

Hemophilia Headlines

W I N T E R 2 0 0 2

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Save the Date for the HFO Health Fair — June 1, 2002!

BY LINDA CHARLES

Planning is under way for an in-depth educational health fair on Saturday, June 1, 2002, from 9:00 am to 4:00 pm in Portland (place TBA). Please mark your calendars and plan to attend!

We will have four concurrent programs for adults, targeting the unique needs of each of the following groups:

- Parents and caregivers of newly diagnosed children;
- Parents and caregivers of school-age children;
- Adults affected by bleeding disorders, hepatitis and/or HIV; and
- Women affected by bleeding disorders.

Childcare will be provided for kids 5 and under; educational (yet fun) programs are being designed for kids 6-12 and for youth and adolescents who are 13-18.

Our goal is to meet the varying needs of each group, as well as provide ample time for everyone to spend time together and discuss issues affecting all those in the bleeding disorders community.

26 Health Fair Volunteers Needed!

We anticipate approximately 125 attendees for this all-day health fair, and we'll need lots of volunteers! This might be a good project for a service organization looking for ways to help in the community.

Program Volunteers Needed:

- 8 for kids' program
- 6 for youth/adolescent program
- 4 for registration, day-of-event details
- 8 childcare workers for kids 5 and under

If you know of people who would like to help us out the day of the event, please contact the HFO office at (503) 297-7207 or hfo@easystreet.com.

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President's Message

World AIDS Day Memorial Held

BY LINDA CHARLES

The Oregon Regional Hemophilia Treatment Center at OHSU, with the support of the Hemophilia Foundation of Oregon, held a brief but poignant memorial for the region's people with bleeding disorders who have died of AIDS & HIV Disease. The ceremony was held on Saturday, December, 1 to coincide with World AIDS Day.

Approximately 20 parents, spouses and friends of victims of the Hemophilia/AIDS epidemic gathered in The Meditation Room at Doernbecher Children's Hospital at OHSU for the memorial. The HTC's Dave Oleson and Robina Ingram read aloud the first names of people in the hemophilia community who have died since the epidemic began 20 years ago. A clergyman from Doernbecher shared some brief words of comfort, and a vocalist sang while attendees reflected on the memories of those no longer with us.

After the ceremony, participants gathered in the HTC lobby for refreshments and to visit with friends. The HFO extends a very special thank you to the Hemophilia Treatment Center staff for coordinating the ceremony and helping the community remember these special individuals. Their struggles have helped make today's hemophilia community have access to safer, purer clotting factor, and have moved us a few steps closer to a cure.

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Material provided in this newsletter is for general information only. The HFO neither gives medical advice nor engages in the practice of medicine. The HFO under no circumstances recommends particular treatments for specific individuals, and in all cases recommends you consult your physician or HTC before pursuing any course of treatment.

2001 National Hemophilia Foundation Meeting Worth the Trip!

BY MONICA DICKEY

Our family had the privilege of attending the 53rd annual National Hemophilia Foundation meeting in Nashville last November. The national meetings are a great opportunity to see what other hemophilia groups around the U.S. are doing, and I always find it very rewarding to network with people affected by bleeding disorders from other parts of the country.

Some of the seminar topics we attended included summer camp, issues in the school setting, product politics, gene therapy and hemophilia, sports & fitness, and the First Step program. There were also several "round table discussions," rap sessions and meetings for chapter staff members. Our children also had the opportunity to attend the youth and adolescent program.

One presentation that was very informative was the conference's opening session, which consisted of a multimedia presentation on the scientific and treatment advances in hemophilia over the past 50 years, an overview of advocacy efforts and activism in the bleeding disorders community, and the future of bleeding disorders. I am amazed, fascinated and very thankful to see how far things have come.

