment regarding their requests. As you know, we have provided your office with a draft response to the Commission for the President's signature.

4 Attachments:

TAB-A - List of Commission members

TAB-B - Final Report, **AIDS: An Expanding Tragedy**

TAB C - Letter to the President and Summary of Six
Recommendations Contained in **Mobilizing America's
Response to AIDS**

TAB D - Copies of correspondence to you from the Commission

NATIONAL COMMISSION ON AIDS

June E. Osborn, M.D., *Chairman*
David E. Rogers, M.D., *Vice Chairman*
The Honorable Diane Ahrens
K. Scott Allen
Don C. Des Jarlais, Ph.D.
Eunice Diaz, M.S., M.P.H.
Mary D. Fisher
Donald S. Goldman, Esq.
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The Honorable J. Roy Rowland, M.D.

Ex Officio

Les Aspin, Ph.D., *Secretary of Defense*
Donna E. Shalala, *Secretary of Health and Human Services*
Jesse Brown, *Secretary of Veterans Affairs*

Department Representatives

Department of Defense
Col. Michael R. Peterson, D.V.M., Dr.P.H., Executive Secretary, Armed Forces
Epidemiological Board

Department of Health and Human Services
National AIDS Program Office
James R. Allen, M.D., M.P.H., Former Director
Valerie Setlow, Ph.D., Acting Director

Department of Veterans Affairs
Irwin Pernick, J.D., formerly Counselor to the Secretary,
presently Associate Deputy Assistant Secretary for Policy
Marvelu R. Peterson, Ph.D., Associate Director, AIDS Services

Former Members

Harlon L. Dalton, Esq.
Earvin Johnson, Jr.
Belinda Mason (1958-1991)
Richard B. Cheney, *Former Secretary of Defense*
Edward J. Derwinski, *Former Secretary of Veterans Affairs*
Louis W. Sullivan, M.D., *Former Secretary of Health and Human Services*

TAB B

FINAL REPORT OF THE NATIONAL COMMISSION ON AIDS
"AIDS: AN EXPANDING TRAGEDY"

Summary of the Final Report

The body of the 21 page report contains an Introduction and a section on "The Future of the HIV/AIDS Epidemic." This section includes a discussion of the following topics: (1) trends in U.S. HIV incidence and prevalence; (2) HIV as an international problem; (3) prospects for prevention through behavior change; (4) prospects for therapy and cure; (5) prospects for prevention by vaccine prophylaxis; (6) the expanding demand for care and support of persons with HIV disease; and (7) altering the future course of the epidemic: neglected strategies. It closes with a short set of principles that must underlie revitalized efforts to control the epidemic and care for people living with HIV (described below), and two broad recommendations for immediate action to be taken in order to position the nation more appropriately for what promises to be a long, arduous struggle with HIV disease into the next century.

Principles to Guide the Future Response to the Epidemic

- Leadership is essential. Leadership in any context entails developing a vision of the response needed, establishing a plan to realize it, and accepting responsibility for its fulfillment. Leadership in the response to AIDS also provides the visible affirmation of the inclusion of the people affected by HIV in the community.
- Access to basic health care, including preventive, medical and social services should be a right for all. Our nation must find ways to finance that care for all.
- The United States must have a vital and responsive public health system. This means rebuilding an adequately supported public health "infrastructure" with a sufficient number of trained personnel to carry out the primary public health functions of surveillance, assessment and analysis, and prevention. All levels--federal, state, and local--must have the necessary capacity to fill their designated roles.
- The best science will yield the best public strategies. But the best science cannot flourish where it is blocked or constrained for ideological reasons or political convenience. Nor can it contribute properly where it is underfunded or its lessons are ignored in program design.

- To the greatest extent possible, health care solution (including those for HIV/AIDS) must avoid disease specificity. Solutions should offer a broad continuum of comprehensive services to those with problems of chronic relapsing disease. The health of entire communities is often dependent upon the health of the least advantaged.
- Partnerships are necessary. Collaboration between levels of government, with the business community, with the religious community, with the voluntary not-for-profit sector, and with community based organizations is essential to providing a coordinated response. A broad array of persons, including people with HIV disease, AIDS activists, health professionals, and community representatives, must be included in formulating prevention, care and research strategies.
- The human face of AIDS should be ever before us. Respect for personal dignity and autonomy, respecting the need for confidentiality, reducing discrimination, and minimizing intrusiveness should all be touchstones in the development of HIV/AIDS policies and programs.

Recommendations and Closing Statement

While the report calls for a strong emphasis on prevention efforts, because neither a therapeutic nor a vaccine will be available for at least the next decade, the report ends with two recommendations:

- Leaders at all levels must speak out about AIDS to their constituencies, and;
- We must develop a clear, well-articulated national strategic plan for confronting AIDS (should address the issues of prevention, care, and research, required to deal with the HIV epidemic).

The report ends with several very poignant statements, . . . "Clearly our work is unfinished. Although the Commission has listened diligently, considered carefully, and kept the problem of AIDS before the public, most of our recommendations remain to be implemented. But it is time for AIDS to be swept into the mainstream of America's national agenda. To continue to treat HIV/AIDS as a marginal problem gravely threatens our nation's future. Without action on our Nation's unfinished business on AIDS, we will have a continually expanding tragedy. We call on America to get on with the job. What should be done is not complicated. But it requires leadership, a plan, and the national resolve to implement it."

Remainder of the Report

The remainder of the report includes seven appendices: (1) an indexed guide to the reports of the National Commission on AIDS; (2) Commission documents; (3) cumulative recommendations; (4) Commission chronology, 1989 to 1993; (5) a list of witnesses participating in Commission hearings; (6) Public Law 100-607, November 4, 1988; and (7) Commissioner biographies.

Analysis of the Report

Based upon our review of the report, the report does not contain any major new recommendations or findings. The tone of the report is characterized in the preface by the Co-chairman as short, angry, and sad. These three attributes are used because 1) they have said it all before, 2) there has been a failure to implement the Commission's, "carefully considered, widely heralded recommendations, and 3) because a preventable disease continues to relentlessly expand and cause suffering and death.

The report criticizes the previous Administrations for lack of leadership in combatting the epidemic and for a lack leadership in allaying the public fears and discrimination. The report expresses hope that President Clinton will live up to his campaign statements that the nations fight with HIV required urgency and aggressive polices to respond. However, the report next expresses serious concern that the epidemic is once again caught up in politics.

AIDS:

AN EXPANDING TRAGEDY

EMBARGOED UNTIL 10:00 am JUNE 28

NOT FOR RELEASE, ATTRIBUTION OR
DISTRIBUTION

Final Report of the National Commission on AIDS

Appendices are
listed on p. v. —
Please call if
you need any
RW:ids

What should be done is
not complicated. But it requires
leadership, a plan, and the national
resolve to implement it.

