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Issues - Ricky Ray Hemophilia Act

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RICKY RAY HEMOPHILIA RELIEF FUND ACT OF 1997

House Cosponsors (258)

Alabama (3 of 7)

Robert Aderholt (R-4)
Spencer Bachus (R-6)
Earl Hilliard (D-7)

Alaska (0 of 1)

American Samoa (1 of 1)

Eni F.H. Faleomavaega (D)

Arizona (4 of 6)

John Hayworth (R-6)
Jim Kolbe (R-5)
Ed Pastor (R-2)
John Shadegg (R-4)

Arkansas (1 of 4)

Jay Dickey (R-4)

California (28 of 52)

Howard Berman (D-26)
Brian Bilbray (R-49)
George Brown (D-42)
Ken Calvert (R-43)
Walter Capps (D-22)
Gary Condit (D-18)
Randy Cunningham (R-51)
Ronald Dellums (D-9)
Julian Dixon (D-32)
Anna Eshoo (D-14)
Sam Farr (D-17)
Vic Fazio (D-3)
Bob Filner (D-50)
Elton Gallegly (R-23)
Steve Horn (R-38)
Tom Lantos (D-12)
Jerry Lewis (R-40)
Zoe Lofgren (D-16)
Matthew Martinez (D-31)
Robert Matsui (D-5)
Howard McKeon (R-25)
George Miller (D-7)
Nancy Pelosi (D-8)
Pete Stark (D-13)
Esteban Torres (D-10)
Maxine Waters (D-35)
Henry Waxman (D-29)
Lynn Woolsey (D-6)

Colorado (2 of 6)

Diana DeGette (D-1)
Dan Schaefer (R-6)

Connecticut (6 of 6)

Rose DeLauro (D-3)

Sam Gejdenson (D-2)

Nancy Johnson (R-6)
Barbara Kennelly (D-1)
James Maloney (D-5)
Chris Shays (R-4)

Delaware (1 of 1)

Michael Castle (R)

Dist. of Columbia (1 of 1)

Eleanor Holmes Norton (D)

Florida (20 of 23)

Michael Bilirakis (R-9)
Corrine Brown (D-3)
Jim Davis (D-11)
Peter Deutsch (D-20)
Lincoln Diaz-Balart (R-21)
Mark Foley (R-16)
Tillie Fowler (R-4)
***Porter Goss (R-14)**
Alcee Hastings (D-23)
Bill McCollum (R-8)
Carrie Meek (D-17)
John Mica (R-7)
Dan Miller (R-13)
Ileana Ros-Lehtinen (R-18)
Clay Shaw (R-22)
Cliff Stearns (R-6)
Karen Thurman (D-5)
David Weldon (R-15)
Robert Wexler (D-19)
Bill Young (R-10)

Georgia (8 of 11)

Sanford Bishop (D-2)
Saxby Chambliss (R-8)
Nathan Deal (R-9)
Newt Gingrich (R-6)
John Lewis (D-5)
George Linder (R-11)
Cynthia McKinney (D-11)
Charles Norwood (R-10)

Guam (1 of 1)

Robert Underwood (D)

Hawaii (2 of 2)

Neil Abercrombie (D-1)
Patsy Mink (D-2)

Idaho (0 of 2)

Illinois (12 of 20)

Rod Blagojevich (D-5)

Jerry Costello (D-12)

Philip Crane (R-8)
Danny Davis (D-7)
Lane Evans (D-17)
Luis Gutierrez (D-4)
Dennis Hastert (R-14)
Jesse Jackson (D-2)
Ray LaHood (R-18)
Bobby Rush (D-1)
Jerry Weller (R-11)
Sid Yates (D-9)

Indiana (2 of 10)

Julia Carson (D-10)
Peter Visclosky (D-1)

Iowa (2 of 5)

Tom Latham (R-5)
Jim Leach (R-1)

Kansas (0 of 4)

Kentucky (2 of 6)

Scotty Baesler (D-6)
Jim Bunning (R-4)

Louisiana (5 of 7)

Richard Baker (R-6)
William Jefferson (D-2)
Chris John (D-7)
Jim McCrery (R-4)
Billy Tauzin (R-3)

Maine (2 of 2)

Thomas Allen (D-1)
John Baldacci (D-2)

Maryland (4 of 8)

Ben Cardin (D-3)
Wayne Gilchrest (R-1)
Constance Morella (R-8)
Albert Wynn (D-4)

Massachusetts (10 of 10)

William Delahunt (D-10)
Barney Frank (D-4)
Joseph Kennedy (D-8)
Edward Markey (D-7)
James McGovern (D-3)
Marty Meehan (D-5)
Joe Moakley (D-9)
Richard Neal (D-2)
John Olver (D-1)
John Tierney (D-6)

Michigan (14 of 16)

James Barcia (D-5)
David Bonior (D-10)
Dave Camp (R-4)
John Conyers (D-14)
Vernon Ehlers (R-3)
Peter Hoekstra (R-2)
Dale Kildee (D-9)
Carolyn Kilpatrick (D-15)
Joseph Knollenberg (R-11)
Sander Levin (D-12)
Nick Smith (R-7)
Debbie Stabenow (D-8)
Bart Stupak (D-1)
Fred Upton (R-6)

Minnesota (4 of 8)

James Oberstar (D-8)
Collin Peterson (D-7)
Jim Ramstad (R-3)
Martin Olav Sabo (D-5)

Mississippi (2 of 5)

Bennie Thompson (D-2)
Roger Wicker (R-1)

Missouri (7 of 9)

William Clay (D-1)
Pat Danner (D-6)
Jo Ann Emerson (R-8)
Kenny Hulshof (R-9)
Karen McCarthy (D-5)
Ike Skelton (D-4)
Jim Talent (R-2)

Montana (0 of 1)

Nebraska (1 of 3)

Bill Barrett (R-3)

Nevada (2 of 2)

John Ensign (R-1)
James Gibbons (R-2)

New Hampshire (0 of 2)

New Jersey (8 of 13)

Robert Andrews (D-1)
Frank A. LoBiondo (R-2)
Robert Menendez (D-13)
Frank Pallone (D-6)
William Pascrell (D-8)
Donald Payne (D-10)
Steven Rothman (D-9)
Chris Smith (R-4)

New Mexico (1 of 3)
Steven Schiff (R-1)

New York (27 of 31)
Gary Ackerman (D-5)
Sherwood Boehlert (R-23)
Eliot Engel (D-17)
Floyd Flake (D-6)
Michael Forbes (R-1)
Benjamin Gilman (R-20)
Maurice Hinchey (D-26)
Sue Kelly (R-19)
Peter King (R-3)
John LaFalce (D-29)
Rick Lazio (R-2)
Nita Lowey (D-18)
Carolyn Maloney (D-14)
Thomas Manton (D-7)
Carolyn McCarthy (D-4)
John McHugh (R-24)
Michael McNulty (D-21)
Susan Molinari (R-13)
Jerrold Nadler (D-8)
Major Owens (D-11)
Charles Rangel (D-15)
Charles Schumer (D-9)
Louise Slaughter (D-28)
Gerald Solomon (R-22)
Edolphus Towns (D-10)
Nydia Velazquez (D-12)
James Walsh (R-25)

North Carolina (8 of 12)
Cass Ballenger (R-10)
Richard Burr (R-5)
Howard Coble (R-6)
W.G. Hefner (D-8)
Walter Jones ((R-3)
David Price (D-4)
Charles Taylor (R-11)
Melvin Watt (D-12)

North Dakota (0 of 1)

Ohio (6 of 19)
Paul Gillmor (R-5)
Tony Hall (D-3)
Michael Oxley (R-4)
Deborah Pryce (R-15)
Louis Stokes (D-11)
James Traficant (D-17)

Oklahoma (4 of 6)
Tom Coburn (R-2)
Steve Largent (R-1)
Frank Lucas (R-6)
Wes Watkins (R-3)

Oregon (2 of 5)
Pete DeFazio (D-4)

Elizabeth Furse (D-1)

Pennsylvania (19 of 21)
Robert Borski (D-3)
William Coyne (D-14)
Mike Doyle (D-18)
Philip English (R-21)
Chaka Fattah (D-2)
Thomas Foglietta (D-1)
Jon Fox (R-13)
George Gekas (R-17)
Jim Greenwood (R-8)
William Goodling (R-19)
Tim Holden (D-6)
Paul Kanjorski (D-11)
Frank Mascara (D-20)
Joseph McDade (R-10)
Paul McHale (D-15)
John Murtha (D-12)
Joseph Pitts (R-16)
Bud Shuster (R-9)
Curt Weldon (R-7)

Puerto Rico (1 of 1)
Carlos Romero-Barcelo (D)

Rhode Island (1 of 2)
Robert Weygand (D-2)

South Carolina (4 of 6)
James Clyburn (D-6)
Bob Inglis (R-4)
Floyd Spence (R-2)
John Spratt (D-5)

South Dakota (0 of 1)

Tennessee (4 of 9)
Bob Clement (D-5)
John Duncan (R-2)
Harold Ford (D-9)
William Jenkins (R-1)

Texas (11 of 30)
Bill Archer (R-7)
Ken Bentsen (D-25)
Martin Frost (D-24)
Henry Gonzalez (D-20)
Gene Green (D-29)
Rubén Hinojosa (D-15)
Sheila Jackson-Lee (D-18)
Eddie Johnson (D-30)
Nicholas Lampson (D-9)
Pete Sessions (R-5)
Jim Turner (D-2)

U.S. Virgin Islands (1 of 1)
Donna Christian-Green (D)

Utah (1 of 3)

Merrill Cook (R-2)

Vermont (1 of 1)
Bernard Sanders (I)

Virginia (6 of 11)
Herbert Bateman (R-1)
Rick Boucher (D-9)
Thomas Davis (R-11)
James Moran (D-8)
Norman Sisisky (D-4)
Frank Wolf (R-10)

Washington (3 of 9)
Jennifer Dunn (R-8)
Jim McDermott (D-7)
Linda Smith (R-3)

West Virginia (1of 3)
Nick Rahall (D-3)

Wisconsin (2 of 9)
Jay Johnson (D-8)
Ron Kind (D-3)

Wyoming (0 of 1)

Senate Cosponsors (34)

Robert Bennett (R-UT)
Barbara Boxer (D-CA)
John Breaux (D-LA)
Sam Brownback (R-KS)
Richard Bryan (D-NV)
John Chafee (R-RI)
Max Cleland (D-GA)
Thad Cochran (R-MS)
Susan Collins (R-ME)
Paul Coverdell (R-GA)
Tom Daschle (D-SD)
Mike DeWine (R-OH)
Chris Dodd (D-CT)
Richard Durbin (D-IL)
Lauch Faircloth (R-NC)
Dianne Feinstein (D-CA)
Wendell Ford (D-KY)
Bob Graham (D-FL)
Ernest Hollings (D-SC)
Daniel Inouye (D-HI)
Tim Johnson (D-SD)
Edward Kennedy (D-MA)
John Kerry (D-MA)
Mary Landrieu (D-LA)
Frank Lautenberg (D-NJ)
Connie Mack (R-FL)
Barbara Mikulski (D-MD)
Carol Moseley-Braun (D-IL)
Frank Murkowski (R-AK)
Jack Reed (D-RI)
Harry Reid (D-NV)
Olympia Snowe (R-ME)
Robert Torricelli (D-NJ)
Paul Wellstone (D-MN)



National Hemophilia Foundation

Since 1948

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Fax (212) 966-9247
Web Site: www.infonhf.org

CFC #0543

To: Sandy Thurman

From: Val Bias and Ellen Riker

Date: October 29, 1997

Re: Materials on the Ricky Ray Act

Attached are the materials we promised you on H.R. 1023 the Ricky Ray Hemophilia Relief Fund Act, including bullets, the substitute unanimously passed by the Judiciary Committee today, cosponsor list, and the Administration's past statements.