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From the Editor's Desk

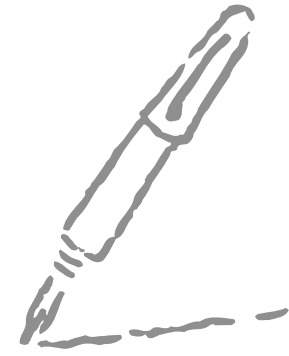
AIDS Day Tribute Prompts Memories of Friends Now Gone

BY MIKE CHARLES

There are times these days, when I'm feeling pretty good, that I can pretty much forget I have hemophilia & AIDS. Then there are events like the December 1st HTC/HFO World AIDS Day Memorial which prompt me to remember those who weren't as lucky to live as long as I have.

The memorial honored many people who enriched my life and the lives of others. In their final days, some of these people died quietly while others made the last months of their lives a crusade to educate about hemophilia, AIDS and blood safety.

If you knew anyone in the hemophilia-AIDS community who is no longer with us, please take time to honor their memory. The sacrifices of these men and women led to the ultra-pure blood products of today. They died with dignity and courage, and they shall not be forgotten.



CONTACT THE EDITOR

To contact Mike Charles, Editor of *Hemophilia Headlines*, his new email address is hemoheadlines@attbi.com

National Meeting

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I found the most informative meeting concerned the politics of blood products (clotting factor concentrates). The format was a panel discussion including representatives from federal agencies, hemophilia treatment centers, various blood product manufacturers, and the NHF. The discussion topics included issues contributing to the recent product shortages, the current supply of blood products and possible ways to avoid such shortages in the future. Even Brian Mahoney, president of the World Federation of Hemophilia, spoke about hemophilia politics from an international perspective. As you can imagine, it was quite an electrically charged meeting.

Because of our son's interest in athletics, the sessions pertaining to sports and fitness were among our favorites. We attended a panel consisting of a Division I baseball player with hemophilia, a Tai Chi expert who also has hemophilia, and a physical therapist knowledgeable about bleeding disorders. This was a very lively, interactive session as people tend to have very strong feelings regarding bleeding disorders and athletic participation. It was also great to hear perspectives from actual athletes who have bleeding disorders.

The other highlight for me was the session on the NHF First Step Program. Although the HFO does not specifically call it the First Step Program, we are in an ongoing collaborative effort with the Hemophilia Treatment Center to get parents of newly diagnosed children with bleeding disorders connected with information and support groups. It was interesting to hear what other chapters are doing in this area.

I encourage anyone who has the opportunity to consider attending a national meeting. It is a wonderful opportunity to meet other people from around the country who are dealing with issues and situations similar to your own.

Board Member Attends NHF Annual Meeting for First Time

BY MONICA GRUHER

I attended this conference as a newcomer to the scene with expectations of meeting many new people and learning much about bleeding disorders. I was not disappointed. I approached my attendance at the conference as not only a consumer and advocate for my own son, but also as a representative of HFO and advocate for the other parents and hemophilia patients in Oregon. As such, I attended sessions and brought back a variety of information that might interest any one of you. I invite anyone who would like further information on these topics (see end of article) to contact me and I will forward the information I have and/or refer you to additional resources.

Attending the conference alone forced me to reach out to the strangers before me who each had their own story and reason for being there. I met men from ages 20 to 75 with hemophilia and obvious other afflictions which had generated from their bleeding episodes. Talking with these men prompted many emotions inside of me, from fear and empathy, to anger and hope. From other parents, I learned of the extreme variations in treatment, specifically the use of prophylaxis, ports, etc. A surprising observation for me was several young toddlers who were wearing helmets most of the day. I learned the eastern half of the U.S. has a much more defensive and aggressive approach to both treatment and protection of the young children with hemophilia.

Below is a summary of a few of the sessions I attended.

Transitions An exploration of how life's developmental phases, particularly childhood to adolescence to young adulthood, affects persons with bleeding disorders and their parents and the role of the HTC throughout this period.

"Product Politics" A panel discussion of the factor shortage. Wow — what a lively discussion! This was a very intense and emotionally charged session. The panel included high-level officials from Baxter, Bayer, Genetics Institute (Refacto), NHF, Centers for Disease Control and the MASAC chair.

