

# Hemophilia Headlines

S P R I N G 2 0 0 1

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## HFO Town Hall Meeting discusses clotting factor shortage

Approximately fifty HFO members, representatives from industry and health care providers gathered Saturday, April 28, to discuss the current recombinant clotting factor shortage that has affected many in our community. The meeting allowed hemophilia-affected individuals and families to ask direct questions to representatives from Bayer Corporation, Aventis Behring, Baxter Healthcare, Alpha Therapeutics and Genetics Institute.

Meeting attendees were especially interested in hearing from representatives of Bayer, who discussed why the plant shutdown occurred. The company's representatives told meeting attendees Bayer expects to begin releasing a small amount of product in May, with hopes to return to full capacity by mid-summer.

Also attending the meeting were representatives from home care companies and local hospital-based pharmacies, including Care for Life and Providence Home Infusion. In addition, the staff from the Oregon Regional Hemophilia Treatment Center was on hand to discuss how they have handled the current supply problem.

### *What can consumers do to help alleviate the current shortage?*

One immediate step each of us can take is to write a letter to Kathleen McGee at the Office of Pharmacy Affairs, letting her know the direct impact the recombinant factor shortage is having on our family's health. We need to tell Ms. McGee we are having great difficulty obtaining recombinant factor, and using less pure products is not a risk our community members are willing to take (especially after the history with the hepatitis- and HIV-infected factor in the 1980s). Be sure to tell your own story, describing how having access to the safest clotting factor has helped you or your son live a more normal life.

We are told the Office of Pharmacy Affairs cannot investigate this situation until they are told directly by our community there is a problem. Your letters, calls and e-mails do make a difference — make sure your voice is heard!

Ms. Kathleen McGee  
Office of Pharmacy Affairs  
4350 East West Highway, 10th Floor  
Bethesda, MD 20814  
800-628-6297  
opastaff@hrsa.gov

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OF OREGON**

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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.

# President's Message

## "Community Connections"

BY LINDA CHARLES

On April 28, I had the pleasure of facilitating the HFO's Town Hall meeting to discuss the monoclonal factor shortage. It was powerful to see representatives from the pharmaceutical companies, the Oregon Hemophilia Treatment Center, pharmacies, home health care companies, and members of the hemophilia community all come together to share knowledge, ask questions, socialize, and gain strength during this frustrating factor shortage.

Pharmaceutical reps flew in from other states; community members came from as far away as Southern Oregon, Seattle and Idaho. I met community members I had never met before, reconnected with people not seen in many years, and talked with some I see on a more regular basis. Looking around the room, it was clear others were doing the same thing.

It reminded me exactly why I got involved with the HFO in the first place—the friendships and connections made in this community are very real. Even when it's been years since I've seen people, the bonds that were formed at a past retreat or meeting are still there—it's as if no time has passed at all. Those bonds don't easily happen, but it was obvious the bonding process was there yesterday. New bonds being formed as introductions were made and first handshakes happened, and old bonds being renewed as warm hugs were shared by fast friends.

I again urge those of you who have not connected with others in the hemophilia community for a while to look for an opportunity to do so. We have a strong Board of Directors leading our efforts, and have a renewed energy and enthusiasm for improving the HFO's programs. When you next see the individuals in this issue's Board Profiles, please thank them for their time, energy and commitment—they're all doing an admirable job! And think about how you can reconnect—we'd like each of you to be an integral part of this dynamic community!

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## WinterHawks Family Event

Another great time was had by all at the Portland WinterHawks hockey game on Friday, February 9. The event, co-sponsored by a grant from Bayer and Genetics Institute, was attended by over 70 members of the hemophilia community.

This was a great opportunity for our families to get together in an informal, fun atmosphere. It was also a great place for some of our campers and counselors to get reacquainted and get excited about another great year at Camp Tapawingo.

Although the WinterHawks lost, everyone still enjoyed watching an exciting game and getting a chance to get together. Thanks again to Bayer and Genetics Institute for helping us sponsor this great family event!

# College bound? Scholarships abound!

Several scholarships are available for persons with bleeding disorders wishing to attend college; some of the scholarships are even available to family members. Below is a partial listing of scholarships. For a more detailed listing of scholarships for persons with bleeding disorders and/or their family members, contact the National Hemophilia Foundation (800-42-HANDI) or The Hemophilia Federation (800-230-9797).