As we discussed, it is very possible that the bill will make it to the House floor by the end of the session. A supportive Statement of Administration Policy is critical to our success. Thank you for your willingness to help.

marc ASSOCIATES, INC.

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National Hemophilia Foundation

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H.R. 1023, THE RICKY RAY HEMOPHILIA RELIEF FUND ACT

H.R. 1023 may be considered by the full House before the end of the Congressional session. It was passed by the Judiciary Committee on Wednesday, October 29 by voice vote. It has been sequentially referred to the Ways and Means and Commerce Committees which are expected to expedite action.

The bill, as passed by the Judiciary Committee (Chairman Hyde offered a substitute that was unanimously approved), authorizes a fund to provide \$100,000 in compassionate payment to individuals with hemophilia that were infected with HIV through blood products taken between 1982 and 1987. The fund would be administered by the Secretary of HHS and would sunset in five years. Title II of the bill, under the other Committees' jurisdiction, protects the eligibility of individuals in Medicaid and SSI upon receipt of funds from a private settlement offered by the manufacturers of the blood products.

President Clinton became aware of the tragedy of the hemophilia community and specifically the Ray's story during the Presidential campaign. Ricky Ray, the bill's namesake, was diagnosed with HIV when he was 9. Ricky and his brothers were kicked out of school because of their HIV status and when their parents won a decision in court to readmit them, arsonists set their house to fire.

During a campaign trip to Florida, the Ray's home state, President Clinton met with Ricky's parents. After the election the Ray family came to the White House at the President's invitation. At that time he learned about the legislation and pledged his support. The Rays have continued their communication with the President who has affirmed his commitment to sign the bill when it reaches his desk.

The House Judiciary Committee held a hearing on the bill last year. Secretary Shalala sent the attached letter stating the Administration's support. Then Assistant Secretary of HHS Phil Lee and Eva Plaza from the Justice Department also testified. While technical questions were raised in their testimony, both offered the Administration's support. The technical issues raised at this hearing have been addressed in Chairman Hyde's substitute that passed in Committee. .

OCTOBER 16, 1997

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 1023
OFFERED BY MR. HYDE**

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

2 (a) SHORT TITLE.—This Act may be cited as the
3 “Ricky Ray Hemophilia Relief Fund Act of 1997”.

4 (b) TABLE OF CONTENTS.—The table of contents of
5 this Act is as follows:

Sec. 1. Short title; table of contents.

TITLE I—HEMOPHILIA RELIEF FUND

Sec. 101. Ricky Ray Hemophilia Relief Fund.

Sec. 102. Compassionate payment relating to individuals with blood-clotting disorders and HIV.

Sec. 103. Determination and payment.

Sec. 104. Limitation on transfer of rights and number of petitions.

Sec. 105. Time limitation.

Sec. 106. Certain claims not affected by payment.

Sec. 107. Limitation on agent and attorney fees.

Sec. 108. Definitions.

TITLE II—TREATMENT OF CERTAIN PRIVATE SETTLEMENT PAYMENTS IN HEMOPHILIA-CLOTTING-FACTOR SUIT UNDER THE MEDICAID AND SSI PROGRAMS

Sec. 201. Treatment of certain private settlement payments in hemophilia-clotting-factor suit under the Medicaid and SSI programs.

1 **TITLE I—HEMOPHILIA RELIEF**
2 **FUND**

3 **SEC. 101. RICKY RAY HEMOPHILIA RELIEF FUND.**

4 (a) **ESTABLISHMENT.**—There is established in the
5 Treasury of the United States a trust fund to be known
6 as the “Ricky Ray Hemophilia Relief Fund”, which shall
7 be administered by the Secretary of the Treasury.

8 (b) **INVESTMENT OF AMOUNTS IN FUND.**—Amounts
9 in the Fund shall be invested in accordance with section
10 9702 of title 31, United States Code, and any interest on
11 and proceeds from any such investment shall be credited
12 to and become part of the Fund.

13 (c) **AVAILABILITY OF FUND.**—Amounts in the Fund
14 shall be available only for disbursement by the Secretary
15 of Health and Human Services under section 103.

16 (d) **TERMINATION.**—The Fund shall terminate upon
17 the expiration of the 5-year period beginning on the date
18 of the enactment of this Act. If all of the amounts in the
19 Fund have not been expended by the end of the 5-year
20 period, investments of amounts in the Fund shall be liq-
21 uidated, the receipts of such liquidation shall be deposited
22 in the Fund, and all funds remaining in the Fund shall
23 be deposited in the miscellaneous receipts account in the
24 Treasury of the United States.

1 (e) AUTHORIZATION OF APPROPRIATIONS.—There is
2 authorized to be appropriated to the Fund to carry out
3 this title \$750,000,000.

4 **SEC. 102. COMPASSIONATE PAYMENT RELATING TO INDIVIDUALS WITH BLOOD-CLOTTING DISORDERS**
5
6 **AND HIV.**

7 (a) IN GENERAL.—If the conditions described in sub-
8 section (b) are met, the Secretary shall make a single pay-
9 ment of \$100,000 from amounts available in the Fund to
10 any individual who has an HIV infection and who is de-
11 scribed in one of the following paragraphs:

12 (1) The individual has any form of blood-clot-
13 ting disorder, such as hemophilia, and was treated
14 with antihemophilic factor at any time during the
15 period beginning on July 1, 1982, and ending on
16 December 31, 1987.

17 (2) The individual —

18 (A) is the lawful spouse of an individual
19 described in paragraph (1); or

20 (B) is the former lawful spouse of an indi-
21 vidual described in paragraph (1) and was the
22 lawful spouse of the individual at any time after
23 a date, within the period described in such sub-
24 paragraph, on which the individual was treated
25 as described in such paragraph and through

1 medical documentation can assert reasonable
2 certainty of transmission of HIV from individ-
3 ual described in paragraph (1).

4 (3) The individual acquired the HIV infection
5 through perinatal transmission from a parent who is
6 an individual described in paragraph (1) or (2).

7 (b) CONDITIONS.—The conditions described in this
8 subsection are, with respect to an individual, as follows:

9 (1) SUBMISSION OF MEDICAL DOCUMENTATION
10 OF HIV INFECTION.—The individual submits to the
11 Secretary written medical documentation that the in-
12 dividual has an HIV infection.

13 (2) PETITION.—A petition for the payment is
14 filed with the Secretary by or on behalf of the indi-
15 vidual.

16 (3) DETERMINATION.—The Secretary deter-
17 mines, in accordance with section 103(b), that the
18 petition meets the requirements of this title.

19 **SEC. 103. DETERMINATION AND PAYMENT.**

20 (a) ESTABLISHMENT OF FILING PROCEDURES.—The
21 Secretary of Health and Human Services shall establish
22 procedures under which individuals may submit petitions
23 for payment under this title. The procedures shall include
24 a requirement that each petition filed under this Act in-
25 clude written medical documentation that the relevant in-

1 individual described in section 102(a)(1) has (or had) a
2 blood-clotting disorder, such as hemophilia, and was treat-
3 ed as described in such section.

4 (b) DETERMINATION.—For each petition filed under
5 this title, the Secretary shall determine whether the peti-
6 tion meets the requirements of this title.

7 (c) PAYMENT.—

8 (1) IN GENERAL.—The Secretary shall pay,
9 from amounts available in the Fund, each petition
10 that the Secretary determines meets the require-
11 ments of this title.

12 (2) PAYMENTS IN CASE OF DECEASED INDIVID-
13 UALS.—

14 (A) IN GENERAL.—In the case of an indi-
15 vidual referred to in section 102(a) who is de-
16 ceased at the time that payment is made under
17 this section on a petition filed by or on behalf
18 of the individual, the payment shall be made as
19 follows:

20 (i) If the individual is survived by a
21 spouse who is living at the time of pay-
22 ment, the payment shall be made to such
23 surviving spouse.

24 (ii) If the individual is not survived by
25 a spouse described in clause (i), the pay-

1 ment shall be made in equal shares to all
2 children of the individual who are living at
3 the time of the payment.

4 (iii) If the individual is not survived
5 by a person described in clause (i) or (ii),
6 the payment shall be made in equal shares
7 to the parents of the individual who are
8 living at the time of payment.

9 (iv) If the individual is not survived
10 by a person described in clause (i), (ii), or
11 (iii), the payment shall revert back to the
12 Fund.

13 (B) FILING OF PETITION BY SURVIVOR.—
14 If an individual eligible for payment under sec-
15 tion 102(a) dies before filing a petition under
16 this title, a survivor of the individual may file
17 a petition for payment under this title on behalf
18 of the individual if the survivor may receive
19 payment under subparagraph (A).

20 (C) DEFINITIONS.—For purposes of this
21 paragraph:

22 (i) The term “spouse” means an indi-
23 vidual who was lawfully married to the rel-
24 evant individual at the time of death.

1 (ii) The term "child" includes a recog-
2 nized natural child, a stepchild who lived
3 with the relevant individual in a regular
4 parent-child relationship, and an adopted
5 child.

6 (iii) The term "parent" includes fa-
7 thers and mothers through adoption.

8 (3) TIMING OF PAYMENT.—The Secretary may
9 not make a payment on a petition under this title
10 before the expiration of the 120-day period begin-
11 ning on the date of the enactment of this Act or
12 after the expiration of the 5-year period beginning
13 on the date of the enactment of this Act.

14 (d) ACTION ON PETITIONS.—The Secretary shall
15 complete the determination required by subsection (b) re-
16 garding a petition not later than 120 days after the date
17 the petition is filed under this title.

18 (e) HUMANITARIAN NATURE OF PAYMENT.—This
19 Act does not create or admit any claim of or on behalf
20 of the individual against the United States or against any
21 officer, employee, or agent thereof acting within the scope
22 of employment or agency that relate to an HIV infection
23 arising from treatment with antihemophilic factor, at any
24 time during the period beginning on July 1, 1982, and
25 ending on December 31, 1987. A payment under this Act

1 shall, however, when accepted by or on behalf of the indi-
2 vidual, be in full satisfaction of all such claims by or on
3 behalf of that individual.

4 (f) ADMINISTRATIVE COSTS NOT PAID FROM
5 FUND.—No costs incurred by the Secretary in carrying
6 out this title may be paid from the Fund or set off against,
7 or otherwise deducted from, any payment made under sub-
8 section (c)(1).

9 (g) TERMINATION OF DUTIES OF SECRETARY.—The
10 duties of the Secretary under this section shall cease when
11 the Fund terminates.