↓
Includes
Cumulative
Recommendations
and indexed Guide
to Commission
Reports

WASHINGTON

1993

JUNE 1993

AIDS: An Expanding Tragedy

**The Final Report of the
National Commission on AIDS**

National Commission on AIDS

WASHINGTON, DC • UNITED STATES OF AMERICA

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. Five permanent members of the Commission were appointed by the Senate, five by the House, and two by former President George Bush. In addition to these twelve voting members, the Secretaries of Defense, Health and Human Services, and Veterans Affairs serve as nonvoting members of the Commission.

Under its legislative mandate, the National Commission on AIDS will cease operation on September 3, 1993. After that time, Commission reports can be obtained through the CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, Maryland 20849-6003, Tel. 1-800-458-5231, TDD 1-800-243-7012. Official records of the Commission and the proceedings are lodged within the National Archives and Records Administration, Office of Federal Records Center, Washington, DC 20408, Tel. 202-501-5425.

NATIONAL COMMISSION ON AIDS

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David E. Rogers, M.D., *Vice Chairman*
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presently Associate Deputy Assistant Secretary for Policy
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Belinda Mason (1958-1991)
Richard B. Cheney, *Former Secretary of Defense*
Edward J. Derwinski, *Former Secretary of Veterans Affairs*
Louis W. Sullivan, M.D., *Former Secretary of Health and Human Services*

COMMISSION STAFF

(as of June 1993)

Roy Widdus, Ph.D., *Executive Director*

Thomas D. Brandt, M.L.S.

Tracy L. Brandt

Megan L. Byrd

Adriana Carmack

Jason Heffner, M.Ed.

Sherell Jackson

Carlton H. Lee, Jr.

Juanita O. Pendleton

Tracy J. Shycoff

Patricia Sosa, Esq.

Vicky M. Tsaparas

Editor for *AIDS: An Expanding Tragedy*

Linda C. Humphrey

Consultant for the indexed guide to Commission reports

Heddy F. Reid

Former Staff

Maureen Byrnes, M.P.A. (Executive Director, August 1989-September 1991)

A. Frank Arcari, M.P.A.

Nat Blevins, M.Ed. (1949-1992)

Stacey D. Bush

LuVerne Hall

Melanie Lott

Lee Marovich

Kerry McClurg

Frances E. Page, B.S.N., M.P.H.

Renée Peterson

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

Karen Porter, Esq.

Nicole Ryan

Carla Sharp

Jane Silver, M.P.H.

Jeff Stryker

Holly Taylor, M.P.H.

Ellen J. Tynan, M.A.

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PREFACE

Composing a "final report" on a massive, dynamic, and unstable epidemic as it engulfs our nation and the world is like trying to take a snapshot of a tidal wave: its pace and scope defies capture. The enormous burden of grief and loss that AIDS will impose on our society has yet to be felt fully, and the work in care, prevention, and research must be not merely sustained but accelerated just to keep pace.

The National Commission on AIDS has completed its four-year assignment to advise our government and our nation on issues and needs arising from the AIDS epidemic. We have listened to literally thousands of concerned Americans in dozens of hearings and site visits across the country, made recommendations on critical issues, and worked hard, with occasional success, for their adoption. However, our authorization expires in September 1993 and we will cease our contributions to that Herculean task. Thus, despite the enormity of the work remaining to be done, this report is truly final so far as our specifically mandated efforts are concerned.

This is a short, sometimes angry report tinged with sadness and foreboding. It is short, because all of what we say here has been said many times before. It is sometimes angry because the carefully considered, widely heralded recommendations contained in our previous reports have been so consistently underfunded or ignored. It is sad because a potentially preventable disease continues to expand relentlessly and cause loss of life in young Americans on an unprecedented and unacceptable scale. The human immunodeficiency virus (HIV) has profoundly changed life on our planet. America has not done well in acknowledging this fact or in mobilizing its vast resources to address it appropriately. Many are suffering profoundly because of that failure, and America is poorer because of this neglect. We are apprehensive because the situation will inexorably worsen without immediate action.

So in this last document we will offer a snapshot on the current location of the "tidal wave," suggest a series of principles that should underlie the mobilization of the response required to contain the epidemic, and close with two broad recommendations that could start that mobilization process. We refer the reader to our previous reports for details on how better to confront the epidemic in ways that could minimize the damage of the tidal wave.

We end our four years' work hoping for a new era.

June E. Osborn, M.D.
Chairman

David E. Rogers, M.D.
Vice Chairman

ACKNOWLEDGMENTS

A few words of acknowledgment cannot capture the degree to which the Commission and its staff are indebted to the legions of people who, in so many ways, helped us execute the legislative mandate for our work over the past four years. Similarly, to list names would surely miss some among the thousands we encountered along the way; they provided us with critical insights and kept us going when our energy was low. Therefore, it is more appropriate for us to thank all Americans concerned about AIDS for sharing, in one way or another, their wisdom and experience with the Commission. But particular thanks must go to those living with HIV for their special insights.

The Commission and staff also wish to offer their thanks for the opportunity to serve the nation in confronting this pandemic.

AIDS: An Expanding Tragedy

Introduction

Two years ago, when the National Commission on AIDS prepared its report, *America Living with AIDS*, we tried to shout a warning to our nation that would reverse a decade of unreasoning fear and cruel indifference to the AIDS epidemic, an historic health disaster that threatened all of us. We gave voice to our sense of urgency, saying, “. . . in the months to come [the people of the United States] must either engage seriously the issues and needs posed by this deadly disease or face relentless, expanding tragedy in the decades ahead. . . .”

But alas, our nation has continued on that short-sighted course. Sadly, we must continue to report that America is still doing poorly. Our warnings have fallen far short of their intended effect. The epidemic numbers continue to expand, the trends toward universality of involvement have intensified, and the ghastly twin epidemics of AIDS and drug abuse have been joined by a third deadly fellow traveler—tuberculosis.

There has been some progress. The definition of AIDS has been expanded to represent more accurately the lethal swath of disease from the human immunodeficiency virus (HIV), especially among women and minorities. But even before that extended definition influenced the statistics, more than a quarter of a million Americans had been diagnosed with AIDS in just the first twelve years of the ongoing epidemic. Cumulative mortality now exceeds three times the toll of American deaths exacted in the Vietnam War. Efforts to care for people living with HIV and AIDS have been hampered by consistent underfunding at the federal, state, and local levels—and this underfunding grows worse.

More and more the claim that “AIDS is just one disease” is used to argue that we should divert funds to other concerns. Yet it is an epidemic disease, a potentially preventable deadly infection for which there is only palliative treatment, no cure, no vaccine, and it is *not* under control. Moreover, it typically strikes in the prime working years of life. Relative to other health concerns HIV disease continues to increase. The failure to respond adequately represents at best, continued dogged denial, and at worst a dismaying hidden and unvoiced belief that this is “just” a disease of gay men and intravenous drug users, both groups that are perceived as disposable. One would not have heard such comments during the years before poliomyelitis was contained—and yet there were more cases of AIDS diagnosed last year in the United States than there were cases of paralytic polio in the worst epidemic summers before the advent of the Salk or Sabin vaccines.

