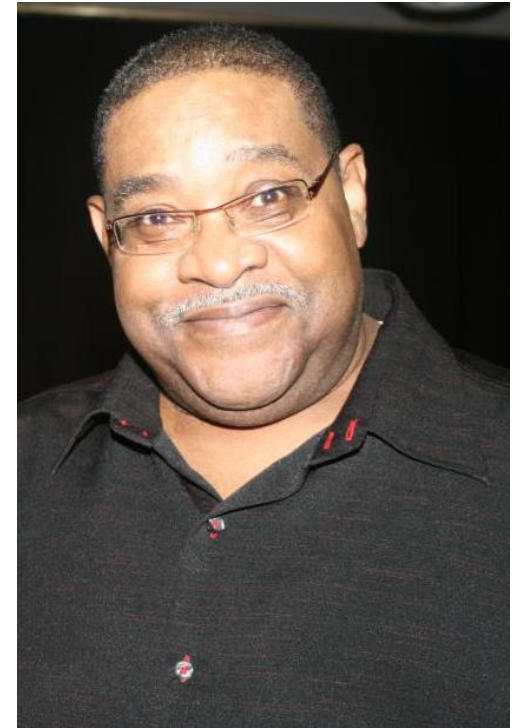


## Honoring World AIDS Day

Phil Kucab  
Barry Haarde  
Greg McClure

# Meet the Panelists





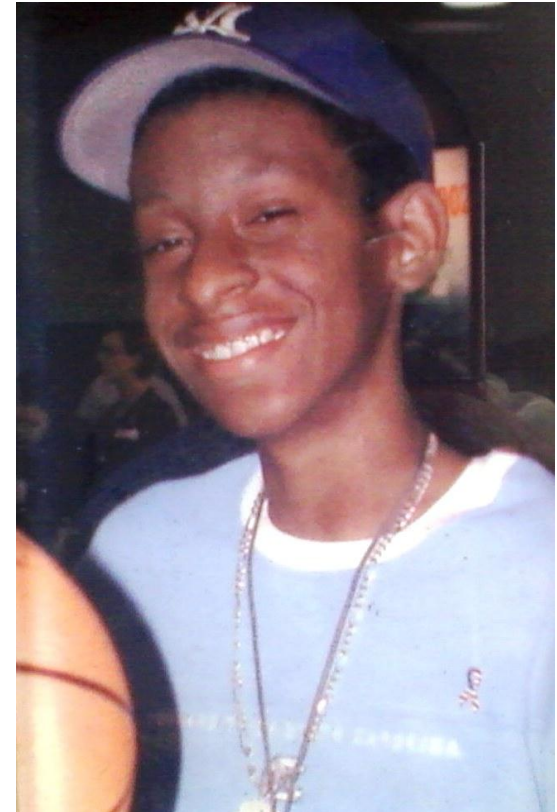
# WORLD AIDS DAY DETROIT



John Francis Haarde  
Brother & Hemophiliac  
1952 - 2007



Joseph Patrick Grant  
Brother-in-law & Hemophiliac  
1943 - 1990



# 1950-1960's: Improving Life Expectancy & Quality of Life



## Precipitate from Cold-thawed Plasma Potent in Therapy for Hemophiliacs

MEDICAL NEWS

Use of a precipitate from cold-thawed plasma—until recently thought to be valueless—may solve several major problems inherent in conventional therapy for hemophiliacs.

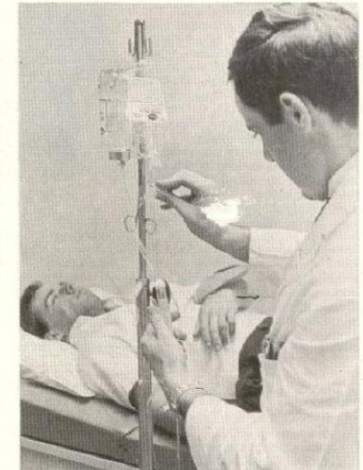
Judith G. Pool, PhD, Stanford University Medical Center, is the investigator who first found—almost by accident—that the thread-like substance precipitated during standard cold-thawing of plasma contains concentrated antihemophilic globulin (AHG).