## **The Hemophilia Federation of America**

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<i>Deadline</i>	June 1, 2001
<i>Award amounts</i>	Approximately three \$1,500 scholarships.
<i>Eligibility</i>	Any person with a bleeding disorder (hemophilia or vWD) attending any accredited 2- or 4-year college, university or vocation/technical school in U.S.
<i>More info</i>	Hemophilia Federation of America 800-230-9797

## **The Kevin Child Scholarship**

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<i>Deadline</i>	June 30, 2001
<i>Award amounts</i>	\$500 and \$1,000
<i>Eligibility</i>	Any person with a bleeding disorder
<i>More info</i>	Karen Parchment, Nat'l Hemophilia Foundation 800-42-HANDI, x3748

## **The Eric Delson Memorial Scholarship**

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<i>Deadline</i>	July 1, 2001
<i>Award amounts</i>	Three \$2,500 awards to students in college, plus one \$1,500 award to a student attending a private school, grades 7-12.
<i>Eligibility</i>	Any student with a bleeding disorder
<i>More info</i>	Caremark 800-225-5967

## **The Mike Hylton & Ron Niederman Memorial Scholarships**

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<i>Deadline</i>	July 15, 2001
<i>Award amounts</i>	Five \$2,000 scholarships
<i>Eligibility</i>	Any person with a bleeding disorder or their family members wishing to pursue college education
<i>More info</i>	Sharon Hylton, Factor Support Network Pharmacy 877-FSN-4-YOU

## **Genetics Institute, Inc.**

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<i>Deadline</i>	July 15, 2001
<i>Award amounts</i>	\$5,000 awards for college; \$1,000 awards for voc/tech education
<i>Eligibility</i>	Any person with Hemophilia A or B
<i>More info</i>	Genetics Institute, Inc. 800-841-6871

## **CONTACT THE EDITOR**

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

## **E-MAIL!**

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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.

# Meet your Officers and Board Members



Linda Charles

President **Linda Charles** got involved with the HFO shortly after meeting Mike Charles eight years ago. "I knew very little about hemophilia and other bleeding disorders back then, but my knowledge has definitely grown by leaps and bounds." Linda has attended many retreats, educational workshops, trainings and social events, and has volunteered on numerous committees. "I am very pleased to be working with the exceptional individuals on the HFO board." Linda has also worked for the law firm of Davis Wright Tremaine since 1988, where she handles the advertising for their 11 offices.



Dave Worthington

Vice President **Dave Worthington** has been involved with the HFO for many years. He served as HFO president the past five years, and also previously held the position of Vice President in 1995. Dave and his wife Pam have two children, Piper, 15, and Stewart, 13. Dave and Pam have a long involvement with the HFO's Camp Committee. Dave works for Dennis' Seven Dees Landscaping.



Monica Dickey

Secretary **Monica Dickey** first got involved with the HFO shortly after her son Mitch was diagnosed with hemophilia. After attending a couple of women's support group meetings, she and her husband Tom became involved helping organize the HFO picnic. They then branched out to help with the Camp Committee. Tom and Monica have shared a board position, and Monica has served for three years as HFO Secretary. Her involvement with the Hemophilia Foundation of Oregon stems from a desire to be more directly involved and to give something back to the hemophilia community. Besides their son Mitch, 6-1/2, Monica and Tom have a 3-1/2-year-old daughter, Alli. Monica also manages the HFO office, and in her spare time enjoys spending time with her family.



David Chvatal

Treasurer **David Chvatal** was recruited to serve as HFO Treasurer in 1996 by a friend of his wife, Marci. Marci Kociemba was then-president of the Boeing Employee Good Neighbor Fund, and she heard through former HFO president Gail Liberman that the HFO needed a treasurer, preferably a CPA who could help with necessary audits and tax filings. "I was glad I could be of assistance, and that I was able to save the HFO some outside accounting fees," he says. Dave received his CPA license in 1988 and has an accounting practice in SW Portland. He and Marci have been married 17 years, and they enjoy bird watching and volunteering at The Oregon Zoo.