- The most provocative discussions involved the official from Bayer. It was interesting to note that Bayer was specifically "uninvited" to the majority of the meeting; however, they were invited to attend this session. The Bayer executive admitted that he was "embarrassed and sorry" and wants to "restore credibility within the hemophilia community." He stated that as of January 1, 2002, they expected to be in a position to begin forecasting production of Kogenate FS but that they were still only expecting to be a "supplemental supplier" of factor in Quarter 1 with "normalization of supply by the end of Quarter 2." These statements were received with great skepticism by many in the large crowd and there were some very confrontational challenges to these predictions based on last year's consistently missed production target dates. Laureen Kelley (noted author of hemophilia books) was in attendance and has followed up with a recent issue of her publication The Parents Exchange Newsletter (PEN) dedicated to discussing the factor shortage.

I learned the eastern half of the U.S. has a much more defensive and aggressive approach to both treatment and protection of the young children with hemophilia.

- The Vice President from Baxter mentioned their expectation to be licensed in the U.S. in early 2003 for a third generation recombinant product. He said it was currently in clinical trials. He also indicated that all facilities were running at maximum round-the-clock capacity and that it takes the company approximately 6-7 years to get a new production facility up and running through the FDA approval process.
- The Group Marketing Director from Genetics Institute said that the St. Louis plant will increase U.S. factor availability and they expect regulatory approval in 2002. GI is also running at maximum capacity.
- Dr. Glenn Pierce, NHF President-elect, urged consumers to continue to conserve factor usage as many have been doing all year. He indicated the NHF is working with the emergency factor task force recently created to address distribution during a national crisis, attack, or other event. He warned that complacency is dangerous!

Dr. Glenn Pierce, NHF President-elect, urged consumers to continue to conserve factor usage as many have been doing all year.

A Legislative Update on the patient bill of rights, insurance reform, direct access, insurance caps, etc. The bottom line on this one was disappointing, but not surprising. They expect to get something passed with the patient bill of rights, but with the legislative focus diverted to the war on terrorism, they told us not to expect much this year in the other areas.

Articles and other information I picked up at the conference:

- Gene Therapy Updates
- Insurance Reimbursement Issues
- Prophylaxis and Sports
- Making the Transition: Pediatric to Adult Care
- Weighing the Options on Central Venous Access Devices

Also, there are many excellent books and workbooks available through the NHF HANDI publications organization on almost any topic you can imagine. Call 1-800-42-HANDI to order copies. You can also contact me through the HFO office to discuss topics or information in this article.

In all, the trip was very worthwhile and extremely educational, and I appreciated the opportunity to represent the HFO at the conference.



Family Focus

Parents' Support Group

BY PATINA FIEKEN

Our last support group meeting was held January 8. We were delighted to have a new family join us for the first time. Our discussions included ports, school and this summer's HFO camp. The children had a great time playing on the many play structures and on the rubberized flooring.

Our next meeting will be March 5, 6:30 pm at the Rainbow Play Systems in Tigard. I look forward to seeing more new faces! If you have any questions or comments, you may contact me at (503) 625-6508 or patinaf@aol.com.

2002 Meeting Dates (all at Rainbow Play Systems, 6:30-8:30pm)

- March 5
- May 7
- July 2
- Sept. 10
- Nov. 5

E-MAIL!

If you would like to receive updates, medical recall information, meeting notices and other time-sensitive information via e-mail, please send your e-mail address to hfo@easystreet.com

Summer Whitewater Rafting Trip!

If you're between the ages of 13 and 21, affected by a bleeding disorder, and love to camp and whitewater raft, read on!

Planning is under way for an overnight youth raft trip in mid-July. This is a joint event organized by the Puget Sound Blood Center, Hemophilia Foundation of Washington, Oregon Hemophilia Treatment Center, and Hemophilia Foundation of Oregon, and is being funded through a grant from the NHF. We haven't yet determined which river you'll be rafting, but we'll make it as centrally located as possible for those coming in from the far corners of the two states!

Watch your mailbox for an event notification with all the details!