Recently, Dr. Pool reported a simple technique for extracting this protein fraction. Since then, clinicians at Stanford Medical Center have used the precipitate in solution to infuse 14 patients more than 60 times. There were no apparent side effects.

Dr. Pool, a physiologist, described to THE JOURNAL these advantages of the concentrate:

- In vivo assay indicates the cryoprecipitate is 30 times as potent in AHG activity per given weight of protein as fresh frozen plasma, the conventional therapy, and 20 times that of normal fresh plasma.

Hematologist Paul K. Johnson, MD, administers 55 ml of new cryoprecipitate solution to severe hemophiliac. Only 12 ml of concentrate mixed with 43 ml citrated saline solution was required to raise patient's AHG to desired level.



### JAMA News Interview

- Since the precipitate can be dissolved in small amounts of citrated saline solution, more AHG activity can be delivered to the patient without risk of overloading his circulation. Moreover, this reduces infusion time from hours to minutes.

- Because the cryoprecipitate is prepared in single units and can be administered on a type specific basis, many complications caused by isantibodies in mixed pools of plasma and the risk of hepatitis are reduced.

- The precipitate is available at small cost in blood replacement or service charges, depending on the local blood bank.

- The concentrate is extracted within a sterile system of two or three plastic bags which is available in all blood banks. The blood from which the precipitate is taken can be reconstituted as "whole"

blood and used for any appropriate patient except the classic hemophiliac.

"This makes the AHG-rich concentrate—which traps 70% of the plasma unit's AHG—a by-product of blood banking," Dr. Pool said.

To illustrate clinical usefulness, Dr. Pool described conventional frozen plasma therapy for a severely bleeding adult hemophiliac as compared to that with cryoprecipitate solution.

The AHG level in such a patient is less than 1% of normal. To raise this patient's AHG level to a desired 50% of normal would require approximately 6 units or 1,600 ml of plasma. (Frozen plasma contains an average of 65% of AHG in fresh plasma.)

Infusion would take two hours or more; and the patient might not be able to tolerate this increase in circulatory volume.

In contrast, to obtain the same AHG level of 50%, only 55 ml or less of the concentrated solution is

needed. Infusion takes at most 5 minutes.

"AHG concentration of the solution averages about 2,000%," Dr. Pool said. "Thus it is about 30 times as potent as the frozen plasma on an equal protein basis. Since the total infusion volume is reduced to 1/30 that of plasma, there is no danger of overload." Moreover, "the patient gets this highly concentrated AHG source at a considerably lower cost per unit AHG activity than with two commercial products, or fresh frozen plasma," she said.

### No Additional Factor

The investigator stressed that classic hemophilia is apparently the only coagulation deficiency for which the new concentrate is therapeutically valuable. Except for fibrinogen, there is no concentration of any factor other than AHG.

Work leading to clinical use of the cryoprecipitate began in 1959. Using a quantitative in vitro assay

JAMA, Aug 23, 1965 • Vol 193, No 8

<CONT. OR BACK>

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# 1970's: No Longer Tethered to the Hospital

## Hemophiliac Doctor Helps Find Way to Save Bleeders

Los Angeles, May 14 — (AP) — Two researchers—one of them dramatically saved by a drug he helped develop — announced today development of a way to mass produce a blood-clotting agent which eventually may let chronic bleeders live normal lives.

Drs. Edward Shanbrom and G. M. Thelin, of Hyland Laboratories, said they had found a way of producing on a commercial scale a concentrate of antihemophilic factor (AHF) which is missing in hemophiliacs.

Hemophilia is a hereditary disorder in the body's blood-clotting mechanism. Its victims bleed internally without apparent cause, usually in the joints, and even minor cuts can be fatal because their blood is slow to clot in the wound.

