



# Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

Summer 2003

Volume 8, Number 3

## In This Issue

**Welcome:** Bleeding Disorders Association of the Southern Tier  
By: Jon Davis, President of BDAST

**Life, Love, Loss and Legacy**  
By: Donald Akers, Jr.

**The Charles Stanley Hamilton Legacy Award** By: Leo & Shirley Dixon

**Scholarship Winners:** Wyeth, Kelley Communications, AHF, Aventis Behring, Hemophilia Health Services and Positudes

**New Data Analyses Evaluate the Use of Baxter's Investigational Factor VIII Therapy** By: Baxter

**FYI Corner:** Dead's Lesh Greets Pennsylvania Blood Donors; Hep C FIBROSpect Test Instead of Biopsy; New Recombinant Product for Hemophilia B

**Dads in Action Training Session**

**Wyeth Requests Approval on BeneFIX** By: Wyeth

**New Assay Standard for ReFacto** By: Hemophilia Solutions

**Choice Assurance<sup>SM</sup> and Gammar-P I.V.:** By: Aventis Behring

**Alcohol Increases Hepatitis C Virus in Human Cells** By: U.S. Department of Health and Human Services

Hemophilia Federation of America  
102-B Westmark Boulevard  
Lafayette, LA 70506  
Web: [www.hemophiliamed.org](http://www.hemophiliamed.org)  
Toll Free: (800) 230-9797  
Local: (337) 991-0067  
Fax: (337) 991-0087

## A MOTHER'S STORY

"Transforming Tragedy into Triumph"

By Alice C. Ferguson



Human nature propels us forward, urging us to make our mark on the world, even - perhaps especially - when the world has left one too many marks on us. How else could one explain that certain something that enables a mother to transcend the loss of a child, to reach into the depths of disaster and pull out a handful of helping for her fellow man?

Jan Hamilton, director of the Lafayette (Louisiana)-based Hemophilia Federation of America, attests to that elusive human quality every day, in her work to combat the blood disease that claimed her son in August 1979. His loss, devastating as it must have been, became a catalyst for giving.

"I was motivated to become involved with hemophilia organizations after the loss of my son," said Hamilton, who has spent the past two decades working on behalf of many nonprofit and volunteer organizations in the Lafayette area. "We moved the Federation's offices here from Washington, D.C. and I've been amazed at how much we've grown since then." She spent seven years on the board of the National Hemophilia Foundation, and for a number of years worked with the Acadiana Culinary Classic, which was a primary fund-raiser for hemophilia organizations. More recently, she helped spearhead the foundation of the Louisiana Blood Commission, to emphasize the need for safe, frequent blood donors for all communities. Her community service activities, however, have not been limited to hemophilia-related organizations.

"I've met so many people through these activities, and one thing always seemed to lead to another," she said. "My family was active in Ascension Church and Ascension Day School, where our children were educated; so my involvement with volunteering there was a natural," she said.

Hamilton, who is married to retired Lafayette physician Dr. Charles Hamilton, has also served on the Mayor's Commission on the Needs of Women; Hospice of Acadiana, which assists the terminally ill and their families; and the Acadiana Safety Association, giving her time to serve on national boards as well as local ones.

Continued on page 3



Welcome

## Bleeding Disorders Association of the Southern Tier

The Bleeding Disorders Association of the Southern Tier was established in 1995 to serve a nine county region in New York and Northern Pennsylvania. BDAST annually sponsors campers to attend a regional camp for boys and runs camp Miles of Smiles for girls with bleeding disorders.

In addition, the organization has a college scholarship program and has several annual fund-raisers that include a golf tournament.

BDAST decided to become the Hemophilia Federation of America's first New York Chapter after meeting with Jan Hamilton and deciding that it was time for the organization to become nationally involved with consumer issues and education.

The HFA's focus on chapter development and the varied needs of consumers will help support BDAST in achieving its mission.



Submitted By: Jon Davis  
President of BDAST

Look for information about  
Symposium 2003 videos on  
sale in next issue.

### About This Publication

Dateline Federation is a publication of the Hemophilia Federation of America (HFA). It is published four times a year. The material in Dateline is provided for your general information only. We do not give medical advice or engage in the practice of medicine. The HFA recommends that you consult your physician or local treatment center before beginning any form of treatment. Send all comments, suggestions, and article submissions to: Dateline Federation, 102-B Westmark Blvd., Lafayette, LA 70506.

### Mission Statement

Hemophilia Federation of America is a national nonprofit advocacy organization established for and directed by persons with hemophilia and other coagulation disorders and their families of origin and/or families of choice. The Federation exists for the sole purpose of serving its constituents as a patient advocate for, but not limited to, product safety, treatment, insurance and quality of life issues in a positive and proactive manner. Its mission is to serve the needs of all families with coagulation disorders and complications of treatment, such as HIV.

### Officers

Bob Marks, President  
Barbara Chang, Vice President  
Peter Bayer, Secretary  
Randyll Ratcliff, Treasurer  
Rich Vogel, Immediate Past President

### Staff

Jan Hamilton, Executive Director  
Susan Swindle, Administrative Director  
Michelle Scricca, Communications Director  
Wendy Hearne, Administrative Assistant  
Desiree Gothreaux, Accounting Secretary

### Member Organizations

Bleeding Disorders Association of the Southern Tier  
Florida Chapter of NHF  
Gateway Hemophilia Association  
Hemophilia Association of New Jersey  
Hemophilia Association of the Capital Area  
Hemophilia Foundation of Maryland  
Hemophilia Foundation of Nevada  
Hemophilia Foundation of Northern California  
Hemophilia of North Carolina  
Hemophilia of South Carolina  
Hemophilia Outreach of El Paso  
Lone Star Chapter of the NHF  
Nebraska Chapter of the NHF  
Northern Ohio Hemophilia Foundation  
Oklahoma Hemophilia Foundation  
Hemophilia Foundation of Southern California  
Texas Central Hemophilia Foundation

## **A Mother's Story, Continued**

Assuring a safe blood supply and fighting the disease that claimed her son's life are the enduring causes that remain closest to her heart. She says anyone can become a valuable and successful volunteer, but the best ones are those who are motivated by deeply felt, personal reasons for reaching out to others.