Sharon Amos

Board member **Sharon Amos** recalls becoming active with the HFO very shortly after her daughter, Monica Dickey, had Mitch. "I decided to join the board so our family would always have firsthand knowledge of what was going on in the hemophilia community," she says. Sharon has been on the HFO's education committee, has helped plan the annual meeting for several years, and has put together many successful HFO family outings. Sharon works part-time as a bookkeeper, and when she's not volunteering for the HFO board she and her husband Mike enjoy gardening and outdoor activities.



Mike Charles

Board member **Mike Charles** says he has been involved with the Hemophilia Foundation for "essentially my whole life." He credits growing up at a time when there were no factor concentrates as helping him to take responsibility for his body, and his bleeding, at an early age. "Until I was seven or eight, the only treatment for a bleed was to rush to a hospital and receive fresh frozen plasma," he says. Mike has worked full-time for a local media company since 1989, and began dating his wife Linda in 1992. The two were married in 1998. Linda now serves as HFO President, and Mike is a board member. He also has edited Hemophilia Headlines since 1994.

Board member **Patina Fieken** has a mild bleeding disorder (vonWillebrand's Disease) which runs in her family—both her husband and one of her sons have a mild blood clotting problem, and she has a 3-year-old with a severe form of the disease. Patina contacted the HFO to be more involved in the bleeding disorders community and to meet others who have experienced similar circumstances. Patina and husband Tim says that their family of four "always seem to be busy, between school, soccer and outdoor activities." Patina has chosen not to work outside her home. She enjoys camping, horseback riding, 4-wheeling, and spending time with her children, family and friends.



Patina Fieken

**Monica Gruher** has been invited to join the Board, and we hope she will become a full-fledged board member in the next month or two. Monica has a son, Benjamin, who is 20 months old. He was diagnosed with severe factor VIII deficiency nine months ago at the OHSU Hemophilia Treatment Center. Professionally, Monica has earned both an MBA degree and CPA license. She has a consulting practice assisting small- and mid-size companies with financial/executive strategies. Monica and her husband Jim live in Tigard, and in their spare time the family enjoys outdoor activities, music events and sports.



Monica Gruher

**Jim and Marj McAllister** are helping out once again with the HFO after a hiatus. The couple had two sons with hemophilia, both of whom have passed away. Marj and Jim first became involved with the local hemophilia community in the late 1960s, when the HFO was known as the Oregon Chapter of the National Hemophilia Foundation. The McAllisters were part of a core group of families in the early 1970s who lobbied for state legislation that established the Adult Hemophilia Assistance Program. Marj is a teacher; before retiring, Jim owned a small business. In addition to their involvement with hemophilia, both remain active with Kiwanis and The Doernbecher Foundation.



Jim and Marj McAllister

New to the board, **Nicole Moles** decided to get involved because of her friendship with Linda Charles and her desire to assist in the community at large. "I saw a way to do that through my current skills as a web designer and publication editor. This is my first involvement with the HFO and I'm pleased to be contributing to a worthy cause." Nicole currently works full-time at Davis Wright Tremaine as their internal communications coordinator, producing a weekly news source for DWT's 11 offices. This job includes responsibility for the development, design and content of the website and relaying the goals and culture of the firm. Nicole also says she is an avid reader, mediocre golfer and forever interested in furthering her communications skills, particularly through multimedia formats.



Nicole Moles

**Gregory Thomas, MD**, Board Liaison to the Oregon HTC, is in his third year as Medical Director of the Oregon Regional Hemophilia Treatment Center. Some may know Dr. Thomas from when he previously practiced pediatric hematology/oncology here in Portland at Kaiser-Permanente. Dr. Thomas served his residency and fellowship at the University of Utah Medical School. He has two sons. His wife, Martha McMurry, is a research dietitian at OHSU's Clinical Research Center. In his spare time, Dr. Thomas enjoys hiking, backpacking, skiing (both downhill and Nordic), and walking.



Gregory Thomas, MD



# Family Focus

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This new feature will provide an avenue for parents and caregivers to get practical answers to some of the questions that arise when raising a child with a bleeding disorder. Each newsletter we will pose a question and solicit answers from our own community members! Who better to share experiences, successes and lessons learned than those who are living it?

## *Summer 2001 issue question:*

**Do you allow your school-age child with a bleeding disorder to participate in organized sports? What other limits, if any, do you impose?**

To submit an answer to the Summer 2001 issue question, please send an email to [hfo@easystreet.com](mailto:hfo@easystreet.com) or mail your response to the office by July 15, 2001. Please indicate whether you wish us to include your name or whether you would prefer to remain anonymous.

