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Collection/Record Group: Clinton Presidential Records
Subgroup/Office of Origin: National AIDS Policy Office
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Subseries: National AIDS Strategy

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White House Correspondence to ONAP [Office of National AIDS Policy] [2]

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Office of
National AIDS Policy

FILE COPY

Correspondence Routing Slip

Tracking Number: G1952

Date Rcvd: 10/10/95

From: White House Special Counsel, Jane C.
Sherburne memo to P.F. + ~~Eq~~ JL

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy ✓

Assigned To: PF

RCVD: _____ DONE: _____

Recommendations/Instructions:

~~Carmina~~ ~~Jeffrey~~ ~~Salley~~ ~~Sally~~
Log out

To Support Staff: _____

Date of Response: 10-12-95

n:\corresli

THE WHITE HOUSE

WASHINGTON

October 6, 1995

MEMORANDUM FOR ALL STAFF OF THE WHITE HOUSE OFFICE,
OFFICE OF THE VICE PRESIDENT, OFFICE
OF POLICY DEVELOPMENT AND EXECUTIVE
RESIDENCE

FROM: JANE C. SHERBURNE
SPECIAL COUNSEL TO THE PRESIDENT

DAVID B. FEIN
ASSOCIATE COUNSEL TO THE PRESIDENT

RE: Clarification on Document Request from the Senate
Special Committee

In regard to our October 4, 1995 Memorandum, "Document Request from Senate Special Committee," we have clarifying information based on our continuing discussions with the Senate Special Committee.

1. The Committee has agreed to eliminate records from the following offices from its document request:

Cabinet Affairs
Correspondence
Fellowships
Management and Administration
~~National AIDS Policy~~
~~Office of Policy Development~~
Political Affairs
Presidential Personnel
Public Liaison
Scheduling and Advance
Usher's Office

Accordingly, if you work in one of the above listed offices, you do not need to search your files for documents responsive to the October 4, 1995 Memorandum.

2. The Committee has agreed to the following limitations on records maintained by White House staff in these offices:

Intergovernmental Affairs:

White House staff may limit their search for material responsive to the October 4 Memorandum to documents related to Governor Jim Guy Tucker.

Legislative Affairs:

White House staff who did not work on the 1994 Congressional hearings on Whitewater do not need to search for documents responsive to the October 4, 1995 Memorandum.

3. Request 6 of the October 4 Memorandum asks for records of communications between White House officials and some 56 different people, among them Roger Altman, Webster Hubbell and Betsey Wright. The Committee has agreed that records of communications, contacts or meetings between White House officials and Roger Altman, Webster Hubbell or Betsey Wright need be provided only if they relate to Whitewater or Madison Guaranty.

Please keep in mind that this request, and all requests in our October 4, 1995 Memorandum, call for **White House records prepared or dated between January 20, 1993 and August 5, 1994.** If you have any questions about this clarification or the original request, please contact Jane Sherburne (6-5116) or David Fein (6-6219).

Thank you for your cooperation.

FLEMING, PATRICIA S.
WHITE HOUSE OFFICE

DOMESTIC POLICY COUNCIL

750 17TH ST NW

FILE COPY

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: 61941

Date Rcvd: 10/4/95

From: letter from Michelle Eirich to Mrs.

Gore + response of Skila Harris - Chief of Staff for Mrs. Gore

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy _____

Assigned To: file

RCVD: _____ DONE: ✓

Recommendations/Instructions:

NR

To Support Staff: _____

Date of Response: 10-11-98

n:\corresli



OFFICE OF THE VICE PRESIDENT
WASHINGTON

September 25, 1995

Ms. Michelle Eirich
AIDS Action Endowment
1811 - South 43rd Street
West Milwaukee, WI 53214

Dear Ms. Eirich:

Thank you very much for the letter and resume you sent to Mrs. Gore. While there are no openings in Mrs. Gore's office at this time, I will keep your letter and resume on file in the event an appropriate position becomes available in this office.

You should know that since the Clinton/Gore Administration has as one of its priorities streamlining government, there are fewer positions open now than in the past. However, from time to time there are still opportunities for talented and qualified individuals so I have taken the liberty of sending your resume to the National AIDS Policy Office.

Thank you for expressing an interest in working for this Administration. Good luck in all your efforts.

Sincerely,

A handwritten signature in cursive script that reads "Skila Harris".

Skila Harris
Chief of Staff
for Mrs. Gore

cc: National AIDS Policy Office

SEP 25 1995

September 20, 1995

Michelle Eirich
AIDS Action Endowment
1811 - South 43rd Street
West Milwaukee, WI 53214

Ms. Tipper Gore
The White House
Washington, D.C. 20500

Dear Ms. Gore,

Hello. My name is Michelle Eirich and I am an author from Milwaukee, Wisconsin. Recently, you made a very positive impact by visiting our city for the AIDS Walk on September 17, 1995. We were very honored to have you here. Currently, I am writing a book about individuals infected with the HIV and AIDS virus. In addition, a production studio has recently asked to create a documentary based upon my book-in-progress. All proceeds from my book will be donated to AIDS organizations nationwide.

I have been working with AIDS patients for five years through my career in the insurance industry, as well as volunteering for local AIDS projects. I decided to write a book of this nature to increase awareness of the spectrum of the disease, as well as to reduce the prejudice encompassing it. My book will delve into the "real world" of eight individuals infected with the virus, bearing no mask, no bias--only a human face.

Throughout the past year, I have met many AIDS victims and interviewed them at length. Comments from my participants range from, "My doctor wouldn't treat me because I had AIDS," to "I've lost all my friends since I've been diagnosed," to "The City of Kenosha won't take care of my son because he has a mental illness and AIDS," to "My mother calls this disease the 'thing' I have." These are some of the milder statements I have heard.

I have a passion for this cause and I want to be able to do more. Since I am "straight and HIV negative," I find that I am able reach a wide audience with my AIDS awareness message. Recently, I organized an AIDS Awareness Benefit in Kenosha, Wisconsin. I brought Sean Sasser, the partner of the Late Pedro Zamora, to speak to the community about the perils of AIDS and its consequences. My event made a significant impact; however, I feel the need to do more.

I strongly would like to be a part of the national council on AIDS awareness. I am enclosing my resume, along with several articles pertinent to my research over the past year. Are there any opportunities for me to work with you in this area? Senator Herbert Kohl has been involved in sponsoring my book and could give you a reference in regard to my caliber and dedication to

this cause.

I hope to hear from you at your earliest convenience. Thank you for taking time to read my letter and I wish you continued luck in your endeavors.

Sincerely,

A handwritten signature in cursive script that reads "Michelle Eirich".

Michelle Eirich
Director
AIDS Action Endowment

Michelle Ann Eirich
1811 - South 43rd Street
West Milwaukee, WI 53214
(414) 383-1162

Objective A career-oriented position offering opportunities for development, growth, and advancement in return for my supervisory, customer service, analytical, and communication skills.

Experience *Claim Services Resource Group*, Milwaukee, Wisconsin.
Team Leader, March 1995 to present.
Northwestern Mutual Life Insurance Company, Milwaukee, Wisconsin.
Customer Relations Representative, May 1994 to March 1995.
Trustmark Insurance Company, Lake Forest, Illinois.
Technical Specialist, May 1993 to April 1994.
Senior Claims Examiner, December 1992 to May 1993.
Claims Examiner, July 1991 to December 1992.

- * Supervised Customer Service Unit in monitoring production and quality of team.
- * Coached, taught, and trained team members to meet and exceed company standards.
- * Handled difficult telephone calls and solved problems to reach satisfactory solutions for each customer and the company.
- * Analyzed detail-oriented claims to determine eligibility for benefits and approved large dollar claims.
- * Demonstrated superior written communication skills in correspondence, memos, and reports.
- * Guided team members on state mandates and legal aspects of insurance, in regard to major medical post-claim underwriting, rider, and rescind cases.
- * Learned computer applications including WordPerfect, Dbase, Microsoft Windows, and dedicated systems from end-user and client perspectives.
- * Facilitated case management reviews with doctors, nurses, and attorneys.
- * Utilized call management system to assure timely responses to customer inquiries.
- * Mentored newly-hired employees in six-week training classes.
- * Improved department processes and procedures by participating as an active member of a quality team.

Education University of Wisconsin-Parkside, Kenosha, Wisconsin.
Bachelor of Arts, May 1991. Major in Communication, Minor in Writing.

PF- ✓
fyi
file

September 11, 1995

The Honorable Nettie Mayersohn
Member of the Assembly
of the State of New York
Albany, New York 12248

Dear Nettie:

Thank you for the articles regarding
AIDS testing. I appreciate your longstanding
involvement in this important issue, and I am
glad to know of your concerns. I have shared
your articles with my staff in the National
AIDS Policy Office.

Sincerely,

BILL CLINTON

BC/SEM/KW/bws-emu-lynn-ckb (Corres. #2403864)
(8.mayersohn.n)

cc: IGA w/copy of inc.
cc: w/inc Jeff Levy, WH AIDS Policy Office

HIV Results Not Positive

NEW YORK State's programs to prevent AIDS and to help people infected with HIV are among the most expensive and least effective in the nation.

These are the early findings of a state audit that reported that some hospitals are spending as much as \$50,000 in state money just to identify one pregnant woman with HIV. One hospital spent more than \$161,000 in state money for every infected woman it found — a cost that is 90 times the national average of \$1,800.

Despite the high costs, only one of every five HIV-positive women is identified through the state program of voluntary testing and counseling.

The agency in charge of the program, the AIDS Institute, has challenged the comptroller's report, although many of the conclusions come from the agency's own internal evaluations.

These evaluations show that colossal sums of money are being wasted, thousands of sick people aren't being helped, and the AIDS Institute stubbornly clings to failing programs.

The agency "has not taken action to improve cost efficiency and has generally disregarded evaluations aimed at helping them improve their operation," said the report, which was prepared by Todd Seiberger of the state comptroller's office.

The AIDS Institute is a branch of the state Health Department that receives \$187 million a year in state and federal funding. About a quarter of that is spent on "prevention initiatives," most of which have failed.

New York has 30 percent of the nation's AIDS patients. In general, the hospitals with the most AIDS patients do the worst job of testing and bringing them into care. The Institute did little to pressure those hospitals into improving their performance, the report says.

Dr. Barbara DeBuono, who was appointed state health commissioner in January when George Pataki became governor, said she intends to make changes. "I'm not sure what the culture was within the organization and what the relationship was between the institute and its contractors," she said. "We have a responsibility to be sure that they are providing the counseling that is supposed to be done."

money to counsel pregnant women about the wisdom of voluntarily taking an HIV test when they are delivering their babies. The Obstetrical Initiative's "rate of success has not been very good and has been dropping," the comptroller's office reported.

Of 1,459 HIV-positive women who were counseled in four years, only 286 took the test. That is a success rate of under 20 percent — bad news both for the women and their children.

But the AIDS Institute resisted a proposal to focus on women who came from neighborhoods known to be HIV "hot spots." The idea was to target the women if they lived in ZIP codes with high rates of HIV infection.

"The program manager did not agree with the recommendation," said the comptroller's report. "She felt that the zip-code information was not reliable at identifying HIV-positive women and would only add extra, unnecessary work for her unit. In the meantime, there

has been no improvement in [the Obstetrics Initiative's] performance."

DeBuono said she hopes to use the Obstetrical Initiative money to push for testing before the mother arrives to deliver. "I want the emphasis to be in the prenatal period," she said. "In prenatal settings, in sexually-transmitted-disease clinics, and in family-planning clinics, you have to counsel women on the benefits of testing. It is also the responsibility of private care-givers, who are not getting state funding."

The AIDS Institute already administers tens of millions in grants to those kinds of programs, with mixed results at best.

Bronx Lebanon Hospital Center is the only hospital in the comptroller's sample that used its obstetrics money wisely. Its costs were close to national averages, and it succeeded in bringing a majority of women into care.

But the expenses are not as bad as they look, health officials claim. "We knew going in that the costs of identifying the HIV-positive women would be high," said Michael Rampollo, a director of the AIDS Institute.



**Jim
Dwyer**

NEW YORK NEWSDAY

FRIDAY, JULY 14, 1995



THE ASSEMBLY
STATE OF NEW YORK
ALBANY

NETTIE MAYERSOHN
27th Assembly District

I thought the enclosed might be of interest to you.

Cordially,

Nettie Mayersohn

CAPITOL OFFENSE

I FEEL COMPELLED to respond to the letter from Assembly Member Deborah Glick [June 20], in which she stated that I have used "half-truths" and "hyperbole" in fighting for passage of my Baby AIDS bill, which would require disclosure of newborns' HIV antibody status to their mothers or other appropriate guardians.

Ms. Glick's statement that I have been "unable to gain substantial support in the medical/health community" is absurd. The bill has received the support of numerous individuals and organizations which provide medical care and social services to children.

The New York State Association of County Health Officials, the Council of Family and Child Caring Agencies, the New York Chapter of the American College of Emergency Physicians, and the AIDS Institute Committee for the Care of Children and Adolescents With HIV Infection are just four of 15 organizations supporting the bill.

In addition, the legislation has received the support of many prominent individuals in the health care field, such as former U.S. surgeon general C. Everett Koop, New York State health commissioner Barbara DeBuono, Westchester County health commissioner Mark

Rapoport, and Rockland County health commissioner Marvin Thalenberg. Both the Medical Society of the State of New York and the New York State Academy of Family Physicians have passed resolutions in support of testing newborns for HIV in the same manner the we now test for seven other diseases.

Your readers should ask themselves if it is I or Ms. Glick who is engaging in hyperbole and half-truths.

NETTIE MAYERSOHN

Assembly Member

Queens



THE ASSEMBLY
STATE OF NEW YORK
ALBANY

NETTIE MAYERSOHN
27th Assembly District

I thought the enclosed might be of interest to you.

Cordially,

Nettie Mayersohn

Village Voice

7-18-95

House Panel to Draft Bill Requiring AIDS Tests of Newborns

By KEVIN SACK

WASHINGTON, July 13 — Despite heavy opposition from medical groups and advocates for people with AIDS, leaders of the House Commerce Committee said today that they had agreed to draft bipartisan legislation that would require newborns to be tested for the virus that causes AIDS unless their mothers had been tested in pregnancy.

The agreement, announced during a committee vote on Federal AIDS financing, heightens the chance that Congress will approve a bill requiring states for the first time to conduct tests on some newborns for the virus, H.I.V. The Federal Government would finance the testing.

The proposed legislation, which pits the privacy concerns of mothers against the medical needs of infected infants, has generated widespread debate in Washington and in several state capitals. The debate has been particularly heated in Albany, where the New York Legislature has been trying to deal with the issue

for nearly three years.

Most states have tested newborns for H.I.V. in an effort to track the spread of the disease. Parents were not told of the test results, meaning that some infected newborns went without treatment until physical symptoms led to the discovery of their illnesses.

A positive test result does not necessarily indicate that a newborn is infected with H.I.V. The test may simply have detected antibodies passed from the mother to the infant. An estimated 7,000 of the 2.5 million babies born each year test positive for H.I.V. but only about 2,000 actually have the virus, Federal health officials say. Those with only the antibodies will test negative several months after the initial test.

What makes the testing issue nettlesome is that a positive test result always means that the mother is infected. The mandatory testing of newborns, therefore, is equivalent to the mandatory testing of new mothers.

The Commerce Committee

seemed prepared today to pass an amendment that would force states to require H.I.V. tests for newborns or risk losing Federal money for AIDS treatment and prevention provided under the Ryan White Care Act. That concept apparently has broad support in the House from members of both parties.

But in response to objections raised by the National Governors' Association and Governors like George E. Pataki of New York and Christine Todd Whitman of New Jersey, some members of the committee said they were unwilling to support legislation that would impose new costs on the states.

Other members objected to payments of Ryan White financing — a total of \$632 million a year — conditional on state support for mandatory testing of newborns.

The amendment's sponsor, Representative Tom Coburn, an Oklahoma obstetrician who was elected last year as a Republican, withdrew it today after reaching agreement with Democratic and Republican col-

leagues to provide Federal money to pay states for the testing.

Some Democrats, including Representative Henry A. Waxman of California, said they hoped the ultimate agreement would use the promise of Federal money as an incentive for states to require testing of newborns, rather than as a punishment for states that do not.

The committee passed the Ryan White bill unanimously today without the testing amendment. Mr. Coburn and the committee chairman, Representative Thomas J. Bliley Jr., Republican of Virginia, said they would work with Democrats to write the new testing proposal that would be submitted as an amendment to the AIDS financing bill on the House floor.

They said they expected it to receive overwhelming support. Representative Gary L. Ackerman, a Queens Democrat who has championed the issue but is not on the Commerce Committee, echoed that view.

The agreement to provide Federal financing for H.I.V. testing presumably will alleviate the fiscal concerns of state and local officials. But it has not lowered the strenuous opposition of advocates for people with AIDS and health experts who believe that the specter of mandatory testing may deter some pregnant women from seeking adequate prenatal and maternity care.

The American Medical Association, the AIDS Action Council and the Association of State and Territorial Health Officials all oppose the measure on those grounds.

Those groups also argue that the most effective means of preventing the transmission of H.I.V. from mother to fetus is to require doctors to advise their pregnant patients to be tested. Recent studies have shown that the risk of transmission can be cut to 8 percent from 25 percent if infected pregnant women take the drug AZT.

Last week, the Centers for Disease Control and Prevention issued new guidelines recommending that doctors counsel pregnant women to be tested. Those guidelines are now expected to become part of standard medical practice. The mandatory testing of newborns would only apply to the children of mothers who were not voluntarily tested.

I thought the enclosed might be of interest to you.

Cordially,

Nette Mayersohn

I thought the enclosed might be of interest to you.

Cordially,

Nettie Mayersohn

THE NEW YORK TIMES MONDAY, JULY 17, 1995

Debate on H.I.V. Testing Raises Ackerman's Profile

By KEVIN SACK

WASHINGTON, July 14 — In his 12 years in Congress, Representative Gary L. Ackerman, a Queens Democrat, has been known as much for his flamboyance as for his legislative record.

The plump and affable Mr. Ackerman sports a white carnation boutonniere each day and lives on a houseboat on the Potomac River that he named the Unsinkable II (after the Unsinkable I sank). While his colleagues walk or take the subway two blocks to the Capitol from the Rayburn House Office Building, Mr. Ackerman cruises over in his Aunt Chachi's clunky 1966 Plymouth Valiant. Before strolling into the House chamber to vote, he stops to give a security guard a crushing bear hug.

But after years of clowning, the 52-year-old Mr. Ackerman finds himself at the center of Congressional debate on an issue that could not be more sober — whether the Government should require the testing of newborns for the human immunodeficiency virus.

Most states test infants for H.I.V. to help track the spread of the AIDS epidemic. But because the test may merely detect antibodies passed from the mother to her child, an accurate positive test result does not necessarily indicate that the child is infected. It always means, however, that the mother is infected. To preserve the mother's right to choose whether to learn her H.I.V. status, states do not inform either parent of the results. Each year, therefore, several thousand babies who inherit the virus from their infected mothers go without treatment that could prolong their lives.

Taking his lead from the New York Assemblywoman Nettie Mayersohn, a longtime friend and constituent who has pushed the issue unsuccessfully in the State Legislature, Mr. Ackerman has worked aggressively this year to build support for a bill that would require states to disclose H.I.V. test results to parents.

This week, his efforts began to pay off. Leaders of the House Commerce

more prominent members of the New York City delegation, like Representatives Charles B. Rangel of Manhattan and Charles E. Schumer of Brooklyn. In the past, Mr. Ackerman has made his reputation on foreign affairs issues involving North Korea, Ethiopia and other far-away places, and on his very New York sense of humor.

To explain his vote for the Persian Gulf War resolution, during one of the most solemn debates in Congressional history, Mr. Ackerman penned doggerel that began, "Slam, bam, thanks, Saddam." Speaking on the floor two weeks ago against a constitutional amendment that would allow states to ban flag burning, Mr. Ackerman waved a pair of red, white and blue socks and asked whether the amendment would make it illegal to wear them. "Does it matter if your feet are clean or dirty?" he asked.

By his own admission, the H.I.V. testing issue may be the most significant domestic policy issue he has tackled in Congress.

"I'm usually not involved in these kinds of issues," he said. "I've made my mark on human rights and foreign concerns. But this one is rather compelling."

Mr. Ackerman's stance is also likely to be immensely popular in his district, which includes parts of Queens and the North Shore of Long Island.

"It's the kind of bread-and-butter issue that can only help him," said State Representative Thomas J. Manton, the Queens Democratic leader. "He was the spearhead here, and it makes him look a little more mainstream when he's been criticized for being too liberal."

The opponents of mandatory H.I.V. tests for newborns include a number of medical associations and advocates for people who have AIDS, who contend that Mr. Ackerman's position is simplistic. They argue that the specter of mandatory testing is likely to scare some women away from proper prenatal and maternity care and that the testing of newborns is equivalent to involuntarily testing new mothers.



Kirsten Elstner for The New York Times

Representative Gary L. Ackerman of Queens is at the center of Congressional debate on H.I.V. testing for newborns.

helpless children to the privacy rights of women.

"There is a fear among a group, with which I usually agree, that this will open the door to mandatory testing of everyone in society," he said. "That's not what this bill is about."

Mr. Ackerman became interested in H.I.V. testing during conversations with Ms. Mayersohn. When she began to confront opposition in the Democratic-controlled Assembly last year, Mr. Ackerman started calling for a Federal law. Assembly Speaker Sheldon Silver has shelved Ms. Mayersohn's proposal to await Congressional action.

Last year, Mr. Ackerman unveiled a bill that would have required states to tell parents the results of the H.I.V. tests already being conducted on newborns. But the Federal Centers for Disease Control suspended the testing program in May, in what Mr. Ackerman viewed as an attempt to sabotage his legislation.

In response, Mr. Ackerman and Representative Tom Coburn, an Oklahoma Republican, designed a proposal that would require states to test newborns for H.I.V. if their mothers were not tested while pregnant. States that did not comply would face the loss of Federal financing for AIDS treatment and prevention. House leaders from both parties agreed on Thursday to work

*I thought that the enclosed might be of
interest to you.*

Cordially,

Nettie Mayerson

The Washington Post

AN INDEPENDENT NEWSPAPER

AIDS Tests for Babies

WE PUBLISH on the preceding page today an article by Helen Rodriguez-Trias, a pediatrician, and Ana O. Dumois, a social scientist, both of whom specialize in the area of women's health and AIDS. The writers disagree with a May 29 editorial that criticized a decision of the U.S. Centers for Disease Control to suspend anonymous testing of newborns for the AIDS virus. Our position was, and remains, that these tests should be resumed, extended and handled in a manner that will make it possible to match blood samples with individuals so that test results can be provided to those infected.

The writers argue that it is preferable to counsel pregnant women about AIDS and persuade them to be tested voluntarily so that treatment that might help their babies can be begun before birth. We agree entirely. Studies have indicated that the rate of transmission of the virus from mothers to children can be reduced by two-thirds if the drug AZT is administered late in pregnancy, during labor and for six weeks after birth. CDC guidelines strongly recommend counseling and voluntary testing, and experience indicates that more than 90 percent of pregnant women approached in this manner will consent to testing.

But what should be done for the children whose mothers have never been tested and who might benefit greatly from AZT therapy even if it's only made available after birth? Contrary to what the writers indicate, the CDC advises that HIV test results

can be made available in a matter of hours. Knowing the baby's status right away would also allow an informed decision about breast feeding, which transmits the virus too.