"Many times people volunteer out of boredom, perhaps because their children have grown up and they are experiencing that empty nest syndrome, finding that they have time on their hands," she said. "Often, though, we see volunteers who had family members who were touched by something in their lives. For example, a lot of Hospice volunteers have had family members or friends who have been helped by Hospice; that's how they learn about the organization and how they become interested in volunteering. It's the same situation with a lot of our hemophilia organization board members; they've been touched in one way or another by the disease."

Hamilton's volunteer work has taken her across the country and to Capitol Hill, to hobnob with those in the highest ranks of government, science and business on behalf of the cause that is dearest to her heart. "I certainly never thought I would find myself on the Hill, speaking in front of all these important people, all these big-time doctors and scientists. I'm just little ole me," she said, laughing. "That was so far removed from anything I thought I would ever do! But one thing leads to another, and I had a solid preparation through my Junior League background and as a Tri-Delta alumna; all those things helped lead me into this kind of service."

"The most rewarding thing is to see these small efforts grow into something bigger, something that makes a difference even if it's just for one person," she said. "At Hospice, for example, we always felt that if we could help just one family to get through those terrible times, then everything would be worthwhile."

Having the opportunity to build relationships with other people is also deeply rewarding," Hamilton said. "This kind of work throws a person together with other people from all different walks of life, people from coast to coast and from north, south, east and west," she said. "I've learned that people all over the country have the same needs and the same problems; we all have a need to be educated and to understand that we can be advocates for our own care."

"All those people, from all those different walks of life, demonstrate to the rest of us that anyone can make a difference. One doesn't need advanced degrees, loads of time or stacks of extra cash to make the world a better place for our fellow human beings."

"Anyone can make a difference as long as you care and do your research," Hamilton said. "Anybody can do it; you just have to make up your mind that you will do it. It's the love of our fellow man that draws people in that motivates them to try to make things better for others and to improve our quality of life."

More and more, Hamilton said, she sees people of all ages becoming active in volunteerism. "Some people volunteer through their churches or through charitable organizations or civic clubs. We've seen many, many more school groups, even as young as elementary and junior high school groups, getting involved in volunteer work. People seem to be remembering the old saying, 'There, but for the grace of God, go I', and it motivates them to help others."

"There are so many different ways and places to volunteer," she said. "The most important thing is to pick something that's meaningful to you, whether it's Hospice or the Hemophilia Federation or anything else. Talk to people at work or at your church, and you will hear of places that need your help. You'll enjoy it more if you're doing something that is meaningful to you; if you have a personal connection to the cause."

Also, Hamilton said, "it's crucial to remember that every little bit counts." "There is no amount of time or money or help that is too small," she said. "If you have one hour a week, that one hour will help someone. If you have one dollar, it will help; remember that every \$100 in donations is made up of 100 one-dollar bills! So no one should feel that they haven't enough time or money or skills to help. If you know how to answer a telephone or stuff an envelope, you can make a difference."

Editor's Note: Edited and reprinted with permission from an original article that appeared in the Personality Profile Section of *LifeStyle Lafayette*, May 12-June 15, 2000 edition. HFA Dateline thanks *LifeStyle Lafayette* for their assistance.

Photo by Dennis Sullivan

## LIFE, LOVE, LOSS & LEGACY

By: Donald Akers, Jr.

These powerful expressions are easily used to describe, individually and collectively, the attributes of Dr. and Mrs. Charles E. Hamilton, the Hemophilia Federation of America's first recipients of the Charles Stanley Hamilton Legacy Award named in honor of their late son who had hemophilia. To their friends, and certainly they are amongst HFA's best friends, "Chuck and Jan" embody all of that and so much more. HFA looks forward to the bestowing of this well deserved honor at its Annual Board Retreat in Lafayette, Louisiana October 2-5, 2003. Their life and work has been an extraordinary contribution to the hemophilia and bleeding disorders world.

Here is a little background information about our honorees with coverage of the award to be featured in the next issue of Dateline Federation. It is easy to see why so much value has been added to the bleeding disorders community by this terrific couple.

**CHARLES E. HAMILTON, MD, MSHA**, was born in Altus, Oklahoma and was educated at USC, Tulane University School of Medicine where received his MD degree and the University of Colorado at Denver where he received his Masters degree in Health Care Administration. His internship and residency was at Charity Hospital, New Orleans. Dr. Hamilton served his country as a Captain in the U.S. Navy and Navy Reserve Medical Corps from which he retired. Dr. Hamilton is a Fellow of the American Academy of Pediatrics and Diplomats, American Board of Pediatrics.

Dr. Hamilton practiced pediatrics with the Hamilton Medical Group from 1954 to 1988 when he retired from practice having served as that Groups Chairman of the Board and Medical Director. Dr. Hamilton has been a Clinical Professor of Pediatrics at Tulane Hospital and is certified by the American College of Physician Executives and a Professional in Health Care Quality.

Dr. Hamilton is expert in the field of hemophilia as a father and as a pediatrician, having hands on experience from the familial and medical prospective. He authored "*The Impact on Health Care of the Louisiana Hemophilia Program*," VIIIth International Congress on Thrombosis and Hemostasis, July 1979 and has testified as an expert in court regarding hemophilia related issues.

After his retirement from the practice of Pediatrics in 1988, Dr. Hamilton continued his work as a Physician Field Representative and Team Leader, for the Joint Commission on Accreditation of Healthcare Organizations, a position he holds to this date (although rumor has it that he plans to retire, again, at the end of this year).

Dr. Hamilton's contributions include his service as Chairman, Legislative Advisory Committee, State of Louisiana Hemophilia Program, 1976 - 1988; Past President, Louisiana Chapter, National Hemophilia Foundation; Former Board Member, Southwest Louisiana Rehabilitation Center; and Former Board Member, Southwestern Louisiana Education and Referral Center among others.

Dr. Hamilton is equally known for being the husband of HFA's Executive Director Jan Hamilton and they are the parents of four children, Charles, in whose honor the legacy award is named, Carol, Mark and Mary Beth.

**JANICE HARGIS HAMILTON** was born in Baton Rouge, Louisiana and is a graduate of the University of Louisiana, Lafayette, Louisiana with a B.S. in Business Administration, 1958.

Jan has worked in Radio and Television where she was an On Air Personality with WHER Radio, Memphis Tennessee, worked at KPEL Radio, Lafayette, and was a hostess for the noon interview show on KATC TV, Lafayette. For 12 years, Jan owned and operated a Baskin-Robbins Store and also owned and operated a Wedding Consultation Service.