## *Winter 2001 issue responses:*

**How and when did you or your child learn to home-infuse? What are the benefits or drawbacks to having this ability? If your child self-infuses, does he keep clotting factor at school?**

*Bruce Dessellier is a 43-year-old with hemophilia:* I was taught to self-infuse by Diane Vincent, RN, at the CDRC (then CCD) when I was 18 (about 1975). In my case the benefits were dramatic. Growing up I missed an average of 20-30 school days each year. I typically spent up to two weeks a year in hospitals. Once I started self-infusing, lost time for school and then work dropped to a few hours per year instead of days. From 1976 through 1994 I had no overnight hospital stays, other than once for elective surgery (knee replacement). When I was young, conventional surgery was unthinkable, and I used to give fits to my dentist with oral bleeding even for simple cleanings. Without factor concentrate my life would have been vastly different with limited choice of jobs and travel. In my case I don't keep factor at work. If I feel a bleed starting I head home to infuse. My employer is very accommodating on this issue. I always have factor with me when I travel overnight. The reasons why I don't keep factor at work are small, but I'm concerned about exposure to my fellow employees about sharps and hepatitis risks.

*Anonymous:* My husband and I started home infusion when our son was 15 months old. We haven't had any drawbacks to home infusion, only positive experiences. We have had very few emergency room visits due to hemophilia — only two in the last six years. We do not keep clotting factor at school. We infuse prior to going to school. We also live fairly close to the school and I am always reachable in case of an emergency.

*Mike Charles is a 39-year-old with hemophilia:* I was trained for self-infusion when I was 13 by Sue Underwood at what is now the Hemophilia Treatment Center. When home infusion began, they were training kids as young as

## NEW SCHEDULE FOR PARENT SUPPORT GROUP MEETINGS!

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Mark your calendars! The Parent Support Group will meet on the first Tuesday of odd months from 6:30-8:30 pm at the Rainbow Play Systems in Tigard; dinner and beverages are provided. Our next meeting is Tuesday, July 1. Please contact Patina Fieken at (503) 625-6508 or [patinaf@aol.com](mailto:patinaf@aol.com) to RSVP.

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eight and nine. My experience with home infusion was pretty identical to Bruce's: home infusion opened up the world to me. My family no longer had to plan vacations around emergency rooms. In the early 1970s, my family drove around Oregon's most scenic sites, and we knew the location of every emergency room from Portland to Eugene and Roseburg, then to Crater Lake, Burns, Bend, John Day and Hood River. It took LOTS of planning. But once factor concentrates became available, we could, quite literally, take the ER with us in the form of clotting factor. One of the proudest moments of my life was my first backpacking trip at age 13 — four days around the Three Sisters Wilderness Area. I was so excited, I didn't even bleed! But I had the factor with me if I had needed it. I always kept two doses of clotting factor in the nurse's office. Why take the chance, since I knew how to infuse myself? However, I had to use a lot of self-control to not suddenly develop an ankle bleed when I wanted to get out of a class or two. Our nurse's office was really comfy at Gresham High School, and the nurse never did figure out why sometimes it took me a real...long... time... to push that factor into my arm. Nowadays, I always carry 2,000 units of factor, plus all the infusion supplies, in a portable medical kit in my car. During the warm months, I transfer the medical kit to a cooler. That way, if I injure myself at work, I can infuse within minutes.

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## NEWS FROM THE CAMP DESK

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Planning for Camp Tapawingo 2001 is well under way! We have another exciting year in store for our campers. While we have many camper applications turned in, we still have a few spaces left for any of those who have not yet mailed yours in. There are also scholarships available for those needing assistance.

Once again, camp is open to all children with bleeding disorders who are between the ages of 6 and 15. To apply for a counselor in training position, applicants must be 16 by August 1, 2001. We still have some counselor positions available, so if spending a week with a great group of kids sounds good to you, give Monica a call in the HFO office at (503) 297-7207 or e-mail her at [hfo@easystreet.com](mailto:hfo@easystreet.com) and she will send you an application.