### Doctor Treated

Thelin, 39, is a hemophiliac. He suffered a brain hemorrhage a

year ago and was treated experimentally with the AHF concentrate, which he and Shanbrom were developing. Thelin recovered completely and Shanbrom said it was one of the few cases of a hemophiliac recovering from a brain hemorrhage.

Six months later Thelin began hemorrhaging from peptic ulcers and was successfully treated again with AHF.

Dr. Shelby Dietrich, director of the Hemophilia Rehabilitation Project at Orthopaedic Hospital, has been studying 200 hemophiliacs ranging in age from six months to 60 years. She said the new concentrate will improve the outlook for all hemophiliacs.

### Increasing Production

Shanbrom said the concentrate would be released at first only for emergency treatment but that larger supplies would be available within a few months.

He also disclosed that Thelin is being given regular injections experimentally to see if they will prevent future bleeding.

If the experiment is successful, the concentrate may do as much for people suffering from hemophilia as insulin does for diabetics — make it possible for them to live normally with the aid of regular shots.

## New Drug to Give Hemophiliacs Aid

(C) 1969, New York Times News Service

NEW YORK — The federal government has approved for marketing a new drug that supplies in highly concentrated form the clotting factors that are lacking in the blood of some hemophiliacs.

The addition of this new drug, called Konyne, to the medical armamentarium means that nearly all patients with what is known as bleeder's disease can now be treated quickly and effectively without the costly and often dangerous administration of large quantities of blood plasma.

Konyne, prepared by Cutter Laboratories of Berkeley, Calif., contains in concentrated form the clotting factors known as IX, II, VII and X, any one of which is missing in the blood of about 20 per cent of hemophiliacs.

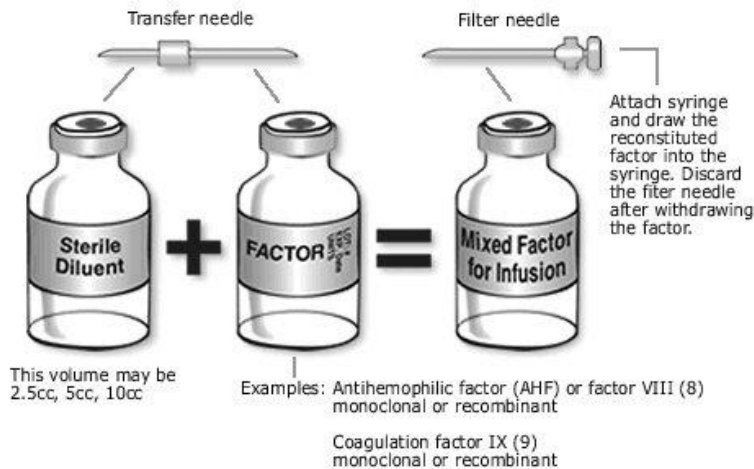
The great majority of hemophiliacs do not have clotting

factor VIII, a concentrate of which is marketed by the Hyland Division of Baxter Laboratories, Inc.