From 1984 to 1986, Jan served as Hospice of Acadiana's, Executive Director and from 1987 to 1988 as Acadiana Safety Association's Executive Director. Since August 1, 1998 Jan has served as Executive Director of the Hemophilia Federation of America.

Jan has been President of the Louisiana Hospice Organization, Secretary of the Social Service Agency Resource Network, a member of the Executive Committee National Safety Council Chapter and Affiliate Division as Southern Region Representative and President of the Mayor's Commission on Needs of Women. Jan has also served in various capacities of the Junior League of Lafayette; the Health and Safety Committee, Local Affairs Committee, and Education Committee of the Lafayette Chamber of Commerce; and the Southwest Louisiana Rehabilitation Center.

Jan has served as Chairman of the United Blood Services Community Advisory Board; a director of the Louisiana Chapter National Hemophilia Foundation; a director of NHF and Secretary to its Executive Committee and other NHF committees; member of Hemophilia of Acadiana; member of the Lafayette Parish Medical Society Auxiliary; and Charter member and first President of the Hemophilia Federation of America (HFA).

Jan has been named an Outstanding Young Women of America; NHF Humanitarian of the Year; Volunteer of the Year, Louisiana Chapter, NHF; and Acadiana Volunteer Activists honoree. Jan has edited brochures for the Southwest Louisiana Rehabilitation Center and edited and contributed to the manual for chapters of NHF. Jan has presented at numerous hemophilia related organizations throughout the nation including NHF national and chapter meetings in New Orleans, LA, Kansas City, MO, and Arlington, VA, to name a few.

Jan was instrumental in the passage and implementation of the Ricky Ray legislation and is active in the Blood Products Advisory Committee and Advisory Committee on Blood Safety and Availability. Jan has testified and presented information regarding hemophilia and bleeding disorders to state and national governing bodies and in the courts. She has testified at committees on Government Oversight and Reform.

Jan is the wife of honoree Dr. Charles Hamilton, and together they have graciously shared their lives, their loves, their losses and their legacy with the hemophilia community and the rest of our world. We are truly grateful to both.

## The Charles Stanley Hamilton Legacy Award

The following statement was submitted by Leo and Shirley Dixon:

After transferring from Mobile, Alabama to Lafayette, Louisiana in the summer of 1981 my family and I (Shirley, Kenneth and Tyrone) met Dr. C. H. Hamilton who began to treat Kenneth and Tyrone for their hemophilia.

Through him we met his family and others in the hemophilia community here. Mrs. Jan Hamilton has been involved with the hemophilia community for as long as we have known her locally, statewide, regionally and nationally. Jan was determined to get us involved at all levels. The people in this area are so unique, ask for help and you get help. I can remember the camps, poinsettias, culinary classics and many other events that we had. For some reason no one that I know can say no to Jan. Along with Dr. Hamilton, Jan and others in this loving community we grew individually and as a family. God sends the people in your life at the times they are needed to be there for you. We've all had tough times but it's so good to have friends and family members like the Hamilton's in your corner. We cannot think of anyone more deserving of this award than the Hamilton's. May God continue to bless them and all members of this community.

**"We cannot think of anyone more deserving of this award than the Hamilton's."**



Lovingly,  
Leo & Shirley Dixon

## 2003-2004 Scholarship Winners

### **AHF® Inc.: Beth Carew Memorial Scholarship**

**Ryan A. Egger** will be entering Carnegie Mellon University in Pittsburgh in the fall.

**Michael D. Fitzpatrick** attends Keene State College in New Hampshire.

**Mark W. Guest** will be attending Notre Dame University in Indiana this fall as a sophomore.

**Brandon A. Lilly** attends Oklahoma State University and will be a junior in the fall.

**Adam L. Wilmers** graduates this June from the Roeper School in Michigan.



### **Aventis Behring Choice: Arthur B. Kane Memorial Scholarships**

- **Craig T. Wright** of Franklin, Tennessee
- **Thomas E. Cleveland** of Mandeville Louisiana
- **Heather S. Jones** of New Castle, Pennsylvania
- **Matthew R. Markman** of Margate, New Jersey

### **Hemophilia Helath Services: HHS Memorial Scholarship/Scott Tarbell Memorial Scholarship**

#### **HHS Memorial Scholarship:**

**Joshua Friesen** - Southeastern Baptist Theological Seminary

**Lindsey Hanson** - Tulane University

**Jordan Katz** - Pennsylvania State University

**Travis Ward** - University of Texas at Austin

#### **Scott Tarbell Memorial Scholarship:**

**Gregory Price** - Carnegie Mellon University

**Jason Simmonds** - St. Cloud Technical College

### **Kelley Communications: Winners of the Eric Dostie Memorial College Scholarship 2003**

**Adam Wilmers** plans to pursue a pre-medical degree at the University of Michigan.

**Michael Reutershan** will attend Bowdoin College as a biology major.

**Victoria Vieira** plans to pursue a degree in graphic arts and illustration.

**Travis Ward** attends the University of Texas, Austin.

**Lindsey-Joy Gillian Hanson** attends Tulane University and plans to obtain a Master's degree in oriental medicine.

**Rachelle Rubin** is a business administration major at the University of Florida.

**Marcus Hurt** is a psychology major at Hannibal-LaGrange College.

**Matthew LaPine** is a music education major at Westminster Choir College of Rider University.

### **Positudes: The Lawrence Madeiros Scholarship**

**Elise L. Anderson** of Schenectady, New York will study psychology at Utica College in the fall of 2003.

**Samuel W. Doughty** of Salisbury, Maryland is planning a course of study in the recording industry at Middle Tennessee State University in the fall of this year.

**Joseph R. Pileri** of Newbury Park, California has been accepted at U.C.L.A. in September 2003.

**Neil G. Swanson** of Virginia Beach, Virginia has been accepted in the Intelligence Analyst Research Program at Mercyhurst College in Erie, Pennsylvania and plans to major in history and a minor in foreign language.