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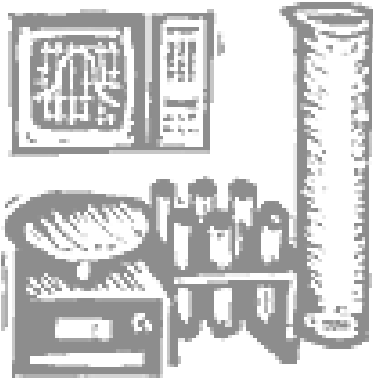
## Region VIII and X Annual Meeting

BY MONICA GRUHER

Representing Oregon consumers, I was among the many consumers, physicians, nurses, physical therapists and social workers who attended the three-day conference in Sedona, Arizona in March. Many important issues impacting all the represented groups were discussed and debated. My experience at the meeting made me realize the extreme importance of all of these groups collaborating together with information, rather than only in our own circles.

The topics included gene therapy updates, adolescent transition, new concentrates, supply shortages, inhibitor issues, and the immune tolerance study. One of the more lively and informative sessions was the consumer discussion on the funding received by HTC's from the Maternal Child & Health Bureau. The funding has not been increased in many years and there is ongoing concern about the continuance of separate funding for hemophilia in the future.

Another lively session regarded the clotting factor shortage. It is a very frustrating and scary situation which could reoccur in the future. The National Hemophilia Foundation (NHF) is currently working with the FDA and the manufacturers to obtain information on the shortage status and how it can be resolved.



## News from Industry

### Reserve your tickets now for Aventis Behring's "Family Day at the CART Races"

Sunday, June 24, 2001

#### Portland International Raceway

Interested in seeing the world's best drivers square off on a championship road course, driving the fastest cars in racing?

Through their "Victory Lane Kids" program, Aventis Behring is sponsoring a family day at the Freightliner/GI Joe's 200 CART (Indy Car) Races at the Portland International Raceway on Sunday, June 24, 2001. The event is one of the most popular on the CART circuit, with drivers from around the world in competition. Past winners of the GI Joe's 200 include Michael Andretti, Al Unser, Jr., Emerson Fittipaldi, and other of racing's biggest names. Top speed for these cars approach 240 mph!

The day's events begin with breakfast pastries being served at the Aventis Behring Chalet at 9:00 a.m. Also included is a buffet lunch before the race begins at 1:00 p.m.

Tickets are available on a first-come, first-serve basis by calling the **AB Choice Center** at **1-888-508-6978**. Tickets cannot be obtained through the HFO office, so be sure to call and reserve your space today!

**Call now to reserve  
your race-day tickets!  
1-888-508-6978**

### How are Hemophilia products produced? Take a factory tour!

To help celebrate its 20th year, Aventis Behring is sponsoring one person from each hemophilia organization to travel to Kankakee, Illinois to take part in a series of events culminating in the Hemophilia Foundation of Illinois Hemophilia Walk-a-thon on Saturday, June 9, 2001. Monica Gruher has graciously agreed to be the HFO representative!

The activities will begin in Chicago (a short distance from Kankakee) on Thursday, June 7. Friday morning, the representatives will be taken on a tour of the Aventis Behring plant for a behind-the-scenes look at how its hemophilia products are produced. Friday evening's activities include a steak fry at a local Sportsman's Club and a cocktail reception back at the hotel. The walk-a-thon will be held Saturday, and the representatives will return home Sunday, June 10.

#### Pacific Northwest Tour

If you are interested in an opportunity to tour the Kankakee plant, please contact John Self at Aventis Behring (1-888-508-6978). Aventis may be able to sponsor a separate group from the Northwest area at a later date, depending on interest shown by our community!

### SUPPORT THE HFO!

If you would like to make a pledge to support Monica Gruher's participation in the 8-mile Walk-a-thon, please call or email the HFO with the amount of your pledge (typically a specific amount per mile). All pledges will directly benefit our programs and services!

# News from the Treatment Center

## New program helps emergency care providers treat Hemophilia

A new project co-sponsored by the American College of Emergency Physicians (ACEP) and the American Academy of Pediatrics (AAP) could help solve the problems families with children with unique and chronic medical conditions face in emergency rooms. Emergency rooms may not have essential information about the “special needs” of children with rare conditions. There can be difficulties communicating the technical aspects of hemophilia or other medical problems, especially if there is a language barrier.