The results of this denial are tragic. Homelessness is an increasingly visible consequence of HIV disease, as young people exhaust their resources and fall below a subsistence level of income. The pace of research is hampered by underfunding, and drug costs remain astronomical. The behavioral research needed to understand better how to prevent HIV infection is almost nonexistent. Funds for acute care and facilities or services for long-term care are in cruelly short supply.

Despite billions spent on the "War on Drugs," addiction treatment on demand is not available to the vast majority of people who need it, and state laws that prohibit the purchase of syringes and needles have not been repealed despite the fact that such laws obviously incite the sharing of drug paraphernalia, which efficiently transmits HIV.

MATHILDE KRIM, M.D., Ph.D.
November 1992

After its comprehensive report two years ago, the efforts of the National Commission on AIDS continued to meet with complacent unresponsiveness. To eight urgently reiterated recommendations presented directly to the Secretary of Health and Human Services in the summer of 1992, the official response was that enough was being done. Despite a strongly worded plea for facilitation of housing support for people living with AIDS, there was no response at all from the leadership of the Department of Housing and Urban Development. To date, no opportunity has yet been found to discuss six recommendations sent to President Clinton upon his taking office.

The strong recommendation of both this Commission and its predecessor that drug treatment on demand be available for addicted persons resulted in only marginal increases in prevention treatment slots, while interdiction at the borders, although shown to be singularly ineffectual, and other coercive efforts continued to receive the major share of drug funding.

Perhaps most tragic, federal funds for prevention have been essentially level in recent years—and were actually cut in the 1992 budget. Further functional diversion was implicitly sanctioned through a federal directive to transfer AIDS funds to the response to tuberculosis. Thus, although HIV was creating by far the richest substrate on which the newly revived tuberculosis epidemic could thrive, expenditures to prevent it decreased.

So there is an urgent need for the people of the United States and their leadership to play catch-up. Past inattention has already exacted prices that are painful to enumerate, including such problems as:

No one would suggest that we reduce the surgeons' fees for cutting out someone's lung so that we can pay for ads to encourage people not to smoke. No one makes that kind of connection. But the fact of the matter is that in AIDS, I believe, both federally and at the state level, people are [regrettably] making these trade-offs all the time.

MARK SMITH, M.D., M.B.A.
January 1992

- The tuberculosis crisis, especially that involving multiple drug resistance, which arises from a synergy of neglect: neglect in the early 1980s of the public health system that had controlled TB in prior decades, neglect of the need for proper housing, neglect of the need to intensify research on new TB therapies, and neglect of the health care system in correctional facilities.
- The failure to prevent substance abuse, to provide treatment for drug users, and to implement programs for safer injection has left a legacy with "flash fire" potential for HIV transmission.
- The nation's beleaguered public health system, neglected in the 1980s and increasingly burdened with unreimbursable care for the indigent, which is in poor shape to carry out its primary public health and disease prevention role.
- The neglect of teaching tolerance and compassion, which has allowed homophobia to fester, "gay bashing" to increase, and discrimination to flourish.
- The neglect of basic health services for communities of color, which has left a legacy that now makes prevention efforts more difficult.

- The neglect of education and building of decision-making skills for adolescents concerning sexuality, which has left them at high risk of pregnancy and sexually-transmitted diseases (STDs).

Strong, positive leadership is needed to overcome entrenched ignorance and fear, as well as to rectify the serious flaws and deficits in care and prevention strategies. We are witnessing an expanding national disaster, and there is greater urgency than ever to mobilize against the scourge of AIDS.

New hope surged with the election of President Clinton. During the campaign he indicated that he grasped the scope and urgency of the HIV/AIDS epidemic, and that he intended to pursue an aggressive set of policies in response to it. Indeed, there was concern immediately after his election that the very high expectations engendered by the advent of a new and activist administration might be almost self-defeating. As one observer put it, it had taken a long time to create such a vast swamp of neglect, so it was sure to take a while simply to drain that swamp before real headway could be made against the fundamental dynamics of the epidemic's progress.

Now there is cause for serious concern that response to the epidemic is again tangled in politics. To the shame of the nation and the embarrassment of the scientific community and the public health sector, HIV remains one of the diseases that bars immigration and mandates deportation. President Clinton's commendable request for supplemental FY 1993 funding of the Ryan White CARE Act has been—at least for the moment—capsized along with the President's proposed job stimulus package in which it was legislatively housed; implementation of the promised coordination of AIDS activities within the executive branch has yet to materialize. Meanwhile, the clock ticks ominously. Delay in response to AIDS inevitably spells further expansion of the scope of future trouble. Hope was fueled, however, by the Presidential budget request for FY 1994 that proposed significant increases for the Ryan White CARE Act, prevention and research. This request needs complementary action by Congress but is, in itself, an encouraging signal. Another hopeful note is the movement toward universal health coverage, but that is muffled by concern that the transition will take longer than those with AIDS have to live.

In this final report of the National Commission on AIDS we attempt to accomplish several limited objectives. First, we will briefly summarize projections of the future scope and dynamics of the spread of HIV and its destruction of human life over the remainder of the decade. We will not project further, since we strongly believe that the future magnitude of diseases can be influenced by preventive actions taken now. We will also summarize current best thinking about the uncertain prospects for therapy, cure, and vaccine in the remainder of the decade. We will project the need for expanded efforts to care for the vast numbers of young adults who assuredly will become ill during that time period.

We will close with a short set of principles that must underlie revitalized efforts to control the epidemic and care for people living with HIV, as well as some broad recommendations for immediate action to be taken in order to position the nation more appropriately for what promises to be a long, arduous struggle with HIV disease into the next century.

Detailed recommendations concerning specific topics related to the epidemic are contained in one or more of the 15 reports published by the National Commission on AIDS since it began its work in August 1989. These reports are indexed in Appendix A.

A tremendous reservoir of decency and good will is ready to be tapped by a humane and visionary administration.

SANDRA SINGLETON McDONALD
November 1992

This report is our final heartfelt public plea that this nation face squarely and forthrightly the implications and the magnitude of the human disaster created by HIV infection and AIDS. We call on the President to develop a comprehensive national plan to deal with it effectively. We call on Congress to fund the research necessary to achieve better preventive and therapeutic solutions to it. We call on the President and Congress to design and underwrite a responsive system of health and medical care for all HIV-infected people who need it. And we call on all Americans to work single-mindedly to lessen the cruel discrimination that has added such horror to the lives of those infected. As a nation we can do vastly better in confronting this crisis than we have to date.

The Future of the HIV/AIDS Epidemic

As the second decade of the HIV/AIDS pandemic progresses, it becomes increasingly clear that it will alter the course of many societies. It is worth a brief attempt to outline projections for the United States and the world to the year 2000.