### **Wyeth: Sharing a Brighter Tomorrow Hemophilia Scholarship Program**

**Undergraduates:** **Tom Budescu** \*, Champaign, IL - University of North Carolina, Chapel Hill

**Daniel Chorney** , Vancouver, B.C. - University of British Columbia

**Yuri Chumak** \*, Toronto, Ontario - University of Western Ontario

**Ryan Egger**, Temecula, CA - Carnegie Mellon University

**Patrick Lynch**, Stewart Manor, NY - Boston University

**Benjamin Murphy**, Onancock, VA - University of Virginia

**Ebrahim Paryavi**, Gaithersburg, MD - University of Maryland – College Park

## Wyeth: Sharing a Brighter Tomorrow Hemophilia Scholarship Program

**Undergraduates:** **Greg Price**, Falls Church, VA - Carnegie Mellon University  
**Christopher Reiser**, Monroe Township, NJ - Rutgers University  
**Akram Shayeb**, Alta Mesa, Puerto Rico - U.P.R.; Rio Piedras Campus  
**Travis Ward**, Llano, TX - University of Texas at Austin  
**Craig Wright \***, Franklin, TN - Lipscomb University

**Graduates:** **Jeffrey Balekamp**, Clifton, NJ - Yale University  
**Kenneth Hitchner**, Somerset, NJ - Rutgers University Business School Vocational  
**Edgar Martinez**, Oviedo, FL - Orlando Culinary Academy  
**Jason Simmonds**, Annandale, MN - St. Cloud Technical College  
**Maxime Veilleux**, Beauceville, Quebec - TBD

\* Indicates a repeat scholarship winner.

---

## Staff Changes at HFA

By: Jan Hamilton



Time marches on and with it comes change in our lives and in the staff at HFA. For five years, Mary Beth Carrier has been a steady part of our HFA family first as staff assistant and later as Program Director. She is leaving us to spend more time with her family. We will miss her but will still have access to her many talents as needed.



Michelle Scricca has been our Communications Director for a year now. She took over the reins from Jill Habetz once Jill completed her Masters degree in Communication. Michelle has brought her background of printing experience to us and we have enjoyed her. Unfortunately, the lure of the smell of printers ink has called and she is returning to Express Printing where our printing is done. We will miss her on a daily basis but will see her often. *"I would like to extend my gratitude to the Hemophilia Federation of America for giving me the experience and knowledge that I will take with me and use to help others."* Thank you, Michelle



Wendy Hearne, our three-year veteran as staff assistant and girl Friday is taking over the job of producing Dateline Federation. She will do a fine job and we are pleased to see her grow into this position.



Susan Swindle who has been our Office Manager, bookkeeper and Helping Hands administrator has moved into a position as Administrative Director and Project Director for our emerging ER Triage Education Program. She will relieve me of the day-to-day responsibilities of overseeing the office operations and spearhead the launch of this important new program.



Desiree Gothreaux has joined us as bookkeeper and secretary. She will also give support to the Executive Director position. She is learning about hemophilia quickly and will also be the administrator for Helping Hands. You will have a chance to meet her in Salt Lake City at the NHF annual meeting. Please stop by the booth and say hello.

**NEW DATA ANALYSES EVALUATE THE USE OF BAXTER'S INVESTIGATIONAL FACTOR VIII THERAPY IN ADULTS AND CHILDREN WITH HAEMOPHILIA A**  
*- Preliminary Analyses of Phase II/III Clinical Data Presented at a Key Haemophilia Congress for Investigational Human- and Animal-Free Blood Clotting Factor VIII - Submitted By: Baxter*

**ZURICH, Switzerland, July 14, 2003** – Preliminary study data presented at the XIX Congress of the International Society for Thrombosis and Haemostasis (ISTH) further add to the body of data evaluating the safety and efficacy of the Antihaemophilic Factor (Recombinant), Plasma/Albumin-Free Method (rAHF-PFM), in stopping bleeding episodes in patients with haemophilia A. The results from data presented are consistent with previously presented studies. rAHF-PFM, an investigational treatment for haemophilia A from Baxter Healthcare Corporation, currently under regulatory review in Europe, the United States, Canada and Switzerland, is a recombinant factor VIII made without any added proteins from human or animal sources in the cell culture process, purification and final formulation. “rAHF-PFM has prevented bleeding episodes in all circumstances where we have treated patients and where we expected it to work. It has provided excellent coverage for surgical interventions and procedures, and has met all therapy expectations,” according to Clinical Study Group Investigator Dr. Amy Shapiro of the Indiana Hemophilia and Thrombosis Center. “Also, because rAHF-PFM is made without the addition of human-or animal-derived proteins in the cell culture and purification processes or final formulation, it removes ongoing concerns about therapy safety that history has shown are legitimate worries.” The data presented at the meeting cover a multitude of situations and haemophilia patient populations including:

**- Previously Treated Patient Continuation Study** - Data presented show that as of the last assessment, no patients have developed immune system inhibitors and 92 percent of the participants' bleeding episodes resolved with two or fewer infusions of rAHF-PFM.

**- Paediatric Study** - Preliminary data evaluating the use of rAHF-PFM in paediatric patients (six years or younger) with severe and moderately severe haemophilia A, show that the half-life of rAHF-PFM was 10.48 hours. Taking into account the higher weight-adjusted plasma volume of younger patients, this value is consistent with the values found in another study of previously treated patients  $\geq 10$  years of age.

**- Surgery Study** - According to preliminary data from an ongoing study of 41 patients with severe and moderately severe haemophilia A who had 44 surgical procedures, rAHF-PFM provided bleed control in those patients undergoing major, minor and dental surgeries. Data from the study show that the ability to control bleeding during surgery was rated excellent/good in 43 of 44 procedures; the rating of the remaining procedure was unknown. The ability to control bleeding after surgery was rated excellent/good in all 44 procedures.

**NEW DATA ANALYSES ABOUT rAHF-PFM**

rAHF-PFM is an investigational blood clotting therapy for haemophilia A to treat and prevent bleeding episodes and control such episodes during surgery. Clinical studies demonstrate that rAHF-PFM, which is infused directly into the bloodstream, works by temporarily raising the level of factor VIII in the blood to a level that allows the body's blood clotting process to function properly. Side effects with the use of rAHF-PFM are uncommon but those reported in the study included: a strange taste, dizziness, hot flashes, headaches, itching at the infusion site, fever, sweating, chills, nausea, diarrhea, shortness of breath and pain in the upper abdomen or lower chest.