State public health laws make all sorts of tests mandatory for newborns. If it is so important to learn whether a baby has been infected with syphilis or hepatitis, why isn't knowledge about HIV status just as critical? We understand that a certain invasion of the mother's privacy is involved here—as it is in the case of other tests—and we acknowledge the interest of doctors in maintaining the trust of patients by emphasizing persuasion. But it makes sense to us to put the baby's life first and require testing of infants whose mothers adamantly refuse to be tested.

Data collection on HIV in newborns has been suspended since May 10, and next month a conference will be held at CDC headquarters in Atlanta to review the situation. The data collection suspension came after pressure began to build in Congress and elsewhere to change anonymous testing to procedures that permit identification and notification of participants. That pressure in fact was merited and deserves support. We believe that the test ought to be given at birth to all babies whose medical status in this respect is unknown so that treatment can be undertaken immediately. The welfare of all children at risk should be the scientists' priority.

Office of
National AIDS Policy

FILE COPY

Correspondence Routing Slip

Tracking Number: G1860

Date Rcvd: 9-6-95

From: Sue J. Smith, White House

Forwarding ltr. to Sen. Simon from Jack W. Ginn

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy _____

Assigned To: RS

RCVD: _____ DONE: _____

Recommendations/Instructions:

To Support Staff: _____

Date of Response: 10-3-95

n:\corresli

THE WHITE HOUSE

WASHINGTON

OCT - 3 1995

Mr. Jack W. Ginn
1603 W Devereux Drive
Peoria, Illinois 61614-4009

Dear Mr. Ginn:

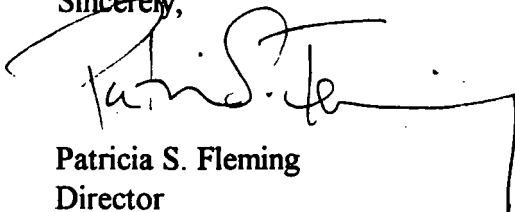
Thank you for your letter regarding the Federal Workplace AIDS Education Initiative.

In September 1993, President Clinton asked all Federal Departments and Agencies to institute workplace education programs on HIV and AIDS. These programs were patterned after existing programs offered by many private companies in the United States. Participation in HIV/AIDS education programs has always been left up to the individual agency. To date nearly 80% of Federal employees have participated in HIV/AIDS education programs and a substantial majority of those who have participated report that the information they received was helpful to them and their families.

Today, AIDS is the leading cause of death among Americans between the ages of 25 and 44 and nearly 80% of American workers are in that age group. It is crucial, therefore, that all Americans learn as much about HIV and AIDS as they can so that they can protect themselves and their families as well as assist people in their community who may be living with this disease.

Again, thank you for sharing your views on this critical issue.

Sincerely,

A handwritten signature in black ink, appearing to read 'Patricia S. Fleming', with a long horizontal flourish extending to the right.

Patricia S. Fleming
Director
Office of National AIDS Policy

cc: Senator Paul Simon

n:\fwaeifm.ltr

THE WHITE HOUSE
WASHINGTON

8/30/75
DATE

MEMORANDUM

FOR:

ONAP

FROM:

SUE J. SMITH *SGS*
DIRECTOR, AGENCY LIAISON

SUBJECT:

REFERRAL OF CASEWORK

I am forwarding the attached letter to your office for appropriate action. Please send us a copy of your written response or your telephone report along with the writer's original correspondence and envelope to the following address:

Ms. Sue J. Smith
Director, Agency Liaison
Room 6, OEOB
The White House
Washington, D.C. 20500

If you have any questions, call my office at 202/456-7486.

Thank you for your help.

*Please cc the Congressman when
you respond. Thank you.*

THE WHITE HOUSE

WASHINGTON

August 25, 1995

MEMORANDUM FOR SUE SMITH

FROM: SUSAN BROPHY *SB*
LEGISLATIVE AFFAIRS

SUBJECT: PRESIDENTIAL CORRESPONDENCE

Enclosed please find a copy of the letter which was sent to the President from Senator Paul Simon, forwarding a letter from his constituent, Mr. Jack W. Ginn, expressing his concern over a proposal to require federal employees to attend courses dealing with acceptance of alternative lifestyles.

I do not believe this letter requires a Presidential response at this time; therefore, I would appreciate your looking into these matters and responding directly to the member's specific concerns. Please forward a copy of the response to Jocelyn Jolley in room 102E of the White House.

If you have any questions regarding this request, please contact Jocelyn at 6-7500.

Enclosure

PAUL SIMON
ILLINOIS

COMMITTEES:
LABOR AND HUMAN RESOURCES
JUDICIARY
BUDGET
INDIAN AFFAIRS

United States Senate

WASHINGTON, DC 20510-1302

August 18, 1995

Mr. Pat Griffin
Assistant To the President For Legislative Affairs
The White House
Washington, D.C. 20500

Dear Pat:

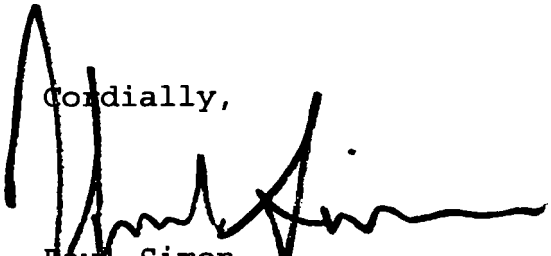
I am writing on behalf of Jack W. Ginn who has written expressing concern over a proposal to require federal employees to attend courses concerning the acceptance of alternative lifestyles. For a more detailed explanation, please see the enclosed letter.

I would appreciate your looking into this matter and responding to Mr. Ginn. In addition, please be sure to send a copy of your response to the attention of my staff assistant, Andrea Mitchell.

Thank you for your attention to this matter. Please let me know if there is anything I can do to help resolve this situation.

My best wishes.

Cordially,


Paul Simon
U. S. Senator

PS/akm
Enclosure

05 AUG 22 11:01

Agency Liaison

425031

Peoria, Illinois
July 31, 1995

1995 AUG -4 AM 10: 15

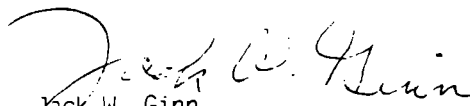
The Honorable Paul Simon
U. S. Senator
Senate Office Building
Washington, D.C. 20510

Dear Senator Simon:

I heard this morning that the Clinton Administration is forcing U. S. Government employees to attend seminars which are allegedly teaching that the homosexual lifestyle is a legitimate alternative lifestyle.

It is hoped that this is not true, but if it is, what can be done to stop it?

Respectfully


Jack W. Ginn
1603 W Devereux Drive
Peoria, Illinois 61614-4009

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G1857

Date Rcvd: 9-5-95

From: Don Maisson to the President

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy _____

Assigned To: LR - ^{draft response} ① check w/ Seth Musket 456-5514 in Pres.

RCVD: 9/8 DONE: _____
Letters - are in drafting response for
Don or PR on behalf of?
② Letter to Don Maisson
③ Notes to the kids

Recommendations/Instructions:

To Support Staff: _____

Date of Response: 10-19-95

n:\corresli

9/12
Sent fax to Seth
asking him Jeff's
question
Seth called back to
say that POTUS
already knew
2/12/95

Jeff wants this
to be done

fax 456-2806

THE WHITE HOUSE

WASHINGTON

OCT 19 1995

AIDS Services of Dallas
P.O. Box 4338
Dallas, Texas 75208-0338

Dear Angel, Teresa, Veronica, Frank and Raciell:

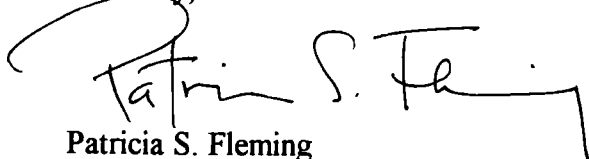
I join the President in thanking you for your letters and beautiful photographs.

You are truly lucky to have found the comfort and support that you need through AIDS Services of Dallas. We know that funds from the Ryan White Care Act have made that support possible. As you are probably aware, the President has increased funding for this program and it is being extended by Congress. We will continue to fight hard to provide the resources we know are so vitally needed in your community.

I hope that you will continue to share your message of hope and inspiration throughout Dallas and in other communities. Sometimes, people think that we here in Washington are the only ones able to make a real difference. But I disagree. I feel strongly that everyone has a role to play, and your voices are just as important in our nationwide efforts to care for those affected by this disease.

Thank you once again for your letters and pictures. We are listening.

Sincerely,

A handwritten signature in black ink, appearing to read "Patricia S. Fleming". The signature is fluid and cursive, with a large initial "P" and a long horizontal stroke at the end.

Patricia S. Fleming
Director
Office of National AIDS Policy

n:\aidsdall

**OFFICE OF NATIONAL AIDS POLICY
EXECUTIVE OFFICE OF THE PRESIDENT**

750 17th Street, N.W.
Washington, DC 20503

Phone: 202-632-1090
Fax: 202-632-1096

FACSIMILE COVER SHEET

TO: SETH MUSKETT

FAX NUMBER: 202-456-2806

FROM: L.S. ROMOCKI

DATE: 12 SEPTEMBER 1995

PAGES INCLUDING COVER SHEET: 2

COMMENTS:

SETH,

WE ARE NOT SURE WHERE THE LETTER CAME
FROM, ONLY THAT IT CAME FROM YOUR OFFICE.

PLEASE ADVISE WHETHER WE SHOULD DRAFT
RESPONSE FROM THE PRESIDENT OR PATSY?

THANKS—

011007

ASD

AIDS Services of Dallas
A Project of the PWA Coalition of Dallas, Inc.

P.O. Box 4338
Dallas, TX 75208-0338
(214) 941-0523 Voice/TDD
FAX (214) 941-8144
Internet: asd0523@aol.com

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Don Maison, Esq.

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Michael R. Merdian (1956-1993)
Daryl Moore (1960-1988)

July 19, 1995

President of the United States
1600 Pennsylvania Ave.
Washington, DC

Re: S.641 & HR 1872

Dear President Clinton,

Several weeks ago I was invited to attend the Resident Council meeting at our Revlon facility, one of two licensed Special Care Facilities providing nursing case management, social work, around-the-clock home health care and nutritional support to approximately 60 individuals and families living with AIDS. I had been asked to provide them with an update on the status of the Ryan White reauthorization.

Nearly half of our funding comes from the Ryan White Care Act. We provide care through the terminal phase of the disease and we are licensed as a Residential AIDS Hospice Program. We provide a supportive environment and care to an average of 64 men, women and children at a cost of approximately \$66.00 per day, compared to hundreds for nursing home care, and up to \$1,200.00 per day for inpatient care at Parkland Memorial County Hospital. We have saved local taxpayers millions in what it would have cost to provide care in other models.

A number of the children who live at AIDS Services of Dallas felt that it was important to write to you and let you know how they felt about the importance of Ryan White funding to them. The children are living in a situation where one or in some cases both parents are infected with the HIV virus. Our residents average 12% of median income in the Dallas area. They would not be able to access the care and services they need.

Our children have never before asked to be involved in an issue. This is their first letter to a Member of Congress. Thank you for listening to them.

Sincerely yours,

Don Maison

Don Maison

DJM:m

(Enclosures)



- Housing
- Education
- Advocacy

A Community Housing Development Organization
An Equal Opportunity Employer



Equal Housing Opportunity

Map

ASD

AIDS Services of Dallas
A Project of the PWA Coalition of Dallas, Inc.

P.O. Box 4338
Dallas, TX 75208-0338
(214) 941-0523 Voice/TDD
FAX (214) 941-8144
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Sincerely yours,

Don Maison

Don Maison

DJM:m

(Enclosures)



- Housing
- Education
- Advocacy

A Community Housing Development Organization
An Equal Opportunity Employer



Equal Housing Opportunity

Dear Mr. Congressman,

My Mother have AIDS We live in a place that gets its money
from the Ryan White Funds. If this money goes away

from us we have to move my Mother and my ~~brother~~ brother
are not sure that ~~the~~ people don't care about
AIDS. Here the people of revlon help

my family. Please, vote to keep funds so my parents
can have peace and the medicines they need

Angel

Dea Mr. Congressman,

My ~~Dad~~ ~~Dad~~ ~~Dad~~ has AIDS. We live in a place
that gets its money from the
Ryan White funds.

If this money goes away we will
have to move. I'm way
Not everybody cares ^{not sure where} for people
with AIDS.

Here the people help us and treat
my Dad good.

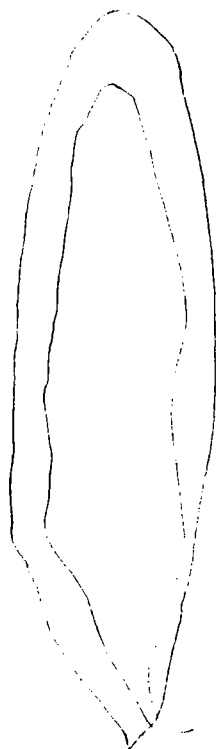
Please vote to keep funds so my
Dad can have peace and the
medicines they need.

Love

Teresa to my Dad,



Dear Mr. Congressman
My Dad has ~~AIDS~~ AIDS. We live in ASD and they get
money from the Ryan White funds.
If this money goes away we
will have to move. I'm not sure where.
Not everybody has AIDS. Please ~~help~~ care for people with
AIDS. ~~not for~~ non-
take away our
Money



Veronica

can live long many

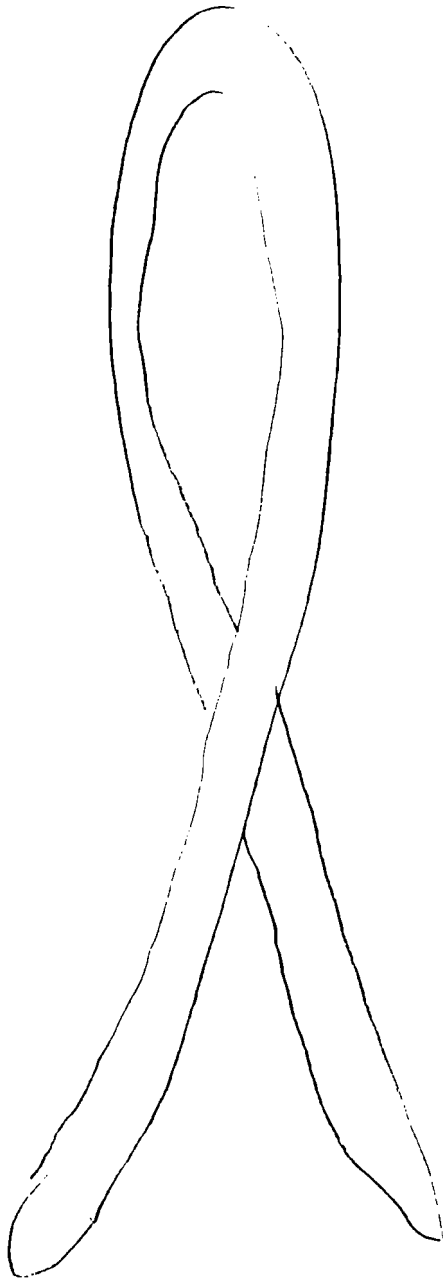
My father has Aids. We live in a place that gets its
Money from Ryan White fund.

If this money goes away we will have to move somewhere else that
does not care about Aids. Here the people are good and treat my f-
~~my~~ good. Please, ~~help~~ ^{Vote} to keep funds so my father can live
the rest of his life peacefully before he passes out

Love. Frank Gonzalez

Please help my father

Please help



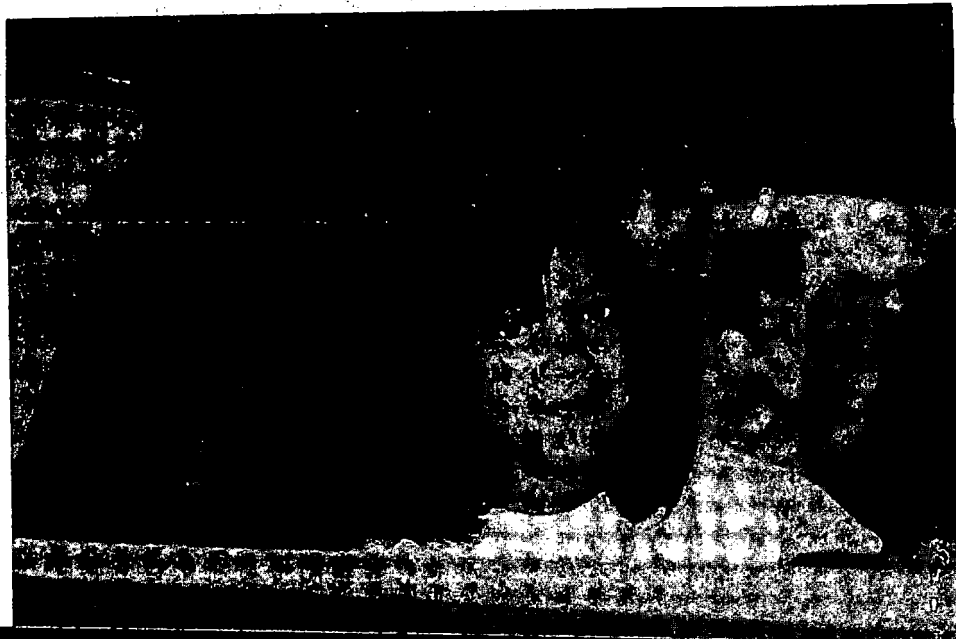
Dear Mr. Congressman,

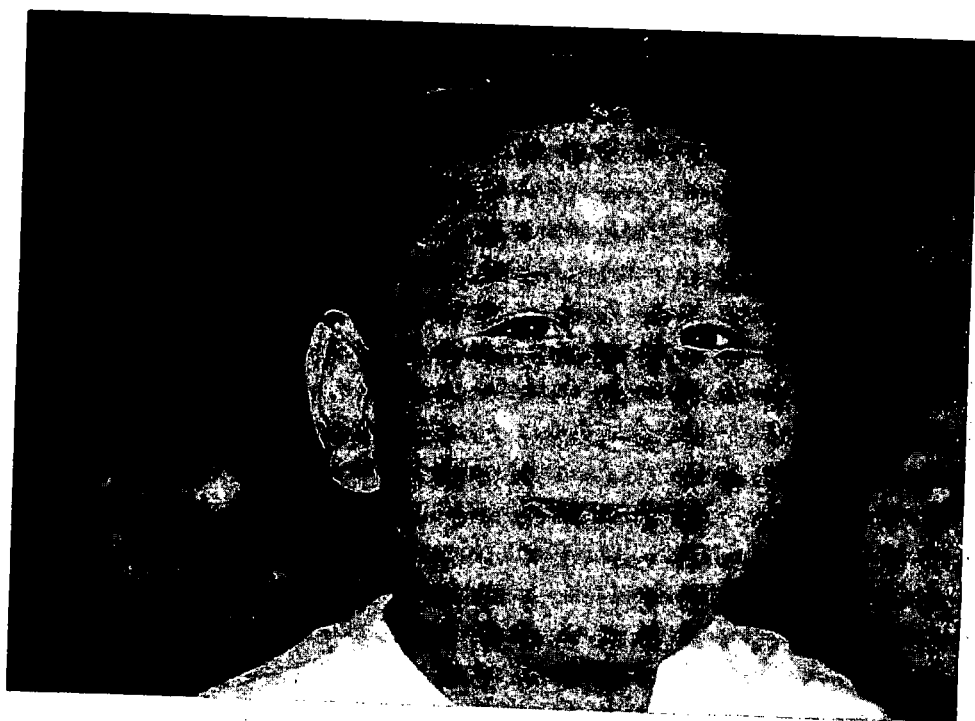
My dad and mom have AIDS. We live in a place that gets its money from the Ryan White funds. If this money goes away we will have to move. I'm not sure where. Not everyone cares for people with AIDS. Here the people help us and ^{treat} my mom and Dad good. Please vote to keep funds so my mom and Dad can have peace and the medicines they need.

Love

Raciel

Macias





FILE COPY

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: G1848

Date Rcvd: 8-31-95

From: Leon Panetta's ltr. to Timothy L. Gibbs

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy ✓

Assigned To: PF - fyi - response optional

RCVD: _____ DONE: _____

Recommendations/Instructions:

Very brief response please.

NR

To Support Staff: _____

Date of Response: 9-11-95

n:\corresli

THE WHITE HOUSE
WASHINGTON

July 28, 1995

Mr. Timothy L. Gibbs
Post Office Box 733
Lusby, Maryland 20657

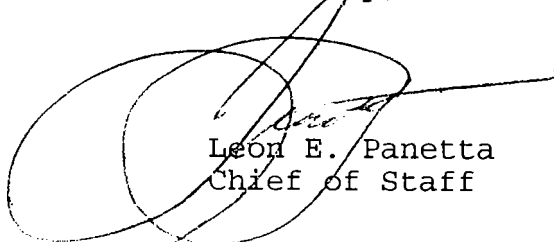
Dear Mr. Gibbs:

Thank you for your letter, and I appreciate your contacting me regarding HIV clinical research.

So that your concerns may receive the appropriate attention, I have forwarded your letter to Togo D. West, Secretary of the Army, for review. I have also provided a copy of your letter to Patricia Flemming, Director of National AIDS Policy, so that she may be aware of the situation. Please be assured that this Administration will keep your concerns in mind.

Again, thank you for writing.

Sincerely,



Leon E. Panetta
Chief of Staff

cc: The Honorable Togo D. West
The Honorable Patricia Flemming

LEP/tab

*Forward to
Patsy Flemming
N.A.P.O.
MAY 21 1995*

Timothy L. Gibbs
P.O. Box 733
Lusby, MD 20657-0733
May 17, 1995

Chief of Staff
The White House
Washington, DC 20510

Dear Mr Panetta:

I am writing you as a HIV positive patient enrolled in studies with the Henry M. Jackson Foundation for the Advancement of Military Medicine.

I personally have enrolled in every protocol made available to me through the Jackson Foundation and the military since 1986. I am greatly distressed to hear that HIV clinical research in the military is coming to an end. As a patient and participant, I feel betrayed. The Department of the Army as the lead agency for Infectious Disease received full funding for FY95. Although this money was intended for clinical and laboratory based research, the Department of the Army has elected to direct all the money away from clinical research which will result in clinical sites closing as of December, 1995. Patients who have volunteered for these protocols have given their blood, tissues, time, and fears as well as taking the risk of exposure to experimental medications. This was all done in an effort to further knowledge concerning HIV infection. The thought that my efforts may have been wasted as the clinical studies come to a close before they progress to the next step is deplorable.

It is my understanding that the majority of the money will go to Thailand for preventive vaccine trials. Even if these trials are successful, it will probably take ten to twenty years. Where does this leave those currently infected and the probable thousands of service men and women who will become infected in this country? As a recently retired service member I am very concerned at the possibility of not having access to clinical research and to be told I longer matter. After 19 years of honorable and faithful service to our country and Constitution it is particularly disturbing that the military's commitment to me in this matter is apparently not reciprocated. For the Department of Defense beneficiaries who live far away from major medical centers conducting HIV research, this is a tremendous blow. Come December 1995 they lose the opportunity to take part in military sponsored clinical research and have little to no access to civilian HIV research. What will happen to them?

In conclusion, I urge you look into this important matter and convince the Department of the Army to continue proper funding of the highly successful domestic military HIV research program. The data obtained thus far benefits more than just the armed services but the nation as a whole. I thank you for your valuable time and consideration.

Sincerely,

Timothy L. Gibbs

Office of
National AIDS Policy

Correspondence Routing Slip

FILE COPY

Tracking Number: G1810

Date Rcvd: 8/17/95

From: Carol Rasco

URGENT

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy _____

Assigned To: jt

RCVD: _____ DONE: jt

Recommendations/Instructions:

To Support Staff: _____

Date of Response: _____

n:\corresli

jt - ✓
Carol has -
Pat will let
us know if
she needs any
thing else
C 8/17

Draft response to parents of Ricky Ray

Thank you for your letter regarding the Ricky Ray Relief Fund Act. Ricky's story and your family's story is one that I think of often. Ricky's picture is on my table as a constant reminder of the tragedy of AIDS and the trials your family has endured.