12 (h) TREATMENT OF PAYMENTS UNDER OTHER
13 LAWS.—A payment under subsection (c)(1) to an individ-
14 ual—

15 (1) shall be treated for purposes of the internal
16 revenue laws of the United States as damages re-
17 ceived on account of personal injuries or sickness;

18 (2) shall not be included as income or resources
19 for purposes of determining the eligibility of the in-
20 dividual to receive benefits described in section
21 3803(c)(2)(C) of title 31, United States Code, or the
22 amount of such benefits, and such benefits shall not
23 be secondary to, conditioned upon reimbursement
24 from, or subject to any reduction because of receipt
25 of, any such payment; and

1 (3) shall not be treated as a third party pay-
2 ment or payment in relation to a legal liability with
3 respect to such benefits and shall not be subject
4 (whether by subrogation or otherwise) to recovery,
5 recoupment, reimbursement, or collection with re-
6 spect to such benefits (including the Federal or
7 State governments or any entity that provides such
8 benefits under a contract).

9 (i) REGULATORY AUTHORITY.—The Secretary may
10 issue regulations necessary to carry out this title.

11 (j) TIME OF ISSUANCE OF PROCEDURES.—The Sec-
12 retary shall, through the promulgation of appropriate reg-
13 ulations, guidelines, or otherwise, first establish the proce-
14 dures to carry out this title not later than 120 days after
15 the date of the enactment of this Act.

16 **SEC. 104. LIMITATION ON TRANSFER OF RIGHTS AND NUM-**
17 **BER OF PETITIONS.**

18 (a) RIGHTS NOT ASSIGNABLE OR TRANSFERABLE.—
19 Any right under this title shall not be assignable or trans-
20 ferable.

21 (b) 1 PETITION WITH RESPECT TO EACH VICTIM.—
22 With respect to each individual described in paragraph
23 (1), (2), or (3) of section 102(a), the Secretary may not
24 make payment with respect to more than 1 petition filed
25 in respect to an individual.

1 **SEC. 105. TIME LIMITATION.**

2 The Secretary may not make any payment with re-
3 spect to any petition filed under this title unless the peti-
4 tion is filed within 3 years after the date of the enactment
5 of this Act.

6 **SEC. 106. CERTAIN CLAIMS NOT AFFECTED BY PAYMENT.**

7 A payment made under section 103(c)(1) shall not
8 be considered as any form of compensation, or reimburse-
9 ment for a loss, for purposes of imposing liability on the
10 individual receiving the payment, on the basis of such re-
11 ceipt, to repay any insurance carrier for insurance pay-
12 ments or to repay any person on account of worker's com-
13 pensation payments. A payment under this title shall not
14 affect any claim against an insurance carrier with respect
15 to insurance or against any person with respect to work-
16 er's compensation.

17 **SEC. 107. LIMITATION ON AGENT AND ATTORNEY FEES.**

18 Notwithstanding any contract, the representative of
19 an individual may not receive, for services rendered in con-
20 nection with the petition of an individual under this title,
21 more than 2 percent of a payment made under this title
22 on the petition. Any such representative who violates this
23 section shall be fined not more than \$50,000.

24 **SEC. 108. DEFINITIONS.**

25 For purposes of this title:

1 (1) The term "AIDS" means acquired immune
2 deficiency syndrome.

3 (2) The term "Fund" means the Ricky Ray
4 Hemophilia Relief Fund.

5 (3) The term "HIV" means human
6 immunodeficiency virus.

7 (4) Unless otherwise provided, the term "Sec-
8 retary" means Secretary of Health and Human
9 Services.

10 **TITLE II—TREATMENT OF CER-**
11 **TAIN PRIVATE SETTLEMENT**
12 **PAYMENTS IN HEMOPHILIA-**
13 **CLOTTING-FACTOR SUIT**
14 **UNDER THE MEDICAID AND**
15 **SSI PROGRAMS**

16 **SEC. 201. TREATMENT OF CERTAIN PRIVATE SETTLEMENT**
17 **PAYMENTS IN HEMOPHILIA-CLOTTING-FAC-**
18 **TOR SUIT UNDER THE MEDICAID AND SSI**
19 **PROGRAMS.**

20 (a) IN GENERAL.—Notwithstanding any other provi-
21 sion of law, a settlement payment shall not be considered
22 income or resources in determining a class member's eligi-
23 bility for, or the amount of—

24 (1) medical assistance under title XIX of the
25 Social Security Act, or

1 (2) supplemental security income benefits under
2 title XVI of such Act.

3 (b) DEFINITIONS.—For purposes of this section:

4 (1) CLASS MEMBER.—The term “class mem-
5 ber” means a member of the Settlement Class in the
6 settlement in *In Re Factor VIII or IX Concentrate*
7 *Blood Products Litigation* (United States District
8 Court, Northern District of Illinois, Eastern Divi-
9 sion; Civil Action No. 96-C-5024).

10 (2) SETTLEMENT PAYMENT.—The term “settle-
11 ment payment” means a payment to a class member
12 under the settlement described in paragraph (1).

Amend the title so as to read “A bill to provide for
compassionate payments with regard to individuals with
blood-clotting disorders, such as hemophilia, who con-
tracted human immunodeficiency virus due to contami-
nated antihemophilic factor, and for other purposes.

RICKY RAY HEMOPHILIA RELIEF FUND ACT OF 1997

House Cosponsors (258)

Alabama (3 of 7)

Robert Aderholt (R-4)
Spencer Bachus (R-6)
Earl Hilliard (D-7)

Alaska (0 of 1)

American Samoa (1 of 1)
Eni F.H. Faleomavaega (D)

Arizona (4 of 6)

John Hayworth (R-6)
Jim Kolbe (R-5)
Ed Pastor (R-2)
John Shadegg (R-4)

Arkansas (1 of 4)

Jay Dickey (R-4)

California (28 of 52)

Howard Berman (D-26)
Brian Bilbray (R-49)
George Brown (D-42)
Ken Calvert (R-43)
Walter Capps (D-22)
Gary Condit (D-18)
Randy Cunningham (R-51)
Ronald Dellums (D-9)
Julian Dixon (D-32)
Anna Eshoo (D-14)
Sam Farr (D-17)
Vic Fazio (D-3)
Bob Filner (D-50)
Elton Gallegly (R-23)
Steve Horn (R-38)
Tom Lantos (D-12)
Jerry Lewis (R-40)
Zoe Lofgren (D-16)
Matthew Martinez (D-31)
Robert Matsui (D-5)
Howard McKeon (R-25)
George Miller (D-7)
Nancy Pelosi (D-8)
Pete Stark (D-13)
Esteban Torres (D-10)
Maxine Waters (D-35)
Henry Waxman (D-29)
Lynn Woolsey (D-6)

Colorado (2 of 6)

Diana DeGette (D-1)
Dan Schaefer (R-6)

Connecticut (6 of 6)

Rose DeLauro (D-3)
Sam Gejdenson (D-2)

Nancy Johnson (R-6)
Barbara Kennelly (D-1)
James Maloney (D-5)
Chris Shays (R-4)

Delaware (1 of 1)

Michael Castle (R)

Dist. of Columbia (1 of 1)
Eleanor Holmes Norton (D)

Florida (20 of 23)

Michael Bilirakis (R-9)
Corrine Brown (D-3)
Jim Davis (D-11)
Peter Deutsch (D-20)
Lincoln Diaz-Balart (R-21)
Mark Foley (R-16)
Tillie Fowler (R-4)
***Porter Goss (R-14)**
Alcee Hastings (D-23)
Bill McCollum (R-8)
Carrie Meek (D-17)
John Mica (R-7)
Dan Miller (R-13)
Ileana Ros-Lehtinen (R-18)
Clay Shaw (R-22)
Cliff Stearns (R-6)
Karen Thurman (D-5)
David Weldon (R-15)
Robert Wexler (D-19)
Bill Young (R-10)

Georgia (8 of 11)

Sanford Bishop (D-2)
Saxby Chambliss (R-8)
Nathan Deal (R-9)
Newt Gingrich (R-6)
John Lewis (D-5)
George Linder (R-11)
Cynthia McKinney (D-11)
Charles Norwood (R-10)

Guam (1 of 1)

Robert Underwood (D)

Hawaii (2 of 2)

Neil Abercrombie (D-1)
Patsy Mink (D-2)

Idaho (0 of 2)

Illinois (12 of 20)

Rod Blagojevich (D-5)
Jerry Costello (D-12)
Philip Crane (R-8)

Danny Davis (D-7)
Lane Evans (D-17)
Luis Gutierrez (D-4)
Dennis Hastert (R-14)
Jesse Jackson (D-2)
Ray LaHood (R-18)
Bobby Rush (D-1)
Jerry Weller (R-11)
Sid Yates (D-9)

Indiana (2 of 10)

Julia Carson (D-10)
Peter Visclosky (D-1)

Iowa (2 of 5)

Tom Latham (R-5)
Jim Leach (R-1)

Kansas (0 of 4)

Kentucky (2 of 6)
Scotty Baesler (D-6)
Jim Bunning (R-4)

Louisiana (5 of 7)

Richard Baker (R-6)
William Jefferson (D-2)
Chris John (D-7)
Jim McCrery (R-4)
Billy Tauzin (R-3)

Maine (2 of 2)

Thomas Allen (D-1)
John Baldacci (D-2)

Maryland (4 of 8)

Ben Cardin (D-3)
Wayne Gilchrest (R-1)
Constance Morella (R-8)
Albert Wynn (D-4)

Massachusetts (10 of 10)

William Delahunt (D-10)
Barney Frank (D-4)
Joseph Kennedy (D-8)
Edward Markey (D-7)
James McGovern (D-3)
Marty Meehan (D-5)
Joe Moakley (D-9)
Richard Neal (D-2)
John Olver (D-1)
John Tierney (D-6)

Michigan (14 of 16)

James Barcia (D-5)
David Bonior (D-10)

Dave Camp (R-4)
John Conyers (D-14)
Vernon Ehlers (R-3)
Peter Hoekstra (R-2)
Dale Kildee (D-9)
Carolyn Kilpatrick (D-15)
Joseph Knollenberg (R-11)
Sander Levin (D-12)
Nick Smith (R-7)
Debbie Stabenow (D-8)
Bart Stupak (D-1)
Fred Upton (R-6)

Minnesota (4 of 8)

James Oberstar (D-8)
Collin Peterson (D-7)
Jim Ramstad (R-3)
Martin Olav Sabo (D-5)

Mississippi (2 of 5)

Bennie Thompson (D-2)
Roger Wicker (R-1)

Missouri (7 of 9)

William Clay (D-1)
Pat Danner (D-6)
Jo Ann Emerson (R-8)
Kenny Hulshof (R-9)
Karen McCarthy (D-5)
Ike Skelton (D-4)
Jim Talent (R-2)

Montana (0 of 1)

Nebraska (1 of 3)

Bill Barrett (R-3)

Nevada (2 of 2)

John Ensign (R-1)
James Gibbons (R-2)

New Hampshire (0 of 2)

New Jersey (8 of 13)