**Our Deepest Sympathies**

**Robbie Johnson of Kentucky passed away in May of this year.**

**Family and friends mourn the passing of Mike Moses who died in July of this year.**



***Our thoughts and prayers are with the family and friends in their time of need***



# FYI CORNER

## Dead's Lesh Greets Pennsylvania Blood Donors

6/26/03

PHILADELPHIA (AP) - The Grateful Dead bassist Phil Lesh was out for blood. He greeted donors at an American Red Cross blood drive Saturday, June 28th, in Philadelphia. The musician's timing couldn't have been better, Red Cross officials say, because blood supplies in the region are critically low.

"All the donors who come to this particular blood drive Saturday will be as a result of Phil being there," said Red Cross Penn-Jersey Region spokeswoman Susan Sponar. "He greets all the donors and everything. He's just terrific about it."

Lesh, who had a liver transplant in 1998, devotes space on his Web site to promoting blood drives and organ donations.

Saturday's appearance was Lesh's third blood drive in Philadelphia and plans to attend a drive in Denver on July 9.

Sponar said blood supplies in the Philadelphia region were at about 25 percent of need. She said hospitals could run out of blood in the case of mass casualties.

Source: [Bellsouth.net](http://Bellsouth.net) News Vault

## Hep C FIBROSpect Test Instead of Biopsy

The test was introduced at the American Association for the Study of Liver Diseases (AASLD) meeting that was held in Boston on November 1-5, 2002.

The new non-invasive liver fibrosis test, called FIBROSpect (SM), measures three biological markers associated with the development of liver fibrosis. The markers are used to help physicians differentiate patients who have no or mild liver fibrosis from patients who have significant liver fibrosis. This information may assist physicians in making diagnostic triage and treatment decisions for patients with chronic hepatitis C. Presently, the "gold standard" used to determine the extent of liver fibrosis in patients is a needle biopsy. Liver biopsies are invasive, costly and can be associated with a number of painful or severe complications. "We believe that the introduction of FIBROSpect is an important and exciting step in the evolution of liver disease assessment and management," stated James A. Schoeneck, Prometheus' President and Chief Executive Officer. "FIBROSpect may help physicians determine the necessity for a liver biopsy, thereby reducing the potential for procedural complications."

"The addition of FIBROSpect to our diagnostic product line reinforces our commitment of bringing innovative diagnostic tests to physicians that we believe will be valuable in managing their patients' care," commented Doug Jermasek, Vice President of Marketing at Prometheus. "FIBROSpect is the first commercially available, non-invasive sero-diagnostic test panel of its kind."

Source: [www.prometheuslabs.com](http://www.prometheuslabs.com)

## Nevada Repeals Medicaid Reimbursement Rate Cuts For Pediatric Specialists

Nevada Medicaid officials on July 14 announced that cuts in payments to pediatric specialists, which took effect in May, will be repealed this week, the reports. According to Charles Duarte, administrator of the Nevada State Division of Health Care Financing and Policy, providers will receive payments retroactive to May 8, when the rates were first cut, and rates will be returned to approximately the amount allocated before they were reduced. Duarte said, "Overall, doctors will be getting paid the same as they did before, but procedure to procedure, reimbursement rates will be a bit different." While the restored rates will be offset by cuts in other parts of Medicaid, it is unclear which areas face reductions, Duarte said. The decision to increase the reimbursement rates comes after at least 25 pediatric specialists stopped treating Medicaid beneficiaries in May and at least one family moved out of the state to receive care for their child, the *Review-Journal* reports. Many pediatric specialists complained that the reimbursement rate cuts, up to 80% in some cases, made it "unaffordable" to care for Medicaid beneficiaries, according to the *Review-Journal*. Duarte said that physicians will be notified this week by letter of the rate changes and the procedure for collecting the retroactive reimbursements (Babula, *Las Vegas Review-Journal*, 6/15).

Source: [www.kaisernetwork.org](http://www.kaisernetwork.org)

## Dads in Action: Building Childhood Heroes

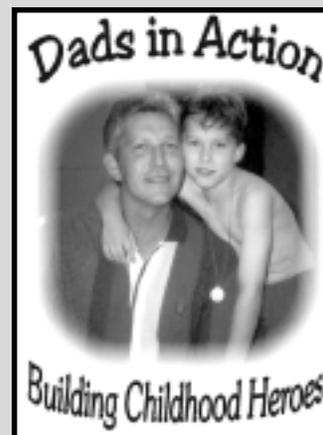
Dads in Action is a new program by HFA designed to get Dads more involved. The mission of Dads in Action is to forge a stronger bond between dads and their children while learning to set priorities in a dad's life, putting family first.

The structure of the program is local, regional and national. Each chapter is encouraged to have a local group that meets quarterly. At least one of these sessions must include their child/children. Local groups will come together with other groups once a year for more fellowship. Additionally, each year at the HFA Symposium, Dads in Action will have a meeting with national scope. Each group is given \$1000 annually to support their activities.

These meetings entail training sessions held at symposium and once in the fall at the HFA national office. Training is done at a two-day weekend workshop with discussions centered on these topics:

- Framework of the Program
- Role play
- Presentation by a child and adolescent psychologist on tools needed for success
- Group sessions designed to simulate activities for the group in their home chapter
- Evaluation

Training sessions are provided at no expense to the participants. The first training session is scheduled for October 24-26 in Lafayette, Louisiana. You can call the Hemophilia Federation office for more information at 1-800-230-9797 or visit our web site at [hemophiliafed.org](http://hemophiliafed.org).



## Wyeth Requests Approval on BeneFIX® to FDA

Submitted By: Wyeth

**St. Davids, Pennsylvania, June 18, 2003**-As a part of Wyeth's ongoing efforts to ensure the supply of effective recombinant factor products with enhanced viral safety for the hemophilia community, they have recently filed an application with the Food and Drug Administration (FDA) to expand their production capacity for BeneFIX® Coagulation Factor IX (Recombinant).\*

BeneFIX® is currently produced in Andover, Massachusetts. Pending approval by the FDA, the additional manufacturing facility, located in Conshohocken, Pennsylvania, will increase Wyeth's capacity to produce BeneFIX® by more than 50%. Wyeth is the only manufacturer of a recombinant factor IX therapy.