The experience of hemophiliacs with the HIV epidemic is one of the great tragedies of the last two decades. I am committed -- and my entire Administration is committed -- to making sure that the policy failures that allowed this tragedy to occur cannot ever be repeated. I am proud that this Administration asked the Institute of Medicine to undertake their study of HIV and the blood supply. I think it demonstrates our commitment to addressing the root causes of this problem.

With the release of the IOM report and its significant recommendations, Secretary of Health and Human Services Donna Shalala has appointed a task force (chaired by Assistant Secretary for Health Phil Lee) to assess the recommendations that have not already been put in place, including the issue of compensation for those who were infected during the 1980s. I know that Secretary Shalala will move quickly on this matter and I hope to have her report on these issues shortly.

Thank you again for writing. I urge you to continue your efforts in Ricky's memory and on behalf of all who have been affected by this terrible epidemic.

Sincerely,

Bill Clinton

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: _____

PATSY / JEFF

Draft response for POTUS

and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer

(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

Schedule ? :

☐ Accept

☐ Pending

☐ Regret

Designee to attend: _____

Remarks:

**PLEASE draft reply
from POTUS ASAP.
Run past CAROL and then
DOERKIND. Thru**

*heir
passed
to
Ray*
Clifford and Louise Ray sent a packet of information concerning the "Ricky Ray Hemophilia Relief Act of 1995." They have three hemophiliac children who have contracted HIV from blood transfusions. Ricky has passed away and his two siblings will eventually follow. They want the Act enacted to help provide financial relief to families with HIV positive hemophiliacs.

THE RICKY RAY HEMOPHILIA RELIEF ACT OF 1995

AUG 15 1995

To Whom It May Concern:

Enclosed you will find several documents concerning the Ricky Ray Hemophilia Relief Fund Act Of 1995. I hope you will take the time to read them.

The first is a short piece on Ricky Ray for whom the bill is named. He was my first born child and the first of my children with hemophilia. I also had three other children, two of which are also hemophiliacs. They all three became infected with H.I.V. due to the medication they require to control their hemophilia.

We have worked very hard the last 2 1/2 years trying to get this bill going. The second piece enclosed is a short synopsis of what the bill entails.

The third is an overview of the F.D.A.'s failure to our community. It includes the 1980's and explains where they were wrong.

The last document is the Executive Summary of HIV and the Blood Supply: An Analysis of Crisis Decisionmaking. This was a study of the Institute of Medicine which is part of the National Academy of Sciences. You will notice that everything we have been trying to show was correct. Please, read this and understand that grave errors were made and that thousands of hemophiliacs and their families were the receiptants of these errors. I want to remind you that these were not minor errors. They have cost many lives already and many more will follow.

We have already lost one son to Aids and have two others who will eventually follow their brother. No amount of money could ever replace the lives of our loved ones, but would help to ease some of the financial hardships created. We all know that nothing will change the paths that many hemophiliacs are already on. Knowing that our government failed us has been very hard to understand, but if you will help us pass this bill, we will know that we are not forgotten. This bill will also help ensure that other families will not have to endure the loss, pain, and suffering that too many families have already felt.

We are grateful for the time you have given us and hope that you will make the right choice. SUPPORT the RICKY RAY BILL.

If we can help answer any of your questions, please call us at 941-358-8605.

Sincerely,

Clifford Ray
Clifford Ray Louise Ray

Handwritten: Please send to Ray
Clifford and Louise Ray sent a packet of information concerning the "Ricky Ray Hemophilia Relief Act of 1995." They have three hemophiliac children who have contracted HIV from blood transfusions. Ricky has passed away and his two siblings will eventually follow. They want the Act enacted to help provide financial relief to families with HIV positive hemophiliacs.

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Sincerely,

Handwritten signatures of Clifford and Louise Ray
Clifford Ray Louise Ray

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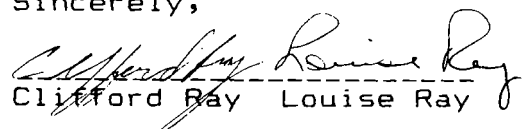
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Sincerely,


Clifford Ray Louise Ray

RICKY RAY HEMOPHILIA ACT OF 1995

AGE 14



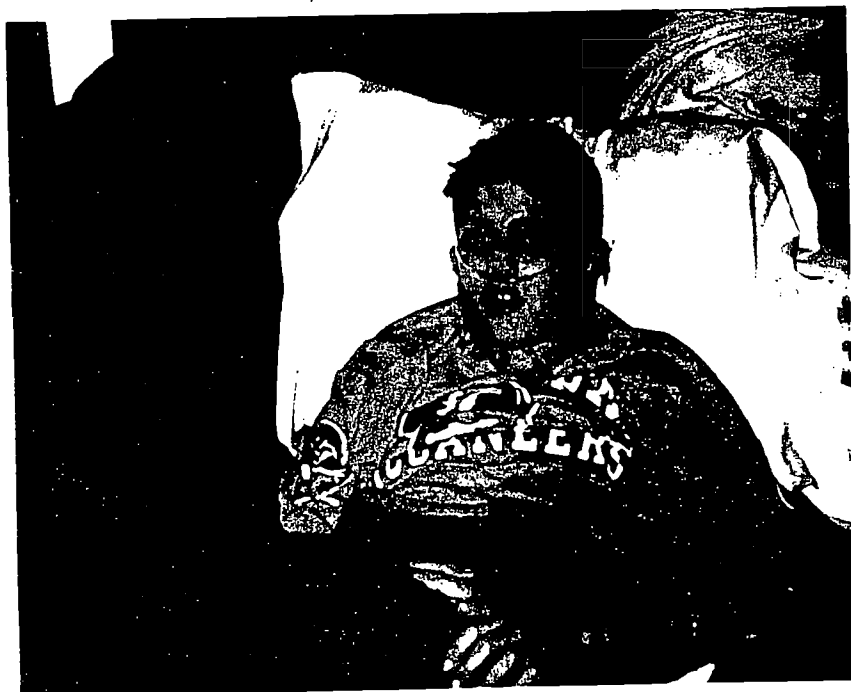
Clifford, Louise, Robert,
Randy, Candy Ray

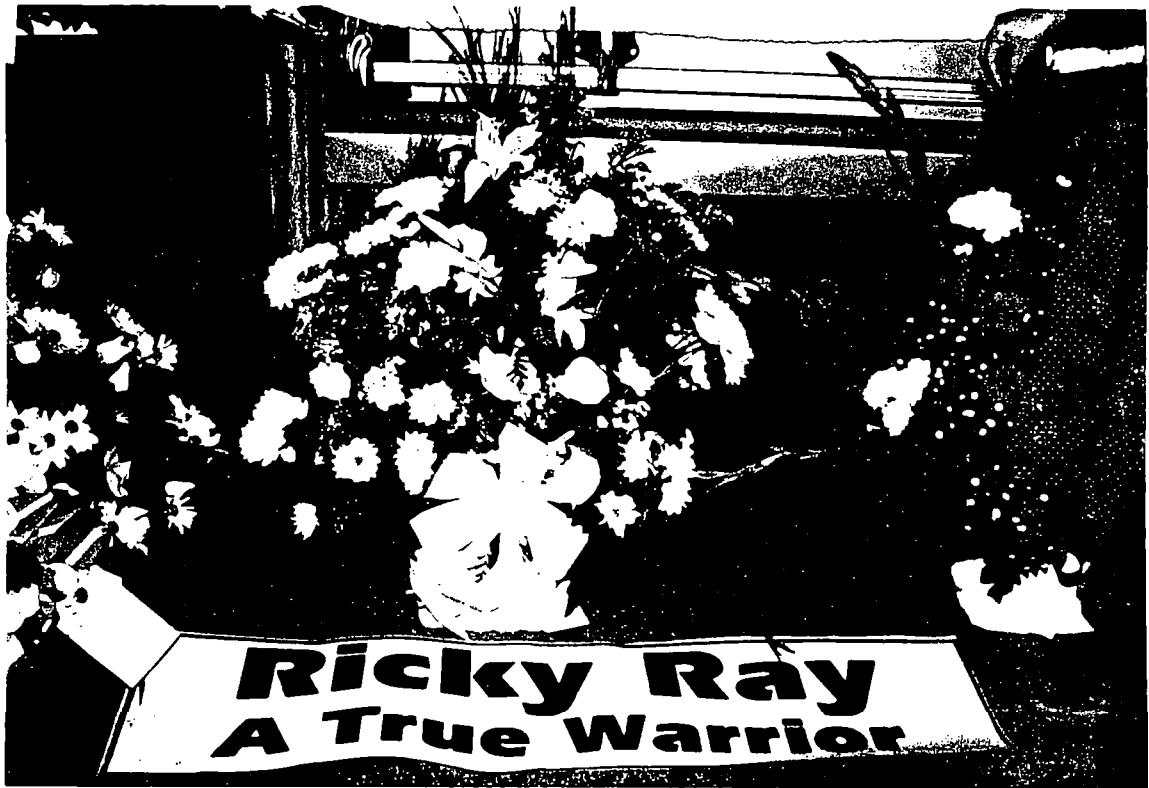
3206 Decker Ave. Orlando, FL. 32833
407-568-1581

ON THE PREVIOUS PAGE YOU SAW A PICTURE OF RICKY RAY AT THE AGE OF 14. HE WAS HEALTHY AND HAPPY. HE WAS LOOKING FORWARD TO THE SAME THINGS THAT ALL OTHER TEENAGERS DO. HIGH SCHOOL, DATES, DRIVING LICENSE, A NEW CAR, AND COLLEGE WERE THINGS RICKY WANTED AND THAT WE WANTED FOR HIM. THESE WERE NOT TO BE HIS REALITY. HIS, LIKE MANY OTHER HEMOPHILIACS, was to BE MARED BY AIDS AND IT'S COMPLICATIONS.

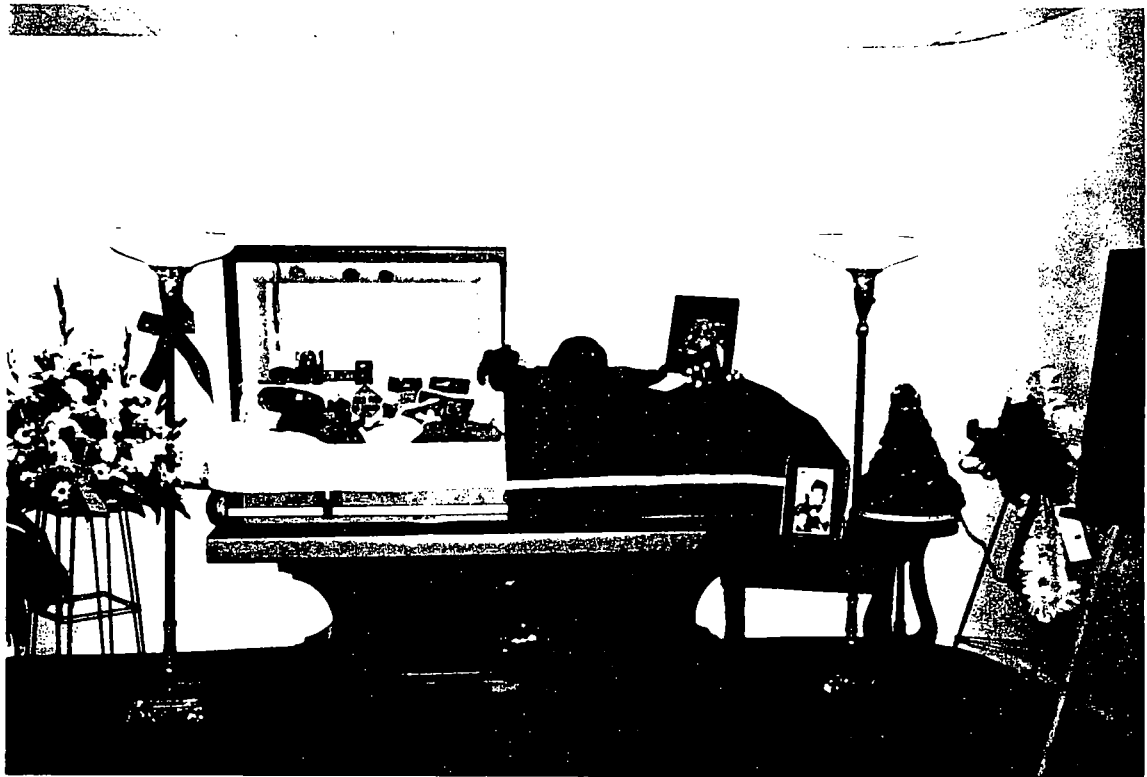
BELOW AND ON THE FOLLOWING PAGE YOU WILL SEE WHAT HIS FUTURE WAS. IT WAS ONE OF ILLNESS AND PAIN AND FINALLY DEATH. BY SUPPORTING THIS BILL, YOU WILL BE HELPING MANY JUST LIKE RICKY.

AGE 15





AGE 15



DEC. 1992

Clinton Presidential Records Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

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The Ricky Ray Hemophilia Relief Fund Act of 1995

The hemophilia holocaust represents the worst medical disaster in United States history. It is an injustice that cries out for redress. Nearly eight thousand persons with hemophilia have been infected with HIV/AIDS from infusions of tainted blood products. Yet, for twelve years the federal government has not acted to redress this disaster. The same federal government totally failed to ensure the safety of the blood supply and protect those dependent upon blood and blood products. Had the Food and Drug Administration (FDA) done its job, three generations of persons with hemophilia and their families would have been spared the nightmare of AIDS.

The FDA allowed the blood product manufacturers and the blood banking industry to self-regulate and the result is now history. Thousands of individuals and families in the hemophilia community are devastated physically, emotionally, and economically from AIDS. Industry and their federal regulators knew by late 1982 that an epidemic was spreading rapidly and that the causative agent for AIDS was in fact, blood borne.

Responsibility for this disaster lies with the manufacturers of blood products, the blood banking industry,

the American Red Cross, FDA regulators, and the medical establishment. The story does not begin with HIV, but with hepatitis in the 1970s. By 1970, the industry already knew that persons with hemophilia were contracting hepatitis from blood products. Throughout the 70s, industry ignored calls for action regarding hepatitis contamination. By the late 1970s, a viral inactivation method had been patented and available, yet the industry rejected its adoption while downplaying the problem. Ultimately, industry chose profit over safety, which set the stage for the hemophilia AIDS disaster.

This is the history of the hemophilia holocaust. The result is suffering and devastation in the hemophilia community, unparalleled in U.S. history. It is within this context that the Committee of Ten Thousand (COTT) began its congressional initiative in early 1993. Through widespread community input, COTT developed a multi-faceted, broad spectrum, community-based agenda. COTT is working on a myriad of fronts to ensure that this disaster does not occur again. COTT is working in the courts through the class action lawsuit; with the FDA to clean up the blood industry; and with Congress to provide compensation based upon

the government's failure to ensure blood and blood product safety.

Senator Bob Graham and Congressman Porter Goss Lead a Bipartisan Bill

Congressman Porter Goss (R-FL) and Senator Bob Graham (D-FL) have been two of our most important friends on Capitol Hill. Bruce Lesley, aide to Senator Graham; and Wendy Donath, aide to Congressman Goss have been instrumental in furthering the hemophilia community's interests on Capitol Hill. We are deeply grateful for their dedicated and persistent efforts on our behalf. We also want to acknowledge the work of Senator John Glenn and his aide, Debbie Cohen, who have worked tirelessly in our endeavor to change the business of blood and reform the FDA. Both Senator Graham and Congressman Goss initially became aware and concerned about the hemophilia holocaust through the persistent work of Cliff and Louise Ray, the parents of Ricky Ray.

A Legacy to Ricky Ray; A Strong Advocate for the Hemophilia Community

On December 13, 1992, Ricky Ray died at the age of 15 in Florida from hemophilia-associated AIDS. Ricky

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FDA FAILURE: HOW & WHY

January 10, 1995

OVERVIEW:

In order to understand the Hemophilia Holocaust one must look at the regulation of the nation's blood supply which lies under the purview of the Food and Drug Administration, the FDA. The FDA has the legal responsibility of ensuring a safe and uncontaminated supply of blood and blood products. While we understand that safe is a relative term in this instance, the FDA's task was and is to establish and enforce the highest degree of safety available regarding blood and blood products. If we trace the history of HIV contamination during the 1980's we find a trail of missed opportunities and outright failure by the FDA to implement changes that would have spared thousands the nightmare that is HIV/AIDS. By mid-1982 it was clear that a growing number of individuals were suffering from large scale immune suppression and failure. At this juncture this illness was primarily impacting some very distinct communities. The gay community, intravenous drug users, and persons with hemophilia. By the end of 1982 the Centers For Disease Control were warning the blood, banks, the blood products industry and the FDA that this new illness was probably caused by a blood borne pathogen that was probably in the nation's blood supply.

These early warnings were ignored by both the blood industry and the only agency that had the power to mandate a response to the warnings, the FDA. In January of 1983 CDC doctor Don Francis stated that persons with hemophilia faced grave danger from blood products contaminated with what the CDC believed was the blood borne viral causative agent for what became known as AIDS. By that time twelve cases had been identified in the hemophilia community which the CDC viewed as indicating the beginnings of an AIDS epidemic in persons with hemophilia. Again these warnings were ignored by the blood industry and their federal regulators at the FDA. In fact, the FDA did not mandate the recall of Anti-Hemophilic Factor until 1985. What happened during that three year lag between CDC warnings and strong FDA action to protect the users of blood and blood products like AHF?

For almost three years the FDA failed to take any definitive action that would have prevented the continued contamination of blood and blood products. According to the blood banking industry, the manufacturers of blood products and the American

Red Cross, their inaction was based on their belief that it had yet to be proven that the causative agent for AIDS was blood borne and a threat to the blood supply or the users of blood and blood products. The FDA agreed in that they refused to order changes in operations that would have significantly reduced the risk of transmission of the virus through blood and blood products. From 1982 through 1985 there were numerous actions that the FDA chose not to take. For instance the FDA could have ordered the blood banks and the Red Cross to test all collected blood with the Hepatitis core anti-body test and dispose of all blood testing positive. While not specific to HIV, there was a strong correlation between AIDS and the presence of Hepatitis B. The disposal of hepatitis infected collected blood would have surely spared thousands of individuals and families from the devastation of AIDS. This test was not mandated, primarily, for economic reasons. The blood banks and the Red Cross did not want to spend the money required to implement across the board testing of all collected blood and clearly the FDA agreed. The FDA also allowed the manufacturers of Anti-Hemophilic Factor to continue marketing untested product produced from pools of collected plasma that were most surely tainted with HIV. Again money was the deciding factor in a decision that sealed the death sentence for three generations of men with hemophilia.

In court testimony former FDA regulator David Aronson admitted that the FDA was worried about the economic impact of forcing changes on the manufacturers of AHF and other blood products. In establishing FDA regulation Congress was clearly interested in safety and not the profit picture of the corporations manufacturing products such as AHF. Yet this was a key factor in the FDA's decisions not to require industry to take actions that would have greatly reduced the AIDS epidemic in the hemophilia community.

Essentially the FDA abdicated its statutory responsibility and continued to allow the blood banks, the Red Cross and the manufacturers to self-regulate. Even in the face of the growing AIDS epidemic, the FDA ignored the obvious conclusion that AIDS was the result of a blood borne pathogen. By the time the FDA finally ordered product recalls it was too late, the damage had been done; nearly ten thousand persons with hemophilia were infected through contaminated AHF and nearly thirty thousand Americans were infected by whole blood.

A clear example of FDA inaction occurred on January 13, 1993. On that date a meeting was held in New York sponsored by the Centers For Disease Control and the National Hemophilia Foundation to discuss the growing problem in the hemophilia community regarding the immune suppression disease. The participants included all the major players in the business of blood, including the CDC, the FDA, the National Institutes Of Health, the American Red Cross, the Canadian Red Cross, the independent blood banks, the American Association Of Blood Banks, the American Blood Resources Association, the four manufacturers of Anti-Hemophilic Factor

(Baxter/Hyland, Miles/Cutter, Alpha Therapeutics and Rhone-Poulanc/Armour), the Canadian Hemophilia Society and other interested parties. This was a veritable who's who of the blood industry and the government. At this two day meeting warnings were again given by the CDC that AIDS was caused by a blood borne virus and that the growing number of cases in the hemophilia community indicated that it had entered the Nation's blood supply. The CDC asserted that the known cases in the hemophilia community indicated an AIDS epidemic in persons with hemophilia. The participants to our surprise discussed the types and severity of opportunistic infections that were occurring in persons with hemophilia. The surprise is based on what patients and families were told by doctors, the NHF, the drug companies and the FDA regarding the risks of contracting AIDS from AHF (factor eight and nine) concentrates. While this meeting was taking place we were continuing to be told that the risks were negligible and that we should continue "to infuse and infuse often".

The entire issue was constantly downplayed and our concerns were invalidated repeatedly through 1985. No one was officially warned of the danger until late 1984 and 1985. Two years after the 1983 meeting at which CDC warned of an AIDS epidemic in the hemophilia community. A reasonable person would have expected that out of that meeting the FDA would have taken definitive action to protect the users of blood and blood products such as AHF product recalls and immediately mandating hepatitis core anti-body testing of all collected blood. However, this was not the case, and the result was the devastation and death of three generations of men and some women with hemophilia. The question of why the FDA failed to act has yet to be answered in a substantive fashion. This represents a complete breakdown of the regulatory system for blood and blood products; A breakdown that has had catastrophe implications of those dependent on blood and blood products.

A major contributing factor to the FDA inaction is the rampant conflict of interest that existed at the FDA in the 1980's and continues unabated today. A good example of this conflict is the composition of the Blood Products Advisory Committee which is the main FDA forum for consideration of all issues regarding the regulation of blood and blood products. The BPAC has always been and continues to be dominated by blood bankers, industry people and those with an interest in the business of blood. A good example of this is Dr. Joseph Bove who was the BPAC Chair during the first half of the 1980's. Bove was the director of the Yale University hospital blood bank and played a key role in the FDA's failure to respond quickly to AIDS and the blood supply. It was Bove who consistently asserted that there was no proof that AIDS was caused by a blood borne virus and therefore the blood banking industry had no responsibility to implement change in their operations. Bove was the lead voice in opposing the adoption of hepatitis core anti-body testing of all collected blood. Bove as a blood bank director had a clear interest in seeing testing not adopted due to the financial burden as well as the increased administrative efforts it would impose on the blood banks. The only consumer representation on the BPAC is a medical doctor who is a n

non-voting member. This is the FDA's view of consumer participation on the committee whose decisions have profound impacts on the lives of the users of blood and blood products.

Ultimately the issue is one of the definition of what federal regulation of the business of blood constitutes. Clearly the hemophilia holocaust has demonstrated that the industry has been allowed to self regulate and therein lies a major portion of the problem. Those with an economic interest in the sale of blood and the manufacture of blood products cannot be expected to always choose safety over profit, especially when we are dealing with a billion dollar industry.

Had the FDA been the independent regulatory agency the public expects, their response to AIDS and the blood supply would have been significantly different and certainly more expeditious. They would have immediately required the adoption of hepatitis core ant-body testing of all collected blood while initiating the immediate recall of all untested AHF products. This, of course, is not what happened and the rest is history; three generations of men with hemophilia devastated by AIDS. The only possible conclusion is that conflict of interest was a significant contributing factor in the FDA's failure to ensure the safety of blood and blood products. Too many people with an economic interest in the business of blood occupying influential positions within the FDA's regulatory structure for blood and blood products.