As of April 1993, a cumulative total of 289,320 AIDS cases and 179,748 deaths from AIDS had been reported to the Centers for Disease Control and Prevention (CDC, 1993b). In 1992, 47,106 newly diagnosed AIDS cases and 29,763 deaths were reported by year's end (CDC, 1993a), but the number of deaths from AIDS in 1992 is expected to rise to around 50,000 as statistics are updated. These awful numbers are in all likelihood lower than the actual toll, both because only about 80 percent of cases are officially reported to CDC and because many people have died of HIV-related disease that did not meet earlier definitions of AIDS.

The number of persons meeting the 1987 criteria for AIDS diagnosis is anticipated to increase from 58,000 in 1991 to approximately 70,000 annually during the next two or three years. Due to longer survival after diagnosis, the numbers of people living with AIDS will increase as well—from 90,000 in January 1992 to 120,000 in January 1995. The number of new AIDS diagnoses among men who have sex with men and among injection drug users is projected to remain level during this period. However, AIDS diagnoses among persons whose infection is due to heterosexual transmission is likely to continue to increase (CDC, 1992). To date, nearly half of all AIDS cases have occurred among African Americans and Hispanics, although they make up only 21 percent of the overall population (CDC, 1993a). This disproportionality is expected to increase in future years.

In January 1993, CDC adopted an expanded AIDS case definition that took into account severe immunosuppression *per se* and added recurrent bacterial pneumonias, pulmonary tuberculosis, and invasive cervical carcinoma in HIV seropositive people to the long list of AIDS-defining conditions. That change will increase the absolute numbers of AIDS cases reported in the next few years, particularly among drug users and women, compared with projections that used the 1987 definition. In the past, many people died with severe immunosuppression but without meeting criteria for AIDS diagnosis, so this change will increase the accuracy of the mortality toll.

AIDS diagnoses, of course, tell a story that is out of date, since it takes an average of 10 years between onset of infection and appearance of AIDS-defining disease manifestations. Present CDC estimates suggest that at least one million people are infected, so that during the remainder of the decade the annual number of new AIDS diagnoses will remain high, probably at between 40,000 and 80,000 per year. Indeed, even if there were no new instances of infection from now on, the nation would be severely challenged just

The physician attending told her [JG] that these were not HIV-related, and that the clinic had no gynecological provider anyway. "JG" did not have time to find another doctor or to work up the nerve to question her doctor further about these gynecological conditions.

She died a week later, after waiting hours in an emergency room, of septicemia caused by massive pelvic inflammatory disease.

Theresa McGovern, J.D.
December 1991

to meet the care needs of those already infected. Yet new infections will continue unless we do far better at prevention, and of course their impact will extend beyond the year 2000.

Trends in U.S. HIV Incidence and Prevalence

As noted, the spread of AIDS among heterosexuals will account for all increasing percentages of new AIDS diagnoses in upcoming years, and thus care of women and children will present a more prominent need in the epidemic. With injection drug use and sexual transmission fueling that dynamic, births to infected mothers will result in more HIV-infected infants, and the death of infected mothers and fathers will result in growing numbers of "AIDS orphans." This has been the case already along the East Coast and is a dreadful problem in many countries around the world.

Some significant shifts are taking place in new HIV infection patterns compared with the pattern of AIDS to date. While HIV transmission among older men who have sex with men is sharply reduced from the early 1980s, transmission continues at high levels in younger gay men where a "generation gap" seems to have led to rejection of warnings from survivors of the first tragic decade. HIV transmission through injection drug use continues to pose a threat of "flash fire" spread of infection among drug users, through multiperson use of injection equipment, which can be followed by sexual transmission to their partners. Noninjecting drug use—especially of crack cocaine but also of alcohol—is a significant risk behavior for transmission, either from exchange of sex for drugs or impairment of behavioral decision making.

Expansion of the base of the epidemic, in large part through spread among heterosexuals, continues to gain ground, particularly among communities of color, women, and adolescents. AIDS cases in people exposed through heterosexual contact increased 17 percent in 1992 (CDC, 1993a). AIDS cases among women increased by 9 percent between 1991 and 1992, compared with 2.5 percent among men (CDC, 1993a); and in some "snapshots" of HIV prevalence among adolescents, HIV infection had a one-to-one ratio of women to men, as it does throughout much of the world. The disproportionate representation of communities of color is at its most striking among women and children; while African American and Hispanic women make up 21 percent of all U.S. women, they constitute three-quarters of women diagnosed with AIDS. Among infants born with HIV infection due to drug use by their mothers or her sex partner, about 85 percent are African American or Hispanic (CDC, 1993a).

Trends in HIV transmission among adolescents raise particular concerns. Between 1991 and 1992, AIDS cases among people 13 to 19 years of age arising from heterosexual HIV transmission increased by 65 percent; and increasing numbers of men and women in their twenties are developing AIDS, signifying infection in their teenage years (CDC, 1993a). Among African American and Latino youth in the northeastern United States, 1 in 40 Job Corps applicants between 13 and 21 years of age was infected with HIV; and among teens aged 16 to 17 in the southeast, more females than males were infected (St. Louis et al., 1991).

The potential for spread of HIV is made clear by recent studies that estimated that 25 percent of the population were likely to have a sexually transmitted disease at some point in their lives (Donovan, 1993). Furthermore, CDC has found that about 75 percent of

When I found out I was HIV positive, I was lost. There were very few places that I could go to get help. Because even the places that were used to dealing with people with HIV, they were not surprised to hear I was HIV positive. They were surprised to see that I was 18 years old and that I had the virus.

PEDRO ZAMORA
May 1992

graduating high school seniors were sexually active, while studies of condom usage revealed mostly inconsistent or no use (Curran, 1992). Adult risk of sexually transmitted diseases including HIV was illustrated by one recent survey that found that between 15 percent and 30 percent of a large survey sample reported unprotected sexual intercourse with multiple partners (Catania et al., 1992). Nevertheless, among the heterosexual population, disbelief and denial persist: in another recent study, condom use was less than 20 percent in risky sexual encounters (Catania et al., 1992). Clearly, many individuals do not recognize or take action to reduce their vulnerability to infection and probably many parents believe mistakenly that their children are not at risk.

HIV as an International Problem

The crisis faced in the United States has its counterpart in virtually every country in the world. Spread of HIV varied by a few years from one region to another, but by now there is no place free of the virus. The global number infected may double or triple by the year 2000 (WHO, 1993). Denial has been a regular component of initial national response virtually everywhere, but many countries have overcome that first reaction and have mobilized in ways that need to be shared with others. The United States, by virtue of its early involvement, its biomedical research capacity, and the experience accumulated by many agencies and community groups in responding to the crisis, is in a position to be helpful; but we have also ignored some important lessons and thus are also in a position to learn from nations that have mobilized more effectively. All nations would benefit from a greater sharing of expertise and experience.