Robert Andrews (D-1)
Frank A. LoBiondo (R-2)
Robert Menendez (D-13)
Frank Pallone (D-6)
William Pascrell (D-8)
Donald Payne (D-10)
Steven Rothman (D-9)
Chris Smith (R-4)

New Mexico (1 of 3)
Steven Schiff (R-1)

New York (27 of 31)
Gary Ackerman (D-5)
Sherwood Boehlert (R-23)
Eliot Engel (D-17)
Floyd Flake (D-6)
Michael Forbes (R-1)
Benjamin Gilman (R-20)
Maurice Hinchey (D-26)
Sue Kelly (R-19)
Peter King (R-3)
John LaFalce (D-29)
Rick Lazio (R-2)
Nita Lowey (D-18)
Carolyn Maloney (D-14)
Thomas Manton (D-7)
Carolyn McCarthy (D-4)
John McHugh (R-24)
Michael McNulty (D-21)
Susan Molinari (R-13)
Jerrold Nadler (D-8)
Major Owens (D-11)
Charles Rangel (D-15)
Charles Schumer (D-9)
Louise Slaughter (D-28)
Gerald Solomon (R-22)
Edolphus Towns (D-10)
Nydia Velazquez (D-12)
James Walsh (R-25)

North Carolina (8 of 12)
Cass Ballenger (R-10)
Richard Burr (R-5)
Howard Coble (R-6)
W.G. Hefner (D-8)
Walter Jones ((R-3)
David Price (D-4)
Charles Taylor (R-11)
Melvin Watt (D-12)

North Dakota (0 of 1)

Ohio (6 of 19)
Paul Gillmor (R-5)
Tony Hall (D-3)
Michael Oxley (R-4)
Deborah Pryce (R-15)
Louis Stokes (D-11)
James Traficant (D-17)

Oklahoma (4 of 6)
Tom Coburn (R-2)
Steve Largent (R-1)
Frank Lucas (R-6)
Wes Watkins (R-3)

Oregon (2 of 5)
Pete DeFazio (D-4)
Elizabeth Furse (D-1)

Pennsylvania (19 of 21)
Robert Borski (D-3)
William Coyne (D-14)
Mike Doyle (D-18)
Philip English (R-21)
Chaka Fattah (D-2)
Thomas Foglietta (D-1)
Jon Fox (R-13)
George Gekas (R-17)
Jim Greenwood (R-8)
William Goodling (R-19)
Tim Holden (D-6)
Paul Kanjorski (D-11)
Frank Mascara (D-20)
Joseph McDade (R-10)
Paul McHale (D-15)
John Murtha (D-12)
Joseph Pitts (R-16)
Bud Shuster (R-9)
Curt Weldon (R-7)

Puerto Rico (1 of 1)
Carlos Romero-Barcelo (D)

Rhode Island (1 of 2)
Robert Weygand (D-2)

South Carolina (4 of 6)
James Clyburn (D-6)
Bob Inglis (R-4)
Floyd Spence (R-2)
John Spratt (D-5)

South Dakota (0 of 1)

Tennessee (4 of 9)
Bob Clement (D-5)
John Duncan (R-2)
Harold Ford (D-9)
William Jenkins (R-1)

Texas (11 of 30)
Bill Archer (R-7)
Ken Bentsen (D-25)
Martin Frost (D-24)
Henry Gonzalez (D-20)
Gene Green (D-29)
Rubén Hinojosa (D-15)
Sheila Jackson-Lee (D-18)
Eddie Johnson (D-30)
Nicholas Lampson (D-9)
Pete Sessions (R-5)
Jim Turner (D-2)

U.S. Virgin Islands (1 of 1)
Donna Christian-Green (D)

Utah (1 of 3)
Merrill Cook (R-2)

Vermont (1 of 1)
Bernard Sanders (I)

Virginia (6 of 11)
Herbert Bateman (R-1)
Rick Boucher (D-9)
Thomas Davis (R-11)
James Moran (D-8)
Norman Sisisky (D-4)
Frank Wolf (R-10)

Washington (3 of 9)
Jennifer Dunn (R-8)
Jim McDermott (D-7)
Linda Smith (R-3)

West Virginia (1of 3)
Nick Rahall (D-3)

Wisconsin (2 of 9)
Jay Johnson (D-8)
Ron Kind (D-3)

Wyoming (0 of 1)

Senate Cosponsors (35)

Robert Bennett (R-UT)
Barbara Boxer (D-CA)
John Breaux (D-LA)
Sam Brownback (R-KS)
Richard Bryan (D-NV)
John Chafee (R-RI)
Max Cleland (D-GA)
Thad Cochran (R-MS)
Susan Collins (R-ME)
Paul Coverdell (R-GA)
Tom Daschle (D-SD)
Mike DeWine (R-OH)
Chris Dodd (D-CT)
Richard Durbin (D-IL)
Lauch Faircloth (R-NC)
Dianne Feinstein (D-CA)
Wendell Ford (D-KY)
Bob Graham (D-FL)
Ernest Hollings (D-SC)
Tim Hutchinson (R-AR)
Daniel Inouye (D-HI)
Tim Johnson (D-SD)
Edward Kennedy (D-MA)
John Kerry (D-MA)
Mary Landrieu (D-LA)
Frank Lautenberg (D-NJ)
Connie Mack (R-FL)
Barbara Mikulski (D-MD)
Carol Moseley-Braun (D-IL)
Frank Murkowski (R-AK)
Jack Reed (D-RI)
Harry Reid (D-NV)
Olympia Snowe (R-ME)
Robert Torricelli (D-NJ)
Paul Wellstone (D-MN)



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

JUN - 5 1996

The Honorable Lamar Smith
Chairman. Subcommittee on
Immigration and Claims
Committee on the Judiciary
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Chairman:

This is in response to your request for the views of the Department of Health and Human Services on H.R. 1023, the "Ricky Ray Hemophilia Relief Fund Act of 1995". The Department of Justice concurs with these views.

H.R. 1023 would create a compensation fund for individuals (or the estates or survivors of individuals) who have HIV infection and who either (i) have hemophilia or a similar blood-clotting disorder and were treated with blood-clotting agents during the period from January 1, 1980, through December 31, 1987, or (ii) are the spouses or children of such individuals. The bill would authorize appropriations to the fund of \$1 billion, and would entitle each individual who demonstrated eligibility to receive \$125,000 from amounts available in the fund. The program would terminate five years after enactment.

On behalf of the Administration, let me first express our deep concern about the tragedy that has so affected the hemophilia community with respect to HIV transmission through blood and blood products. We have great sympathy for the victims and their families who suffered and continue to suffer from consequences of the contamination of antihemophilic factors in the 1980s.

In recognition of this tragedy, in July 1993 this Department asked the National Academy of Sciences' Institute of Medicine (IOM) to conduct a rigorous review of Federal blood regulation during the 1980s. The IOM reported back to us in July 1995. As a result of information gained in that review, we have instituted several blood safety reforms, including the establishment of an interagency Blood Safety Committee to monitor the safety of blood products. As you know, however, the IOM review found no negligence in the Federal Government's regulation of blood

Page 2 - The Honorable Lamar Smith

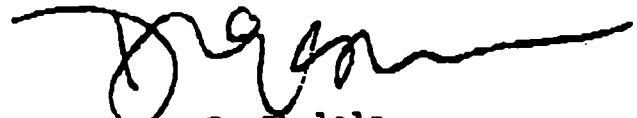
products in the 1980s. Rather, the IOM determined that during a period of tremendous scientific uncertainty, our scientists made good-faith decisions based on available data. These same Federal Government scientists later discovered that heat treatment of blood products kills HIV. By March 1985, FDA approved tests to identify HIV in blood. These tests were rapidly put into widespread use. Additionally, between 1983 and 1985, FDA approved heat treatment methods of viral inactivation for manufacturers of clotting factor concentrates to address the risk of HIV contamination. The implementation of the test and heat treatment has combined to virtually eliminate the threat of HIV contamination of people with hemophilia through blood products.

We share your concern about the individuals with hemophilia and their families who suffered as a result of the events of the 1980s. Although the IOM found no negligence on the part of U.S. Government officials, the IOM did conclude that the entire public health system, including both the private and public sectors, may have missed opportunities to reduce the risk of HIV infection from blood products.

The Administration will be pleased to work with the Congress to develop an appropriate way to assist those infected with HIV through the use of blood and blood products in the 1980s. In developing a bipartisan program to assist people with hemophilia who were infected by HIV, a number of important issues of policy as well as numerous technical and statutory issues will need to be addressed, including the ramifications of the precedent that would be set and how to pay for the benefits.

We look forward to working with you to address this tragedy. We have been advised by the Office of Management and Budget that there is no objection to the submission of this letter to the Congress from the standpoint of the Administration's program.

Sincerely,



Donna E. Shalala

STATEMENT OF PHILIP R. LEE

ASSISTANT SECRETARY FOR HEALTH
DEPARTMENT OF HEALTH AND HUMAN SERVICES

AT HEARING BEFORE THE
SUBCOMMITTEE ON IMMIGRATION AND CLAIMS

SEPTEMBER 19, 1996

Good morning, Mr. Chairman and members of the subcommittee.

I appreciate the opportunity to assist you as the subcommittee considers the Ricky Ray Hemophilia Relief Fund Act. Congress has the responsibility to determine whether Federal compensation is an appropriate remedy to a medical tragedy. I am prepared to offer the resources of the Department of Health and Human Services to provide the answers to any medical or scientific questions you may have regarding this legislation.

I think it will help you to be aware of what the Federal Government is already doing to assist persons with hemophilia and other bleeding disorders, as well as their families. The National Hemophilia Program, operated by the Health Resources and Services Administration, was established in 1975. Through this program, 135 affiliate and satellite hemophilia treatment centers provide care in 44 states, the District of Columbia, and Puerto Rico.

Current funding for hemophilia treatment represents \$5.3 million of the Maternal and Child Health Services Block Grant. Prevention and risk reduction services provided by the treatment centers are funded at another \$6 million, which comes from the Centers for Disease Control and Prevention.

Additional aid for persons with hemophilia who require treatment for HIV is provided under the Ryan White Act, which authorizes grants for early intervention and primary care services. Access to health care is also supported by Medicaid. At least half of all adults and 90 percent of children with HIV are eligible for Medicaid to fund their treatment needs.

Concurrently, the Department is engaged in research to find improved treatments that would prolong and improve the quality of life for HIV patients. We will also continue to seek the solution that would eradicate the disease or render it nonfatal.

Today's hearing will look back at a time when the blood supply had been rendered temporarily unsafe by contamination from AIDS, a virulent, previously unknown disease. We now know how to screen for this disease and have virtually eliminated it from the blood supply.

As a result, the three and one half million Americans a year who receive transfusions and the additional millions who receive blood products can be assured that the United States has one of the safest blood supplies in the world. No one should hesitate to donate blood or receive blood when required.

In the early 1980s, the research community had not identified the AIDS virus and could not test for its presence in blood. It was not until 1985 that blood banks could confidently screen blood for the HIV virus and all but eliminate the risk to the blood supply. Viral inactivation methods were implemented at

about the same time.