The lessons learned from the hemophilia holocaust remain relevant today as little has significantly changed in the business of blood or in the regulation of that business. Many of the problems that existed during the 1980's at the FDA remain unchanged today. Conflict of interest continues to be a determining factor while the blood banks and the manufacturers are still, for the most part, allowed to self-regulate. A good example of this is the issue of intravenous gamma globulin, IVIG. In February of 1994 there was a outbreak of Hepatitis C transmissions from contaminated IVIG. Baxter/Hyland and the American Red Cross initiated voluntary recalls of the remaining stocks of tainted IVIG, yet the FDA seemed almost bewildered about why IVIG, long touted as the safest of blood products, was now contaminated with Hepatitis C. Had the FDA never studied the possibility of Hepatitis C contamination of IVIG?

Significant problems also remain in the area of blood collection. The Red Cross and the independent blood banks still are not governed by the kind of national standards necessary to attain the highest degree of safety possible. There are numerous instances of substandard Red Cross facilities and laboratories as well as blood banks that cannot even consistently meet the current inadequate standards. If our blood supply is to be safe then these issues must be substantively addressed within the context of stronger regulations and diligent enforcement by the FDA. Without significant change we will most assuredly face another catastrophe like the hemophilia holocaust and the contamination of our national blood supply. We must not

allow history to repeat itself by ignoring similar warning signals to the ones ignored in the first half of the 1980's.

WHAT IS TO BE DONE

- ** Congress must promulgate and implement new conflict of interest rules that will ensure that those with an economic interests in the business of blood will be barred from the regulatory decision making processes as well as from exerting undue influence upon FDA regulation of blood and blood products.
- ** Safety must always be the primary consideration, never to be unduly impacted by concerns regarding the economic survivability and profit picture of the manufacturers and producers of blood and blood products
- ** The FDA needs a look back system so they can go back and review the safety of products that have already been approved to reassess asses safety in light of technological advances and improved techniques for addressing viral contamination.
- ** The FDA's Blood Products Advisory Committee must be significantly opened up to consumers who must have voting membership.
- ** The FDA must require significant changes in the blood collection system. The Red Cross and the independent blood banks must be held accountable for their operations and required to meet national standards established by the FDA.
- ** The FDA must mandate the usage of smaller donor pools for the production of blood(plasma) products such as factor concentrates(AHF) and IVIG.
- ** The FDA must promulgate and enforce stringent new national standards for blood collection operations.

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NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of the appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under the Academy's 1863 congressional charter responsibility to be an adviser to the federal government and its own initiative in identifying issues of medical care, research, and education. Dr. Kenneth I. Shine is president of the Institute of Medicine.

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The image adopted as a logo-type by the Institute of Medicine is based on a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

Executive Summary

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Executive Summary

INTRODUCTION

A nation's blood supply is a unique, life-giving resource and an expression of its sense of community. In 1993, voluntary donors gave over 14 million units of blood in the United States (Wallace, et al. 1993). However, the characteristic that makes donated blood an expression of the highest motives also makes it a threat to health. Derived from human tissue, blood and blood products can effectively transmit infections such as hepatitis, cytomegalovirus, syphilis, and malaria from person to person (IOM 1992). In the early 1980s blood became a vector for HIV infection and transmitted a fatal illness to more than half of the 16,000 hemophiliacs in the U.S. and over 12,000 blood transfusion recipients (CDC, MMWR; July 1993).

Each year, approximately four million patients in the United States receive transfusions of approximately 20 million units of whole blood and blood components. The blood for these products is collected from voluntary donors through a network of nonprofit community and hospital blood banks. Individuals with hemophilia depend upon blood coagulation products, called antihemophilic factor (AHF) concentrate, to alleviate the effect of an inherited deficiency in a protein that is necessary for normal blood clotting. The AHF concentrate is manufactured from blood plasma derived from 1,000 to 20,000 or more donors, exposing individuals with hemophilia to a high risk of infection by blood-borne viruses.

The safety of the blood supply is a shared responsibility of many organizations including the plasma fractionation industry, community blood banks, the federal government, and others. The Food and Drug Administration (FDA) has regulatory authority over plasma collection establishments, blood banks, and all blood products. Since 1973, the FDA has established standards for plasma collection and plasma product manufacture and a system for licensing those who met standards. The Centers for Disease Control and Prevention (CDC) has responsibility for surveillance, detection, and warning of potential public health risks within the blood supply. The National Institutes of Health (NIH) supports these efforts through fundamental research. During the 1950s and 1960s blood shield laws were adopted by 47 states. These laws exempt blood and blood products from strict liability or implied warranty claims on the grounds that they are a service rather than a product. The laws were developed on the premise that given the

inherently risky nature of blood and blood products, those providing them required protection if the blood system was to be a reliable resource.

As a whole, this system works effectively to supply the nation with necessary blood and blood products and its quality control mechanisms check most human safety threats. The events of the early 1980s, however, revealed an important weakness in the system—in its ability to deal with a new threat that was characterized by substantial uncertainty. With intent to prepare the guardians of the blood supply for future threats concerning blood safety, the Department of Health and Human Services commissioned the Institute of Medicine to study the transmission of HIV through the blood supply. The *Committee to Study HIV Transmission Through Blood and Blood Products* undertook this assignment fully aware of the advantages and dangers of hindsight. Hindsight offers an opportunity to gain the understanding needed to confront the next threat to the blood supply. The danger of hindsight is unfairly finding fault with decisions that were made in the context of great uncertainty.

HISTORY

The Risk of AIDS

Starting with the identification of 26 homosexual men with opportunistic diseases in June 1981, the CDC's *Morbidity and Mortality Weekly Report* became the source for reports of the epidemic. By July 1982, enough cases had occurred with common symptomatology to name the new disease "Acquired Immune Deficiency Syndrome" (AIDS). By January 1983, epidemiological evidence from CDC's investigations strongly suggested that blood and blood products transmitted the agent causing AIDS and that the disease could also be transmitted through intimate heterosexual contact. The conclusion that the AIDS agent was blood-borne was based on two findings. First, AIDS was occurring in transfusion recipients and individuals with hemophilia who had received AHF concentrate; these patients did not belong to any previously defined group at risk for contracting AIDS. Second, the epidemiologic pattern of AIDS was similar to hepatitis B, another blood-borne disease.

Immediate Responses to Evidence of Blood-Borne AIDS Transmission

In the first months of 1983, the epidemiological evidence that the AIDS agent was blood-borne led to meetings and public and private decisions that set the pattern of the blood industry's response to AIDS, starting with a public meeting convened by the CDC in Atlanta on January 4, 1983. Later that month, the leading blood bank organizations, and, separately, the National Hemophilia Foundation (NHF) and the blood products industry issued statements about preventing exposure to AIDS. In March 1983, the Assistant Secretary for Health promulgated the first official PHS recommendations for preventing AIDS, and the FDA codified safe practices for blood and plasma collection.

The government and private agencies quickly identified, considered, and in some cases adopted strategies for dealing with the risk of transmitting AIDS through blood and blood

products. The recommended safety measures, however, were limited in scope. Examples include: questions to eliminate high-risk groups such as intravenous drug users, recent immigrants from Haiti, and those with early symptoms of AIDS or exposure to patients with AIDS; direct questions about high-risk sexual practices are generally not used. They reflected a lack of consensus about the magnitude of the threat, especially among physicians and public health officials, who had trouble interpreting the unique epidemiological pattern of AIDS. The recommendations also reflected uncertainty about the benefits of identifying and deferring potentially infected blood and plasma donors, treatment of blood products to inactivate viruses, recall of products derived from donors known to have or suspected of having AIDS, and changes in transfusion practice and blood product usage. The costs, risks, and benefits of these and other potential control strategies were uncertain.

Opportunities to Reformulate Policy

In the interval between the decisions of early 1983 and the availability of a blood test for HIV in 1985, public health and blood industry officials became more certain that AIDS was a blood-borne disease as the number of reported cases of AIDS among hemophiliacs and transfused patients grew. As their knowledge grew, these officials had to decide about recall of contaminated blood products and possible implementation of a surrogate test for HIV. Meetings of the FDA's Blood Product Advisory Committee in January, February, July and December 1983 offered major opportunities to discuss, consider, and reconsider the limited tenor of the policies.

Despite these opportunities and others to review new evidence and to reconsider earlier decisions, blood safety policies changed very little during 1983. Many officials of the blood banks, the plasma fractionation industry, and the FDA accepted with little question estimates that the risk of AIDS was low ("one in a million transfusions"), and they accepted advice that control strategies (such as automatic withdrawal of AHF concentrate lots containing blood from donors suspected of having AIDS, or a switch from AHF concentrate to cryoprecipitate in mild or moderate hemophiliacs) would be ineffective, too costly, or too risky. During this period, there were missed opportunities to learn from local attempts to screen potentially infected donors or implement other control strategies that had been rejected as national policy.

Research Activities

From 1983 through 1985, research on AIDS included epidemiological analysis to understand patterns of spread and etiology, the search for methods to control or eliminate the disease, and evaluation of the efficacy of potential safety measures such as surrogate tests for the infection. Related research on methods to inactivate hepatitis B virus in AHF concentrate had begun in the 1970s and came to fruition in the early 1980s.

In the early 1980s the CDC's surveillance program identified AIDS patients and rapidly characterized the disease. Scientists at NIH isolated and characterized HIV in 1984. Viral inactivation methods for AHF concentrate were developed in laboratories of the plasma

fractionators and the FDA licensed the new processes quickly. Although the pace of viral inactivation research had been slow, it accelerated in the 1980s largely in response to hepatitis, and had identified effective strategies by 1984. However, research into other potential ways to safeguard the blood supply such as the use of surrogate tests was not pursued vigorously and there was relatively little research on blood safety issues per se.

FINDINGS

The Committee framed its approach by examining four topics that are essential components of a focused strategy for ensuring the safety of the blood supply: blood product treatment; donor screening and deferral; regulation of removal of contaminated products from the market, and communication to physicians and patients.

Product Treatment

Plasma products can be treated by a variety of physical and chemical processes to inactivate viruses and thus to produce a product free from contamination and relatively safe for transfusion. Shortly after the development of the technology to manufacture AHF concentrate it was recognized that these products carried a substantial risk of transmitting hepatitis B. Although some blood derivative products had been treated with heat to destroy live viruses since the late 1940s, Factor VIII and IX concentrates in the United States were not subject to viral inactivation procedures until 1983 and 1984. If this technology had been developed and introduced before 1980 to inactivate hepatitis B virus and non-A, non-B hepatitis virus, fewer individuals with hemophilia might have been infected with HIV.

Overall, the record of the plasma fractionators and the FDA with respect to the development and implementation of heat treatment is mixed. The Committee's analysis focused on whether the basic knowledge and technology for inactivating viruses in AHF concentrate had been available before 1980 and whether industry had appropriate incentives (from FDA, NIH, NHF, or others) to develop viral inactivation procedures. In the Committee's judgment, heat treatment processes to prevent the transmission of hepatitis, an advance that would have prevented many cases of AIDS in individuals with hemophilia, might have been developed before 1980. For a variety of reasons (e.g., concern about possible development of inhibitors and higher costs), however, neither physicians caring for individuals with hemophilia nor the Public Health Service agencies actively encouraged the plasma fractionation companies to develop heat treatment measures earlier. The absence of incentives, as well as the lack of a countervailing force to advocate blood product safety, contributed to the plasma fractionation industry's slow rate of progress toward the development of heat-treated products. Once plasma fractionators developed inactivation methods, however, the FDA moved expeditiously to license them.

Donor Screening and Deferral Policies

The purpose of donor screening and deferral procedures is to minimize the possibility of transmitting an infectious agent from a unit of donated blood to the recipient of that unit, as well as to insure the welfare of the donor. Donor screening includes the identification of suitable donors; the recruitment of donors; and the exclusion of high-risk individuals through methods and procedures used at the time of donation, such as questionnaires, interviews, medical exams, blood tests, and providing donors with the opportunity to self-defer. Donor deferral is the temporary or permanent rejection of a donor based on the results of the screening measures.

By January 1983, in addition to suggesting that the agent causing AIDS was transmitted through blood and blood products and could be sexually transmitted, the epidemiological evidence also demonstrated that there were several groups who had an increased risk of developing AIDS. The highest incidence of the disease was in male homosexuals, who donated blood frequently in some geographic regions. The Committee found that organizations implemented donor screening measures in different ways at different times. Plasma collection agencies had begun screening potential donors and excluding those in any of the known risk groups as early as December 1982, and CDC scientists suggested in January 1983 that blood banks do likewise. Also in January, the blood banking organizations (AABB, ARC, and CCBC) issued a joint statement that recommended the use of donor screening questions to detect early symptoms of AIDS or exposure to AIDS patients. The statement, however, did not advocate directly questioning donors about their sexual preferences. Blood banks did institute some screening measures in early 1983, but only a few asked potential donors questions about homosexual activities. At the same time, CDC scientists also suggested that all blood and plasma collection agencies employ an available surrogate test for hepatitis B core antigen (anti-HBc). Most blood and plasma collection agencies rejected this recommendation. Although the precise impact of these two actions is not known, earlier implementation of either probably would have reduced the number of individuals infected with HIV through blood and blood products. In March 1983, the PHS issued recommendations that identified high-risk individuals for AIDS and stated that these individuals should not donate plasma or blood.

Based on its review of the evidence, the Committee found that decision makers involved with donor screening and deferral acted with good intent in some instances. In other instances, however, preference for the status quo under the prevailing conditions of uncertainty and danger led decision makers to underestimate the threat of AIDS for blood recipients. The Committee concluded that when confronted with a range of options for using donor screening and deferral to reduce the probability of spreading HIV through the blood supply, blood bank officials and federal authorities consistently chose the least aggressive option that was justifiable. In adopting this limited approach, policymakers often passed over options that might have initially slowed the spread of HIV to individuals with hemophilia and other recipients of blood and blood products, for example, screening male donors for a history of sexual activity with other males and screening donated blood for the anti-HBc antibody. The Committee believes that it was reasonable to require blood banks to implement these two screening procedures in January 1983. The FDA's failure to require this is evidence that the agency did not adequately use its regulatory authority and therefore missed opportunities to protect the public health.

Regulations and Recall

The FDA is the principal regulatory agency with authority for blood and blood products, but it exercises its authority largely through informal action. Recall—the removal of a product from the market—exemplifies the relationship between the FDA's potent formal powers and its informal modus operandi. Recall is a voluntary act undertaken by the manufacturer but overseen by the FDA, which has the authority to seize or revoke the license of a product. Regulation of blood and blood products has been generally based on establishing a scientific consensus. Because the FDA's resources are limited, it relies upon the blood industry and others for cooperation. The FDA Blood Products Advisory Committee is a venue for consensus-building about blood regulatory policy. In an industry in which firm and product reputation is critical to market success, the FDA's collegial approach is usually effective.

The Committee analyzed the FDA's exercise of its regulatory powers by examining how it acted during four critical events: (1) letters issued by the FDA in March 1983 requiring particular practices related to donor screening and the segregation of high-risk plasma supplies; (2) a July 1983 decision not to recall plasma products "automatically" whenever they could be linked to individual donors who had been identified as having or as suspected of having AIDS; (3) a decision not to recall nontreated AHF concentrate when heat-treated AHF concentrate became available in 1983; and (4) a delay of years in the FDA's formal decision to recommend tracing recipients of transfusions from a donor who was later found to have HIV. For each of these, the Committee posed a series of hypotheses to explain the FDA's actions. These focused on the reach of the agency's legal powers, the information available at the time in relation to relevant public health considerations, the agency's resources, the FDA's institutional culture, the economic costs of particular actions, and the prevailing political climate.

The analysis of these four events led the Committee to identify several weaknesses in the FDA's regulatory approach to blood safety issues. The agency's March 1983 letters may have been unclear concerning whether all of their recommendations were required to be implemented by the addressee. Handling of the case-by-case recall decision suggested that the agency lacked both the capacity to structure its advisory process adequately and to analyze independently the recommendations that were made to it. In the Committee's judgment, these and other events indicate the need for a more systematic approach to blood safety regulation when there is uncertainty and danger to the public.

Communication to Physicians and Patients

As evidence for the possibility that the blood supply was a vector for AIDS accrued, consumers of blood and blood products and their physicians found themselves in a complex dilemma about how to reduce the risk of infection. Restricting or abandoning the use of blood and blood products could lead to increased mortality and morbidity. On the other hand, continued use of these products apparently increased the risk of AIDS. The Committee investigated the processes by which physicians and patients obtained information about the epidemic and the costs, risks, and benefits of their clinical options.

A wide range of clinical options were available by late 1982 and might, in some instances, have reduced or eliminated dependence on AHF concentrate and thereby reduced the risk of HIV transmission. As often happens in times of intense scientific and medical uncertainty such as in the early 1980s, individuals with hemophilia and transfusion recipients had little information about risks, benefits, and clinical options for their use of blood and blood products.

The dramatic successes of treatment with AHF concentrate in the 1970s provided a context in which thresholds for abandoning or radically restricting the use of these products for individuals with severe hemophilia were high. Both physicians and individuals with hemophilia expressed reluctance about returning to the era of clinical treatment before the introduction of AHF concentrate. The National Hemophilia Foundation (NHF) and physicians, in their effort to find the right balance between the risks and benefits of continued use of AHF concentrate, tended to overweight the well-established benefits of AHF concentrate and underestimate the risks of AIDS, which were still uncertain.

In addition, the Committee found that prevailing assumptions about medically acceptable risks, especially regarding hepatitis, led to complacency and a failure to act upon reports of a new infectious risk with sufficient concern. Ultimately, assumptions about medical decision making practices in which patients played a relatively passive role led to failures to disclose completely the risks of using AHF concentrate and thereby did not enable individuals to make informed decisions for themselves. As the potential dimensions of the epidemic among individuals with hemophilia became clear, communication between physicians and patients was further compromised by physicians' reticence to discuss the dire implications of widespread infection with their patients and families.

Institutional barriers to patient-physician communications and relationships between relevant organizations also impeded the flow of information. If the NHF had received input from a wider group of scientific and medical experts, more explicit and systematic dissemination of a range of clinical options might well have been possible. In addition, the financial and other relationships between the NHF and the plasma fractionation industry created a conflict of interest that seriously compromised the perceived independence of NHF's recommendations.

No organization stepped forward to communicate widely the risks of blood transfusions to potential recipients. Many blood bank officials during this period publicly denied that AIDS posed any significant risk to blood recipients. In this context, and because many transfusions occurred on an emergency basis, patients were typically not apprised of the growing concerns about the contamination of the blood supply. For both individuals with hemophilia and recipients of blood transfusions, physician concern that their patients might refuse care deemed a "medical necessity" further contributed to failures to inform them of the risks.

CONCLUSIONS

Decision Making Under Uncertainty

The events and decisions that the Committee has analyzed underscore the difficulty of personal and institutional decision making when the stakes are high, when knowledge is imprecise and incomplete, and when decision makers may have personal or institutional biases.

EXECUTIVE SUMMARY

The Committee attempted to understand the complexities of the decision-making process during this uncertain period and to develop lessons to protect the blood supply in the future. In retrospect, the system did not deal well with contemporaneous blood safety issues such as hepatitis, and was not prepared to deal with the far greater challenge of AIDS.

Although enough epidemiological evidence had emerged by January 1983 to strongly suggest that the agent causing AIDS was transmitted through blood and blood products and could be sexually transmitted to sexual partners, the magnitude of the risk for transfusion and blood product recipients was not known at this time. Policymakers quickly developed several clinical and public health options to reduce the risk of AIDS transmission. There was, however, substantial scientific uncertainty about the costs and benefits of the available options. The result was a pattern of responses which, while not in conflict with the available scientific information, were very cautious and exposed the decision makers and their organizations to a minimum of criticism.

Blood safety is a shared responsibility of many diverse organizations. They include U.S. Public Health Service agencies such as the CDC, the FDA, and the NIH, and private-sector organizations such as community blood banks and the American Red Cross, blood and plasma collection agencies, blood product manufacturers, groups like the National Hemophilia Foundation, and others. The problems the Committee found indicated a failure of leadership and inadequate institutional decision making processes in 1983 and 1984. No person or agency was able to coordinate all of the organizations sharing the public health responsibility for achieving a safe blood supply.

Bureaucratic Management of Potential Crises

Federal agencies had the primary responsibility for dealing with the national emergency posed by the AIDS epidemic. The Committee scrutinized bureaucratic function closely and came to the following conclusions about the management of potential crises.

First, unless someone from the top exerts strong leadership, legal and competitive concerns may inhibit effective action by agencies of the federal government. Similarly, when policymaking occurs against a backdrop of a great deal of scientific uncertainty, bureaucratic standard operating procedures designed for routine circumstances seem to take over unless there is a clear-cut decision-making hierarchy. An effective leader will insist upon coordinated planning and execution. Focusing efforts and responsibilities, setting timetables and agendas, and assuming accountability for expeditious action cannot be left to ordinary standard operating procedures. These actions are the responsibilities of the highest levels of the public health establishment.

Second, the FDA and other agencies in the early 1980s lacked a systematic approach to conducting advisory committee processes. These agencies should tell their advisory committees what it expects from them, keep attention focused on high priority topics, and independently evaluate their advice. Because mistakes will always be made and opportunities missed, regulatory structures must organize and manage their advisory boards to assure both the reality and the continuous appearance of propriety.

Third, agencies should not rely upon the entities they regulate for analysis of data and modeling of decision problems.

Fourth, agencies need to think far ahead. They must monitor more systematically the long-term outcomes of blood transfusion and blood product infusion to anticipate both new technologies and new threats to the safety of the blood supply. The Committee believes that the Public Health Service should plan what it will do if there is a threat to the blood supply. It should specify actions that will occur once the level of concern passes a specified threshold. The Committee favors a series of criteria or triggers for taking regulatory or other public health actions which the response is proportional to the magnitude of the risk and the quality of the information on which the risk estimate is based. Taking on small steps allows for careful reconsideration of options, particularly as information about uncertain risks unfolds. Not all triggering events need lead to drastic action; some may merely require careful reconsideration of the options or obtaining new information.

RECOMMENDATIONS

The Committee's charge was to learn from the events of the early 1980s to help the nation prepare for future threats to the blood supply. From the record assembled for this study, the Committee identified potential problems with the system in place at that time and has identified some changes that might have moderated some of the effects of the AIDS epidemic on recipients of blood and blood products. The federal and private organizations responsible for blood safety and the public health more generally will have to evaluate their current policies and procedures to see if they fully address the issues raised by these recommendations.

The Public Health Service

Several agencies necessarily play important, often differentiated, roles in managing a public health crisis such as the contamination of blood and blood products by the AIDS virus. The National Blood Policy of 1973 charged the Public Health Service (including the CDC, the FDA, and the NIH) with responsibility for protecting the nation's blood supply.

The Committee has come to believe that a failure of leadership may have delayed effective action during the period from 1982 to 1984. This failure led to less than effective donor screening, weak regulatory actions, and insufficient communication to patients about the risks of AIDS. In the event of a threat to the blood supply, the Public Health Service must, as in any public health crisis, insist upon coordinated action. The Secretary of Health and Human Services is responsible for all the agencies of the Public Health Service,¹ and therefore the Committee makes

¹In the 1980s and now, the PHS agencies report to the Assistant Secretary of Health. As this report was being written, the Department of Health and Human Services has proposed to eliminate the office of the Assistant Secretary, so that the PHS agencies would report directly to the Secretary.