Time to Re-Examine Hemophilia Triage Policies

A Parent's Worst Nightmare Sends a Wake-Up Call to Emergency Room Staffs Across the United States

BY WILLIAM SCHUMACHER, MD, FACEP

An incident took place recently in a hospital emergency department was brought to my attention recently by Jan Hamilton, Executive Director of the Hemophilia Federation of America, an advocacy group which promotes better understanding and treatment of this rare bleeding disorder.

The incident involved a 14-year-old boy with severe factor VIII deficient hemophilia who was experiencing a potentially dangerous attack of hematuria (blood in the urine). While attempting to register his son at the ER, the boy's

Triage Policies

continued from previous page

father was informed by the triage nurse that it would be two hours before the boy could be seen. The father explained the boy's condition again, and was again told of the two-hour wait. The father then requested a well-lit place within the waiting room or the hall where he could infuse his son himself. For the third time, he was told there would be a two-hour wait. In growing consternation, the father asked if he could infuse his son in a well-lit section of the hospital's parking lot, and was told he could suit himself.

While performing the infusion by the headlights of an ambulance, the father managed to attract the attention of emergency services personnel who, realizing the urgency of the situation, came to his assistance. Once the boy was infused, he and his father returned to the ER and waited the stipulated two hours. The father was then told that he had done all that was necessary and could go home.

Had the father not brought fVIII concentrates and infusion equipment with him, and known how to use it, this encounter could have ended with grave consequences for the patient, as well as the hospital. Because hemophilia is rare (there are approximately 20,000 individuals with hemophilia in the U.S.), some ER personnel are unfamiliar with the potential severity of the disease and the necessity for timely treatment.

This incident leads me to question current emergency room triage policies in relation to hemophilia. The Hemophilia Federation of America strongly recommends an industry-wide revision of triage policies. According to the concerns of the HFA, The Schumacher Group has developed guidelines to heighten awareness of the risks associated with severe bleeding disorders. Among the guidelines:

- A history of hemophilia is an indication for emergent (immediate) evaluation, regardless of the individual's complaint.
- It is of particular importance for caregivers to listen to the patient/family. Persons with hemophilia as a whole are highly educated about their bleeding disorder and often know more about treatment than some health care professionals.

[Reprinted from the October 2001 issue of Emergency Physicians Monthly, a publication with over 20,000 subscribers nationwide.]

HAPPY BIRTHDAY, CAMPERS!

JANUARY

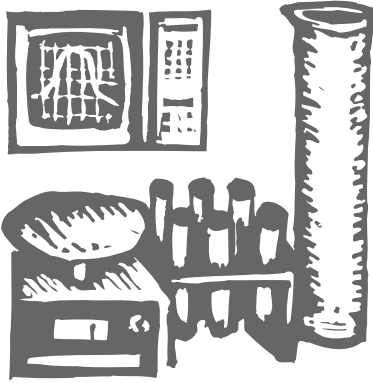
Alex Burden	1/27
Dimitri Cacouris	1/3
Joey Coffin	1/23
Josh Hall	1/15
Tyler Hargett	1/23

FEBRUARY

Eddie Charron	2/27
Alex Christiansen	2/2
Alex Ell	2/6
Michael Glenzer	2/1
Nathan Oleson	2/11
Ben Puckett	2/24
Joseph Ransom	2/6

MARCH

Josh Bulfinch	3/6
Ben Coatney	3/8
Raymond Winn	3/28



News from Industry

RESERVE YOUR BASEBALL TICKETS TODAY!

Reservations can be made through the Aventis Behring Choice Center toll free number at 1-888-508-6978. Tickets cannot be obtained through the HFO office, so be sure to call AB and reserve your space today!

Questions? Call the AB representative, John Self, at (503) 702-1974.

“Take Me Out To The Ballgame” – March 29, 2002

It may still be winter, but major league baseball spring training is right around the corner. Aventis Behring and the Aventis Behring Choice program would like to invite you to a fun-filled day at PGE Park and “Getting In The Game” with former Detroit Tiger Corey Parker, followed by an exhibition baseball game between the San Diego Padres and the Seattle Mariners. Corey will be on hand to talk about his experience in playing major league baseball while managing his hemophilia, as well as sharing tips on stretching and warm up exercises and autographing baseballs for all.