These developments did not occur soon enough to prevent a true human tragedy. Thousands of people with hemophilia were infected by the HIV virus through blood products, such as the coagulant known as Factor VIII. Thousands of others, including persons without hemophilia, were infected by blood transfusions.

Mr. Chairman, the Secretary of Health and Human Services testified last year before Congress about this terrible period in our public health history. Secretary Shalala said, "I would be remiss if I did not attempt to put a human face on these statistics that we sometimes cite too quickly. These thousands of cases represent fathers and mothers and sons and daughters. Our hearts go out to them, and we do not consider the Department's responsibilities regarding blood safety without thinking of the human faces behind the statistics."

In response to Congressional and other public concerns about the events of the 1980s, two years ago, the Department asked the Institute of Medicine (IOM) to undertake a comprehensive study of the events surrounding HIV transmission to people with hemophilia. The Institute's report, published in July 1995, covers the period 1982-1986 and the decision-making process during that time.

IOM did not review blood regulation after 1986. The Institute stated that it undertook its assignment "with the intent to prepare the guardians of the blood supply for future threats concerning blood safety." Upon issuance of the report, IOM cautioned: "The danger of hindsight is unfairly finding fault with decisions that were made in the context of great uncertainty."

I agree. As a physician and researcher, I can tell you that it is important to explore the past primarily so the present and future blood supplies will be safer.

As IOM noted, the report deals with a period of uncertainty, when medical providers and researchers grappled with a disease of unknown origin, with unpredictable outcomes. As early as 1982, there were cases of AIDS in persons who received blood products, suggesting that some components of the blood supply might be contaminated. These suspicions created a major dilemma for the public health community.

In the case of people with hemophilia, the quandary was especially difficult. Blood clotting factors were miracle products primarily responsible for nearly doubling the life span of people with hemophilia. When questions arose about possible contamination of these products, patients and their doctors had legitimate concerns that any attempts to safeguard clotting

factors could also jeopardize their availability.

The IOM report notes that recommendations about donor screening, viral inactivation, and recalls of blood products were considered in the early 1980s. According to IOM, it took some time before sufficient scientific and public support was in place to facilitate the implementation of such safeguards.

With hindsight, we can say that opportunities were missed to adopt those proposals.

On July 13, 1995, the day the IOM report was issued, the Department created a task force of seven senior public health officials to assess the IOM's recommendations and report their conclusions to the Secretary. I chaired the Task Force, which was comprised of the Commissioner of FDA, the Director of CDC, and the Director of NIH. Three senior career officers from each of the Public Health Service agencies also served on the Task Force.

The Task Force accepted most of the IOM recommendations to improve the safety of the blood supply. Many of the recommendations had already been implemented due to the lessons learned from the AIDS experience long before we received the IOM's findings.

Among those recommendations was that the Department give higher level management priority to blood safety. In response, the Secretary created the Blood Safety Committee, an interagency panel that operates at the highest level of the Department. The Secretary's action ensures that blood issues will never receive routine treatment within the Federal Government.

Our public health system is better prepared today to deal with an emerging infectious agent than it was in 1981. There is better science resulting from intensive research into blood-borne diseases. Nationwide disease surveillance systems cast wider and deeper nets. There is greater oversight of blood manufacturing and collection. Extensive donor screening is required, as well as routine testing for such diseases as HIV, hepatitis, and syphilis.

In order to maintain the safety of America's blood supply, it is important to be prepared to meet new challenges. If another infectious disease emerges, we want the Department to be fully prepared to deal with it quickly and effectively.

Blood and blood products will always be capable of transmitting disease, and their use will never be completely free of risk. But for everyone who relies on blood to sustain life, the Federal Government will do everything in its power to reduce risk and assure availability.

I reiterate the Administration's willingness to work with you as Congress seeks to respond to a large number of our fellow citizens and their families who experienced a terrible public health tragedy.



Department of Justice

STATEMENT OF

EVA M. PLAZA
DEPUTY ASSISTANT ATTORNEY GENERAL
CIVIL DIVISION

CONCERNING

H.R. 1023 -- THE RICKY RAY HEMOPHILIA RELIEF FUND ACT

BEFORE THE

SUBCOMMITTEE ON IMMIGRATION AND CLAIMS
COMMITTEE ON THE JUDICIARY
UNITED STATES HOUSE OF REPRESENTATIVES

PRESENTED ON

SEPTEMBER 19, 1996

I am here today, in response to the Committee's invitation, as it considers H.R. 1023, a bill to "provide procedures for claims for compassionate payments with regard to individuals with blood-clotting disorders, such as hemophilia, who contracted human immunodeficiency virus due to contaminated blood products."

First and foremost, let me point out that the Administration is painfully aware and sympathetic to the tragedy faced by persons with hemophilia who have contracted the HIV virus through blood and blood products. We share the concerns expressed in the bill concerning the effects of this tragedy upon individuals with hemophilia and their families.

I want to stress the Administration's willingness to work with the Congress to develop an appropriate means to assist those who have been infected with HIV, including through the use of blood and blood products.

The Department of Justice's Perspective

The Attorney General and the Department of Justice are charged with protecting the interests of the United States in judicial forums and proceedings. See, 28 U.S.C. § 516-519. In particular, the Attorney General and the Department of Justice are responsible for the administration of the Federal Tort Claims Act (FTCA) both in the context of litigation and during the process of consideration of claims administratively. See, 28 U.S.C. §§ 2672, 2677. As a consequence of these responsibilities, the Department of Justice's Torts Branch has had to defend many different species

of litigation seeking damages for virtually every conceivable form of injury.

The Federal Tort Claims Act (FTCA) has been a vehicle for damage litigation filed on behalf of persons (or their estates) who claimed that federal agency personnel caused them to contract the HIV virus. For instance, a suit was filed on behalf of a hemophiliac who claimed to be infected from blood products provided to him by the military when he was a military dependent. John Smith v. United States (D. HI, Civil No. 87-0891). In another example, a family claiming to have contracted AIDS as a result of negligence in providing an adult with contaminated blood when he underwent transfusions at an Army hospital sued the United States. C.R.S. by D.B.S. v. United States, 11 F.3d 791 (8th Cir. 1993). Both cases were resolved in favor of the United States. In addition, the Congress does have the power to enact legislation to provide for payments to individuals outside the framework of the FTCA and has done so in a small number of instances. Thus, in a variety of contexts, the United States is, or has been, party to suits in which individuals who claim to have contracted AIDS or have tested positive for the HIV virus assert that the government should answer in damages under the FTCA for their injuries.

Based on our experience with litigation in this area, I have several comments that I believe the Subcommittee will find helpful in its consideration of H.R. 1023.

Manufacturers of anti-hemophilic factor concentrates utilize blood components to create blood-clotting factors. During the

period encompassed by the bill (1980 through 1987), anti-hemophilic factor concentrates were used by hemophiliacs to prevent and control bleeding. During the same period of time, the exact chronology being disputed, the scientific community became aware of AIDS and HIV, the virus that ultimately was identified as the causative agent of AIDS. The major sources of transmission of this deadly virus were found to be bodily fluids, including blood, and methods were assessed for reducing the risk of transmission.

Government agencies, including the National Institutes of Health, the Food and Drug Administration and the Centers for Disease Control and Prevention, all components of the Department of Health and Human Services, were involved in the identification of the virus and in discussion of public health measures to reduce transmission. Whether the government components' response was suitable is a matter that is the subject of heated debate and intense emotion. The government components' response has been the subject of review. The recent Institute of Medicine Report is a comprehensive examination of the components' activities and assessment of what lessons can be learned from their experiences. HHS has embraced the goals reflected in the Report's recommendations and created a task force to assess all of the recommendations in light of current practices. This is a forward-looking manner of dealing with past activities.

Section 2 of the bill sets forth findings that state, for example, that the federal government failed to fulfill its responsibility to regulate the blood-products industry properly.

This finding is not supported by the record. The Department is concerned that this and other findings in the bill could be used, or abused, in litigation or elsewhere.

As we read the bill, it appears that a large number of persons would be eligible for compensation. According to a report by the Committee on Government Reform and Oversight:

In the early 1980's, 10,000 people with hemophilia, fully 50% of all U.S. hemophiliacs at the time, as well as 12,000 other transfusion recipients, were infected with HIV through blood products prior to 1985, when a screening test was implemented that could detect HIV antibodies in donated blood. Many also unknowingly infected their spouses and children before learning of their own infections.

Protecting the Nations's Blood Supply From Infectious Agents: The Need for New Standards to Meet New Threats, House Committee on Government Reform and Oversight (House Report No. 104-746, 1996) at 4. Section 3(e) authorizes the appropriation of \$1 billion to pay claims to infected persons or their estates. As a fiscal matter, one billion dollars is substantial. At the same time, it might be inadequate to pay all claims based on the large number of potentially infected persons or their successors in interests as claimants. These and other issues relating to the payment of claims will need to be addressed.

The provision in Section 5(e) that "acceptance" of a payment award be in full satisfaction of any claim against the United States is ambiguous. If the bill is intended to create an exclusive remedy, thereby barring claims and suits under the Federal Tort Claims Act, it should specifically state that the

remedy the bill would provide is the exclusive remedy against the United States and its employees (discussed below) for any claims falling within its terms, regardless of whether a tort claim or any other type of claim, proceeding, or suit is presented or initiated.

As drafted, the bill would not bar litigation against any entity or person other than the United States or expressly bar those persons from seeking indemnity or contribution from the United States. The "full settlement" provision, as currently drafted, would bar claims against the United States, but not against any other person or entity. If Congress intends the bill to be a full bar against further litigation, it should extend the bar to claims against any employee of the United States acting within the scope of his employment. The United States should be protected from third-party claims, to avoid indirect evasion of the statutory bar.

H.R. 1023 provides for judicial review exclusively in a district court of the United States on the basis of the administrative record. (Section 5(1).) It is not clear whether the general venue provision, 28 U.S.C. § 1391, is to apply to the judicial review proceedings. Also, it is unclear whether the Court could or should order a remand to the Attorney General where the record is deemed inadequate. Further, while it is presumed that Court of Appeals and Supreme Court review may be had following a district court decision pursuant to this subsection, in the same manner, and to the same extent as other district courts' decisions

are subject to appellate review, provisions for appellate review should be included to remove any doubt on this score.

Finally, it would be desirable to specify a period of time (a statute of limitations) within which any judicial review proceeding must be commenced.

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I hope these comments will be helpful in assisting the Subcommittee in its consideration of H.R. 1023. I look forward to talking to you about these and other suggestions the Department has on this legislation as we work together in developing a bipartisan program to assist people with hemophilia who were infected by HIV.

I will be pleased to answer your questions. Thank you.

Val D. Bias

MEMORANDUM

To: Sandra Thurman
From: Val Bias *VB*
Date: July 24, 1997
Subject: Ricky Ray Hemophilia Relief Act of 1997

Enclosed with this memo are all of the basic information on the Ricky Ray Act and the rational for passage we use on the hill. I wanted to speak about the issue from a community member prospective. I have severe hemophilia and am HIV positive, my wife contracted AIDS from me and I lost her in 1992. I have been an active volunteer in the National Hemophilia Foundation since 1990. My experience with AIDS and representing those affected by it is similar to yours in terms of death and emotional devastation it brings to people lives. For the hemophilia community our experience differs only in the impact it has had on the family unit. A family with two or more sons affected by hemophilia all were infected through their dependency and usage of blood products. The extended family was also impacted if there were uncles before who had hemophilia. The impact of losing multiple family members to AIDS has been a tragedy for the community that has intensified AIDS for those families affected.