Recommendation 1: The Secretary of Health and Human Services should designate a Blood Safety Director, at the level of a deputy assistant secretary or higher, to be responsible for the federal government's efforts to maintain the safety of the nation's blood supply.

To be effective in coordinating the various agencies of the PHS, the Blood Safety Director should be at the level of a deputy assistant secretary or higher, and should not be a representative of any single PHS agency.

In considering the history of the contamination of the blood supply with HIV and the current surveillance, regulatory, and administrative structures for ensuring the safety of our nation's blood resources, the Committee became convinced that the nation needs a far more responsive and integrated process to ensure blood safety. To this end, the Committee makes

Recommendation 2: The PHS should establish a Blood Safety Council to assess current and potential future threats to the blood supply, to propose strategies for overcoming these threats, to evaluate the response of the Public Health Service to these proposals, and to monitor the implementation of these strategies. The Council should report to the Blood Safety Director (see Recommendation 1). The Council should also serve to alert scientists about the needs and opportunities for research to maximize the safety of blood and blood products. The Blood Safety Council should take the lead to ensure the education of public health officials, clinicians, and the public about the nature of threats to our nation's blood supply and the public health strategies for dealing with these threats.

The proposed Blood Safety Council would facilitate the timely transmission of information, assessment of risk, and initiation of appropriate action both during times of stability and during a crisis. The Council should report to the Blood Safety Director (see Recommendation 1). The Council would not replace the PHS agencies responsible for blood safety but would complement them by providing a forum for them to work together and with private organizations. The PHS agencies would be represented on the Council.

The Blood Safety Council should consider the following activities and issues: to deliberate the need for a system of active surveillance for adverse reactions in blood recipients; to establish a panel of experts to provide information about risks and benefits, alternative options for treatment, and recommended best practices (see Recommendation 13); and to investigate methods to make blood products safer, such as double inactivation processes and reduction of plasma pool size.

When a product or service provided for the public good has inherent risks, the common law tort system fails to protect the rightful interests of patients who suffer harms resulting from the use of those products and services. To address this deficiency, the Committee makes

Recommendation 3: The Federal government should consider establishing a no-fault compensation system for individuals who suffer adverse consequences from the use of blood or blood products.¹

For such a no-fault system to be effective, standards and procedures would have to be determined prospectively to guide its operations. There needs to be an objective, science-based process to decide which kinds of adverse outcomes are caused by blood-borne pathogens and which individual cases of these adverse outcomes deserve compensation. As with vaccines, such a system could be financed by a tax or fee paid by all manufacturers or by the ultimate recipients of blood products. However, had there been a no-fault compensation system in the early 1980s, it could have relieved much financial hardship suffered by many who became infected with HIV through blood and blood products in the United States. The "no-fault" principles outlined in this recommendation might serve to guide policymakers as they consider whether to implement a compensation system for those infected in the 1980s.

The Centers for Disease Control and Prevention

The CDC has an indispensable role in protecting our nation's health: to detect potential public health risks and sound the alert. In order to improve CDC's efficacy in this critical role, the Committee makes

Recommendation 4: Other federal agencies must understand, support, and respond to the CDC's responsibility to serve as the nation's early warning system for threats to the health of the public.

One way to begin to implement this recommendation is for the Secretary of Health and Human Services to insist that an agency that wishes to disregard a CDC alert should support its position with evidence that meets the same standard as that used by the CDC in raising the alert.

In order to carry out its early warning responsibility effectively, the CDC needs good surveillance systems. The Committee, believing that the degree of surveillance should be proportional to the level of risk inherent in blood and blood products and should include both immediate and delayed effects, makes

Recommendation 5: The PHS should establish a surveillance system, lodged in the CDC, that will detect, monitor, and warn of adverse effects in the recipients of blood and blood products.

¹ One Committee member (Martha Derthick) abstains from this recommendation because she believes that it falls outside of the Committee's charge.

The Food and Drug Administration

The FDA has legal authority to protect the safety of the nation's blood supply, and it is the lead federal agency in regulating blood banking practice, the handling of source plasma, and the manufacture of blood products from plasma. The Committee's recommendations focus on decision making and the role of advisory committees in formulating the FDA's response to crises.

In the Committee's judgment, a more systematic approach to blood safety regulation, one that is better suited to conditions of uncertainty, is needed. In particular, the Committee recommends (see Chapter 8) that the PHS develop a series of criteria or triggers for taking regulatory or other public health actions for which the response is proportional to the magnitude of the risk and the quality of the information on which the risk estimate is based. In order that the perfect not be the enemy of the good, the Committee makes

Recommendation 6: Where uncertainties or countervailing public health concerns preclude completely eliminating potential risks, the FDA should encourage, and where necessary require, the blood industry to implement partial solutions that have little risk of causing harm.

In all fields, decision making under uncertainty requires an iterative process. As the knowledge base for a decision changes, the responsible agency should reexamine the facts and be prepared to change its decision. The agency should also assign specific responsibility for monitoring conditions and identifying opportunities for change. In order to implement these principles at the FDA, the Committee makes

Recommendation 7: The FDA should periodically review important decisions that it made when it was uncertain about the value of key decision variables.

Although the FDA has a great deal of regulatory power over the blood products industry, the agency appears to regulate by expressing its will in subtle, understated directives. Taking this into account, the Committee makes

Recommendation 8: Because regulators must rely heavily on the performance of the industry to accomplish blood safety goals, the FDA must articulate its requests or requirements in forms that are understandable and implementable by regulated entities. In particular, when issuing instructions to regulated entities, the FDA should specify clearly whether it is demanding specific compliance with legal requirements or is merely providing advice for careful consideration.

In the early 1980's, the FDA appeared too reliant upon analyses provided by industry-based members of the Blood Products Advisory Council. Thus the Committee arrived at

Recommendation 9: The FDA should ensure that the composition of the Blood Products Advisory Committee reflects a proper balance between members who are

connected with the blood and blood products industry and members who are independent of industry.

An agency that is well-practiced in orderly decision-making procedures will be able to respond to the much greater requirements of a crisis. This consideration leads to

Recommendation 10: The FDA should tell its advisory committees what it expects from them and should independently evaluate their agendas and their performance.

Advisory committees provide scientific advice to the FDA, but they do not make regulatory decisions for the agency. The FDA's lack of independent information and an analytic capability of its own meant that it had little choice but to incorporate the advice of BPAC into its policy recommendations. To ensure the proper degree of independence between the FDA and the BPAC, the Committee makes

Recommendation 11: The FDA should develop reliable sources of the information that it needs to make decisions about the blood supply. The FDA should have its own capacity to analyze this information and to predict the effects of regulatory decisions.

Communication to Physicians and Patients

One of the crucial elements of the system for collecting blood and distributing blood products to patients is the means to convey concern about the risks inherent in blood products. In today's practice of medicine, in contrast to that of the early 1980s, patients and physicians each accept a share of responsibility for making decisions.

In instances of great uncertainty, it is crucial for patients to be fully apprised of the full range of options available and to become active participants in the consideration and evaluation of the relative risks and benefits of alternative treatments. To encourage better communication, the Committee makes

Recommendation 12: When faced with a decision in which all options carry risk, especially if the amount of risk is uncertain, physicians and patients should take extra care to discuss a wide range of options.

Given the inherent risks and uncertainties in all blood products, the public and providers of care need expert, unbiased information about the blood supply. This information includes risks and benefits, alternatives to using blood products, and recommended best practices. In order to provide the public and providers of care with information they need, the Committee makes

Recommendation 13: The Department of Health and Human Services should convene a standing expert panel to inform the providers of care and the public about

the risks associated with blood and blood products, about alternatives to using them, and about treatments that have the support of the scientific record.

One lesson of the AIDS crisis is that a well-established, orderly decision making process is important for successfully managing a crisis. This applies as much to clinical decision making as to the public health decision process addressed by earlier recommendations. As the narrative indicates, there are both public health and clinical approaches to reducing the risk of blood borne diseases. The Blood Safety Council called for in Recommendation 2 would deal primarily with risk assessment and actions in the public health domain that would reduce the chance that blood products could be vectors of infectious agents. The primary responsibility of the expert panel on best practices called for in Recommendation 13 would be to provide the clinical information that physicians and their patients need to guide their individual health care choices. To be most effective, this panel should be lodged in the Blood Safety Council (see Recommendation 2) so that both bodies can interact and coordinate their activities in order to share information about emerging risks and clinical options.

Recommendation 14: Voluntary organizations that make recommendations about using commercial products must avoid conflicts of interest, maintain independent judgment, and otherwise act so as to earn the confidence of the public and patients.

One of the difficulties with using experts to give advice is the interconnections that experts accumulate during their careers. As a result, an expert may have a history of relationships that raise concerns about whether he or she can be truly impartial when advising a course of action in a complex situation. One way to avoid these risks is to choose some panelists who are not expert in the subject of the panel's assignment but have a reputation for expertise in evaluating evidence, sound clinical judgment, and impartiality.

Financial conflicts of interest influence organizations as well as individuals. The standards for acknowledging, and in some cases avoiding, conflicts of interest are higher than they were 12 years ago. Public health officials, the medical professions, and private organizations must uphold this new, difficult standard. Failure to do so will threaten the fabric of trust that holds our society together.

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FILE COPY

**Office of
National AIDS Policy**

Correspondence Routing Slip

Tracking Number: 61791

Date Rcvd: 8/14/95

From: (White House - copies)

Staff Action:

Reviewed By Jeff: _____ **Reviewed By: Patsy** _____

Assigned To: Log out

RCVD: _____ **DONE:** _____

Recommendations/Instructions:

To Support Staff: _____

Date of Response: _____

n:\corresli

4-9-95

Dear President,

THUPC

I think that people with aids should be treated better. Most people are discusted that people have aids so they get treated very badly. Scientists should be working harder to find a cure for aids. One baby had aids and that baby was cured. Even though they are still trying ~~to~~ to find out what they did to that baby they might not be working to hard. People with Aids are as equal as people without aids, but for some season they are treated differently. People say they are victims but their not. They are ordinary people like us ~~as~~ except they have aid and they shouldn't be treated differently than us.

Sincerely,
Mollie Warden

Malie Wander
c/o Scott Fried
305 West 13th St.
#1K
New York, NY
10014



President Bill Clinton
Agency Liaison Office
Room 6
The White House
Washington DC 20500

Dear Mr. President, (ON APC)

HIV and ~~AIDS~~ AIDS are in the news more every day. People are finally starting to learn about the dreaded disease, but at much too slow a pace. I think the government should do something to help educate people more. Educating about HIV and AIDS is almost if not as important as finding a cure. People have to realize that just because someone has HIV, it doesn't mean they are less of a person. No one shuns or is afraid of a person with a cold, and that is probably more contagious than HIV. I think that ~~to~~ to the patient, society's fear of the disease is worse than the waiting for the inevitable. The only way to change this is through education. Thank you for your time.

Sincerely,
Brandon Diamond
Brandon S. Diamond

brandon S. Diamond
c/o Scott Fried #1K
305 West 13th Street
New York, NY 10014



president bill clinton
Agency Liaison Office
room 6
the white house
Washington DC 20500



FILE COPY

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: G1770

Date Rcvd: 8.8.95

From: White House

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy ✓

Assigned To: PF- Reading (K. D.)

RCVD: _____ DONE: _____

Recommendations/Instructions:

NR log out

To Support Staff: _____

Date of Response: 9-25-95

n:\corresli

THE WHITE HOUSE

WASHINGTON

July 18, 1995

As we mark the fifth anniversary of the Americans with Disabilities Act, I am delighted to join citizens across the country in celebration.

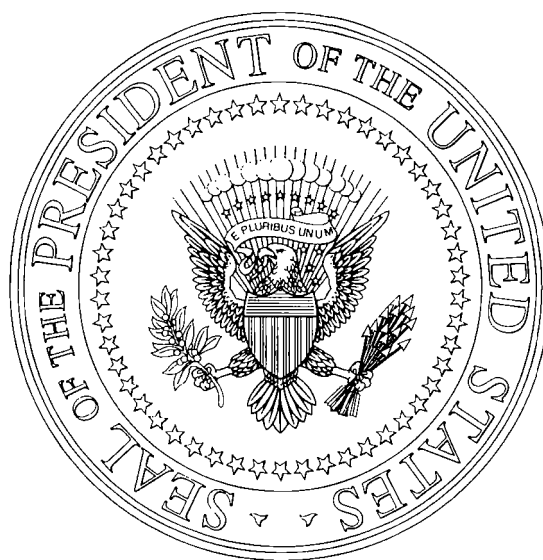
With the enactment of this landmark civil rights law, America became the first country in the world to make equal rights and equal opportunity a guarantee for its 49 million citizens with disabilities. Across the nation, our people began coming together to ensure equal access to the American Dream.

Today, thanks to these efforts, Americans are recognizing that we all gain as citizens of a country in which everyone can participate fully. And America is reaping the benefits of a more inclusive society. Employers have a larger pool of qualified workers. Businesses are opening doors to new customers. State and local governments are enjoying broader citizen participation. Most important, individuals are being judged not by their disabilities, but by their abilities.

We have made great strides as a nation in fulfilling America's promise of commonsense justice. Still, much remains to be done. My Administration is firmly committed to the vigorous implementation and enforcement of the ADA. No longer will Americans with disabilities be kept from realizing their dreams by closed doors or narrow minds. Building partnerships between government and business and people throughout the land, we best celebrate this day by rededicating ourselves to creating a society of equal access and equal rights for all.

A handwritten signature in black ink, reading "Bill Clinton". The signature is written in a cursive, flowing style with a long horizontal stroke at the end.

AFFIRMATIVE ACTION ADDRESS



President William Jefferson Clinton

July 19, 1995
The Rotunda, National Archives
Washington, D.C.

In recent weeks I have begun a conversation with the American people about our fate and our duty to prepare our nation not only to meet the new century, but to live and lead in a world transformed to a degree seldom seen in all of our history. Much of this change is good, but it is not all good, and all of us are affected by it. Therefore, we must reach beyond our fears and our divisions to a new time of great and common purpose.

Our challenge is twofold: first, to restore the American dream of opportunity and the American value of responsibility; and second, to bring our country together amid all our diversity into a stronger community, so that we can find common ground and move forward as one.

More than ever these two endeavors are inseparable. I am absolutely convinced we cannot restore economic opportunity or solve our social problems unless we find a way to bring the American people together. To bring our people together we must openly and honestly deal with the issues that divide us. Today I want to discuss one of those issues: affirmative action.

It is, in a way, ironic that this issue should be divisive today, because affirmative action was begun 25 years ago under a Republican president with bipartisan support. It began simply as a means to an end of enduring national purpose—equal opportunity for all Americans.

So let us today trace the roots of affirmative action in our never-ending search for equal opportunity. Let us determine what it is and what it isn't. Let us see where it has worked and where it hasn't, and ask ourselves what we need to do now. Along the way, let us remember always that finding common ground as we move toward the 21st century depends fundamentally on our shared commitment to equal opportunity for all Americans. It is a moral imperative, a constitutional mandate, and a practical necessity.

There could be no better place for this discussion than the National Archives, for within these walls are America's bedrocks of our common ground—the Declaration of Independence, the Constitution, the Bill of Rights. No paper is as lasting as the words these documents contain. So we put them in these special cases to protect the parchment from the elements. No building is as solid as the principles these documents embody, but we sure tried to build one with these metal doors 11 inches thick to keep them safe. These documents are America's only crown jewels. But the best place of all to hold these words and these principles is the one place in which they can never fade and never grow old—in the stronger chambers of our hearts.

Beyond all else, our country is a set of convictions: "We hold these truths to be self-evident that all men are created equal; that they are endowed by their Creator with certain inalienable rights; that among these are life, liberty and the pursuit of happiness."

Our whole history can be seen first as an effort to preserve these rights, and then as an effort to make them real in the lives of all our citizens. We know that from the beginning, there was a great gap between the plain meaning of our creed and the meaner reality of our daily lives. Back then, only white male property owners could vote. Black slaves were not even counted as whole people, and Native Americans were regarded as little more than an obstacle to our great national progress. No wonder Thomas Jefferson, reflecting on slavery, said he trembled to think God is just.

On the 200th anniversary of our great Constitution, Justice Thurgood Marshall, the grandson of a slave, said, "The government our founders devised was defective from the start, requiring several amendments, a civil war, and momentous social transformation to attain the system of constitutional government and its respect for the individual freedoms and human rights we hold as fundamental today."

Emancipation, women's suffrage, civil rights, voting rights, equal rights, the struggle for the rights of the disabled—all these and other struggles are milestones on America's often rocky, but fundamentally righteous journey to close the gap between the ideals enshrined in these treasures here in the National Archives and the reality of our daily lives.

I first came to this very spot where I'm standing today 32 years ago this month. I was a 16-year-old delegate to the American Legion Boys Nation. That summer was a high-water mark on our national journey. That was the summer that President Kennedy ordered Alabama National Guardsmen to enforce a court order to allow two young blacks to enter the University of Alabama. As he told our nation, "Every American ought to have the right to be treated as he would wish to be treated; as one would wish his children to be treated."

Later that same summer, on the steps of the Lincoln Memorial, Martin Luther King told Americans of his dream that one day the sons of former slaves and the sons of former slaveowners would sit down together at the table of brotherhood; that one day his four little children would be judged not by the color of their skin, but by the content of their character. His words captured the hearts and steeled the wills of millions of Americans. Some of them sang with him in the hot sun that day. Millions more, like me, listened and wept in the privacy of their homes.

It's hard to believe where we were just three decades ago. When I came up here to Boys Nation and we had this mock congressional session, I was one of only three or four southerners who would even vote for the civil rights plank. That's largely because of my family. My grandfather had a grade school education and ran a grocery store across the street from the cemetery in Hope, Arkansas, where my parents and my grandparents are buried. Most of his customers were black,

were poor, and were working people. As a child in that store I saw that people of different races could treat each other with respect and dignity.

But I also saw that the black neighborhood was the only one in town where the streets weren't paved. And when I returned to that neighborhood in the late '60s to see a woman who had cared for me as a toddler, the streets still weren't paved. A lot of you know that I am an ardent movie-goer. As a child I never went to a movie where I could sit next to a black American. They were always sitting upstairs.

In the 1960s, believe it or not, there were still a few courthouse squares in my state where the rest rooms were marked "white" and "colored." I graduated from a segregated high school seven years after President Eisenhower integrated Little Rock Central High School. And when President Kennedy barely carried my home state in 1960, the poll tax system was still alive and well there.

Even though my grandparents were in a minority, being poor, Southern whites who were pro-civil rights, I think most other people knew better than to think the way they did. And those who were smart enough to act differently, discovered a lesson that we ought to remember today: Discrimination is not just morally wrong, it hurts everybody.

In 1960, Atlanta, Georgia, in reaction to all the things that were going on all across the South, adopted the motto, "The city too busy to hate." And however imperfectly over the years, they tried to live by it. I am convinced that Atlanta's success—it now is home to more foreign corporations than any other American city, and one year from today it will host the Olympics—that success all began when people got too busy to hate.

The lesson we learned was a hard one. When we allow people to pit us against one another or spend energy denying opportunity based on our differences, everyone is held back. But when we give all Americans a chance to develop and use their talents, to be full partners in our common enterprise, then everybody is pushed forward.

My experiences with discrimination are rooted in the South and in the legacy slavery left. But I also lived with a working mother and a working grandmother when women's work was far rarer and far more circumscribed than it is today. We all know there are millions of other stories—those of Hispanics, Asian Americans, Native Americans, people with disabilities, others against whom fingers have been pointed. Many of you have your own stories, and that's why you're here today—people who were denied the right to develop and use their full human potential. And their progress, too, is a part of our journey to make the reality of America consistent with the principles just behind me here.

Thirty years ago in this city, you didn't see many people of color or women making their way to work in the morning in business clothes, or serving in sub-

stantial numbers in powerful positions in Congress or at the White House, or making executive decisions every day in businesses. In fact, even the employment want ads were divided, men on one side and women on the other.

It was extraordinary then to see women or people of color as television news anchors, or, believe it or not, even in college sports. There were far fewer women and minorities as job supervisors, or firefighters, or police officers, or doctors, or lawyers, or college professors, or in many other jobs that offer stability and honor and integrity to family life.

A lot has changed, and it did not happen as some sort of random evolutionary drift. It took hard work and sacrifices and countless acts of courage and conscience by millions of Americans. It took the political courage and statesmanship of Democrats and Republicans alike, the vigilance and compassion of courts and advocates in and out of government committed to the Constitution, to equal protection, and to equal opportunity. It took the leadership of people in business who knew that in the end we would all be better. It took the leadership of people in labor unions who knew that working people had to be recognized.

Some people, like Congressman Lewis here, put their lives on the line. Other people lost their lives. And millions of Americans changed their own lives and put hate behind them. As a result, today all our lives are better. Women have become a major force in business and political life and far more able to contribute to their families' incomes. A true and growing black middle class has emerged. Higher education has literally been revolutionized, with women and racial and ethnic minorities attending once overwhelmingly white and sometimes all male schools. In communities across our nation, police departments now better reflect the make-up of those whom they protect. A generation of professionals now serve as role models for young women and minority youth. Hispanics and newer immigrant populations are succeeding in making America stronger.

For an example of where the best of our future lies, just think about our space program and the stunning hook-up with the Russian space station this month. Let's remember that that program, the world's finest, began with heroes like Alan Shepard and Senator John Glenn, but it's also had American heroes like Sally Ride, Ellen Ochoa, Leroy Chiao, Guy Bluford and other outstanding, completely qualified women and minorities.

How did this happen? Fundamentally, because we opened our hearts and minds and changed our ways. But not without pressure—the pressure of court decisions, legislation, executive action, and the power of examples in the public and private sectors. Along the way we learned that laws alone do not change society; that old habits and thinking patterns are deeply ingrained and die hard; and that more is required to really open the doors of opportunity. Our search to find

ways to move more quickly to equal opportunity led to the development of what we now call affirmative action.

The purpose of affirmative action is to give our nation a way to address the systemic exclusion of individuals of talent, on the basis of their gender or race, from opportunities to develop, perform, achieve and contribute. Affirmative action is an effort to develop a systematic approach to open the doors of education, employment and business development opportunities to qualified individuals who happen to be members of groups that have experienced longstanding and persistent discrimination.

It is a policy that grew out of many years of trying to navigate between two unacceptable paths. One was to say simply that we declared discrimination illegal and that's enough. But that way still relegated blacks with college degrees to jobs as railroad porters and kept women with degrees under a glass ceiling with a lower paycheck. The other path was simply to impose change by leveling draconian penalties on employers who didn't meet certain imposed, ultimately arbitrary, and sometimes unachievable quotas. That, too, was rejected out of a sense of fairness.

So a middle ground was developed that would change an inequitable status quo gradually, but firmly, by building the pool of qualified applicants for college, for contracts, for jobs, and giving more people the chance to learn, work and earn. When affirmative action is done right, it is flexible, it is fair, and it works.

I know some people are honestly concerned about the times affirmative action doesn't work, when it's done in the wrong way. There are times when some employers don't use it in the right way. They may cut corners and treat a flexible goal as a quota. They may give opportunities to people who are unqualified instead of those who deserve it. They may, in so doing, allow a different kind of discrimination. When this happens, it is also wrong. But it isn't affirmative action. And it is not legal.

When our Administration finds cases of that sort, we will enforce the law aggressively. The Justice Department files hundreds of cases every year, attacking discrimination in employment, including suits on behalf of white males. Most of these suits, however, affect women and minorities for a simple reason—because the vast majority of discrimination in America is still discrimination against them. But the law does require fairness for everyone, and we are determined to see that that is exactly what the law delivers.