When: Friday, March 29, 2002

Where: PGE Park, Portland, Oregon (formerly Civic Stadium)

Fred Meyer Family Deck (enter gates on 18th & Morrison)

Registration begins at 9:30 am, “Getting In The Game” program at 10 am, with lunch to follow prior to the game. After lunch head for the reserved seats behind the third base dugout or down to the field for more autographs from your favorite players such as Ichiro and Brett Boone.

Tickets are limited and are on a first-come, first-served basis. For your convenience, Portland’s light rail system is free all day with your ticket.

vonWillebrand’s Dinner Forum – 6-8pm, Mar. 26, 2002

If you or someone you know are affected by vonWillebrand’s (vWD), you won’t want to miss this educational dinner forum on Thursday, March 26, at the Downtown Marriott from 6:00-8:00 pm! Aventis Behring has arranged to have Jill Moberley, a woman with severe vWD, visit Portland to share her experiences, including the process of getting a proper diagnosis and treatment, and what she’s learned along the way.

Reservations can be made by calling the AB representative, John Self, at (503) 702-1974 (by Wednesday, March 20).

Attention, Class of 2002!

Hemophilia Health Services, Inc. Announces 2002 Memorial Scholarship Program

Hemophilia Health Services (HHS) is now accepting applications for its 2002 Memorial Scholarship Program. The one-year academic scholarships range from \$750 or more and are awarded annually to U.S. citizens living with hemophilia, von Willebrand disease, or any other factor deficiencies. Applicants must be enrolled full-time at an accredited, non-profit college, university or vocational/technical school in the United States.

May 1 is the application deadline each year. Application material and more detailed information can be obtained by contacting the HHS Scholarship Committee at (800) 800-6606, x5175, www.HemophiliaHealth.com, or email Scholarship@HemophiliaHealth.com

Aventis Behring Voluntarily Recalls One Lot of Recombinant Factor VIII

January 15, 2002, NHF Medical Advisory #389

Aventis Behring, LLC is voluntarily recalling one lot of Helixate FS Anti-hemophilic Factor (recombinant) because the lot failed to meet potency requirements when stored at room temperature. This recall is based on the results of potency testing following 9 weeks of storage at room temperature. Vials kept under continuous refrigeration are not affected by this recall.

Lot Number	Expiration Date	Assay Amount
372J033C	04 September 2002	639 IU/vial

If you have any unrefrigerated vials with this lot and assay number, contact the company or HTC where this product was purchased immediately. If you have any questions, please contact Customer Support at Aventis Behring at 1-800-504-5434.

Aventis Behring Helps Families with Bleeding Disorders Pay for Quality of Life Expenses Not Covered by Insurance

Aventis Behring L.L.C. announced in October 2001 the launch of the Aventis Behring Choice Quality of Life Patient Grant Program, a pilot program designed to help relieve the financial burden of families affected by bleeding disorders.

With initial funding of \$50,000, the program can provide at least 100 grants of up to \$500 each to help families pay for quality of life items associated with managing a bleeding disorder not covered by insurance. Quality of life items intended for coverage under the program may include childcare, travel, dental services and medical devices.

Who is Eligible to Receive a Grant?

The Quality of Life Patient Grant Program is open to all Members of Aventis Behring Choice, a free program available to everyone in the bleeding disorders community. It was developed in an effort to help people with bleeding disorders and their families manage the daily challenges of living with a bleeding disorder.

To receive a Quality of Life Patient Grant Program application, individuals can call the Aventis Behring Choice Member Support Center at 1-888-508-6978. If someone is not already a Member of Aventis Behring Choice, they can enroll when they request their application.

Information contained in "News from Industry" is provided for the benefit of HFO members and supporters. Publication of any material does not imply the HFO's endorsement of any particular activity, product or service.