BeneFIX® is manufactured without any animal or human proteins and is inherently free of the risk of transmission of human blood-borne pathogens. As with the intravenous administration of any protein product, common adverse reactions may include headache, fever, chills, flushing, nausea, vomiting or lethargy. Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported for all factor IX products. Patients should be informed of the early symptoms and signs of hypersensitivity reactions. Patients should discontinue use of the product and contact their health care provider immediately and/or seek emergency care if any hypersensitivity reactions occur.

\* The filing initiates the FDA's formal review of Wyeth's application. It does not in any way anticipate the outcome of that review. The FDA can approve, reject, or seek more information with respect to the application.

## **New Assay Standard for ReFacto®: What Does This Mean to Patients?**

Submitted By: Hemophilia Solutions/Issue 5, 2003

The consistent measurement of clotting factor activity units is important for treating bleeds successfully, especially in the surgery setting. Assays used to measure clotting factor activity are very complex and differ among laboratories.

Wyeth has adopted a new assay standard for ReFacto® Antihemophilic Factor (Recombinant). This new standard should yield greater agreement among test results used to monitor treatment.

As a result, of this change, the amount of ReFacto® protein in each International Unit (IU) will increase by approximately 20%. The price per IU will remain the same.

Individuals who currently use ReFacto® should continue using their current supply. Patients transitioning to ReFacto® calibrated with the new standard should initially use the same dose as previously prescribed. Once transitioned to ReFacto® calibrated with the new standard, they should remain on this product. As will all factor VIII products, patients' dose should be individually titrated to desired clinical response.

Patients should consult with their health care provider regarding their specific treatment regimen.

ReFacto® Antihemophilic Factor (Recombinant) is indicated for the control and prevention of hemorrhagic episodes and for surgical prophylaxis in patients with hemophilia A

(congenital factor VIII deficiency or classic hemophilia) and for short-term routine prophylaxis to reduce the frequency of spontaneous bleeding episodes. The effect of regular routine prophylaxis on long-term morbidity and mortality is unknown.

As with the intravenous administration of any protein product, adverse reactions may include headache, fever, chills, flushing, nausea, vomiting, fatigue, or symptoms of allergic reactions. The remote possibility exists for hypersensitivity to non-human mammalian proteins.

### **New ReFacto® Packaging Coming Soon:**

ReFacto® calibrated with the new standard will be introduced with new and distinctive packaging. Each of the four vial sizes will have color-coded packaging:

- **Yellow-250 IU/kg**
- **Blue- 500 IU/kg**
- **Green- 1000 IU/kg**
- **Red- 2000 IU/kg**

ReFacto® calibrated with the new standard in the color-coded packaging will be available pending approval by the U.S. Food and Drug Administration (FDA).

**“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”**

**- Leo Buscaglia -**

## **Choice Assurance<sup>SM</sup> and Gammar<sup>®</sup>-P I.V. Assurance<sup>SM</sup> Provide a New Level of Service to the Thousands of People Who Require Clotting Factor or IVIG Therapy** — Submitted By: Aventis Behring

**King of Prussia, June 19, 2003** - Aventis Behring L.L.C. today launched two new programs in the U.S. that are designed to help ensure that qualified people who rely on recombinant and plasma-derived therapies can continue to receive these life-saving treatments, even if they experience a lapse in third-party, private health insurance. The Choice Assurance Program will serve the bleeding disorders community, and the Gammar<sup>®</sup>-P I.V. Assurance Program will focus on the needs of people who rely on intravenous immune globulin (IVIG) therapy.

The new Programs operate similarly. Patients who enroll earn one Assurance Award Certificate for every three consecutive months they use one of Aventis Behring's factor products or IVIG therapy. Each Certificate can be redeemed for one month's worth of free product based on the average monthly usage by the patient in the event of a lapse in insurance. Patients can earn up to four months of free product after only a year in the Program and up to a full year after three years in the Program. There is no other program available to the patient communities that Aventis Behring serves that offers as much flexibility or security so quickly.

"Knowing that your life-saving medication can be available in the event of an insurance lapse can be as important to patients and their families as actually accessing that treatment," said Michael Sumner, MD, Senior Medical Director, Aventis Behring North America. "Family members have enough to worry about without fearing that if they lose medical insurance—through job loss or for some other reason—they'll jeopardize their access to medical treatment for life-threatening conditions. The Choice Assurance and Gammar<sup>®</sup>-P I.V. Assurance Programs should help provide an additional level of security to many families."

**Program Eligibility:** Anyone who uses one of the following Aventis Behring products and who has third-party, private health insurance coverage is eligible to enroll in the new Aventis Behring Assurance Programs. Choice Assurance is available to people who use Helixate<sup>®</sup>FS Antihemophilic Factor (Recombinant); Humate-P<sup>®</sup> Antihemophilic Factor/von Willebrand Factor Complex (Human), Dried, Pasteurized; Mononine<sup>®</sup> Coagulation Factor IX (Human) Monoclonal Antibody Purified; or Monoclate-P<sup>®</sup> Antihemophilic Factor VIII: C (Human) Pasteurized, Monoclonal Antibody Purified. Gammar<sup>®</sup>-P I.V. Assurance is available to people who use Gammar<sup>®</sup>-P I.V. Immune Globulin Intravenous (Human).

Commitment to the Communities Aventis Behring Serves Choice Assurance and Gammar<sup>®</sup>-P I.V. Assurance complement the highly regarded Aventis Behring Patient Assistance Program, which will continue to help qualified patients who are uninsured, underinsured or who cannot afford their prescribed therapy.

In an effort to ensure patient privacy, Choice Assurance and Gammar<sup>®</sup>-P I.V. Assurance are being managed by AccessMED, an independent company based in Overland Park, Kansas. Aventis Behring will not have access to any confidential patient information.