Let me be clear about what affirmative action must not mean and what I won't allow it to be. It does not mean—and I don't favor—the unjustified preference of the unqualified over the qualified of any race or gender. It doesn't mean—and I don't favor—numerical quotas. It doesn't mean—and I don't favor—rejec-

tion or selection of any employee or student solely on the basis of race or gender without regard to merit.

Like many business executives and public servants, my views on this subject are, more than anything else, the product of my personal experience. I have had experience with affirmative action, nearly 20 years of it now, and I know it works.

When I was Attorney General of my home state, I hired a record number of women and African American lawyers—every one clearly qualified and exceptionally hardworking. As Governor, I appointed more women to my Cabinet and state boards than any other governor in the state's history and more African Americans than all the governors in the state's history combined. No one ever questioned their qualifications or performance. And our state was better and stronger because of their service.

As President, I am proud to have the most diverse Administration in history in my Cabinet, my agencies and my staff. And I must say, I have been surprised at the criticism I have received from some quarters in my determination to achieve this.

In the last two and a half years, the most outstanding example of affirmative action in the United States, the Pentagon, has opened 260,000 positions for women who serve in our Armed Forces. I have appointed more women and minorities to the federal bench than any other president, more than the last two combined. And yet, far more of our judicial appointments have received the highest rating from the American Bar Association than any other Administration since those ratings have been given.

In our Administration, many government agencies are doing more business with qualified firms run by minorities and women. The Small Business Administration has reduced its budget by close to 40 percent, doubled its loan output, and increased the number of loans to women by more than 80 percent and to minority small business people by nearly sixty percent, without reducing the number of loans to white male business owners and without changing the loan standards for a single, solitary application. Quality and diversity can go hand in hand, and they must.

Affirmative action has also done more than just open the doors of opportunity to individual Americans. Most economists who study it agree that affirmative action has also been an important part of closing gaps in economic opportunity in our society, thereby strengthening the entire economy.

A group of distinguished business leaders told me just a couple of days ago their companies are stronger and their profits are larger because of the diversity and the excellence of their work forces achieved through intelligent and fair affirmative action programs. They said they had gone far beyond anything the government requires they had because managing diversity and individual opportu-

nity and being fair to everybody is the key to their future economic success in the global marketplace.

Now, there are those who say that even good affirmative action programs are no longer needed; that it should be enough to resort to the courts or the Equal Employment Opportunity Commission in cases of actual, provable, individual discrimination because there is no longer any systematic discrimination in our society. In deciding how to answer that let us consider the facts.

The unemployment rate for African Americans remains about twice that of whites. The Hispanic rate is still much higher. Women have narrowed the earnings gap, but still make only 72 percent as much as men do for comparable jobs. The average income for an Hispanic woman with a college degree is still less than the average income of a white man with a high school diploma.

According to the recently completed Glass Ceiling Report, sponsored by Republican members of Congress, in the nation's largest companies only six-tenths of one percent of senior management positions are held by African Americans, four-tenths of a percent by Hispanic Americans, three-tenths of a percent by Asian Americans; women hold between three and five percent of these positions. White males make up 43 percent of our work force, but hold 95 percent of these jobs.

Just last week, the Chicago Federal Reserve Bank reported that black home loan applicants are more than twice as likely to be denied credit as whites with the same qualifications; and that Hispanic applicants are more than one and a half times as likely to be denied loans as whites with the same qualifications.

Last year alone the federal government received more than 90,000 complaints of employment discrimination based on race, ethnicity or gender. Less than three percent were for reverse discrimination.

Evidence abounds in other ways of the persistence of the kind of bigotry that can affect the way we think, even if we're not conscious of it, in hiring and promotion in business and education.

Crimes and violence based on hate against Asians, Hispanics, African Americans and other minorities are still with us. And, I'm sorry to say, that the worst and most recent evidence of this involves a recent report of federal law enforcement officials in Tennessee attending an event literally overflowing with racism—a sickening reminder of just how pervasive these kinds of attitudes still are.

By the way, I want to tell you that I am committed to finding the truth about what happened there and to taking appropriate action. If anybody who works in federal law enforcement thinks that that kind of behavior is acceptable, they ought to think about working someplace else.

Now, let's get to the other side of the argument. If affirmative action has worked and if there is evidence that discrimination still exists on a wide scale in

ways that are conscious and unconscious, then why should we get rid of it as many people are urging? Some question the effectiveness or the fairness of particular affirmative action programs. I say to all of you, those are fair questions, and they prompted the review of our affirmative action programs, about which I will talk in a few moments.

Some question the fundamental purpose of the effort. There are people who honestly believe that affirmative action always amounts to group preferences over individual merit; that affirmative action always leads to reverse discrimination; that ultimately, therefore, it demeans those who benefit from it and discriminates against those who are not helped by it.

All of you have to decide how you feel about that, and all of our fellow countrymen and women have to decide as well. But I believe if there are no quotas, if we give no opportunities to unqualified people, if we have no reverse discrimination, and if, when the problem ends—the program ends, that criticism is wrong. That's what I believe.

Now let's deal with what I really think is behind so much of this debate today. There are a lot of people who oppose affirmative action today who supported it for a very long time. I believe they are responding to the sea change in the experiences that most Americans have in the world in which we live.

If you say now you're against affirmative action because the government is using its power or the private sector is using its power to help minorities at the expense of the majority, that gives you a way of explaining away the economic distress that a majority of Americans honestly feel. It gives you a way of turning their resentment against the minorities or against a particular government program, instead of having an honest debate about how we all got into the fix we're in and what we're all going to do together to get out of it.

That explanation, the affirmative action explanation for the fix we're in is just wrong. It is just wrong. Affirmative action did not cause the great economic problems of the American middle class. And because most minorities or women are either members of that middle class or people who are poor who are struggling to get into it, we must also admit that affirmative action alone won't solve the problems of minorities and women who seek to be a part of the American Dream. To do that, we have to have an economic strategy that reverses the decline in wages and the growth of poverty among working people. Without that, women, minorities and white males will all be in trouble in the future.

But it is wrong to use the anxieties of the middle class to divert the American people from the real causes of their economic distress—the sweeping historic changes taking all the globe in its path, and the specific policies or lack of them in our own country that have aggravated those challenges. It is simply wrong to play

politics with the issue of affirmative action and divide our country at a time when, if we're really going to change things, we have to be united.

I must say, I think it is ironic that some of those—not all, but some of those who call for an end to affirmative action also advocate policies that will make the real economic problems of the anxious middle class even worse. If the real goal is economic opportunity for all Americans, why in the world would we reduce our investment in education from Head Start to affordable college loans? Why don't we make college loans available to every American instead?

If the real goal is empowering all middle class Americans and empowering poor people to work their way into the middle class without regard to race or gender, why in the world would the people who advocate that turn around and raise taxes on our poorest working families, or reduce the money available for education and training when they lose their jobs or they're living on poverty wages, or increase the cost of housing for lower-income, working people with children?

Why would we do that? If we're going to empower America, we have to do more than talk about it, we have to do it. And we surely have learned that we cannot empower all Americans by taking opportunity away from some Americans.

So to those who use this as a political strategy to divide us, we must say: no.

But to those who raise legitimate questions about the way affirmative action works, or who raise the larger question about the genuine problems and anxieties of all the American people and their sense of being left behind and treated unfairly, we must say, yes, you are entitled to answers to your questions. We must say yes to that.

That's why I ordered this review of all of our affirmative action programs; a review to look at the facts, not the politics of affirmative action. This review concluded that affirmative action remains a useful tool for widening economic and educational opportunity. The model used by the military, the Army in particular—and I'm delighted to have the Commanding General of the Army here today because he set such a fine example—has been especially successful because it emphasizes education and training, ensuring that it has a wide pool of qualified candidates for every level of promotion. That approach has given us the most racially diverse and best-qualified military in our history. There are more opportunities for women and minorities there than ever before. And now there are over 50 generals and admirals who are Hispanic, Asian or African Americans.

We found that the Education Department had programs targeted on under-represented minorities that do a great deal of good with the tiniest of investments. We found that these programs comprised only 40 cents of every \$1,000 in the Education Department's budget.

College presidents say that their schools benefit from diversity. If their colleges look like the world students are going to live and work in, and they learn

from all different kinds of people things they can't learn in books, our systems of higher education are stronger.

On the other hand, every child, without regard to race or gender, needs the chance to go to college. Every child. That means every child has to have a chance to get affordable and repayable college loans, Pell Grants for poor kids and a chance to do things like join AmeriCorps and work their way through school. Every child is entitled to that. But that is not an argument *against* affirmative action, it's an argument *for* more opportunity for more Americans until everyone is reached.

This review also found that the executive order on employment practices of large federal contractors also has helped to bring more fairness and inclusion into the work force. Since President Nixon's Administration, America has used goals and timetables to preserve opportunity and to prevent discrimination, to urge businesses to set higher expectations for themselves and to realize those expectations. But we did not and we will not use rigid quotas to mandate outcomes.

We also looked at the way we award procurement contracts under the programs known as set-asides. There's no question that these programs have helped to build up firms owned by minorities and women, who historically have been excluded from the old-boy networks in these areas. They have helped a new generation of entrepreneurs to flourish, opening new paths to self-reliance and an economic growth in which all of us ultimately share. Because of the set-asides, businesses ready to compete have had a chance to compete, a chance they would not have otherwise had. But as with any government program, set-asides can be misapplied, misused, even intentionally abused. There are critics who exploit that fact as an excuse to abolish all these programs, regardless of their effects. I believe they are wrong, but I also believe, based on our factual review, we clearly need some reform. So first, we should crack down on those who take advantage of everyone else through fraud and abuse. We must crack down on fronts and pass-throughs, people who pretend to be eligible for these programs and aren't. That is wrong.

We also, in offering new businesses a leg up, must make sure that the set-asides go to businesses that need them most. We must really look and make sure that our standard for eligibility is fair and defensible. We have to tighten the requirement to move businesses out of programs once they've had a fair opportunity to compete. The graduation requirement must mean something—it must mean graduation. There should be no permanent set-aside for any company.

Second, we must, and we will, comply with the Supreme Court's *Adarand* decision of last month. In particular, that means focusing set-aside programs on particular regions and business sectors where the problems of discrimination or exclusion are provable and are clearly requiring affirmative action. I have directed the Attorney General and the agencies to move forward with compliance with *Adarand* expeditiously.

But I also want to emphasize that the *Adarand* decision did not dismantle affirmative action and did not dismantle set-asides. In fact, while setting stricter standards to mandate *reform* of affirmative action, it actually reaffirmed the *need* for affirmative action and reaffirmed the continuing existence of systematic discrimination in the United States.

What the Supreme Court ordered the federal government to do was to meet the same more rigorous standard for affirmative action programs that state and local governments were ordered to meet several years ago. And the best set-aside programs under that standard have been challenged and have survived.

Third, beyond discrimination we need to do more to help disadvantaged people and distressed communities, no matter what their race or gender. There are places in our country where the free enterprise system simply doesn't reach. It simply isn't working to provide jobs and opportunity. These areas in urban and rural America are populated by racial minorities, but not entirely. To make this initiative work, I believe the government must become a better partner for people in places in urban and rural America that are caught in a cycle of poverty. And I believe we have to find ways to get the private sector to assume their rightful role as a driver of economic growth.

It has always amazed me that we have given incentives to our business people to help to develop poor economies in other parts of the world, our neighbors in the Caribbean, our neighbors in other parts of the world, which I have supported except when they have been abused, but we ignore the biggest source of economic growth available to the American economy, the poor economies isolated within the United States of America.

There are those who say, well, even if we made the jobs available people wouldn't work. They haven't tried. Most of the people in disadvantaged communities work today, and most of them who don't work have a very strong desire to do so. In central Harlem, 14 people apply for every single minimum-wage job opening. Think how many more would apply if there were good jobs with a good future. Our job is to connect disadvantaged people and disadvantaged communities to economic opportunity so that everybody who wants to work can do so.

We've been working at this through our empowerment zones and community development banks, through the initiatives of Secretary Cisneros and the Housing and Urban Development Department, and many other things that we have tried to do to put capital where it is needed. And now I have asked Vice President Gore to develop a proposal to use our contracting to support businesses that locate themselves in these distressed areas or hire a large percentage of their workers from these areas—not to substitute for affirmative action, but to go beyond it, to do something that will help to deal with the economic crisis of America.

My fellow Americans, affirmative action has to be made consistent with our highest ideals of personal responsibility and merit, and our urgent need to find common ground, and to prepare all Americans to compete in the global economy.

Today, I am directing all our agencies to comply with the Supreme Court's *Adarand* decision, and also to apply the four standards of fairness to all our affirmative action programs that I have already articulated: No quotas in theory or practice; no illegal discrimination of any kind, including reverse discrimination; no preference for people who are not qualified for any job or other opportunity; and as soon as a program has succeeded, it must be retired. Any program that doesn't meet these four principles must be eliminated or reformed to meet them.

But let me be clear: Affirmative action has been good for America.

Affirmative action has not always been perfect, and affirmative action should not go on forever. It should be changed now to take care of those things that are wrong, and it should be retired when its job is done. I am resolved that that day will come. But the evidence suggests, indeed screams, that that day has not come.

The job of ending discrimination in this country is not over. That should not be surprising. We had slavery for centuries before the passage of the 13th, 14th and 15th Amendments. We waited another hundred years for the civil rights legislation. Women have had the vote less than a hundred years. We have always had difficulty with these things, as most societies do. But we are making more progress than many other nations.

Since, based on the evidence, the job is not done, here is what I think we should do. We should reaffirm the principle of affirmative action and fix the practices. We should have a simple slogan: Mend it, but don't end it.

Let me ask all Americans, whether they agree or disagree with what I have said today, to see this issue in the larger context of our times. President Lincoln said we cannot escape our history. We cannot escape our future either. And that future must be one in which every American has the chance to live up to his or her God-given capacities.

The new technology, the instant communications, the explosion of global commerce have created enormous opportunities and enormous anxieties for Americans. In the last two and a half years, we have seen seven million new jobs, more millionaires and new businesses than ever before, high corporate profits, and a booming stock market. Yet, most Americans are working harder for the same or lower pay. And they feel more insecurity about their jobs, their retirement, their health care, and their children's education. Too many of our children are exposed to poverty and welfare, violence and drugs.

These are the great challenges for our whole country on the homefront at the dawn of the 21st century. We've got to find the wisdom and the will to create family-wage jobs for all the people who want to work; to open the door of college to

all Americans; to strengthen families and reduce the awful problems to which our children are exposed; to move poor Americans from welfare to work.

This is the work of our Administration—to give the people the tools they need to make the most of their own lives, to give families and communities the tools they need to solve their own problems. But let us not forget affirmative action didn't cause these problems. And it won't solve them. And getting rid of affirmative action certainly won't solve them.

If properly done, affirmative action can help us come together, go forward and grow together. It is in our moral, legal and practical interest to see that every person can make the most of his or her life. In the fight for the future, we need all hands on deck. And some of those hands still need a helping hand.

In our national community we're all different, but we're all the same. We want liberty and freedom. We want the embrace of family and community. We want to make the most of our own lives and we're determined to give our children a better one. Today there are voices of division who would say forget all that. Don't you dare. Remember we're still closing the gap between our founders' ideals and our reality. But every step along the way has made us richer, stronger and better. And the best is yet to come.

Thank you very much. And God bless you.

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

July 26, 1995

REMARKS BY THE PRESIDENT
IN OPENING REMARKS
TO THE AMERICANS WITH DISABILITIES ACT ROUNDTABLE

U.S. Treasury

10:22 A.M. EDT

THE PRESIDENT: Thank you very much. Secretary Rubin, Attorney General Reno; to the distinguished members of this panel, Senator Harkin and Congressman Hoyer, Chairman Coehlo, Dr. Hitt, Gil Casellas, Marca Bristo; the members of the administration who are here -- I see Reed Hunt and Patsy Fleming out there -- I thank all of you for being here to celebrate this fifth anniversary of the Americans with Disabilities Act.

Five years ago, when the ADA became law, we became the first nation in the world to commit ourselves to equal rights and equal opportunities for all citizens with disabilities. Because of the ADA, our country is stronger today. Our fellow citizens are being judged by their ability to contribute, not by their disabilities. Now, all of you, and millions of others all across this country have an opportunity they never had before to make the most of their own lives.

That opportunity is critical to what we have to do as a nation to meet the great challenges we face and to move forward into the next century. In many ways, the ADA is the perfect example of what I mean when I talk about our job is to create more opportunity and demand more responsibility from all of our citizens.

The ADA has meant more opportunity for 49 million Americans with disabilities to their part to make us a stronger and better country. It has meant that more people could go to work and participate in community life, and do things that most Americans take for granted, like helping to take care of their families or getting a good education or registering and voting. It's also a

perfect example of what I have meant in recent weeks when I have urged the American people to come together to find common ground in order to move forward together as a nation.

That was true across party lines. Members of both parties, including three who are here today -- Senators Harkin, Representative Hoyer and former Congressman Tony Coelho -- fought for the ADA in the Congress. And President Bush signed it into law. The ADA became law because Americans like so many of you worked together in the best interest of everyone, putting party behind country. There was a realization that the best way to keep our country moving forward was to allow every American, regardless of whether he or she used a wheelchair, was blind, had a mental disability or was HIV positive, to live up to his or her God-given potential.

And today, even as we celebrate the rights gained under the ADA, the budget cuts proposed by the congressional majority would sharply reduce the services and the supports that enable people to effectively exercise the rights granted by the ADA. Under the proposed cuts, states would be forced to drop 1.4 million people with disabilities from Medicaid rolls, and 4 million disabled Americans on Medicare would have to pay more every year for the same health care. They also have proposed eliminating funds for training special education teachers.

Now, we have to join together to maintain our commitment and our common ground. I will vigorously implement and enforce the ADA through the Cabinet and the administration. We will not allow Americans with disabilities to be kept from realizing their dreams by closed doors or narrowed minds.

We should also celebrate, all of us, this fifth anniversary of the Americans with Disabilities Act in the best way possible: By all, each of us, rededicating ourselves to creating a society of equal access and equal rights for all. That is the best kind of affirmative action for all the American people.

Thank you very much. (Applause.)

END

10:26 A.M. (EDT)

PRESIDENT CLINTON PARTICIPATES IN ROUNDTABLE ON THE 5TH ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT

July 26, 1995

President Clinton will commemorate the five-year anniversary of the signing of the Americans with Disabilities Act (ADA) by participating in a roundtable discussion with 12 distinguished Americans, including Miss America 1995, Heather Whitestone.

The event will open with remarks by the President, which will be open to pool coverage. The President will then participate in a private roundtable discussion with these 12 Americans, Attorney General Janet Reno, Chairman Gilbert Casellas of the Equal Employment Opportunity Commission, Chair Marca Bristo of the National Council on Disability, Chair Scott Hitt of the President's Advisory Council on HIV/AIDS and Tony Coehlo, Chairman of the President's Committee on Employment of People with Disabilities and author of the original Americans with Disabilities Act. Senator Harkin and Congressman Hoyer will also participate. A list of the roundtable participants is attached, as is a schedule of other administration events commemorating the ADA's 5th anniversary.

The audience for the roundtable discussion will be comprised of approximately 75 disability rights activists from around the country, heads of national disability organizations, and senior appointees with disabilities, or those who work closely with the disability community implementing and enforcing the ADA.

In his remarks, the President will restate his support of the ADA and his commitment to fight attempts to weaken the law.

Background on The ADA

July 26 marks the fifth anniversary of the signing of the Americans with Disabilities Act, landmark civil rights legislation that prohibits discrimination against people with disabilities in employment, services rendered by state and local governments, places of public accommodation, transportation, and telecommunications.

Passage of the ADA was driven by a growing realization that government is spending far too much on custodial, medical and income support in ways that perpetuated the isolation and dependency of people with disabilities, while spending far too little on measures that would enable people with disabilities to live productively and independently.

Five years later, although there has been much progress under the ADA, people with disabilities and their families acknowledge that much remains to be done in order to achieve economic independence for people with disabilities: eliminating physical and attitudinal barriers that obstruct people with disabilities from getting jobs or accessing goods and services; empowering students with disabilities; and training adults of all ages for productive lives.

PARTICIPANTS

Julie Clark; Springfield, Virginia: She recently filed and won a suit (now appealed) against the Virginia Board of Bar Examiners to bar a mental health inquiry that violated the ADA on the law license application in Virginia. She now works at Bazelon Center for Mental Health Law in Washington D.C.

Justin Dart; Washington D.C.: He is former Chair of the President's Committee on Employment of People with Disabilities under Presidents Clinton and Bush.

Danny Delcambre; Seattle, Washington: Mr. Delcambre owns the Ragin' Cajun restaurant in Seattle and recently participated in the Pacific Rim Economic Conference in Portland. In 1994 he won an Employer of the Year Award from the President's Committee on Employment of People with Disabilities.

Anthony Jones, Prince Frederick, Maryland: Mr. Jones, who is mentally retarded works for Dorsey Gray, a car dealership, cleaning cars, transporting customers home and doing general custodial work. He receives support services through The Arc of Southern Maryland.

Diane Lipton; Richmond, California: Lipton is the parent of a 23-year old woman with cerebral palsy. She has been a lawyer at the Disability Rights Education Defense Fund since 1985, where she directs The Children with Disabilities and Family Advocacy Program. She became a lawyer in order to advocate more effectively for her daughter.

Laurie Powers, Ph.D.; Hanover, New Hampshire: Dr. Powers is Associate Director of the Hood Center for Family Support at Dartmouth Medical School and Assistant Professor of Pediatrics and Adolescent Medicine.

Ronnie Pulliam; Philadelphia, Pennsylvania: Pulliam is an Americorps volunteer who graduated from Temple University this year, and was accepted into graduate school for sports administration. He is active with "The Rolling Owls," Temple University's wheelchair basketball team.

H. Rutherford (Rudd) Turnbull; Lawrence, Kansas: Co-Director of the Beach Center on Families and Disability and Professor of Special Education and Courtesy Professor of Law at the University of Kansas. He is the father of a 27-year old man with mental retardation and autism.

Heather Whitestone, Miss America 1995; Birmingham, Alabama: In addition to being Miss America 1995, she is also an accounting student at Jacksonville State University in Alabama and an Executive Member of the President's Committee on Employment of People with Disabilities. She serves as the national spokesperson for the public service campaign aimed at early identification of hearing loss, created by Alexander Graham Bell Association for the Deaf and the Miss America Organization.

Pat Yates; Little Rock, Arkansas: Yates is a special education teacher at Hall High School in Little Rock.

OTHER ADMINISTRATION EVENTS COMMEMORATING ADA

In addition to the President's event, other activities include:

DEPARTMENT OF JUSTICE:

The Attorney General will participate in "Voices of Freedom: America Speaks Out on ADA" with Dick Thornburgh, former Attorney General under President Bush, at the National Press Club in Washington D.C. The National Council on Disability has organized this forum to celebrate the 5th Anniversary of the ADA and to release the report of their findings from their 50 state tour of town hall meetings on the ADA.

The Attorney General will also participate in the President's roundtable discussion.

Deval Patrick, Assistant Attorney General for Civil Rights, will attend and deliver remarks at a reception co-chaired by Tony Coelho and Senator Bob Dole to celebrate the ADA and to announce the formation of a new, national, non-partisan membership organization called the American Association of People with Disabilities.

The Department of Justice has also issued a special fifth anniversary status report on Enforcing the ADA, that included a message from Deval Patrick and other enforcement and technical assistance highlights.

DEPARTMENT OF EDUCATION:

Secretary Riley celebrated the 5th Anniversary of the ADA in Tallahassee, Florida with Governor Chiles on Monday, July 24th. Together they symbolically etched the date the ADA was signed into law into the commemorative wall in Tallahassee which marks all of the civil rights milestone events and dates besides the ADA. **Judy Heumann**, Assistant Secretary of Education for the Office of Special Education and Rehabilitative Services, accompanied the Secretary.