People with hemophilia are treated through a network of federally funded Comprehensive Hemophilia Treatment Centers patient provider relationships last a lifetime. The AIDS epidemic prescribed by the physician your family depended on for hemophilia care was also discouraging and remains an issue for rebuilding trust between providers and patients. Exposure to blood borne viruses was always accepted as a natural consequence of treatment for hemophilia. An average adult my age has been exposed to a variety of blood borne viruses including hepatitis B, hepatitis C, hepatitis D, Creudfeld Jakob disease, and Parvovirus. The Ricky Ray Hemophilia Relief Act is about a history of exposure to blood borne diseases. Our communities exposure to AIDS has been the most demanding both emotionally and financially but our rational is based in our history of exposure.

Our hope is that the passage of Ricky Ray will serve as a recognition from Congress that our infection did occur and that the impact could have been reduced. We remain concerned that the Public Health Service has not taken the steps necessary to prevent such an event from occurring again. Today blood product manufacturers regulate themselves by threat of sanctions by the FDA. The FDA still relies on manufacturers as their expert advisors on further regulation. Fifteen years after our communities infection there is no

national notification system to alert patient or physicians of adverse events concerning these products.

The hemophilia community has no desire to impact AIDS funding on any level and we will oppose any such proposal. As a member of the NORA Executive Committee I feel it is inappropriate for me to advocate that NORA support Ricky Ray with the current challenges facing the AIDS funding. However I remain a resource for any organization that sees Ricky Ray as a issue and will continue to provide information.

The Administration has always been sympathetic to the Ricky Ray Act, the President has a relationship with the Ray family and is familiar with the issue. Secretary Shalala with the help of OMB and your office has always issued a empathetic response with a commitment to work with the Congress to address the tragedy. Our challenge has been with the Congress, in the House we currently have 244 cosponsors and our champion is Porter Goss (R-FL), the bill is under the jurisdiction of Judiciary, Chairman Henry J. Hyde and is scheduled for mark up in early September. In the Senate we have 23 cosponsors our champions are Mike DeWine (R-OH) and Bob Graham (D-FL), the bill is before Labor and Human Resources, Chairman Jim Jeffords. We have five cosponsors on the committee but are working to solicit more support.

We have been unable to solicit any response from Senator Kennedy and would like your advice and assistance on how to approach his office. I hope you find the enclosed information useful and would encourage you to speak with myself or Kathy Gerus for any clarification you may need.



National Hemophilia Foundation

Since 1948

110 Greene Street, Suite 303
New York, New York 10012-3832
(212) 219-8180 or (888) INFO-NHF
Fax (212) 966-9247
Web Site: www.infonhf.org

CFC #0543

FACT SHEET **RICKY RAY HEMOPHILIA RELIEF FUND ACT OF 1997**

The Impact of HIV on the Hemophilia Community

Hemophilia is a genetic condition which impairs the ability of blood to clot effectively. If untreated, persons with hemophilia suffer internal bleeding, leading eventually to the destruction of the joint and muscle tissues. Since the 1970's, the development of blood-derived clotting factor concentrates and the introduction of comprehensive care have allowed most individuals with hemophilia to manage their bleeding episodes at home. Clotting factor eliminated the need for frequent and costly hospitalization and ensured that even persons with severe hemophilia were able to attend school, obtain full time employment, and enjoy greatly increased life expectancy.

People with hemophilia are reliant on blood products and must continue to depend on our nation's blood supply. Derived from 1,000 to 20,000 or more donors, clotting factor concentrates expose individuals with inherited bleeding disorders to a high risk of infection by blood-borne viruses.

During the early 1980's, the nation's blood supply and blood-derived products became contaminated with the AIDS virus. More than 80 percent of people with severe hemophilia and half of all persons with hemophilia were infected with HIV, including between 10-20 percent of the spouses, children, and partners of these individuals.

The impact of HIV on the nation's hemophilia population has been devastating. The HIV contamination of the blood supply has caused significant emotional and financial losses to this community. These burdens jeopardize the future of the hemophilia community. The average cost of hemophilia therapy alone is nearly \$100,000 each year. The cost of HIV/AIDS care is estimated to be \$10,000-\$50,000 annually per patient. These staggering costs for care are far beyond the financial capacities of most people.

Rationale for Compassionate Payment

The Ricky Ray Hemophilia Relief Fund Act of 1997 recognizes that the federal government has a shared responsibility for protecting the safety of the blood supply and for regulating blood products. When passed, the Act will establish a trust fund, administered by the Secretary of Health and Human Services, to be distributed to eligible individuals or families of deceased individuals. The federal government has stepped in when similar cases of disaster have struck. Precedent such as the Black Lung Disability Trust Fund, the Radiation Exposure Compensation Trust Fund, and the Vaccine Injury Compensation Program Trust Fund exists for the establishment of this fund. More than

26 other developed countries have established compensation programs to assist individuals with blood-clotting disorders who were infected with HIV by contaminated blood products.

Institute of Medicine Report on HIV and the Blood Supply

In April 1993, Representative Porter J. Goss (R-FL) and Senators Edward Kennedy (D-MA) and Bob Graham (D-FL) requested the Secretary of Health and Human Services to open an investigation into the events leading to the transmission of HIV to individuals with hemophilia. The Institute of Medicine, in its 1995 report entitled "HIV And the Blood Supply," found that "inadequate institutional decision-making and a failure of leadership" within the federal government led to the HIV infection of more than one half of the nation's 16,000 persons with hemophilia. The HIV virus and AIDS revealed a weakness in the federal government's system for ensuring the safety of the nation's blood supply, particularly when the potential new threat was surrounded by uncertainty and great risk. (IOM Press Release, 1995)

Private Settlement Medicaid Eligibility Concerns

On April 19, 1996, four manufacturers of clotting factor concentrates publicly announced a settlement proposal through the United States District Court of Northern Illinois to provide \$100,000 to each person injured through the use of factor concentrates processed by one of the manufacturers between 1978 and 1985. This offer was accepted by 90 percent of the hemophilia community, but the Court has made payment contingent upon obtaining certain protections for settlement recipients who may be adversely affected by the receipt of the settlement claim. Specifically, recipients currently receiving federal aid for health care or due to disability potentially risk losing this means-tested assistance if the settlement payments are accepted. The Ricky Ray Hemophilia Relief Fund Act extends its Medicaid and SSI program protections to these payments. NHF and the hemophilia community support legislative efforts to provide needed assurances for maintaining settlement recipients eligibility for Medicaid and SSI assistance programs.

Ricky Ray Hemophilia Relief Fund Act: IOM Study and Recommendations

Findings from the Institute of Medicine Study - "HIV and the Blood Study"

In April 1993, in response to concerns voiced by the hemophilia community, Representative Porter J. Goss (R-FL) and Senators Edward Kennedy (D-MA) and Bob Graham (D-FL) requested that Secretary of Health and Human Services Donna Shalala open an investigation into the events leading to the transmission of HIV to individuals with hemophilia from contaminated blood products. (IOM, 1995)

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. Derived from 1,000 to 20,000 or more donors, AHF exposes individuals with hemophilia to a high risk of infection by blood-borne viruses. (IOM, 1995)

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. (IOM, 1995)

The events of the early 1980s, revealed an important weakness in the system which supplies the nation with blood and blood products - in its ability to deal with a new threat that was characterized by substantial uncertainty. During this period, there were missed opportunities to learn from local attempts to screen potentially infected donors or to implement other control strategies that had been rejected as national policy. (IOM, 1995)

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 cases of mild or moderate hemophilia) would be ineffective, too costly, or too risky. (IOM, 1995)

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. (IOM, 1995)

The Committee concluded that when confronted with a range of options for using donor screening and referral to reduce the probability of spreading HIV through the blood supply, blood bank officials and federal authorities consistently chose the **least aggressive option** that might have initially slowed the spread of HIV to individuals with hemophilia and other recipients of blood and blood products (IOM, 1995).

The problems that 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. (IOM, 1995)

Recommendation

The Committee has come to believe that a failure of leadership may have delayed effective action during the period from 1982-1984. This failure led to less than effective donor screening, weak regulatory actions and insufficient communication to patients about the risks of AIDS. When a product or service provided for the public good has inherent risks, the common law tort system fails to protect the rightful interest of patients who suffer harm resulting from the use of those products and services. (IOM, 1995)

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.

The "no-fault" principles outlined in this recommendation might serve to guide policy makers as they consider whether to implement a compensation system for those infected in the 1980s. 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 U.S. (IOM, 1995)

In the Committee's judgement, a more systematic approach to blood safety regulation, one that is better suited to conditions of uncertainty, is needed. (IOM, 1995)

HIV and the Blood Supply: An Analysis of Crisis Decision Making

by Institute of Medicine

Recommendations

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.
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.
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.
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.
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.
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.
7. The FDA should periodically review important decisions that it made when it was uncertain about the value of key decision variables.
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 considerations.
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.
10. The FDA should tell its advisory committees what it expects from them and should independently evaluate their agendas and their performance.
11. The PHS should develop reliable sources of the information that it needs to make decisions about the blood supply. The PHS should have its own capacity to analyze this information and to predict the effects of regulatory decisions.
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.