The international impact of HIV disease will expand dramatically in upcoming years, and with it will come the need and obligation to share progress in research, therapeutics, and vaccines as they develop. Notwithstanding its members' personal and collective concern for the situation abroad, our major task as a commission has been to focus on issues within the United States. It is our clear national obligation, however, to participate in a global response that is equitable, compassionate, and founded on a fundamental commitment to human rights.

Prospects for Prevention through Behavior Change

We must use the tools that are available now to confront the epidemic, especially since prospects for cure or vaccine are distant. Much success has been achieved in demonstrating the feasibility of preventing HIV transmission through interventions directed at reducing risky sexual or drug-injecting behavior. In general, successful research or pilot/demonstration projects have been targeted to particular groups (for example, older men who have sex with men, runaway street youth, early to mid adolescents, or injection drug users). These projects have enabled the identification of general principles and practices of intervention likely to predicate success.

It has become clear that, to be successful, HIV prevention efforts need to provide information, build skills to reduce risk, and provide easy access to the means to do so, for example, access to condoms and sterile injection equipment. They must also be culturally sensitive, reiterated, sustained over time, and complemented by broader efforts over the long haul, both to change behavioral norms within communities at risk and to empower individuals to change. It is also clear that those at highest risk *can* be reached

What we really want is technology to save us and we have this firm wonderful hope in technology, rather than changing our behavior. We don't believe in behavioral interventions. We just don't think people can change their behavior. We don't believe it. But we need to believe it, because it works. It does work.

JAMES W. CURRAN, M.D., M.P.H.
March 1993

and will change behavior in significant numbers if appropriate motivations are identified, explicit and targeted campaigns are developed, and natural and credible channels of communication are used. However, many more people need to be reached. The number of people at some degree of risk is large and the future patterns of the epidemic will make it more and more difficult to "target" them if we do not intensify efforts at prevention now.

Evidence to date has taught that prevention will be most effective when specific communities are involved in all facets of planning and implementation; the only way to communicate effectively with each cultural group what we know about avoidance of HIV disease is to use the language and vernacular of the intended audiences. Thus, community involvement is critically important to the success of prevention programs. In this context, technical assistance programs must be expanded so that prevention workers are kept at the cutting edge of progress in effective intervention.

Present knowledge about the feasibility of achieving behavior change is already such that the prediction of 40,000 to 80,000 new HIV infections per year should be unacceptable. HIV is preventable, and increased resources must be devoted to prevention as well as to research to make such efforts more effective.

Prospects for Therapy and Cure

The very nature of HIV infection—in which the virus' genetic material is woven into the DNA of cells—makes true cure difficult to imagine, once infection is established. The cells infected by HIV are important in their immune system and neurologic function, so destroying infected cells in order to get rid of the virus is not a realistic approach. Thus far the antiviral treatments available against HIV (AZT, ddI, and ddC) all work by inhibiting a viral enzyme necessary for replication; but while those drugs enhance well-being and delay onset of severe disease, their effect is finite and patients ultimately become refractory to them. In addition, HIV has shown the ability to develop resistance to the drugs themselves.

Potential new antiviral drugs and strategies are under development now, but most of them are still at the test tube stage, where their effectiveness and toxicity in patients cannot yet be gauged. Thus, while progress can be expected in the range of treatments available, truly curative therapies are unlikely in the foreseeable future and improvement in clinical strategies will be incremental.

It is important, during this frustrating interval of drug development, that treatment and prophylaxis of the opportunistic infections and tumors suffered by people with AIDS be advanced. The treatment of these complications of immune suppression present complex research challenges as well, but progress to date has been highly significant in improving the quality of life and extending the survival of people with HIV disease, and it is important that progress in the availability and use of such drugs continue to be given major priority and attention.

Prospects for Prevention by Vaccine Prophylaxis

Evidence from animal model research over the past few years has suggested that a vaccine against HIV may be possible. While many legitimate possibilities are under investigation, there is not yet agreement among researchers as to the most promising approaches for a vaccine that would protect humans. Thus, the vaccine effort must be pursued energetically and on a broad front.

While laboratory work is progressing, however, it is important that strategies and plans for testing HIV vaccines be carefully developed so that they can be activated as soon

as promising candidates appear. Work will almost surely have to be undertaken both in the United States and in other countries to assess the efficacy of such vaccines, so the planning must be done cooperatively. Early planning for possible distribution of an effective vaccine is also desirable.

Regardless of vaccine progress, however, it is imperative that behavioral and educational approaches to HIV prevention be maintained, since even an ideal vaccine would only serve as a supplement to the fundamental prevention strategies already at hand. It is particularly important to reiterate this point, since fully tested vaccines of any sort for general use are certain to be at least five to ten years off. In the meanwhile, we already know what is needed to help people avoid HIV. It would also be highly unrealistic to believe that the future availability of a technological prevention option would eliminate the necessity of behavioral prevention and care.

The Expanding Demand for Care and Support of Persons with HIV Disease

To the extent that care of people with HIV disease is already difficult within the unwieldy health care system, greater stress can be predicted in the near future for a number of reasons. The increasing disproportion of people of color, many of whom are already caught in a web of poverty and disadvantage, will apply pressure where health care resources are already at the point of collapse.

The expansion of the AIDS case definition in 1993 will accelerate the identification of people living with HIV in its earlier stages, making feasible the "early intervention" strategies that have been shown to extend and enhance the quality of the lives of such people. However, the arrangement for such anticipatory care will add further stress to the system.

The management of HIV disease is likely to become more complex: combination therapy and prophylaxis will both become more common. Use of new diagnostic technologies (as, for instance, for antiviral resistance) will probably increase. The number of persons for whom support—such as home care, child care, and transport—will make the difference between indigency and continued productivity will increase sharply. The number of persons with tuberculosis (both those with HIV and those with tuberculosis alone) will increase. These people will need early diagnosis, and their treatment must be carefully monitored and sustained to avoid creation of multiple-drug-resistant strains.

Increasingly, whole families will be affected by HIV disease: not only will HIV-infected children and their parents need clinical care and social services, but the welfare and psychological needs of orphans must also be met.

Altering the Future Course of the Epidemic: Neglected Strategies

There is much that could be done, even with present knowledge, that could soften the impact of the epidemic. Major benefits can be achieved in a synergistic, cost-effective manner through coordination and consolidation of HIV/AIDS-related programs with other health care and public health activities. For instance:

- *Coordinated planning.* The substantial benefits of information exchange and coordination of activities among federal, state, and local government agencies

We would be extremely hard-pressed to meet the likely added service demands resulting from the proposed revision of the case definition. It has been suggested that this might itself be a way to drive increased funding for such services. I think that would require a leap of faith that the history of health care, particularly health care for people of color, women and substance users and low-income people, simply does not allow us to make. The more likely scenario would be increased need and shrinking resources.

RON JOHNSON
December 1991

People are not just "doing drugs." There is some real pain going on in people's lives. And this needs to be addressed. I think historically this country has never considered the emotions of real people, of poor people. They have never considered us as people.