Judy Heumann attended and delivered remarks at a Disability Independence Day Rally at Orange Pavilion near San Diego on Saturday, July 22.

Judy Heumann will also deliver remarks at the reception for the American Association of People with Disabilities.

DEPARTMENT OF TREASURY:

On Wednesday, July 26, Deputy Secretary Frank Newman and U.S. Treasurer Mary Ellen Withrow will conduct an accessible tour of the Bureau of Printing and Engraving. Participants will include guests at the President's roundtable earlier in the day.

DEPARTMENT OF TRANSPORTATION:

Secretary Pena: On July 25, in Atlanta, Secretary Pena announced a \$13 million grant to the city for operation and maintenance of buses to be used in transporting athletes and visitors during the Olympics and to support the special services of the Paralympics Transportation system.

The Federal Transit Administration (FTA):

The FTA is sponsoring a two-day "paratransit forum" in Washington on July 27 and 28, co-hosted by the National Easter Seal Society Project ACTION.

They are also hosting a 5th Anniversary ADA Reception on Wednesday evening July 26.

FEDERAL COMMUNICATIONS COMMISSION:

FCC Chairman Reed Hundt and Miss America 1995, Heather Whitestone, will kick off a campaign to increase public awareness of the Telecommunications Relay Service (TRS) at a press conference on Wednesday, July 26. They will conduct a live telephone call through a TRS operator with Chairman Hundt on one phone and Ms. Whitestone at a second phone using TTY text telephone device.

VETERANS AFFAIRS:

The Under Secretary of Health distributed to each VA Medical Center copies of several publications from the President's Committee on Employment of People with Disabilities that address advancement of employment opportunities under the ADA.

The Under Secretary for Benefits issued a notice advising all VA Regional Offices of the ADA anniversary, encouraging participation in local activities.

The Under Secretary for Benefits will recognize ADA and its importance in his remarks at the Disabled American Veterans Convention in Las Vegas, Nevada this week.

Please note that this is not meant to be a comprehensive account of all administration activities.

THE WHITE HOUSE
Office of the Press Secretary

July 26, 1995

AMERICANS WITH DISABILITIES ROUNDTABLE EVENT

Cash Room
Treasury Building

SECRETARY RUBIN: Thank you, and welcome, Mr. President, members of Congress, distinguished panelists, ladies and gentlemen. Welcome to the Treasury Department and our historic Cash Room.

The Treasury Department has been on this location since 1800. Our building was burned down in 1814 by the British -- that was the beginning of our special relationship. (Laughter.) Well, it was burned down again in 1839 by the employees. (Laughter.) Mr. President, that was under prior management. (Laughter.) We have improved our management practices.

We're honored that we could provide today the setting for this morning's event on the 5th anniversary of the Americans With Disabilities Act. We at Treasury are deeply committed to ensuring the fullest access to all Americans, whether it's access to our facilities or to opportunities in our work force. We at Treasury are fully committed to the operating principle that our nation is most productive when all Americans have the opportunity to contribute to the fullest extent of their abilities.

To demonstrate that commitment at Treasury we're having our own event today at the Bureau of Engraving and Printing, where one of Washington's favorite attractions for visitors, for tourists, and a very large work force is now far more accessible to those who are physically challenged. I'm pleased to say, too, that every Treasury bureau has provided us with plans to make their facilities more accessible.

It is now my honor to introduce an American deeply concerned about making sure that all Americans have the opportunity to live their lives to the fullest and with dignity; a person that recognizes that every American has a contribution to make if given the chance. Ladies and gentlemen, I introduce the President of the

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United States. (Applause.)

THE PRESIDENT: Thank you very much. Thank you. (Applause.) Thank you very much. Secretary Rubin, Attorney General Reno; to the distinguished members of this panel, Senator Harkin and Congressman Hoyer, Chairman Coehlo, Dr. Hitt, Gil Casellas, Marca Bristo; the members of the administration who are here -- I see Reed Hunt and Patsy Fleming out there -- I thank all of you for being here to celebrate this fifth anniversary of the Americans with Disabilities Act.

Five years ago, when the ADA became law, we became the first nation in the world to commit ourselves to equal rights and equal opportunities for all citizens with disabilities. Because of the ADA, our country is stronger today. Our fellow citizens are being judged by their ability to contribute, not by their disabilities. Now, all of you, and millions of others all across this country have an opportunity they never had before to make the most of their own lives.

That opportunity is critical to what we have to do as a nation to meet the great challenges we face and to move forward into the next century. In many ways, the ADA is the perfect example of what I mean when I talk about our job is to create more opportunity and demand more responsibility from all of our citizens.

The ADA has meant more opportunity for 49 million Americans with disabilities to their part to make us a stronger and better country. It has meant that more people could go to work and participate in community life, and do things that most Americans take for granted, like helping to take care of their families or getting a good education or registering and voting. It's also a perfect example of what I have meant in recent weeks when I have urged the American people to come together to find common ground in order to move forward together as a nation.

That was true across party lines. Members of both parties, including three who are here today -- Senators Harkin, Representative Hoyer and former Congressman Tony Coehlo -- fought for the ADA in the Congress. And President Bush signed it into law. The ADA became law because Americans like so many of you worked together in the best interest of everyone, putting party behind country. There was a realization that the best way to keep our country moving forward was to allow every American, regardless of whether he or she used a wheelchair, was blind, had a mental disability or was HIV positive, to live up to his or her God-given potential.

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And today, even as we celebrate the rights gained under the ADA, the budget cuts proposed by the congressional majority would sharply reduce the services and the supports that enable people to effectively exercise the rights granted by the ADA. Under the proposed cuts, states would be forced to drop 1.4 million people with disabilities from Medicaid rolls, and 4 million disabled Americans on Medicare would have to pay more every year for the same health care. They also have proposed eliminating funds for training special education teachers.

Now, we have to join together to maintain our commitment and our common ground. I will vigorously implement and enforce the ADA through the Cabinet and the administration. We will not allow Americans with disabilities to be kept from realizing their dreams by closed doors or narrowed minds.

We should also celebrate, all of us, this fifth anniversary of the Americans with Disabilities Act in the best way possible: by all, each of us, rededicating ourselves to creating a society of equal access and equal rights for all. That is the best kind of affirmative action for all the American people.

Thank you very much. (Applause.)

MS. LIPTON: -- Senator Harkin, Congressman Hoyer, without whom the ADA would never have happened. I'm also very honored to be in this room with all of the disability leaders who are in the audience, also without whom there would be no ADA.

I can speak a little bit basically from two perspectives. I have a daughter who is 23 years old, Chloe, who is disabled. She has Cerebral Palsy and cognitive disabilities. And she uses an electric wheelchair. She just completed her public education and was really among the first generation of children to go through her entire school career with the Individuals With Disabilities Education Act in place.

That did not mean it was easy. It was really a struggle to make sure that the law was enforced and that all of her rights were guaranteed. In fact, as I told Senator Harkin recently, I had to take -- go to the rather extreme measure of going to law school and becoming a lawyer to make sure that all of her rights would be enforced. I am also a lawyer right now at the Disability Rights Education and Defense Fund, and I work daily with parents and families of children with disabilities.

It's thanks to the Individuals with Disabilities Education Act that our children had an opportunity for equal educational

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opportunity, as other children in our country do. And as the IDA goes through the reauthorization and budget process, Mr. President, we are sure we have your total support to maintain all of the protections and full funding for this critical law.

But because of the skills and experiences that our children have gotten in their education, they really have been given a foundation to participate in the community. My daughter, Chloe, spent years practicing to shop, to handle money, to work, to order in restaurants, and she spent a lot of her education in McDonald's. (Laughter.) But she was prepared, and she was prepared well to go out into the community. The problem was at the late '80s it didn't look like there was much of a community for her to go out into.

Fortunately, in the nick of time, the disability community came through and Congress came through and the President came through and passed the ADA. Basically, what this meant for us as a family and for my daughter was that there was life after school. It meant that there were jobs, that there's transportation, that she could be integrated -- our daughter -- into the economic and social mainstream.

For my daughter in particular it meant that as of six months ago she was able to move out of our family home, into her own apartment, with live-in roommates and attendants, because transportation was now available, programs and services that had been closed to her prior to the ADA were now available. It meant that she could be in community-based programs and not isolated and segregated and warehoused in a sheltered program.

So, for families, the ADA has been quite remarkable in ending the terrible isolation, the loneliness that families with members who are disabled experience -- and the segregation. For families with younger children, it's meant for the first time that day care programs, after-school programs, recreation programs are open to them.

I know when Chloe was young, I was not able to work full-time because there was not child care available, and I could not hire our local teenager on the block to take care of her. This has changed.

However, if the law is new, we have to ward off attacks on the ADA, as on all civil rights laws. We are really looking to you, just as you have on affirmative action, to send a very clear, strong message to this country and to the Congress that the ADA will be implemented and ADA will be enforced. The parent and disability community will be completely behind you, and we are geared up. I can tell you, we are geared up for the fight.

Thank you. (Applause.)

THE PRESIDENT: Thank you.

CHAIRMAN COEHLO: Next we'll hear from Danny Delcambre, Mr. President, who you know, who is the owner and chef of Ragin' Cajun in Seattle.

MR. DELCAMBRE: Hi, I'm Danny Delcambre, and I'm deaf-blind. I'm profoundly deaf, but I can hear two things. I can hear a boom box, the vibrations from that, and I can hear when my wife sneezes. (Laughter.) I also have tunnel vision -- Usher Syndrome. And Usher Syndrome means that, for example, if you were to close one eye and put a straw up to the other eye, that's what I can see. So it's called Usher Syndrome. I'm actually deaf and blind, with retinitis pigmentosa.

But the most important thing to know about me is I'm from Louisiana and I'm Cajun. (Laughter and applause.) I moved to Seattle in 1987, and attended college. Before I moved there my father had told me, "Danny, when you grow up get a job in a Navy base." And I put that in the back of my mind. And that was my goal. So in 1987, when I moved to Seattle, I went to college. I worked at the Lighthouse for the Blind in a machine shop, and I applied to a number of jobs -- Navy bases -- all around Seattle, and was not successful in getting hired. No one would hire me.

So I went back to college and studied machine shop some more. And while I was doing that I was also applying for these jobs and getting turned down. But at my break time at college I went into the cafeteria and I became fascinated with the cooking program that they had. So I decided to change my major and went into culinary education. I was lucky, I got an internship with Paul Prudhomme and worked with him. When I graduated, all the people in my class who were hearing-sighted people got jobs as chefs and cooks. But no restaurant would hire me. They offered me jobs as dishwashers. So I decided to set up my own restaurant. I worked with the Small Business Administration and was successful in getting a loan.

Along the way, I've had people who have had negative attitudes, who have the idea that, oh, a deaf-blind person can't do. And my way of approaching that situation was to look for more positive people. I was successful in setting up my own restaurant, and I showed people now that I could be successful as a chef. I've hired seven deaf people and two hearing people who know sign language to work with me.

The Americans With Disabilities Act is a wonderful piece of

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legislation. I remember, I went to the signing of the ADA at the White House five years ago, and I was very proud. And I thought that the ADA would be a wonderful thing. It's helped with the bus services in Seattle. It's helped with interpreting services, in providing relay services for deaf people. So I think that's it's really had some positive impacts.

Thank you. (Applause.)

THE PRESIDENT: I can also tell you that I am a satisfied customer. (Laughter.) It's also resulted in good food. (Laughter.) And I thought I would just ask the two of you together what we could do to increase employment levels, because the unemployment rate among people with disabilities is still about two-thirds, and about 80 percent of the people who are unemployed would like to work and probably could in some form or fashion.

Obviously, if this were -- if we could change this, it would add to the wealth of the country and it would create jobs for other people without disabilities. I mean, if you think about the -- if you look at the results of Mr. Delcambre's restaurant in Seattle, he not only has nine employees and he's not only been recognized as an employer of people with disabilities, but he has contributed to the economy of the city. If you multiplied that times all the people in this country with disabilities who could work who aren't, it would dramatically add to the per capita income of the United States as a whole.

And that's a very big deal now, because even though we created seven million jobs and the unemployment rate has dropped, we're not growing fast enough for people's incomes to go up. There are headline stories now, even Business Week has recognized -- the cover of the last addition of Business Week recognizes that we're in an unusual economic period where we've got all kinds of jobs, but not enough and not enough growth to raise incomes. And if you think about where the opportunities are to raise the growth rate of America, putting all the people with disabilities to work who can work is one, it seems to me, of the most obvious opportunities to add to the stock of wealth.

So I was wondering what advice you have for us specifically on that issue, either one of you.

MS. LIPTON: I think that one of the things that's really critical is job training. People have to be trained for the realistic job market so that they can have the skills to compete in the job market.

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I think another problem with a lot of disabled people not working is our benefit structure. Many people who could be working or possibly could be working in some limited way are afraid to work because they will lose their health care benefits, which they depend on for survival. So I think we really need to look at our whole health care system in order to encourage more disabled people to work.

THE PRESIDENT: You know, one thing we did a few years ago, back in 1988, the Congress did when the first big welfare reform bill was passed, was to say people on AFDC who went to work could carry their Medicaid with them for a certain number of months, and the coverage for their children. And it made a big difference. And maybe we ought to have some -- it probably wouldn't be very costly to the country to make some similar provision, especially for people going to work for small businesses that might otherwise not be able to afford a health insurance policy. That's worth looking into.

Thank you. Danny?

MR. DELCAMBRE: Yes. My experience is that -- I've said that ADA, I think it's a great piece of legislation. But five years ago I thought -- when they signed the ADA I thought, oh, this is going to be a wonderful opportunity for people with disabilities, it will help them in getting -- having more employment opportunities, especially for my friends who are deaf-blind. And we do have support there. But I think it really is an attitudinal issue. I think people with disabilities are ready to work; they want to work. And I'm really disappointed not to see an improvement in the job opportunities for my friends.

But there's lots of things that get in the way. For example, with me, my goal is to become a professional speaker. And I wanted to join this organization for professional speakers, and I paid for membership. And when I told them that I was deaf and I needed an interpreter, they told me I needed to bring my own interpreter or I needed to recruit 50 other deaf people to come to their meeting before they would provide interpreters.

My friends have said, oh, Danny, you should get a lawyer, you should sue them, you should go to court. I don't have energy and I don't have time to be filing complaints all the time and to sue people and stuff. My time and energy needs to go into my business. So those are some of the issues that we run into. It's attitudes.

MS. LIPTON: -- transportation is another very critical issue because without accessible transportation people simply

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cannot get to work. So --

CHAIRMAN COEHLO: Now, let's hear from Heather Whitestone, Miss America. Heather.

MS. WHITESTONE: I wanted to tell you that I saw your car pass by. I was out to walk, I took a walk and I saw your car pass by as it went to the White House. And I thought, I'm going to see him tomorrow. (Laughter.) It was so funny.

But six years ago, Miss Washington was the best deaf contestant competing for the Miss America Scholarship Program on an equal ground. Six years ago. So I became the second deaf contestant for the Miss American Pageant, and also became the first deaf woman to be accepted as Miss America.

This is a most demanding job, because she's the spokesperson for the platform -- 20,000 miles for a national speaking tour. So this is really unusual for a deaf girl to speak for her platform. Before I competed for this job I had no job experience. I only had experience through my community service, and I baby-sat once. That's it -- in my lifetime. And it just amazed me that I was getting a chance. And I had a strong faith in God and I really believe it is part of God's plan.

But I have been discriminated against before. I have been. And my mother and I, we struggled a lot. And we wonder -- if it was to go to the court, it takes time. It's just so much time. But we just decided to find the obstacle as an opportunity for creative ideas. So we found our own paths to overcome. But success for people with disabilities does take longer, because we have to find the path to overcome.

And I had the opportunity to meet with young people across the country, all people. And I want you to know that young people with disabilities are really working hard, because they have high hopes for their dreams. Some want to be a lawyer -- a lot want to be lawyers. Some want to be astronauts. Some want to be a schoolteacher, and so forth. Just like all of us. And I want them to have the educational opportunities, and education, we have no doubt, will help them to succeed.

And I also had the opportunity to meet businesswomen... And we would talk about ADA a lot -- once in a while. And they think ADA has had good results, but at the same time they are confused and frustrated. It really is frustrating. And I was shocked this year that we still have more than 60 percent of people with disabilities who are not employed. I thought a lot of them had

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jobs -- I just assumed until I read the fact.

So my goal as Miss America is to help people both -- people with disabilities and people without disabilities -- to look at each other with a positive attitude. And I want everybody to have equal rights, because I know when we treat everybody fair -- just like my mom treated my sister and me -- my mother always treated my sister and me fairly. Otherwise, we would not obey her. She treated us fairly. She never treated me differently from my sister. She didn't baby me more than my sister, either. She treated us equal. And it gave us more opportunity to work together as a team. Same thing in America.

And that's what's so special about the United States, the good people are united together. The last four letters in the word American spell I Can. So we have the freedom to succeed. The problem is the people's perspective. We handicap ourselves by thinking negative. We need to change our thinking to positive. That's what I feel. (Applause.)

THE PRESIDENT: One of the things that I think is very important in this whole endeavor is what I think you're doing now. I mean, I think that people have to have examples or experience that makes them either think they can do something that they didn't think they could do before, or changes the attitudes of other people who are holding them back. So I think you can have a huge impact on that. But I think that we need to look for other things that we can all do which would also contribute to that.

A couple of years ago -- I can't remember -- maybe it was just last year -- Senator Harkin and I kicked off the telephone relay system, the two-way telephone relay system. And I thought that, in addition to actually enabling people to use the telephone who couldn't before, it would also make a statement that we thought they were important and deserved to be able to use the telephone, and that maybe the statement it made would be just as important as the conversations which could occur.

Do you think a lot of people are using that telephone relay system now? Do you think that more people are using it -- do you hear that? Maybe Danny and Heather both would like to comment on that.

MS. WHITESTONE: Because I had early training when I was little, my mother taught me to listen with my hearing aid. And now I talk on the phone most of the time. And I use TTY sometimes, but I've heard from other deaf people that it's a struggle. Sometimes it's hard to get some help. But I think communication really helps

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all of us to pull together, so I do support TTY -- I mean, relay -- a lot, 100 percent. And I talked with him earlier about it.

He had a better explanation. So I asked him, can he take my place? (Laughter.) So he will. And he can tell you more about it because he's had more experience.

MR. DELCAMBRE: Yes, I do have a lot of experience with the relay in my business and I've been using the relay since 1987, the state relay. And most deaf people really use the relay. We use it to make appointments to go to the doctor, to the dentist for jobs. It would always be better for the hospital to have a TTY itself and know how to use it instead of having to depend on the relay. And sometimes there's a problem with -- (gap in tape) --

-- that they're setting up out there. And TTYs are few and far between. Hearing people are fortunate because you can just walk outside and there will be a phone right there at your service versus us, we have to search for them.

In my restaurants I use the relay every day and I have to use the relay. And some of those operators are very skilled and conversation is smooth and it's just wonderful. I can't speak positively about it enough. But sometimes they have new people who come in and that can really impact my business. I don't answer the phone at all. I just have voice mail. So, when people call in I don't accept -- when I call the relay sometimes they won't accept interpreting both the TTY calls and the voice calls. So, I'll ask to speak to the supervisor and the supervisor always kind of balls them out but it's just a training issue.

So they're still working on the educational issues with the relay and a lot of people have those kinds of experiences with not having people who are educated enough about how to use that service.

MS. WHITESTONE: I also want to add more information to you. Remember I said most young people study harder and need educational opportunities. I remember when I went to school I called my friend and asked her for help for homework and other stuff. These deaf students who go to regular school or who need help from people who can hear, it's harder to get help. And also they want to have social lives -- like more economic competition. I mean we have a lot of deaf people in America, 49 million people with hearing loss, and I believe communication will build the economy more. I really believe that. That's why the telephone is so important. And also many jobs they are required to use the telephone to work together as a team.

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So it's really important.

CHAIRMAN COEHLO: Now we're going to hear from somebody, Mr. President, that you may know about. He is part of Americorps right now from Philadelphia, but formerly from North Carolina, Ronnie Pulliam.

MR. PULLIAM: Mr. President, I grew up in North Carolina and I went to school at Temple University and that is where I received my Bachelors Degree. I'm not here because of my speaking ability. I'm here because of my work in the Americorps Program at Temple University's Institute on Disabilities.

As an Americorps member I support Speaking For Ourselves, a self-advocacy group to assist mental retardation -- people with mental retardation who are forced to live in institutions. I, along with other members of Speaking For Ourselves, go out into the community and take these people with us and try to help them see that there is another side. We want to give them an opportunity to see that there are other opportunities that exist out there.

I also provide community service in North Philadelphia and recently provided emergency personal assistance to a man who was temporarily without a home and he needed support because he didn't have support at all. My Americorps colleagues and I surrounded this man, Tom, with assistance so he had an option other than being admitted to a rest home. We feel that there is a greater need for personal assistance services. We do what we can, but there's still a much greater need.

Americorps service has given me confidence in myself as far as I can go out into the community. I know I can go out into the community and make a difference while helping change the lives of other people.

We in the Americorps program want to thank you for giving us an opportunity to go out and make a difference. Thank you. (Applause.)

THE PRESIDENT: I thought you spoke just fine. (Laughter.)

I would like to make one comment about this, and maybe either Senator Harkin or Congressman Hoyer might want to say something, too. First of all, you know I believe in the Americorps program and I think it's done a lot of good. And I think it gives the taxpayers a lot more back than we pay for it by encouraging community service and helping people to pay for their education with no national bureaucracy to speak of. All of these programs

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are grass-roots programs. And I thank the Congress, the last Congress and especially Senator Harkin for his leadership role in setting it up.

On the personal assistance issue, let me say that I believe we will never have comprehensive health care reform until we provide more personal assistance for things like in-home care and going to and from work and things like that. (Applause.)

Many of you here know that was a big part of the health care bill I asked the Congress to pass last year. But what you may not know is that I believe it is possible that we can make some progress on that issue this year. (Applause.) And here's how. I have proposed that the Congress, if we're going to say we're realizing some savings from Medicare and Medicaid because we're going to slow the rate of inflation growth, first of all, the cuts have to be far smaller than are proposed by the congressional majority. And, secondly, we ought to take a small amount of that money -- it doesn't have to be a lot of money, but a small amount of that money -- give it back to the states to create the beginnings of more in-home care. You'd be amazed.

If you take any kind of survey in America about what people really want in health care and the number-one thing always comes up from families worried about their older parents, and families with people with disabilities say we need more support for personal assistance in the home or getting to and from someplace, from the home going to and from someplace else.

So I would urge all of you to watch this very closely and see whether or not, if we can't -- when we get down toward the end of this budget debate, if we can't say, look, let's take a small portion of these savings we're trying to achieve from Medicare and Medicaid and put them in to the work of independence and in-home care. We could make a huge difference with a small amount of money because what everybody will see is that it is so cost-effective that that will leverage more funds coming from the states and this thing, I think, will snowball over the next five years where we'll really create a system that the country needs.

So some might think that's too optimistic, but I believe, given the fact that there's going to be -- I think it's going to be a lot more difficult than some in Congress now think to make these big slashes for Medicare and Medicaid. You all ought to come forward, be counted and say, listen, if you're going to slow the rate of inflation, increase the rate of independence, increase the rate of family strength. Give us some beginning framework for in-home personal services. (Applause.)

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I think we can do it.

CHAIRMAN COEHLO: Now why don't we hear from Justin Dart, the father of the movement.