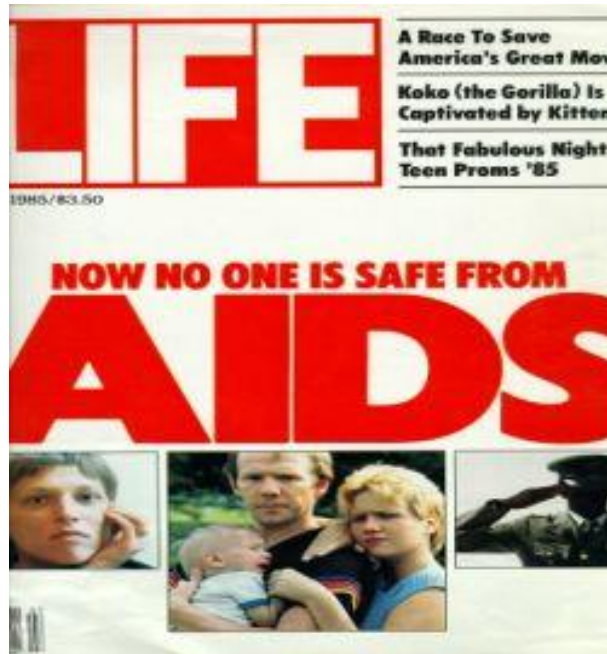
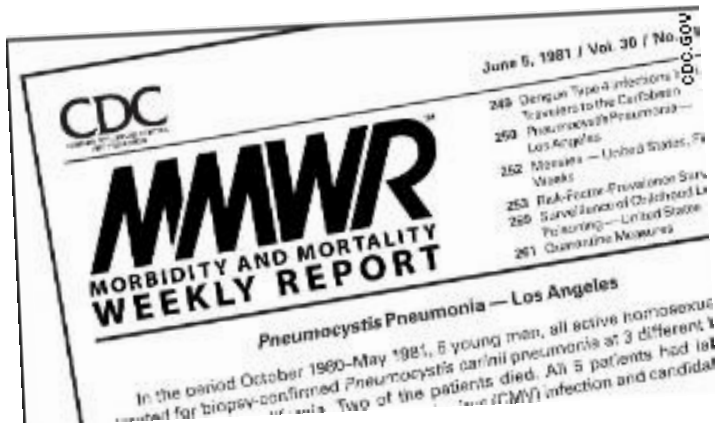
Like the Hyland concentrate, Konyne has about 60 times the potency of blood plasma in terms of the clotting factor it contains, according to Cutter Laboratories. Both drugs can be injected intravenously by a syringe or by an intravenous drip bottle.

These concentrates allow doctors to administer large doses of needed clotting factors without risking the overloading of the patient's circulatory system that could accompany the administration of large amounts of plasma.

The concentrates have made it possible to perform major surgical operations on hemophiliacs, that could not be done when doctors had to rely on plasma as the source of clotting factors.



# 1980's: Canaries in the Coal Mine



CENTERS FOR DISEASE CONTROL

**MMWR**

MORBIDITY AND MORTALITY WEEKLY REPORT

October 26, 1984 / Vol. 33 / No. 42

- 888 Update: Acquired Immunodeficiency Syndrome (AIDS) in Persons with Hemophilia
- 892 Organophosphate Insecticide Poisoning Among Siblings — Minnesota
- 899 Cryptosporidiosis among Children Attending Day-Care Centers — Georgia, Pennsylvania, Michigan, California, New Mexico
- 901 Outbreak of Tick-Borne Tularemia — South Dakota
- 903 Availability of MMWR-Related Publications

## Current Trends

### Update: Acquired Immunodeficiency Syndrome (AIDS) in Persons with Hemophilia

Reports of hemophilia-associated acquired immunodeficiency syndrome (AIDS) in the United States were first published in July 1982 (1). Since then, the number of U.S. patients with underlying coagulation disorders who develop AIDS has increased each year. In 1981, one U.S. case was reported; in 1982, eight; in 1983, 14; and, as of October 15, 29 cases have been reported in 1984, for a total of 52 cases (Figure 1). Two of these 52 patients had hemophilia B; one, a factor V deficiency; and one, factor VIII deficiency due to her postpartum acquisition of a factor VIII inhibitor. The remaining 48 cases occurred among hemophilia A patients. Three patients are known to have had risk factors for AIDS other than hemophilia. These 52 persons resided in 22 states. Only 10 states have reported more than one case, and no state has reported more than eight cases.