### **Enrolling in Choice Assurance or Gammar<sup>®</sup>-P I.V. Assurance**

Patients who want more information or want to enroll in Choice Assurance can:

- Call the toll-free Choice Assurance Hotline at **866-415-2164**
- Visit **[www.ChoiceAssurance.com](http://www.ChoiceAssurance.com)**

Patients who want more information or to enroll in Gammar<sup>®</sup>-P I.V. Assurance can:

- Call the toll-free Gammar<sup>®</sup>-P I.V. Assurance Hotline at **866-415-2165**
- Visit **[www.GammapivAssurance.com](http://www.GammapivAssurance.com)**

**ALCOHOL INCREASES HEPATITIS C VIRUS IN HUMAN CELLS**

Drinking May Compromise Treatment Success

A team of NIH-supported researchers today reports that alcohol increases replication of the hepatitis C virus (HCV) in human cells and, by so doing, may contribute to the rapid course of HCV infection. The researchers tested the actions of alcohol in HCV replicon - viral HCV-ribonucleic acid or HCV-RNAs that, when introduced into human liver cell lines, replicate to high levels. In separate laboratory experiments they showed that:

- alcohol increases HCV replication at least in part by upregulating a key cellular regulator of immune pathways and function known as nuclear factor kappa B
- alcohol inhibits the anti-HCV effect of interferon-alpha therapy; and
- treatment with the opioid antagonist naltrexone abolishes alcohol actions.

Wenzhe Ho, M.D., and Steven D. Douglas, M.D., Department of Pediatrics, University of Pennsylvania, and the Joseph Stokes, Jr. Research Institute at The Children's Hospital of Philadelphia, and colleagues in the Department of Psychiatry, University of Pennsylvania School of Medicine report their results in the July 2003 issue of "Hepatology" (Volume 38, Number 1, pages 57-65).

Speculating that alcohol somehow promotes HCV expression, the researchers relied on a recently available cellular system for studying the dynamics of virus replication (developed and provided to the investigators by Drs. C. M. Rice, The Rockefeller University, and Christoph Seeger, Fox Chase Cancer Center) to demonstrate for the first time that alcohol enhances HCV replicon expression at both the

messenger RNA and protein levels. In the cell lines used for the study, the research team also showed that alcohol activation of nuclear factor kappa B was responsible for increasing HCV expression. "Although the replicon system mimics only some aspects of HCV replication, we have identified at least a likely mechanism whereby alcohol increases viral load and thus may become an important cofactor in HCV severity," Dr. Douglas said.

"These findings are immediately useful to clinicians for counseling HCV-positive patients about alcohol use," said Ting-Kai Li, M.D., Director, National Institute on Alcohol Abuse and Alcoholism (NIAAA). "For clinical and basic scientists, they raise new research questions, many of which no doubt will be explored using the model and methods introduced today." NIAAA supported the experiments through a grant to Dr. Douglas, whose work also was supported by the National Institute of Mental Health and the National Institute on Drug Abuse (NIDA). The NIAAA and NIDA supported Dr. Ho's work on the study.

HCV is an RNA virus of the flavivirus family that infects about 4 million U.S. residents and produces some 30,000 new infections each year. HCV typically escapes clearance by the immune system and leads to persistent, chronic infection in 70 to 85 percent of infected individuals, of whom fewer than 50 percent respond to interferon-alpha, the HCV therapy of choice. Over the long term, HCV infection can lead to cirrhosis, liver failure, and liver cancer. As a group, HCV-infected individuals are the major recipients of liver transplantation.

Clinicians have long observed a high incidence of HCV infection in heavy drinkers, including those without other risk factors such as intravenous drug abuse or history of blood transfusions. In addition, the virus is more likely to persist in heavy drinkers and to lead to such complications as cirrhosis and liver cancer. Suspected mechanisms for the latter effects include alcohol's capacity to compromise immune function and enhance oxidative stress. The role of alcohol use in HCV acquisition has been more of a mystery.

During the 1990s, several studies reported higher blood levels of HCV in drinkers than abstainers and in habitual than infrequent drinkers. Further, drinking reduction was shown to diminish the number of virus particles in the blood. These observations led Dr. Douglas and his colleagues to pursue the role of alcohol in HCV replication.

Using the same replicon, Drs. Ho, Douglas and their colleagues also demonstrated that alcohol compromises interferon-alpha action against HCV and explored a plausible mechanism for alcohol's role in HCV expression. Alcohol interferes with endogenous opiates, which have a key role in its addictive properties. The researchers found that the opiate receptor antagonist naltrexone, better known for its utility in helping alcoholism treatment patients to avoid relapse, not only blocked the promoting effect of alcohol on HCV expression but also diminished alcohol activation of nuclear factor kappa B in these cells. "These data strongly suggest that activation of the endogenous opioid system is implicated in alcohol-induced HCV expression," the authors conclude.

For an interview with Dr. Douglas, please telephone (215) 590-1978; for an interview with Dr. Ho, please telephone (215) 590-4462. For an interview with NIAAA staff members, please contact the NIAAA Press Office. Publications and additional alcohol research information are available at <<http://www.niaaa.nih.gov>>.

The National Institute on Alcohol Abuse and Alcoholism, a component of the National Institutes of Health, U.S. Department of Health and Human Services, conducts and supports approximately 90 percent of U.S. research on the causes, consequences, prevention, and treatment of alcohol abuse, alcoholism, and alcohol problems and disseminates research findings to science, practitioner, policymaking, and general audiences.

National Institute on Alcohol Abuse and Alcoholism (NIAAA) <http://www.niaaa.nih.gov/>



**AHF**  
INCORPORATED

*The Hemophilia Disease Management Company*

AHF@Inc. 31 Moody Road P.O. BOX 985 Enfield, CT 06083  
800-243-4621 FAX 860-763-7022  
Website: ahfinfo.com E-mail: info@ahfinfo.com

the  
**A.C.C.E.S.S.**  
program

A service provided by Hemophilia Health Services, Inc.

Advocating for Chronic Conditions, Entitlements and Social Services

A team of dedicated experts helping people with hemophilia and related bleeding disorders explore state and federal entitlement programs and associated health insurance coverage issues.



**HEMOPHILIA  
HEALTH SERVICES**  
*...for the human factor.*

1.888.700.7010



Assuring you the very best in customer care speaks to our commitment to your satisfaction.

Therapeutic Care  
**Apex**  
A CURATIVE COMPANY

888.808.7441  
www.apextc.com

31332 Via Colinas, Suite 106, Westlake Village, CA 91362

Novo Nordisk Pharmaceuticals, Inc.

makers of

**NovoSeven®**  
Coagulation Factor VIIa  
(Recombinant)



For more information about NovoSeven®, please call 1-877-NOVO-777 or visit [www.novoseven.com](http://www.novoseven.com)

© 2003 Novo Nordisk Pharmaceuticals, Inc. 126468



Our latest advance in hemophilia treatment

**HISTORY**  
**FUTURE**

is the best of both.