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

RICKY RAY HEMOPHILIA RELIEF FUND ACT OF 1997

House Cosponsors (244)

Alabama (2 of 7)
Spencer Bachus (R-6)
Earl Hilliard (D-7)

Alaska (0 of 1)

American Samoa (1 of 1)
Eni F.H. Faleomavaega (D)

Arizona (4 of 6)
John Hayworth (R-6)
Jim Kolbe (R-5)
Ed Pastor (R-2)
John Shadegg (R-4)

Arkansas (0 of 4)

California (28 of 52)
Howard Berman (D-26)
Brian Bilbray (R-49)
George Brown (D-42)
Ken Calvert (R-43)
Walter Capps (D-22)
Gary Condit (D-18)
Randy Cunningham (R-51)
Ronald Dellums (D-9)
Julian Dixon (D-32)
Anna Eshoo (D-14)
Sam Farr (D-17)
Vic Fazio (D-3)
Bob Filner (D-50)
Elton Gallegly (R-23)
Steve Horn (R-38)
Tom Lantos (D-12)
Jerry Lewis (R-40)
Zoe Lofgren (D-16)
Matthew Martinez (D-31)
Robert Matsui (D-5)
Howard McKeon (R-25)
George Miller (D-7)
Nancy Pelosi (D-8)
Pete Stark (D-13)
Esteban Torres (D-10)
Maxine Waters (D-35)
Henry Waxman (D-29)
Lynn Woolsey (D-6)

Colorado (2 of 6)
Diana DeGette (D-1)
Dan Schaefer (R-6)

Connecticut (6 of 6)
Rose DeLauro (D-3)
Sam Gejdenson (D-2)

Nancy Johnson (R-6)
Barbara Kennelly (D-1)
James Maloney (D-5)
Chris Shays (R-4)

Delaware (1 of 1)
Michael Castle (R)

Dist. of Columbia (1 of 1)
Eleanor Holmes Norton (D)

Florida (20 of 23)
Michael Bilirakis (R-9)
Corrine Brown (D-3)
Jim Davis (D-11)
Peter Deutsch (D-20)
Lincoln Diaz-Balart (R-21)
Mark Foley (R-16)
Tillie Fowler (R-4)
***Porter Goss (R-14)**
Alcee Hastings (D-23)
Bill McCollum (R-8)
Carrie Meek (D-17)
John Mica (R-7)
Dan Miller (R-13)
Ileana Ros-Lehtinen (R-18)
Clay Shaw (R-22)
Cliff Stearns (R-6)
Karen Thurman (D-5)
David Weldon (R-15)
Robert Wexler (D-19)
Bill Young (R-10)

Georgia (8 of 11)
Sanford Bishop (D-2)
Saxby Chambliss (R-8)
Nathan Deal (R-9)
Newt Gingrich (R-6)
John Lewis (D-5)
George Linder (R-11)
Cynthia McKinney (D-11)
Charles Norwood (R-10)

Guam (1 of 1)
Robert Underwood (D)

Hawaii (2 of 2)
Neil Abercrombie (D-1)
Patsy Mink (D-2)

Idaho (0 of 2)

Illinois (11 of 20)
Rod Blagojevich (D-5)
Jerry Costello (D-12)
Danny Davis (D-7)
Lane Evans (D-17)
Luis Gutierrez (D-4)
Dennis Hastert (R-14)
Jesse Jackson (D-2)
Ray LaHood (R-18)
Bobby Rush (D-1)
Jerry Weller (R-11)
Sid Yates (D-9)

Indiana (2 of 10)
Julia Carson (D-10)
Peter Visclosky (D-1)

Iowa (2 of 5)
Tom Latham (R-5)
Jim Leach (R-1)

Kansas (0 of 4)

Kentucky (2 of 6)
Scotty Baesler (D-6)
Jim Bunning (R-4)

Louisiana (5 of 7)
Richard Baker (R-6)
William Jefferson (D-2)
Chris John (D-7)
Jim McCrery (R-4)
Billy Tauzin (R-3)

Maine (2 of 2)
Thomas Allen (D-1)
John Baldacci (D-2)

Maryland (4 of 8)
Ben Cardin (D-3)
Wayne Gilchrest (R-1)
Constance Morella (R-8)
Albert Wynn (D-4)

Massachusetts (10 of 10)
William Delahunt (D-10)
Barney Frank (D-4)
Joseph Kennedy (D-8)
Edward Markey (D-7)
James McGovern (D-3)
Marty Meehan (D-5)
Joe Moakley (D-9)
Richard Neal (D-2)
John Olver (D-1)
John Tierney (D-6)

Michigan (14 of 16)
James Barcia (D-5)
David Bonior (D-10)
Dave Camp (R-4)
John Conyers (D-14)
Vernon Ehlers (R-3)
Peter Hoekstra (R-2)
Dale Kildee (D-9)
Carolyn Kilpatrick (D-15)
Joseph Knollenberg (R-11)
Sander Levin (D-12)
Nick Smith (R-7)
Debbie Stabenow (D-8)
Bart Stupak (D-1)
Fred Upton (R-6)

Minnesota (4 of 8)
James Oberstar (D-8)
Collin Peterson (D-7)
Jim Ramstad (R-3)
Martin Olav Sabo (D-5)

Mississippi (2 of 5)
Bennie Thompson (D-2)
Roger Wicker (R-1)

Missouri (7 of 9)
William Clay (D-1)
Pat Danner (D-6)
Jo Ann Emerson (R-8)
Kenny Hulshof (R-9)
Karen McCarthy (D-5)
Ike Skelton (D-4)
Jim Talent (R-2)

Montana (0 of 1)

Nebraska (1 of 3)
Bill Barrett (R-3)

Nevada (2 of 2)
John Ensign (R-1)
James Gibbons (R-2)

New Hampshire (0 of 2)

New Jersey (7 of 13)
Robert Andrews (D-1)
Robert Menendez (D-13)
William Pascrell (D-8)
Donald Payne (D-10)
Steven Rothman (D-9)
Chris Smith (R-4)

New Mexico (1 of 3)
Steven Schiff (R-1)

New York (27 of 31)
Gary Ackerman (D-5)
Sherwood Boehlert (R-23)
Eliot Engel (D-17)
Floyd Flake (D-6)
Michael Forbes (R-1)
Benjamin Gilman (R-20)
Maurice Hinchey (D-26)
Sue Kelly (R-19)
Peter King (R-3)
John LaFalce (D-29)
Rick Lazio (R-2)
Nita Lowey (D-18)
Carolyn Maloney (D-14)
Thomas Manton (D-7)
Carolyn McCarthy (D-4)
John McHugh (R-24)
Michael McNulty (D-21)
Susan Molinari (R-13)
Jerrold Nadler (D-8)
Major Owens (D-11)
Charles Rangel (D-15)
Charles Schumer (D-9)
Louise Slaughter (D-28)
Gerald Solomon (R-22)
Edolphus Towns (D-10)
Nydia Velazquez (D-12)
James Walsh (R-25)

North Carolina (6 of 12)
Richard Burr (R-5)
Howard Coble (R-6)
W.G. Hefner (D-8)
David Price (D-4)
Charles Taylor (R-11)
Melvin Watt (D-12)

North Dakota (0 of 1)

Ohio (6 of 19)
Paul Gillmor (R-5)
Tony Hall (D-3)
Michael Oxley (R-4)
Deborah Pryce (R-15)
Louis Stokes (D-11)
James Traficant (D-17)

Oklahoma (4 of 6)
Tom Coburn (R-2)
Steve Largent (R-1)
Frank Lucas (R-6)
Wes Watkins (R-3)

Oregon (2 of 5)
Pete DeFazio (D-4)
Elizabeth Furse (D-1)

Pennsylvania (16 of 21)

Robert Borski (D-3)
William Coyne (D-14)
Mike Doyle (D-18)
Philip English (R-21)
Chaka Fattah (D-2)
Thomas Foglietta (D-1)
Jon Fox (R-13)
George Gekas (R-17)
Jim Greenwood (R-8)
Tim Holden (D-6)
Paul Kanjorski (D-11)
Frank Mascara (D-20)
Paul McHale (D-15)
John Murtha (D-12)
Bud Shuster (R-9)
Curt Weldon (R-7)

Puerto Rico (1 of 1)
Carlos Romero-Barcelo (D)

Rhode Island (1 of 2)
Robert Weygand (D-2)

South Carolina (4 of 6)
James Clyburn (D-6)
Bob Inglis (R-4)
Floyd Spence (R-2)
John Spratt (D-5)

South Dakota (0 of 1)

Tennessee (2 of 9)
Harold Ford (D-9)
William Jenkins (R-1)

Texas (11 of 30)
Bill Archer (R-7)
Ken Bentsen (D-25)
Martin Frost (D-24)
Henry Gonzalez (D-20)
Gene Green (D-29)
Rubén Hinojosa (D-15)
Sheila Jackson-Lee (D-18)
Eddie Johnson (D-30)
Nicholas Lampson (D-9)
Pete Sessions (R-5)
Jim Turner (D-2)

U.S. Virgin Islands (1 of 1)
Donna Christian-Green (D)

Utah (1 of 3)
Merrill Cook (R-2)

Vermont (1 of 1)
Bernard Sanders (I)

Virginia (5 of 11)

Rick Boucher (D-9)
Thomas Davis (R-11)
James Moran (D-8)
Norman Sisisky (D-4)
Frank Wolf (R-10)

Washington (3 of 9)
Jennifer Dunn (R-8)
Jim McDermott (D-7)
Linda Smith (R-3)

West Virginia (1 of 3)
Nick Rahall (D-3)

Wisconsin (1 of 9)
Ron Kind (D-3)

Wyoming (0 of 1)

Senate Cosponsors (23)

John Breaux (D-LA)
Robert Bennett (R-UT)
Barbara Boxer (D-CA)
Sam Brownback (R-KS)
Richard Bryan (D-NV)
Max Cleland (D-GA)
Thad Cochran (R-MS)
Susan Collins (R-ME)
Tom Daschle (D-SD)
Mike DeWine (R-OH)
Chris Dodd (D-CT)
Richard Durbin (D-IL)
Dianne Feinstein (D-CA)
Wendell Ford (D-KY)
Bob Graham (D-FL)
Tim Johnson (D-SD)
Connie Mack (R-FL)
Barbara Mikulski (D-MD)
Carol Moseley-Braun (D-IL)
Harry Reid (D-NV)
Olympia Snowe (R-ME)
Robert Torricelli (D-NJ)
Paul Wellstone (D-MN)

The Ricky Ray Hemophilia Relief Fund Act of 1995

With comparisons between the Ryan White CARE Act and the Ricky Ray Hemophilia Relief Fund Act at times inevitable, it is important to recognize the intent behind each program. The Ryan White CARE Act provides health care services to all persons with HIV and AIDS. The Ricky Ray Hemophilia Relief Fund Act seeks to provide compensation for those persons within the hemophilia community who contracted the HIV virus during the 1980s due to the failure of the federal government to fulfill its obligation to protect the nation's blood supply and blood products.

The intent of the Ricky Ray Hemophilia Relief Fund Act is **not** to reduce or affect funding for AIDS-related services or research, but rather to provide an avenue for the hemophilia community to justly receive compensation for damages resulting from the use of federally regulated products. Compensation for the hemophilia community also would encourage policy changes aimed at preventing future threats to the blood supply. The chart below summarizes the purpose and funding of the Ryan White CARE Act and the Ricky Ray Hemophilia Relief Fund Act.

Ryan White CARE Act

- The Ryan White CARE Act is a law that was first enacted in 1990 for a five year period. It is expected that the Act will be reauthorized in 1995 for another five years.
- The Ryan White CARE Act is a grant program administered by the Secretary of Health and Human Services to ensure primary health care and support services are available for persons infected with HIV and AIDS. The Act provides significant federal assistance to cities, states, and public clinics bearing the brunt of AIDS service needs.
- Funding for the Ryan White CARE Act is part of the Department of Health and Human Services budget. The cities and states receiving these funds determine what programs or services will be funded.

Ricky Ray Hemophilia Relief Fund Act

- The Ricky Ray Hemophilia Relief Fund Act is a bill introduced this year into the House of Representatives as H.R. 1023 by Rep. Porter Goss (R-FL) and into the Senate as S. 358 by Senators Mike DeWine (R-OH) and Bob Graham (D-FL).
- Passage of the Ricky Ray Hemophilia Relief Act would authorize the Department of Health and Human Services to establish a compensation program to which eligible individuals would submit claims for payment. The program would recognize the role of the federal government in approving the products through which HIV was transmitted. Blood shield laws prevent the pursuit of compensation through the courts as would usually occur in a product liability situation.
- Funding for the Ricky Ray Hemophilia Relief Fund Act is not currently provided for in the bills before Congress and would require separate legislation to allocate funds to the Department of Health and Human Services budget. This would likely be accomplished by a one-time appropriation.