With the exception of one 31-year-old factor V-deficient individual with Kaposi's sarcoma (and without risk factors for AIDS other than his hemophilia), each patient had at least one opportunistic infection suggestive of an underlying cellular immune deficiency. *Pneumocystis carinii* pneumonia has been the most common opportunistic infection, occurring in 44 (85%) of the 52 patients. Other opportunistic infections have included toxoplasmic encephalitis (two cases), disseminated *Mycobacterium avium intracellulare* (one), disseminated cytomegalovirus infection (two), disseminated candidiasis (one), and cryptococcal meningitis (one). Thirty hemophilia patients with AIDS have died; only three of the survivors were diagnosed more than 1 year ago.

CDC has investigated the blood product usage of the majority of these cases. In nine cases, factor VIII concentrates have been the only blood product reportedly used in the 5 years before diagnosis of AIDS. These nine persons had no risk factors for AIDS other than hemophilia. The factor V-deficient patient with Kaposi's sarcoma had not used factor VIII concentrate products but had used large volumes of plasma and factor IX concentrates.

The sera of 22 (42%) of the 52 hemophilia-associated AIDS patients have been tested for antibody to antigens of the AIDS virus using Western blot analysis (2). Eighteen (82%) of these specimens contained antibody to one or more antigens (2,3). In cooperation with numerous hemophilia treatment centers and physicians, CDC has studied over 200 recipients of factor VIII and 36 recipients of factor IX concentrates containing materials from U.S. donors. Rates of AIDS virus antibody prevalence were 74% for factor VIII recipients and 39% for factor IX recipients (3,4). Only prospective evaluation will determine what risk of AIDS exists for seropositive individuals. A recently published study evaluated the thermostability of

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES / PUBLIC HEALTH SERVICE

# 1980's: Canaries in the Coal Mine



**January 4, 1983**

CDC hosts meeting of all the interested parties/groups affected by the AIDS epidemic

# 1985 & Beyond: The End of Transmission; Fight Continues

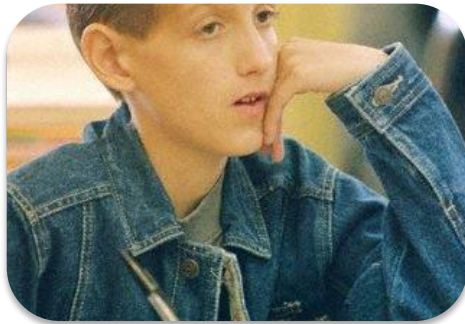
From 1981 – 1984, more than 50% of the hemophilia patients in the United States had been infected



# 1987: The Ray Brothers



# Ryan White's impact



1984 – Denied access to school



1988- Testifies before President's Commission on AIDS



HRSA funds grants that will become cornerstones of Ryan White CARE Act



April 8, 1990, Ryan dies due to AIDS related complications



Summer of 1990 – Congress passes ADA and enacts the Ryan White CARE Act

## Ryan White's impact

"My name is Ryan White. I am sixteen years old. I have hemophilia, and I have AIDS."

"Twice a week I would receive injections or IV's of Factor VIII which clotted the blood and then broke it down."

"We had great faith that with patience, understanding, and education, that my family and I could be helpful in changing their minds and attitudes around."

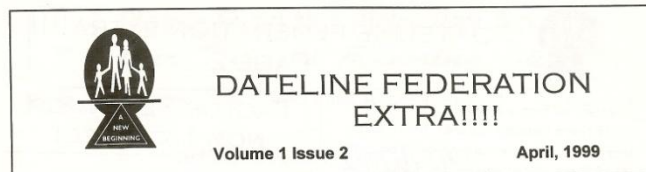
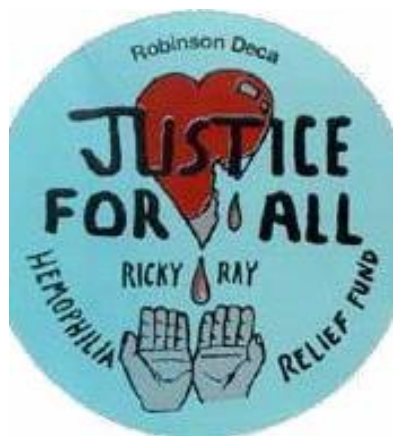
"I miss you so very much, Ryan. I was by your side when you died at Riley Hospital. You've been with me every day since. You inspired me to change my life and carry on your work. Because of you, I'm still in the struggle against AIDS, 20 years later. I pledge to not rest until we achieve the compassion for which you so bravely and beautifully fought."