JANICE JIRAU
January 1992

And yet, when I look at the data that were collected just last year by the Centers for Disease Control that suggest that 38 percent of black Americans who responded to the National Health Survey believed still that HIV infection can occur from mosquitoes and that 20 percent were not sure; that 39 percent of the Hispanics who responded believed that mosquitoes are likely to be able to infect people with HIV, and 18 percent were not sure—these data alone suggest the fact that the time for HIV and AIDS 101 is not over. We have such a long way to go despite what we might believe for the general population.

JACOB GAYLE, Ph.D.
January, 1992

and the private sector (such as community-based organizations and workplace planners) unfortunately have not been achieved to date. It is in this context that the National Commission on AIDS has called for development of a national strategic plan; we continue to do so, since the quality of epidemic response, as well as inherent savings, could be significantly enhanced.

- *Comprehensive reform of the national health care system.* HIV disease (and other chronic diseases) should be carefully factored into the design of health care reform proposals. Universal access to coverage for a continuum of comprehensive services including home care and long-term care, and support of case management approaches are key ingredients in such reform.
- *Human resources planning for underserved communities.* Overall health manpower needs should be assessed in light of the upcoming pressures of the epidemic. As noted, these are likely to be at their least adequate among populations at greatest need.
- *A more effective drug policy.* The crucial variable represented by substance use in determining the scope of the future epidemic must be grappled with realistically. An approach that emphasizes "harm reduction," for example, access to sterile injection equipment, is essential: this would not only prove more humane and effective in controlling drug use *per se* than the past "war on drugs," but would also yield dividends in reduced HIV and tuberculosis transmission. Resources should be shifted from interdiction and mandatory punishment toward drug treatment availability for all who seek it.
- *Housing, rather than hospitalization, for people with HIV.* More flexibility and attention by the Department of Housing and Urban Development regarding the housing needs of people living with HIV would diminish the problems associated with homelessness, which is a frequent consequence of illness and loss of income in poorly insured young adults. In particular, unnecessary hospitalizations can be substantially reduced by assuring stable housing arrangements appropriate for people with HIV disease.
- *Educational efforts to increase understanding of HIV disease.* Discrimination, stigmatization, or other callous and inappropriate responses to people living with HIV often arise out of unwarranted fear from lack of knowledge. Increased general awareness of basic facts can reduce such ignorant responses substantially and lay a foundation for preventive efforts. Public education should be redesigned and intensified with these goals in mind.

- *Adolescent health initiatives.* School-based health programs can provide a particularly effective resource for assuring access to basic health education and services for underserved adolescents. In addition to teaching about HIV and other STDs, information about teenage pregnancy, awareness of substance abuse hazards, nutritional knowledge, and other fundamental health skills can be conveyed in such a setting to teens whose home environments are deficient in such knowledge. Issues such as “safer sex” strategies must be dealt with in a manner acceptable to communities in which the programs are housed; but lack of access to such information can be life-threatening to youth at risk, and school-based health programs have yielded promising results to date.
- *Support for community-based organizations, providers, and volunteers.* The key role of community-based organizations in responding to the complex needs of people living with HIV must be acknowledged and fostered. The history of response to the epidemic in the United States includes countless instances of community-based leadership and individual heroism without which the present picture would be much bleaker. The effectiveness of such organizations reflects their critical links with and trust from the community, whether the community is defined by ethnicity, geography, or sexual orientation. Of equal importance is the commitment of community workers—often volunteers. Such crucial functions must be sustained through enhanced mechanisms for funding, technical assistance, and recruitment of other organizations (especially religious groups or those in the workplace) not yet optimally involved.

Principles to Guide the Future Response to the Epidemic

While a series of clear and present steps are needed to initiate a more aggressive approach to the HIV epidemic, the Commission believes certain general principles can serve as a compass that can help guide the national response. Not all are AIDS specific.

1. Leadership is essential. Leadership in any context entails developing a vision of the response needed, establishing a plan to realize it, and accepting responsibility for its fulfillment. Leadership in the response to AIDS also provides the visible affirmation of the inclusion of people affected by HIV disease in the community.
2. Access to basic health care, including preventive, medical, and social services, should be a right for all. Our nation must find ways to finance that care for all.
3. The United States must have a vital and responsive public health system. This means rebuilding an adequately supported public health "infrastructure" with a sufficient number of trained personnel to carry out the primary public health functions of surveillance, assessment and analysis, and prevention. All levels—federal, state, and local—must have the necessary capacity to fulfill their designated roles.
4. The best science will yield the best public strategies. But the best science cannot flourish where it is blocked or constrained for ideological reasons or political convenience. Nor can it contribute properly where it is underfunded or its lessons are ignored in program design.
5. To the greatest extent possible, health care solutions (including those for HIV/AIDS) must avoid disease specificity. Solutions should offer a broad continuum of comprehensive services to those with problems of chronic relapsing disease. Strategies should recognize that the health of entire communities is often dependent upon the health of the least advantaged.
6. Partnerships are necessary. Collaboration between levels of government, with the business community, with the religious community, with the voluntary not-for-profit sector, and with community-based organizations is essential to providing a coordinated response. A broad array of persons, including people with HIV disease, AIDS advocates, health professionals, and community representatives, must be included in formulating prevention, care, and research strategies.
7. The human face of AIDS should be ever before us. Respecting personal dignity and autonomy, respecting the need for confidentiality, reducing discrimination, and minimizing intrusiveness should all be touchstones in the development of HIV/AIDS policies and programs.

We need a language of hope which affirms life. I didn't become uncreative or unproductive with the announcement that I had tested positive. As a matter of fact, my life is hardly over.

... we need a language of respect. I am not a statistic. And to reduce me to a heap of numbers is to make of me something that is no longer human.

Respect must affirm personhood. It recognizes and communicates that I am a mom, not a victim; a daughter, not a tragedy; a friend, not a casualty.

MARY FISHER
June 1992

Recommendations

We will close with but two recommendations. They will not be unfamiliar to those who have followed our work, but we believe they are central, vital, and critical to launching a more adequate national response to the central human crisis of our times. The details of implementation are less important. Many are contained in our previous reports. But we need a new mind set, a new, less selfish national resolve, a new way of thinking about the epidemic that says this toll of human suffering and death is unacceptable to us. We need to acknowledge better the heroic contributions of those individuals and organizations who have been working so single-mindedly in the field of HIV and AIDS. Each of us must ask, "How can I be of help?"

Recommendation 1

Leaders at all levels must speak out about AIDS to their constituencies.

Our President must speak out clearly and forcibly about the nature, extent, and needs of the AIDS disaster. This has been our foremost recommendation since 1991. One AIDS activist group has as its symbol a pink triangle with the phrase, "silence=death." There is much to suggest that they are right. The appalling lack of frank discussion about the epidemic at all levels of national leadership fostered a woefully inadequate response, yielding death and suffering well in excess of what might have been. Silence has existed at too many levels of responsibility. Few governors, mayors, members of Congress, corporate executives, community or religious leaders, have stepped forward—perhaps taking their cue from previous Presidents. Consequently, the scale of the problem is seriously underestimated, and fear, prejudice, and misinformation abound. Leaders have both the capacity and the responsibility to coalesce their communities to find solutions.