THE PRESIDENT: Ever since John Wayne passed on, Justin's had the most famous cowboy hat in America. (Laughter.)

MR. DART: Mr. President, there has been great progress under the ADA and much of it under your administration and with the leadership of Attorney General Reno and some other great members in your administration. But now, on the fifth birthday of the ADA, proposed changes in public spending and public responsibility threaten to devastate the programs that empower people with disabilities to move from institutions and welfare to work and to live like human beings.

And the same few lobbyists who opposed ADA in 1990 have flooded the nation with fallacies about the ADA, the IDEA and people with disabilities.

Fallacy -- people with disabilities are a small minority of tragic victims whose fate is only marginally relevant to Americans. We can take good care of them through welfare and charity. ADA, IDEA -- why?

Fact: Science has created a new human. The average American is going to have a disability at some point in his or her lifetime. Disability will occur many times in every American family. Disability is not them, it's us, all of us.

Fact: Today's Americans with disabilities have a prove potential for productivity and quality of life that is far beyond our strongest and smartest ancestors of just 100 years ago. But we allow old attitudes and old systems to discriminate them out of schools, out of the workplace, out of the community.

Fallacy: ADA idea costs too much.

Fact: Discrimination costs too much. (Applause.)

According to President Bush's estimate, discrimination against people with disabilities cost \$200 billion a year and going up. Mr. President, America can't afford another century of discrimination against people with disabilities. The ADA, the IDEA, decent education and health care will pay for themselves 10 or 100 times in every generation.

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Fallacy: The ADA imposes abrupt expenses that will bankrupt businesses and communities.

Fact: After five years ADA has caused no bankruptcies, no serious economic problems, not one. It never will.

Fallacy: The ADA will cause an avalanche of lawsuits.

Fact: No avalanche. There never will be because the ADA doesn't allow million-dollar judgments. In five years there have been just 650 public and private lawsuits under the ADA. And, Mr. President, at that rate it will take 50,000 years to sue every business and community covered by the ADA. (Laughter and applause.)

THE PRESIDENT: That's good. (Laughter.)

MR. DART: Mr. President, all of the tiny handfuls of horror story lawsuits that are endlessly cited by the propagandists either lost or were otherwise misrepresented. And implying that these lawsuits were authorized by the ADA is just blatantly dishonest. Now, Mr. President, 49 million Americans with disabilities and our families appreciate your support for our rights, for our education, for our health care. But, Mr. President, we are in trouble. America is in trouble. We need your public leadership on the television -- (applause) -- on the radio, through the newspapers, to the Congress for the ADA, for the IDEA, for the programs that empower us to work and to live like human beings.

And, finally, Mr. President, we love you and we're going to be around in '96. (Applause.)

THE PRESIDENT: I wish you were my speechwriter. There's an opening on our staff there. (Laughter.)

I think that I have to make one serious response to what Justin has said and maybe ask my friend Scott Hitt if he wants to say anything about this.

I have been trying to convince the American people in the last few weeks with these speeches I have given on trying to achieve common ground and affirmative action and the relationship of religion to our school life and the role of the media in building a strong family or tearing it down. All these things. I've been trying to make the point that we are having debates in Washington today that are -- (gap in tape) -- in a heartbeat, and it couldn't be overlooked. (Applause.) You don't have to worry about that. (Applause.)

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But that's the good news. (Laughter.) The bad news is that the President cannot force the Congress to spend money. That is where your real battleground is. We'll take care of any attempt to -- those of us here and others -- substantively erode this law. But we cannot force the Congress to spend money.

And we need an outreach to the conservative Democrats, to the moderate Republicans, to people who genuinely want to balance the budget. I do, too. But we need an outreach to say, you know, if we're going to reduce spending, that makes how we spend our money even more important. And we cannot have these sort of back-door extremist arguments.

The reason I mention Scott Hitt, of course, is because of the remarks that Senator Helms made the other day about AIDS education and treatment. And I thought I ought to point out that, given his interest, that -- you know, he said people's behavior caused AIDS; therefore, we should spend no money on education and treatment. And I thought that I should point out that smoking causes lung cancer, but I'm still for research and treatment of cancer.

I mean, this is a -- this country cannot be permitted to reopen all these questions that are fundamental to a society living together and working together and going forward together. But you just need to know what Senator Harkin and Congressman Hoyer are up against, I'm talking, every single day. Questions that had not been really seriously debated for 80, 90 years -- not just civil rights, not just the environment, not just the Americans with Disabilities Act, but the very responsibility we have as a people to work together to solve our common problems.

You know, a lot of disabled workers we'd like to get into the work force because they're low-skilled people would, by definition, start out at low wages. And a lot of them would love to have any kind of job opportunity. But if we don't raise the minimum wage this year, we will be at a 40-year low in the minimum wage next year.

My idea for the 21st century is a smart-work, high-opportunity society, not a hard-work, low-wage society for anybody. That's just an example of what we're up against. So you need to see your battle as a part of a larger debate over what kind of people we're going to be and whether we're going forward together. You can make a lot of unusual allies, and you can do a lot of good in this Congress. There are a lot of people with good brains and good hearts who don't want to be pushed off this cliff, and you can help them to do something about it. You can keep them from being politically disabled in this crazy time, and I want you to do it.

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(Applause.)

DR. HITT: Mr. President, as you know, the years of the HIV epidemic have, unfortunately, been marked by ignorance, fear and prejudice. And I can't begin to tell you how deeply grateful the people with AIDS in this country are for your strong, aggressive support for this monumental legislation that has helped them as well.

When you ask what is needed, I think everybody around this table would agree and has already said, your visible leadership. It makes a difference when you speak out. It made a big difference a couple of weeks ago. It did turn things around. And your continued, strong, visible support is what is truly needed. (Applause.)

MARCA BRISTO: Mr. President, as you know the National Council on Disability has been all around America over the last six months meeting with people with disabilities. We've heard from in excess of a thousand people. We saw in excess of 10,000 people from Ohio to Alaska, from Maine to Georgia. And from these people, I present you this report which tells their story of the Americans With Disabilities Act. I promised that I will give you the signed copy and convey to you their heartfelt urging to stand firm behind the principles of the ADA.

These people have told us that the law is making a difference in their lives. Brick by brick, that painful wall of exclusion that George Bush referred to is beginning to come down. And even as we say that, we know there's much more to be done. We continue to hear stories of discrimination.

And, as I mention the ADA, we also heard significantly about IDEA. IDEA is to parents and children what ADA is to adults with disabilities. And the partnership between all of us will be with you as you stand firm in these challenging days to come. Believe me, they're out there.

I did a radio interview yesterday, and they're digging deep now for new myths. Yesterday it was, I hired unqualified disabled workers. Now that the ADA is passed, I won't be willing to take that risk anymore. And I said, it is unfair of you to blame the Americans With Disabilities Act for bad business practice. The law doesn't expect it, and we don't want it. These people don't want it. They want equal opportunity, not charity. And we respect the leadership you've given in urge you to continue on.

Thank you. (Applause.)

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CHAIRMAN COEHLO: We're going to have to bring this to a close. But before we do, I'd like to give three individuals who didn't comment an opportunity to make some short remarks if they would. First off, Laurie Powers, would you like to say anything quickly for the President?

DR. POWERS: Mr. President, you started out by asking what it would take for people to be employed at higher levels. And I think that, just as ADA provides the opportunity and has really catalyzed an attitudinal shift in our society, IDEA really is the investment that's required in order for people with disabilities, for youth with disabilities to be able to actualize that opportunity.

And it won't happen unless there are trained Special Ed staff. It won't happen unless there are technologies that are available in schools for children with disabilities. It particularly will not happen if there aren't opportunities for people with disabilities, for youth with disabilities to get that first critical job experience and demonstrate to themselves as much as to everybody else in the world that they are capable of working and standing as typical, capable Americans.

And I really would -- I really support your continued effort in trying to marshal through IDEA, and I hope that we can really keep that essence of that investment in place for youth because if we don't, we are really saying good-bye to our future. (Applause.)

CHAIRMAN COEHLO: Thank you, Laurie. Laurie, as you may know, is Assistant Professor at Dartmouth Medical School. So she has a little bit of experience about what she's talking about there.

Rudd Turnbull. Rudd, do you want to make a couple of short comments?

MR. TURNBULL: Mr. President, General Reno, our son, Jay Turnbull -- his family is out here with me -- has severe mental retardation and he has autism. He is 27-years-old, and when he was born, he was regarded as less able, and, therefore, less worthy.

Today, Mr. President and General Reno, he lives in his own home with people who don't have disabilities. He works at the University of Kansas. He makes more than the minimum wage. He makes so much money that he pays the principal, interest, taxes and insurance on the house that he is buying himself. (Applause.) He lives in Lawrence, Kansas. He contributes to that Social Security fund that we all want to preserve. He pays his own Blue Cross-Blue Shield.

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And you might ask, General Reno and Mr. President, how it came about. I'll tell you in a word. It came about because we created a reliable alliance between his family and his friends, between special education and general education, and between his parents and his professionals. And it is that reliable alliance that kept Jay Turnbull safe through all of these years and that will keep him safe.

I was once fond of saying, as was Ann and his sisters, that his greatest social security is his friendship. And we will say it is a great social security. But today, Children's SSI Program is under the wrong knife by the wrong surgeon at the wrong time. And Senators Conrad and Chafee have a chance to save it. Mr. President, by God, so do you.

And I would only say that when you create these reliable alliances, we create a situation that you, in your words, want. We will not waste a single life in America. We didn't waste Jay Turnbull's, and we won't waste anyone else's. And we will be with you all the while on this.

Thank you, General Reno. Thank you, Mr. President.
(Applause.)

CHAIRMAN COEHLO: Two more short comments. Julie Clark.

MS. CLARK: I just want to add briefly that, as you continue to be visible on this issue, I would remind you that the ADA also does apply to people with mental disabilities and that tends, I think, to be underemphasized in these discussions.

When the federal court decision was issued in my case, I literally got hundreds of phone calls and letters from people from around our entire country, many of whom did not know or believe that the ADA applied to people with mental disabilities and had very real questions about what did access mean for a person with mental disabilities, what does accommodation mean for person with disabilities?

And most people don't have the energy and the funds and the support to sue every employer that isn't willing to accommodate their needs. But for people who need counseling, for people who have mental illness, there needs to be additional education and discussion about those access and accommodation issues.

CHAIRMAN COEHLO: Thank you.

Last, but not least, from Little Rock, Arkansas, Pat Yates.

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MS. YATES: First, Mr. President, let me tell you how thrilled I am to be here, and how excited I am to take the news back to my students. It will be the most exciting beginning of a school year for me to tell my students that the President of the United States cares about you and is listening to people who are advocating for you and are speaking to him on issues that concern you. And I can't wait to tell my students that.

I have a couple of things in response to the discussions I've had with people around here today. It's been wonderful to meet some of these people and to hear their stories. Ms. Lipton told about having to go to law school so she could make sure that her daughter got the services she needed. And that's one of the points I wanted to bring up today -- every parent can't do that.

The majority of parents of my students are themselves struggling to keep their heads above water. Some of them have two or three jobs, and they do not have the time that it takes to devote themselves full time to making sure their child's needs are being met. The bureaucracy and the procedures that they have to go through are intimidating and overwhelming to them.

And oftentimes, once a child leaves the educational system, the ball is dropped because the parents just don't know how to keep the ball rolling. So, somehow, that process has got to be made more consumer-friendly so that everyone doesn't have to be a lawyer to get those rights for their children.

The other thing you mentioned is in-home care and assistance. This is vital. We do our best in the education system to prepare students to go out and have jobs and work and be contributing members of their communities. And once they leave the school, again, oftentimes, there's not that community support to really help them live independently and get to the jobs. And maybe they just need a little help getting dinner made one evening. They don't need someone there all the time in their way. They just need that little extra in-home support, and it's not out there. The Medicaid -- (gap in tape) -- help them feel comfortable with having special needs students in their classrooms. It takes a lot of work. They're anxious about it. They're not comfortable with it. And you need to educate them on what it's going to take and how to modify their curriculum and their program so that these children can fit into their classrooms.

This needs to be done in the community if we're going to increase the number of jobs in the community. Someone needs to be out there helping businesspeople feel comfortable about hiring

MORE

people with disabilities and helping them understand what it takes to work with someone with a disability and that they have more abilities to offer than they could ever believe if they would just let them in the door.

Thank you very much. (Applause.)

CHAIRMAN COEHLO: Thank you. Thank you, Mr. President, for your willingness to listen to us for an hour. You are truly our leader. You are truly our hope. With your support and enthusiasm, we can get there. Thank you very much.

THE PRESIDENT: We're going to do fine. Thank you. (Applause.)

END

Office of
National AIDS Policy

FILE COPY

Correspondence Routing Slip

Tracking Number: 61734

Date Rcvd: 8/1/95

From: Carol Pasco

Staff Action:

Reviewed By Jeff: _____ Reviewed By: Patsy _____

Assigned To: CP - let Pat Romani know we took
care of this

RCVD: _____ DONE: _____

Recommendations/Instructions:

To Support Staff: _____

Date of Response: _____

n:\corresli

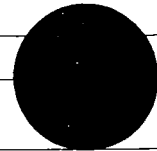
Spoke w/ Pat & left
word w/ Ros. 8/4/95
C

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To:

Patsy Flemming



Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

Schedule ? :

☐ Accept

☐ Pending

☐ Regret

Designee to attend: _____

Remarks:

Please handle -

JUL 5 1995

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
Washington, D.C. 20503-0001

LRM NO: 2203

FILE NO: 1031

7/31/95

LEGISLATIVE REFERRAL MEMORANDUM

Total Page(s): 14

TO: Legislative Liaison Officer - See Distribution below.
FROM: Janet FORSGREN (for) *Janet R. Forsgren*
Assistant Director for Legislative Reference
OMB CONTACT: Melissa COOK 395-3924
Legislative Assistant's line (for simple responses): 395-7362
SUBJECT: ENERGY Qs and As on AIDS/HIV Federal Employee Training

DEADLINE: 11:00am Wednesday, August 02, 1995

In accordance with OMB Circular A-19, OMB requests the views of your agency on the above subject before advising on its relationship to the program of the President.

Please advise us if this item will affect direct spending or receipts for purposes of the "Pay-As-You-Go" provisions of Title XIII of the Omnibus Budget Reconciliation Act of 1990.

COMMENTS: In follow up to the 6/22/95 hearing on Federal employee HIV/AIDS training, attached are Energy's (Corlis Moody's) responses to questions posed by the H. Subcommittee on Civil Service.

AGENCIES:

328-HHS - Sondra S. Wallace - (202) 690-7760
331-Office of Personnel Management - James N. Woodruff - (202) 606-1424

EOP:

Nancy-Ann Min
Bob Rideout
Al Seferian
Barry Clendenin
Richard Turman
Greg White
Gary Bennethum
Allison Eydt
Roz Rettman
Jeremy Ben-Ami
Chris Jennings
Jennifer Klein
Diana Fortuna
Patsy Fleming
Jeff Connaughton
Steve Neuwrith
Jodie Torkelson
Barry Tolv
C. Konigsberg
L. Muniz
Jim Murr
Janet Forsgren

LRM NO: 2203
FILE NO: 1031

POST-HEARING QUESTIONS AND ANSWERS
FROM THE
JUNE 22, 1995 HEARING
BEFORE THE
SUBCOMMITTEE ON CIVIL SERVICE
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT
WITNESS: CORLIS S. MOODY
DIRECTOR, OFFICE OF ECONOMIC IMPACT AND DIVERSITY
DEPARTMENT OF ENERGY

QUESTIONS FROM CONGRESSMAN JOHN L. MICA

QUESTION #1: Why did the Department evaluate the impact of training on employee attitudes (e.g., on their willingness to do volunteer work)?

ANSWER: In the early months of the Federal Workplace HIV/AIDS Education Initiative, the Department did evaluate the impact of the HIV/AIDS training on employee attitudes in limited pilot testing of new survey instruments. These early evaluations were used based on recommendations of the Office of National AIDS Policy, the National Headquarters of the American Red Cross, and the Centers for Disease Control Business Responds to AIDS evaluation staff. Only a small population of the DOE employees, and for the most part only attendees of pilot sessions, were asked questions concerning attitudes.

The American Red Cross pilot tested an instrument in a few initial presentations that were made to DOE staff in Washington, DC and Golden, Colorado. This early survey included items that assessed employee attitudes relevant to the role of HIV/AIDS in the workplace. No other attitudes were assessed. The Red Cross indicated to the pilot attendees that "there were no right or wrong answers to these questions." Because of survey administrative difficulties, an inadequate number of responses were received for these items. Thus, attitude measures were

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neither recorded nor included as a criterion for effectiveness assessment. This has been documented in the Red Cross Final Evaluation previously sent in Binder #1, Section #2.

The Red Cross training survey at our Nevada Operations office as well as the two pilots mentioned earlier, did include the following question. "How likely are you to volunteer for HIV/AIDS related community work?" That is the only place in Red Cross evaluations that we find wording similar to yours. The Red Cross included this question to respond to the Centers for Disease Control Business Responds to AIDS initiative which defines five principles of workplace education, including volunteering in the community. The summary evaluation for the Nevada Operations Office is in Binder #4.

Another survey instrument, designed by the Center for Disease Control Business Responds to AIDS evaluation staff, was used in one pilot session at the Oakland Operations Office and these are included in Binder #6.

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In early 1994, the Department selected another contractor, NOVA Research Company, to provide the HIV/AIDS training at Headquarters, and a new course was implemented. The evaluation instrument designed for these classes, representing a significant majority of the training at Headquarters, did not include questions relating to employees' attitudes. These evaluations were included in our previous submission to you.

The information binders provided to you on July 21, 1995 contain all the surveys and evaluations we received from the HIV/AIDS training coordinators in our regional and area offices. For the most part the evaluations used throughout the regions were shorter and did not include questions about employees' attitudes.

I want to emphasize that the comments we received from our employees throughout the Department were taken very seriously. These comments provided the best guidance in correcting misunderstandings, and more importantly, improving the HIV/AIDS training.

4

QUESTIONS FROM CONGRESSMAN JOHN L. MICA

QUESTION #2: Do you think it is appropriate for a government agency to attempt to change employees minds about AIDS or any other topic, rather than just their behavior on the job?

ANSWER: The Department did not attempt to change employees minds about HIV/AIDS. Any questions asked of our employees attending the HIV/AIDS training were intended to measure the effectiveness of the training and gather their concerns and comments. These comments were always used to improve content and delivery of the course. The Department used materials and instruction techniques to educate our employees about HIV/AIDS in order to reduce fear and to answer employee concerns. The Department followed the recommended guidelines from the Office of National AIDS Policy very closely and the instructors were required to present the subject matter in a professional and clinical manner. More importantly, the HIV/AIDS training focused on these issues which were specific workplace issues.

In conclusion, we followed the guidelines closely, followed directions from the Office of National AIDS Policy, took our employees concerns seriously, and made improvements to the course design, delivery, and the evaluation tool.

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QUESTIONS FROM CONGRESSMAN JAMES MORAN**QUESTION #1:**

You indicated that 85% of the employees who received training at your department rated it very good or excellent. How did the other 15% of the participants rate the training? Did you take any action as a result of what you learned from those giving the training less than a very good rating?

ANSWER:

The following information was compiled from evaluations received from Headquarters employees who attended the HIV/AIDS training and were asked about their "overall impression" of the training.

- o Approximately, 4,400 employees attended
- o 3,639 completed evaluations
- o 1,594 (44%) rated the training as "Excellent"
- o 1,448 (41%) rated the training as "Very Good"
- o 407 (11%) rated the training as "Good"
- o 63 (1%) rated the training as "Fair"
- o 43 (1%) rated the training as "Poor"
- o 84 (2%) did not complete this question

Any questions asked of our employees attending the HIV/AIDS training were intended to measure the effectiveness of the training and gather concerns and comments. This information was used to improve content and delivery of the course. The Department listened seriously to the concerns of our employees and made many improvements throughout the past two years to the course design and delivery, and the evaluation tool.

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Yes, the Department took action to respond to valid employee concerns, and implemented their suggestions for improvement.

Many employees who rated the training other than favorable often did not include comments on which the Department could take action.

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QUESTIONS FROM CONGRESSMAN JAMES MORAN**QUESTION #2:**

What if any disciplinary action was taken against those of your employees who declined to participate in AIDS/HIV training?

ANSWER:

The Department did not take disciplinary action against employees who did not attend the training. During the training at the Department very few employees formally asked to be excluded from the classes. Through their training coordinators and their managers, employees knew they had the right to refuse the class and arrange for alternative education which included a self study manual and watching the Red Cross Video, "AIDS in the Workplace." Any employee who had concerns about their attendance at the training could call the Department HIV/AIDS training contact or the Office of Employee Relations.



QUESTIONS FROM CONGRESSMAN JAMES MORAN**QUESTION #3:**

How has your AIDS/HIV training program been evaluated?
What if any changes have been made in the program as a result
of what has been revealed in participant's evaluations?

ANSWER:

The HIV/AIDS training program was evaluated in several ways
In the beginning several pilot courses were conducted by the
National Headquarters of the American Red Cross. Much of the
information which shaped the Department's HIV training was
received through candid discussion with members of the pilot
groups which included almost every DOE organization.

In addition, in the early months of the Federal Workplace
HIV/AIDS Education Initiative, the Department and the National
Headquarters of the American Red Cross evaluated the impact of
the HIV/AIDS training using a "pilot" survey instrument. These
early evaluations were used based on recommendations of the
Office of National AIDS Policy, the National Headquarters of
the American Red Cross, and the Centers for Disease Control
Business Responds to AIDS evaluation staff. Only a small
population of the DOE employees, and for the most part, only
attendees of pilot sessions completed these surveys at
Washington DC and Golden, Colorado.

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The Red Cross Final Evaluation from this training was previously sent to Chairman Mica on June 14, 1995 in enclosure

Binder #1, Section #2. A similar survey was conducted at the Nevada Operations Office and the results of this survey are included in enclosure Binder #6 which was sent to Chairman Mica on July 21, 1995.

Another survey instrument, designed by the Center for Disease Control Business Responds to AIDS evaluation staff, was used in one pilot session at the Oakland Operations Office and these evaluations are also included in Binder #6.

In early 1994, the Department selected another contractor, NOVA Research Company, to provide the HIV/AIDS training at Headquarters, and a new course was implemented which used a new survey instrument. This survey, used in a significant majority of the Headquarters courses, was brief and focused on gathering concerns from the employees, as well as information about course content and delivery. These evaluations were included in our previous submission to Chairman Mica on June 14, 1995.

The information binders sent July 21, 1995 to Chairman Mica contain all the surveys and evaluations we received from the HIV/AIDS training coordinators in our regional and area offices. For the most part the evaluations used throughout the regions were shorter and focused on gathering employee comments and information about the content and delivery of the course.

Our training at the Department was successful for a few simple reasons. The Department seriously listened to any employee concerns and continually incorporated their suggestions into our training. The questions asked of the employees attending the HIV/AIDS training were intended to measure the effectiveness of the training and gather concerns and comments. These comments were often used to improve content and delivery of the course. These comments provided the best guidance in correcting misunderstandings, and more importantly, improving the HIV/AIDS training.

Assistant Secretary's initials:

07/27/95

Corlis S. Moody

Director, Office of Economic Impact and Diversity

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Concurrences:

Human Resources:

Thomas W. Evans, HR-1, July 26, 1995

General Counsel:

Anne Broker, July 25, 1995

Suzanne Odom for Eric Fygi, July 26, 1995

Congressional Affairs:

Shirley deJavanne, July 26, 1995

Policy Office:

Deferred concurrence to HR-1

Preparation Lead:

Donald Donaldson

Date Questions Received:

July 13, 1995