PATIENT NOTIFICATION SYSTEM

Do you want to be notified directly regarding market withdrawals of hemophilia-related medications, including recombinant and plasma products? If so, please sign up with the Patient Notification System. The System is confidential, time-sensitive, administered by an independent third party. There is no charge to be enrolled in this service. To register, please call 1-888-UPDATE-U or log online to www.notify1.com.



Medical News

CJD Vaccine in the Works

From NHF E-notes, October 2001

Researchers are optimistic concerning a vaccine for CJD. One version of this disease is bovine spongiform encephalopathy, more commonly known as mad cow disease. People with CJD suffer a rapid decrease of mental function and movement abnormalities caused by damage to the tissues of the brain, usually leading to death within six months of the onset of symptoms.

Currently, studies on mice are being conducted and progress has been made against this fatal brain-wasting disease. Research is focusing on genetically altering the immune system to fight abnormal versions of proteins called prions, which are believed to trigger a number of degenerative brain diseases.

Scientists working on the project caution, though, that it will be quite a while before there is a ready-made vaccine for the disease.

FDA Approves Combination Therapy Treatment of Hepatitis C

From GLHF News Brief, November 2001

Some of the estimated four million Americans infected with the hepatitis C virus (HCV) may have new hope for treatment. The U.S. Food & Drug Administration (FDA) has approved Peg-Intron (peginterferon alfa-2b) for use in combination therapy with Rebetol (ribavirin) for the treatment of chronic HCV. Patients with compensated liver disease who have not been previously treated with interferon alpha and are at least 18 years old are eligible for this combination therapy treatment.

The Peg-Intron and Rebetol treatment regimen is the first and only pegylated interferon-based combination therapy approved in the U.S.

A major benefit of the therapy is that it's easy to use. The dosing is weekly, as opposed to the three times a week dosing of standard interferon. HCV infection contributes to the deaths of an estimated 8,000 to 10,000 Americans each year. The CDC reports that HCV-associated end-stage liver disease is the most frequent indication for liver transplantation among U.S. adults. Among persons with hemophilia, many individuals are coinfecting with HIV and have advanced liver disease. Improved treatment is urgently needed, and Peg-Intron and Rebetol represent new choices that should be discussed with a person's physician.

Membership dues, memorials and contributions

The Hemophilia Foundation of Oregon thanks the following individuals and companies for 2002 dues payments and other donations. Dues are \$20 for individuals and \$35 for families, and are payable each calendar year. This list reflects donations received as of January 15, 2002.

Fred and Patty Adams
Mike and Sharon Amos
MaryLou Anderson
Michael Bernstein and Tina Baskin
Gloria Brogan
Mike and Linda Charles
Dave Chvatal and Marci Kociemba
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IN MEMORY OF:

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Mike & Sharon Amos

In Memory of Michael Lofland:

Joan Lofland

In Memory of Wayne Palmer:

Roger Norman

In Memory of Barry Kurath:

Amy Pool

In Memory of David Riker:

Mitch & Rose Mitchell

HONORING:

In Honor of Eddie Charron:

Bill & Susan Gardner

In Honor of Mike & Linda Charles:

Doris Greenfield

In Honor of family & friends:

Anne Pagenstecher

In Honor of Bill & Nancy Worthington:

John & Mary Pelton

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Wes Wolf

CORPORATE CONTRIBUTIONS:

Apex Therapeutic Care, Inc.
Aventis Behring
Gentiva Health Services

Donations to the Hemophilia Foundation of Oregon are tax deductible and can be charged to your VISA or MasterCard. For more details, call Monica Dickey at 503-297-7207.

Dates to Remember

Parents' Support Group March 5, 2002

Aventis Behring's vonWillebrand's Forum March 26, 2002

Aventis Behring's Baseball Day March 29, 2002

HFO Health Fair June 1, 2002

Youth Raft Trip – watch for details! July 2002

2002 Summer Camp! August 4-10, 2002

National Hemophilia Foundation's 54th Annual Meeting Oct. 31-Nov. 2, 2002
www.hemophilia.org **Orlando, Florida**



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Address correction requested