WHY RICKY RAY IS STILL NEEDED

During the 1980s the federal government failed to curtail the impact of HIV by consistently adopting the least aggressive options for slowing the spread of HIV. The Ricky Ray Hemophilia Relief Fund Act (H.R. 1023/S.358) responds to the fatal consequences of the HIV contamination of the blood supply and provides compassionate payments to 7,200 affected members of the hemophilia community and their families.

Intensified Screening of Blood Donors Delayed

- In January, 1983, the Centers for Disease Control met with other federal agencies to consider available data on the spread of HIV and to develop strategies for prevention. CDC concluded that AIDS was transmitted by sexual contact and through blood and made recommendations for enhanced screening of blood donors including the use of a surrogate hepatitis test to screen for potentially HIV-infected blood.

At the time 12 persons with hemophilia had been diagnosed with HIV, and 10 deaths had occurred.

- CDC estimated that intensified screening of blood donors would eliminate over 75 percent of AIDS-infected donors from the blood pool and that the surrogate test would detect 90 percent of donors with AIDS. The testing recommendation was rejected by meeting participants and again at the December 1983 Food and Drug Administration's Blood Products Advisory Committee (BPAC).

At the end of 1983, an additional five cases of HIV in the hemophilia community had been reported, and the death toll had risen to 17.

Delayed Recall of Tainted Products

- In July, 1983, FDA decided not to automatically recall hemophilia clotting factor products linked to donors suspected of having AIDS due to concerns about the impact on the availability of clotting factor.

In 1984, 83 cases of persons with hemophilia were diagnosed with HIV, and 81 deaths occurred.

- While FDA moved quickly throughout 1983 and 1984 to license new manufacturing processes for the heat-treatment of clotting factor, and by 1985 heat-treated factor had been accepted as effective in inactivating HIV, the FDA waited until 1989 to recall untreated products, leaving patients vulnerable to contaminated factor.

In 1985, 207 cases were diagnosed, and 119 persons with hemophilia died of AIDS.

- By 1985, there was wide consensus that transfusion of HIV-infected blood products led to HIV infection. Recipients became infectious immediately, but remained asymptomatic for approximately five years during which time their spouses or sexual partners were at risk of acquiring HIV. Despite a 1988 presidential directive to formulate a formal policy for tracing the recipients of possibly infected blood products, the FDA did not issue recommendations for look-back and notification until 1991.

Government Action Too Late

- While the Public Health Service eventually moved to more aggressively tackle the HIV epidemic through prevention and education, for many members of the hemophilia community this action was too late.

By the time lookback and notification regulations were adopted in 1991, 2040 persons with hemophilia had been diagnosed with HIV, and more than 1500 members of the hemophilia community had died of AIDS.

Congressional Action Needed

The Ricky Ray Hemophilia Relief Fund Act recognizes the failure of federal public health agencies to reduce the spread of HIV through blood and blood products during the 1980s. This legislation provides relief to individuals and families within the hemophilia community who have been devastated by AIDS. The manufacturers of blood products containing tainted blood have reached a tentative monetary settlement with many individuals with hemophilia who contracted HIV. However, even if this settlement is finalized, it will not provide adequate compensation to the victims of this terrible tragedy.

The private settlement should be complemented by the payments authorized in the Ricky Ray Hemophilia Relief Fund Act legislation. The federal government did not take actions to protect this vulnerable population. Today, we know that an estimated 7,200 lives of persons with hemophilia and their families were placed at risk. It is only proper that the federal government take responsibility to compensate those who suffer the consequences.

HIV FINANCIAL ASSISTANCE SCHEMES IN WFH MEMBER COUNTRIES
(abbreviated version)

COUNTRY	FINANCIAL ASSISTANCE/FUNDING PROGRAMS	ELIGIBLE INDIVIDUALS	FUNDING SOURCE	YEAR INSTITUTED	AMOUNT ALLOCATED
Australia	Fund - The Mark Fitzpatrick Fund (MFT)	HIV infected individuals	Federal government	November 1989	A\$13.2million (*US\$10.3 million)
Canada	Financial assistance plan	All persons infected with HIV via blood transfusions.	Federal government	December 1989	CDN\$150million (*US\$10.7 million) budget; CDN\$120,000 (*US\$88,000) per person over 3 years.
	Addendum	Persons infected with AIDS through transfusion of blood or blood products and their survivors	Provincial governments, Red Cross, insurance companies	September 1993	CDN\$130 million (*US\$95.9 million) budget
Denmark	Financial assistance - ex-gratia compensation	Hemophiliacs found to be infected with HIV following treatment in Danish hospitals	Government	June 1988	DKr250,000 (*US\$43,000) per person
				November 1992	Amount raised to DKr 750,000 (*US\$131,100) All payments are tax-free and not accountable on payments made under social legislation.

* Based on current exchange rates as of April 2, 1996.

COUNTRY	FINANCIAL ASSISTANCE/FUNDING PROGRAMS	ELIGIBLE INDIVIDUALS	FUNDING SOURCE	YEAR INSTITUTED	AMOUNT ALLOCATED
France	Compensation fund - state controlled	Any person who became HIV-infected through transfusion of whole blood or blood products. Payment covers only pain and suffering from HIV infection and AIDS; loss of income and other extra expenses will have to be documented.	Government grants, contributions from insurance companies and parties found liable for resources.	December 1991	Installments or lump sum of up to FFr2 million (*US\$300,000) for those accepting the "offer of compensaion;" individuals not accepting the offer receives an advance payment of FFr200,000 (*US\$36,000).
Germany	Financial Assistance based on the German Drug Liability Law covers HIV-related loss of income, treatment costs, increased personal needs, funeral expenses and sustenance of dependent family members.	Individuals with HIV and their affected family	Insurance companies	February 1988	Maximum of DM500,000 (*US\$337,000) per person
Hungary	Compensation payments	Hemophilia patients who are HIV-infected	Government	June 1991	US\$1.2 million or approx. US\$40,000 per person
Ireland	Trust fund	HIV-infected patients with hemophilia	Government	November 1989	£1million (*US\$1.5 million)
	Compensation	HIV-infected patients with hemophilia	Government	June 1991	£8m (*US\$12.5 million)
Italy	Solidarity Fund	Whole blood transfusions or the administration of blood products, plus those suffering from irreversible complications	Government	January 1992	15 million Lire (*US\$9,000) per HIV-infected person annually; 50 million Lire (*US\$31,000) lump sum per family of deceased AIDS victim
Japan	Financial assistance managed by the Yuai Welfare Foundation	HIV-infected hemophiliacs	40% government; 60% industry	1996	US\$420,000

COUNTRY	FINANCIAL ASSISTANCE/FUNDING PROGRAMS	ELIGIBLE INDIVIDUALS	FUNDING SOURCE	YEAR INSTITUTED	AMOUNT ALLOCATED
Netherlands	Disability compensation law Financial assistance - Van Creveld Fund (managed by the Netherlands Hemophilia NVHP) Private fund - Stichting Hemofilie Proposed insurer's fund - a special insurance scheme for hemophiliacs to be established once there are 100 subscribers.	The general social security system provides sufficient help and guarantees 70-80% of salaries/wages on a permanent basis in case of reducing earning capacity resulting from disability. Hemophiliacs in situations of need. Hemophiliacs and their families Asymptomatic hemophiliacs with HIV infection who are under 65 years of age and have subscribed to the Fund	Government Private and corporate contributions Government granted initial funding Dutch Association of Insurance Companies initiated	1988	US\$55,000 start-up Payments depend on number of years affiliation in Fund. All payments to surviving families are tax free.
Norway	Financial assistance	Anti-HIV positive patient with hemophilia and HIV-infected spouses.	Government	December 1987	NKr250,000 (*US\$38,000) - hemophilia patient NKr100,000 (*US\$15,000) - HIV-infected spouses Payments are tax-free and not deducted from other social assistance benefits.
Portugal	Social support fund	HIV-infected patients with hemophilia who have socio-economic problems	Government	September 1992	US\$350,000 (initial fund)
Spain	Special assistance scheme managed by the Royal Foundation Victoria Eugenia	Patients with hemophilia with HIV infection or AIDS, their HIV-infected spouses and children and surviving dependent family members of patients with hemophilia who have died of AIDS.	Government and pharmaceutical companies	Established in 1988, formally decreed in April 1990	25 billion pesetas (*US\$200 million) granted as of April 1993. Payments vary.

COUNTRY	FINANCIAL ASSISTANCE/FUNDING PROGRAMS	ELIGIBLE INDIVIDUALS	FUNDING SOURCE	YEAR INSTITUTED	AMOUNT ALLOCATED
Sweden	Compensation payments made through the Consortium (a group of insurance companies working under the supervision of the government)	HIV-infected and hepatitis-infected patients with hemophilia, plus damages caused by drugs or medical substances	Government and the Consortium (therefore indirectly funded by the pharmaceutical companies)	May 1986	First settlement - lump sums ranging from SKr25,000 (*US\$3,000) to SKr75,000 (*US\$11,000) February 1991 - additional sum of SKr200,000 (*US\$29,000) paid to HIV-infected individuals with hemophilia
Switzerland	Financial assistance Emergency fund Manufacturer's financial aid	Persons who have been HIV-infected Switzerland by means of contaminated blood products or blood transfusions; HIV-infected spouses of patients with hemophilia/blood transfusion recipients. HIV-infected patients with hemophilia showing first symptoms of AIDS. HIV-infected patient with hemophilia who has at least been treated once with an untreated product of their brand and who later developed clinical symptoms of immune deficiency; the surviving family of any deceased patient with hemophilia who was treated with an untreated product of their brand at least once.	Government Swiss Red Cross Foreign pharmaceutical company from which concentrated had been imported	1990	SFr50,000 (*US\$41,000) SFr20,000 (*US\$16,000) SFr25,000 (*US\$20,000) to HIV-infected hemophiliac; SFr15,000 (*US\$12,000) to surviving family. Recipients must sign a disclaimer that no further civil court actions will be taken against the company.
United Kingdom	Ex-gratia financial assistance	Patients with HIV infection or AIDS.	Government	November 1987	£20,000 (*US\$30,000) per HIV-infected patient (1990)

COUNTRY	FINANCIAL ASSISTANCE/FUNDING PROGRAMS	ELIGIBLE INDIVIDUALS	FUNDING SOURCE	YEAR INSTITUTED	AMOUNT ALLOCATED
	Special fund - the MacFarlane Trust	HIV-infected persons with hemophilia and their needy spouses, children, parents or other persons caring for them.	Government initiated; now accepts private contributions	March 1988	£10 million (*US\$15.2 million)
	MacFarlane Special Payments Fund - agreement from a 1990 out-of-court settlement	Conditional on the grounds that all HIV infected patients with hemophilia accept the offer and all claims be dropped once and for all.	Government	December 1990	£76 million (*US\$115.9 million)
United States	Legislation (H.R.1023 and S.1189) introduced into Congress that would provide compensation; 214 cosponsors in the House of Representatives.	HIV-infected persons with hemophilia and their spouses and children, if infected			