**Baxter**  
*Getting hemophilia under control was never so simple.*

Baxter is a trademark of Baxter International Inc. and is registered in the U.S. Patent and Trademark Office. © 2003, Baxter Healthcare Corporation January 2003

**Coram Hemophilia Services**

1551 B Mercantile NE • Albuquerque, NM 87107  
Tel. 800.365.7378

6 Spring Mill Drive • Malvern, PA 19355  
Tel. 800.992.4091

1803 Tribute Road, Suite B • Sacramento, CA 95815  
Tel. 866.432.2867

CORAM Hemophilia Services



**ARJ Infusion SERVICES**

24/7 pharmacy and nursing Same day delivery

Full range products and supplies Certified infusion nurses specializing in pediatrics

(866) 451-8804 [www.arjinfusion.com](http://www.arjinfusion.com)

**"Where caring is the ultimate factor."**



Working with patients and their families to help support the unique needs associated with hemophilia.

**HEMOPHILIA**



**ACCESS, INC.**  
A CURATIVE COMPANY

1.800.399.RELY  
[www.hemophiliaaccess.com](http://www.hemophiliaaccess.com)

A CHRIST-CENTERED SERVICE



# CAREMARK



Hemophilia Services **1-866-RXCARE-1**

Our specialty pharmacy management and care delivery programs are dedicated to serving the needs of the bleeding disorders community.



**eBioCare**  
A CURATIVE COMPANY

1160 Industrial Rd., Unit 19, San Carlos, CA 94070  
800.411.9888 • [www.ebiocare.com](http://www.ebiocare.com)



## Strength.

There is strength in leadership.

Our nationally recognized patient first programs have established us as a principal provider with payors, government programs, and community organizations.

We are the experts in hemophilia care because it is everything that we do.

Nashville 800.800.4404 • Warendale 800.722.1440  
[www.hemophilialeath.com](http://www.hemophilialeath.com)



...for the *hemophilic* factor.



## HRA

**Hemophilia Resources of America**  
(800) 549-2654 • e-mail: [hra@hrahemo.com](mailto:hra@hrahemo.com)  
[www.hrahemo.com](http://www.hrahemo.com)

**A full service provider of products & services for adults & children with hemophilia & other bleeding disorders.**

## Discover the freedom of 2.5 mL diluent.



© 2003 Bayer Corporation.  
Kogenate® is a registered trademark of Bayer Corporation.  
Printed in USA 1/03



**Kogenate FS**  
Anti-hemophilic Factor (Recombinant)  
Formulated with Sucrose



## NuFACTOR

*At home with your care, off home in your community™*

At NuFACTOR, we care for your community — men, women and children with hemophilia, von Willebrand disease and other bleeding disorders. You can count on us to respond to your diverse needs with our unique network of services and products — delivered directly to your home.

**Specialty Pharmacy Services for hemophilia and other bleeding disorders**

- Low pricing and reliable product availability
- Accurate and reliable home delivery of factor
- 24/7 toll-free and online ordering
- In-stock, our patient safety technology
- Free track systems and notifies patients with/without a refill
- Emergency Medical Card, our complementary emergency center that assures you have crucial medical information at hand in emergencies
- Reimbursement counseling and advocacy
- Community support

800-323-4832 • [www.nufactor.com](http://www.nufactor.com)

## Factor Support Network Pharmacy

*“Founded by families with hemophilia to help the hemophilia community”*



FSN Pharmacy supports the community by donating 10% of its profits to organizations and programs that are identified by our patients as ones helping families with hemophilia and other bleeding disorders.

**(877) FSN-4-YOU** [www.FactorSupport.com](http://www.FactorSupport.com)

## Editorial Committee:

**Michelle Scricca, Chair**  
**Donald Akers**  
**Jan Hamilton**  
**Bob Marks**  
**Mike Morse**  
**Carl Weixler**

# Community Calendar 2003

## September

The **Adirondack "Spin" tacular** will be held on September 13 come rain or come shine. Call Lisa or Carol at 1-518-863-2668 or visit [www.positudes.org](http://www.positudes.org) for more information.

**Aventis Behring Choice** is holding their 6th Annual Calendar Contest. All entries must be received by September 19, 2003. For more information, please contact Aventis directly at 888-508-6978.

**BPAC** meeting has been scheduled for September 18-19 and to held at Hilton Gaithersburg in Maryland. To receive information, call BPAC at 1-202-690-5560.

The **U.S. Conference on AIDS 2003** to be held in New Orleans, Louisiana from September 18-21.

## October

**Hemophilia Federation of America's 2nd Annual Board Retreat** to be held in Lafayette on October 2-5. Board members, if you need any information, call the HFA office.

## October

The **Lone Star Chapter of the National Hemophilia Foundation** honors Loras J. Goedken in "A Night at the Cotton Club", October 17th in Houston, Texas. All proceeds benefit the Lone Star Chapter. For more information, you can call 1-281-861-6644. Everyone is invited to attend.

On October 11th, The **Texas Central Hemophilia Association** will be hosting their "Hike for Hemophilia". To get more information, you can contact them at 1-214-351-4595.

## November

The **American Association of Blood Banks** is holding their Annual Meeting in San Diego on November 1-4. For more information email [meeting@aabb.org](mailto:meeting@aabb.org) or call 1-301-907-6977.

From November 6-8, The **National Hemophilia Foundation** hosts their 55th Annual Meeting in Salt Lake City, Utah. Call 1-800-424-2634 or visit their web site at [www.hemophilia.org](http://www.hemophilia.org).

## December

The **American Society of Hematology Annual Meeting** will be held in San Diego, California from December 5-9. For more information, visit [www.hematology.org](http://www.hematology.org).

**BPAC** holds a meeting on December 11-12. Location will be announced in the next issue.

On December 10th, the **Hemophilia Treatment Center of Las Vegas: Spanish-speaking Clinic** held in Las Vegas, NV Phone: Becki Berkowitz, RN, at 1-702-732-0971.

Are You Registered  
with the Patient  
Notification  
System?

Do you receive timely  
notices about product  
withdrawals or recalls?

Register today by calling  
1-888-UPDATE U.

Now it's easy to stay  
informed.

Please register with this  
confidential service today!

"**Success** is not the key to happiness.  
**Happiness** is the key to success.  
If you love what you are doing, you will be successful."

- Albert Schweitzer -