We are vividly aware of the fact that addressing AIDS—and particularly issues that require discussing sexuality or drug use—is difficult for many to deal with comfortably. Further, some of the steps that will be required to address the epidemic better will be unpleasant or unpopular in the minds of many. But to confront difficult and sensitive issues is what true leadership means and requires. It would, in our judgment, make a profound difference in our national response to HIV disease if full and frank discussion of all its implications was initiated and encouraged by those in positions of responsibility at all levels.

Recommendation 2

We must develop a clear, well-articulated national plan for confronting AIDS.

Again, high on our list of recommendations, and that of the Presidential Commission preceding us, has been the development of a carefully crafted national strategic plan to address the issues of prevention, care, and research, required to deal with the HIV epidemic.

Whatever one's religion or moral beliefs, there's plenty of room to teach about the danger of AIDS and how to prevent it. For AIDS is a preventable disease. Every school, church, workplace, union hall and prison offer an opportunity.

JOSEPH A. CALIFANO, JR.
November 1992

To this end, we have suggested such a plan directly to the President in our report, *Mobilizing America's Response to AIDS*. We have spelled out the authority and resources necessary for the coordinating office required to deal with the numerous cabinet departments that must be involved in such planning. Along similar lines, we have pointed to the singular absence of a national prevention strategy worthy of the name. We have also indicated the need for more overall planning for HIV-related research, housed appropriately within the National Institutes of Health, and the desperate need for a compassionate continuum of care for those infected. The obvious reasons for having such overarching plans, still absent in the twelfth year of the epidemic, need little further comment, except perhaps that the underlying theme of the plans should be to address sexual and drug-use behavior from a public health perspective.

All of our other recommendations, past or present, follow logically from the above. There is a compelling need for a functioning public health system with the ability to conduct appropriate prevention programs, free from censorship, that would serve the special needs of gay men, of lesbians, of communities of color, of those who use drugs, of women, of children, and of adolescents. The need for better therapeutic agents, long-term care, housing, social support services, and their financing—all must be embodied in those plans. Our reports to date, and most particularly *America Living with AIDS*, spell out the particulars. Clearly our work is unfinished. Although the Commission has listened diligently, considered carefully, and kept the problem of AIDS before the public, most of our recommendations remain to be implemented. But it is time for AIDS to be swept into the mainstream of America's national agenda. To continue to treat HIV/AIDS as a marginal problem gravely threatens our nation's future. Without action on our nation's unfinished business on AIDS, we will have a continually expanding tragedy. We call on America to get on with the job. What should be done is not complicated. But it requires leadership, a plan, and the national resolve to implement it.

The opportunity is to deal comprehensively rather than haphazardly with the problem as a whole, to see it as a social catastrophe brought on by years of economic deprivation and to meet it as other disasters are met, with an adequacy of resources.

STEPHEN B. THOMAS, PH.D.
June 1992

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TAB C



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815

Washington, D.C. 20006

(202) 254-5125 FAX 254-3060 TDD 254-3816

January 22, 1993

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Secretary of Defense

Secretary of Health and Human Services

Secretary of Veterans Affairs

EXECUTIVE DIRECTOR

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

The President
January 22, 1993
Page 2

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.

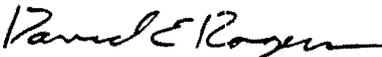
We attach considerable urgency and priority to these suggestions since if they are set in motion very soon, they represent critical opportunities to avert the unnecessary loss of further lives. We have kept the list short since the cost of over-promising is also a concern. We believe all of the recommendations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

MOBILIZING AMERICA'S RESPONSE TO AIDS

Below is a listing and summary of the six recommendations for initiatives that the Commission believed the President could act upon early in his Administration.

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

The National Commission on AIDS and AIDS advocacy organizations have been consistent in their concern that there has been almost no discussion of AIDS by the two former Presidents during the first 12 years of the AIDS epidemic. They interpret the lack of direct, frank and open discussion about this disease by past Presidents as an indication that the previous Administrations placed a very low priority on the AIDS epidemic.

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

The Commission has repeatedly called for a National plan for AIDS that would address a range of problems associated with HIV disease that cut across Federal jurisdictions and require effective horizontal coordination among government departments. The Commission believes such a plan would require oversight by an AIDS Coordinator with authority and responsibilities beyond that of any single Federal Department. The Commission recommends that an AIDS Coordinator have sufficient authority to deal with the numerous cabinet officers whose jurisdictions are affected by AIDS.

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.**

In their recommendations to President Clinton, the Commission does not provide specific background information on this particular recommendation. Instead, the Commission states that the "plan should include" and list five specific steps (see next page).

In its second annual report to the President and the Congress, **America Living with AIDS**, the Commission called upon the President to designate an individual or lead agency with the authority and responsibility for instituting a cabinet level process to articulate the Federal component of an HIV plan, develop a mechanism for interagency as well as state and local participation and coordination, and establish a timeline for completion of key tasks. The plan should include:

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

The Commission states that the spread of HIV can be prevented through frank, culturally-appropriate, sustained interventions that deal realistically with sex and drugs, particularly those developed through community-based efforts. 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.

The Commission states that medical care per se is a very small part of what is needed for people living with HIV infection and AIDS. Counseling, nursing care, housing, nutritional guidance, treatment for drug users, long-term care, and many other social and human support services play vital roles. The Commission says provision of these services 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.

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

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

The Commission states that the scope, direction and funding of our research efforts need enhancing. While biomedical problems have received attention, there has been far less emphasis given to crucial facets of behavioral and social science research that health services research has also been underfunded and cites the "one-stop shopping" approach to the care of HIV/AIDS patients as a strategy that needs to be broadened and pursued. The Commission believes these approaches should be explored in light of general health care reform.

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

This recommendation has not been specifically addressed in previous Commission reports. The Commission's narrative for this issue indicates that the HIV/AIDS pandemic is devastating many developing nations. The Commission also states that a global U.S. perspective and response are required.

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

In the Commission's comprehensive two-year report, **America Living with AIDS**, the Commission recommends that the Federal Government fund the CARE Act at its fully authorized level. The Commission notes that the CARE Act made bold promises which its implementors have been unable to fulfill due to underfunding. In addition, the Commissioners state that further legislation is needed to support communities that are in "danger of collapse" due to the escalating health care crisis exacerbated by the HIV/AIDS epidemic.