--Elton John, *Letter to Ryan*, published April 25, 2010





# 1990's: March on Washington



## Notice of Intent to File for Ricky Ray!

The Department of Health and Human Services has announced procedures for filing NOTICES OF INTENT TO FILE PETITIONS for payment under the newly enacted Ricky Ray Hemophilia Relief Fund Act of 1998. Even though funds have not been appropriated either for the payment of awards to petitioners or for the administrative costs to HHS, the Act states that HHS shall first establish procedures to implement the Act within 120 days of its enactment (November 12, 1998.)

- ♦ The mail box for receipt of these filings will be opened April 23, 1999. **DO NOT SEND PRIOR TO THIS DATE!**
- ♦ Address for sending these notices is as follows:  
Ricky Ray Program Office  
Bureau of Health Professions  
5600 Fishers Lane Room 805  
Rockville, Maryland 20857
- ♦ For further information you may contact Neil Sampson, Deputy Associate Administrator for Health Professions, Health Resources and Services Administration at the same address. His phone number is 301-443-2330.
- ♦ Your Notice of Intent to File a Petition should include:
  - 1) Name of petitioner with current address and phone number.
  - 2) Name, address, and phone number of the petitioner's attorney of record or other representative for the petition, if any.
  - 3) In case of a deceased petitioner, person filing must identify the patient and state relationship.
- ♦ On receipt of your Notice of Intent to File a Petition, they will respond with an acknowledgment reflecting a case number assigned to the filing.
- ♦ IF YOU SHOULD HAVE A CHANGE OF ADDRESS, PHONE NUMBER OR ATTORNEY OF RECORD you MUST advise the Department or your claim will not be processed!
- ♦ Date of receipt of Intent to File will be viewed as date of filing for purposes of the 3-year time limit on filing petitions.
- ♦ However, Notice of Intent WILL NOT activate Departmental consideration beyond acknowledgment of receipt.
- ♦ Once appropriation of funds is complete, notification will be sent to those who filed Notice of Intent.



## Current List of eligibility

1) An individual who contracted HIV through use of contaminated clotting factor between 7/1/82 & 12/31/87.

2) A former legal spouse who contracted HIV thru transmission from the spouse.

3) One who acquired infection thru perinatal transmission from either of those listed above.

IF INDIVIDUAL IS DECEASED, ORDER OF PAYMENT IS:

1) Legal spouse at time of death

2) If not a spouse, equal shares divided



# Memorial



Committee of Ten Thousand Website:  
<http://www.cott1.org/category/memorial/>

## Lest We Forget

- HFA was formed in the ashes of the tragedy to serve as an organization to “assist and advocate” for those living and caring for person with bleeding disorders.
- Next Advocacy Webinar:

**“Tier What?: Understanding What ‘Specialty Tier’ Could Mean For You”**

Wednesday, December 4, 2013

1:00 PM - 2:00 PM EST





Conference Registration:

[https://fs4.formsite.com/hemophiliafed/symposium/secure\\_index.html](https://fs4.formsite.com/hemophiliafed/symposium/secure_index.html)

Hotel Registration:

[https://resweb.passkey.com/Resweb.do?mode=welcome\\_ei\\_new&eventID=10860788](https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=10860788)

For more information: [Info@hemophiliafed.org](mailto:Info@hemophiliafed.org)

# Sources

- ✧ Evatt BL. The tragic history of AIDS in the hemophilia population, 1982–1984. J Thromb Haemost 2006; 4: 2295–301.
- ✧ <http://aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/>