5. **The President should remove unwarranted restrictions relating to HIV infection.**

The Commission states that HIV-infected individuals do not constitute a threat to an informed public. 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. Further, the Commission states that mandatory testing invades personal privacy and perpetuates discriminatory attitudes. In this regard, the Commission urges the President to order the 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.**

The Commission states that every assessment of the epidemic has identified the urgent need to make treatment for addiction the highest priority in an effective health effort to curtail further spread of HIV. Further, The Commission asserts that for those not receiving treatment, other programs to prevent the further spread of HIV disease are urgently needed; e.g., legal access to sterile injection equipment.



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815

Washington, D.C. 20006

(202) 254-5125 FAX 254-3060 TDD 254-3816

June 8, 1993

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Roy Widdus, Ph.D.

Carol Rasco
Special Assistant to the
President for Domestic Policy
The White House
West Wing, 2nd floor
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500

Dear Ms. Rasco:

On June 28th the members of the National Commission on AIDS will present a report that marks the culmination of their four years' work for the nation, under Public Law 100-607, advising the President and Congress on the AIDS epidemic and the necessary response to it.

The forthcoming document extends conclusions drawn in *America Living with AIDS* that was presented to President Bush and the Congress in September, 1991. The Commission was grateful to President Bush for the opportunity he graciously provided to discuss that report directly with him in late 1991.

You will recall that the Commission transmitted six (6) suggestions for early action to President Clinton upon his inauguration. As we indicated at that time, the Commission would greatly appreciate the opportunity to meet with the President to discuss implementation of its previous recommendations, that he eloquently embraced in his election campaign, and the work it has done more recently.

Such an opportunity to discuss the future national response to AIDS could be particularly useful as the Commission's efforts come to a close. (You will recall that the Commission effectively ceases operation on September 3rd.)

I look forward to hearing if you feel an opportunity might soon be available for the meeting, which we previously discussed in late March.

Sincerely,

Roy Widdus
Roy Widdus, Ph.D.
Executive Director

cc: Donna E. Shalala, Secretary of Health and Human Services



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Roy Widdus, Ph.D.

Carol Rasco
Special Assistant to the
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The White House
West Wing, 2nd floor
1600 Pennsylvania Ave., N.W.
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Sincerely,

Roy Widdus
Roy Widdus, Ph.D.
Executive Director

cc: Donna E. Shalala, Secretary of Health and Human Services



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1730 K Street, N.W., Suite 815

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Roy Widdus, Ph.D.

Carol Rasco
Special Assistant to the
President for Domestic Policy
The White House
West Wing - 2nd floor
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500

Dear Ms. Rasco:

In regard to our conversation in late March regarding a meeting between the National Commission on AIDS and President Clinton, it may be useful for you and the President's scheduler to know that the Commissioners will be meeting on Wednesday, April 28th.

If this opportunity is not convenient, we hope that a meeting can take place at some other early time.

Yours sincerely,

Roy Widdus, Ph.D.
Executive Director

bcc: P. Lee, HHS
Donna Shalala, HHS



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

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Washington, D.C. 20006

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Roy Widdus, Ph.D.

**Carol Rascoe
Special Assistant to the
President for Domestic Policy
The White House
West Wing-2nd floor
1600 Pennsylvania Ave., N.W.
Washington, D.C. 20500**

Dear Ms. Rascoe:

The National Commission on AIDS meets on Friday, February 12th, 1993 to discuss its activities for the remainder of FY 1993 (agenda attached).

As I previously indicated the Commission would very much like to meet with President Clinton in the near future, to discuss with him its recent recommendations (sent to you on February 3, 1993).

Any information you could provide prior to Friday, as to the prospect for such a meeting would be greatly appreciated.

Yours sincerely,

Roy Widdus

**Roy Widdus, Ph.D.
Executive Director**



NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

1730 K Street, N.W., Suite 815
 Washington, D.C. 20006
 (202) 254-5125 FAX 254-3060 TDD 254-3816

February 3, 1993

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Secretary of Defense

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EXECUTIVE DIRECTOR

Roy Widdus, Ph.D.

Carol Rascoe
 Special Assistant to the
 President for Domestic Policy
 The White House
 West Wing - 2nd floor
 1600 Pennsylvania Ave., N.W.
 Washington, D.C. 20500

Dear Ms. Rascoe:

I write regarding the request of the National Commission on AIDS to meet with President Clinton to discuss its recent recommendations. The attached materials were sent to Mr. Magaziner on January 22, as we were informed that he was the only person handling health issues actually in the White House at that time.

However, this morning I spoke with Patsy Fleming, Special Assistant to Secretary Shalala, she informed me you had now taken up your position and might be more likely to handle the Commission's request for a meeting with President Clinton (Mr. Magaziner's focus apparently being health care reform).

If after reviewing the enclosed materials you have any question please do not hesitate to call me.

Any assistance you could render in bringing these issues to the President's attention or in clarifying with whom to communicate about a possible meeting with him would be most appreciated.

Yours sincerely,

Roy Widdus, Ph.D.
 Executive Director

file

PRESIDENTIAL HIV/AIDS ADVISORY COUNCIL

CHARTER

1. **Official Description**

The Presidential HIV/AIDS Advisory Council ("Council").

2. **Objectives, Scope of Activities and Description of Duties**

The Council shall advise the President and the Office of the National AIDS Policy Coordinator regarding programs and policies intended to ensure effective prevention of HIV disease, advance research on all aspects of HIV and AIDS, and promote quality services to Americans living with HIV disease and AIDS; and shall advise the President on such other issues he may assign to the Council.

The duties of the Council are solely advisory in nature.

The Council may form subcommittees or teams to assist it in accomplishment of its objectives and duties. The subcommittees or teams may include individuals other than members of the Council and shall be balanced in terms of the interests represented and the Council's objectives and duties. The chairperson of the Council shall appoint subcommittee and team members from outside the Council's membership when necessary. The chairperson of the Council may invite experts to submit information to the Council and report to the Council on specific matters concerning national HIV/AIDS policy.

3. **Duration**

The Council shall exist for a period of two years commencing February 28, 1994, unless extended by the President. The Council will have continuing responsibility for advising the President during its existence.

4. **Official to Whom the Advisory Council Reports**

The Council will report to the President.

5. **Agency Responsible for Providing Support for the Council**

The Council shall receive administrative and other support from the National AIDS Policy Office of the Department of Health and Human Services.

6. **Estimated Annual Operating Costs**

The annual operating costs for the Council are estimated to be approximately \$100,000 per year.

7. **Estimated Number and Frequency of Meetings**

The Council shall meet three times a year, at regular intervals, and at such other times as the President or Council Chair may direct. The total number of meetings during the two years of operation is not expected to exceed eight.

8. **Membership**

There shall be no more than twenty-one (21) members of the Council. The Chairperson of the Council shall be the National AIDS Policy Coordinator. The remaining twenty (20) members of the Council shall be appointed by the President. At least eleven (11) members of the Council shall be persons with HIV disease or AIDS, or the immediate family members of persons with HIV disease or AIDS. Each member shall serve for a period of two years and, in the event this Charter is extended pursuant to Section 3, may be reappointed for additional terms at the President's discretion.