The ACEP and AAP have developed a one-page, two-sided form called “Emergency Information for Children with Special Health Care Needs.” The pediatrician, pediatric subspecialist or other primary care provider completes the form that will outline critical information in a concise, organized manner. The parents then provide copies of this information and distribute it to school teachers, school nurses, relatives, child care providers, neighbors and babysitters. If headed to the emergency room, the information form is given to the EMS personnel or the ER staff. Pediatricians, family practitioners, and other health care and medical systems can also save a copy in their records.

The MedicAlert Foundation is also collaborating on this project and they will store this information for children registered with the program. Parents can provide a copy of the completed information form to MedicAlert. A child wearing a MedicAlert bracelet will prompt an emergency provider to call the toll-free number stamped on the bracelet. Information on an individual child will then be available to any health care provider 24 hours a day.

Let the Hemophilia Treatment Center know if you want to enroll your child in this MedicAlert program. Questions? Call Robi at 503-494-8716.

## Comprehensive Care Clinic moved to 7th floor, DCH

The Hemophilia Treatment Center has moved the Wednesday comprehensive clinics to the 7th floor of Doernbecher Children’s Hospital. Each reception area is designated by an icon, and the Hemophilia Clinic will be held at the “chipmunk” icon. Regular treatment appointments and drop in care will continue to be held on the 10th floor.

The 7th floor clinic area is better suited to comprehensive clinics and provides additional space and services for the patients and staff. The Lab and Radiology Departments are on the same floor. If you have any questions, please call the center.



## NHF National Prevention Program

### Key steps today for giant strides tomorrow.

- 1) Get an annual comprehensive checkup at a hemophilia treatment center.
- 2) Get vaccinated – hepatitis A and B are preventable.
- 3) Treat bleeds early and adequately.
- 4) Exercise to protect your joints.
- 5) Get tested regularly for blood-borne infections.

**DATES TO REMEMBER:**

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**The Shortage of Recombinant Factor VIII**

*continued from back page*

**Family Day at the  
CART Races**

June 24, 2001

**Parent Support Group  
meeting**

July 1, 2001

**Submit answers to  
"Family Focus" question**

July 15, 2001

**Summer Camp**

July 29 to August 4, 2001

**Annual Meeting at  
the Oregon Zoo**

September 23, 2001

**HAPPY BIRTHDAY,  
CAMPER!**

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**APRIL**

Kristin Boni-Burden 4/8

**MAY**

Corey Pierce 5/7

Robert Schadle 5/20

Bryan Dagenais 5/22

**JUNE**

Jakob Fieken 6/15

Bayer Corporation has stopped distributing product beginning in January due to finding some regulatory problems in its environmental monitoring for contamination in the production plant. Bayer expects that it will not release normal amounts of product until June at the earliest, although the company says that small amounts of product will be released in April. Bayer has refused to disclose the exact nature of the problem, although it has assured the community that the product that has been distributed is safe to use. According to Bayer's Doug Bell, Director of Global Public Policy and Communications, "All the product that has been put into the marketplace is safe and effective." The Food and Drug Administration (FDA) has confirmed Bayer's statement that previously released Kogenate FS is safe and efficacious. Bayer is expanding its Berkeley facility with the addition of a 200-liter fermenter, which is expected to significantly increase factor VIII production, and hopes to have FDA approval later this year. Aventis-Behring purchases Kogenate FS from Bayer and markets it as Helixate FS; thus, the company also has no product available and will not until Bayer solves its regulatory problem. Aventis-Behring points out that it has adequate reserves of plasma-derived monoclonal-purified product at this time. The company is attempting to increase its supplies of Monoclate P to provide extra product, if needed.

Baxter Hyland Immuno had shut down its Thousand Oaks facility for routine maintenance for most of March. At the end of March the facility began manufacturing operations once again, and the company anticipates that product will be available in late April. While normally this would not affect factor VIII supply, reserves are so low due to the Bayer shutdown that it further compromises supply. The planned increases in Recombinate supply won't be available until midyear. Baxter obtains raw material from Genetics Institute, and that contractual obligation, which is in dispute in court, appears likely to end. What this means is that as Baxter loses Genetics Institute supply, their own plants are making up for it, but the total amount of factor VIII available to the marketplace is less than Baxter originally anticipated. Baxter also said that Hemofil M, its monoclonal-purified factor VIII, is available in sufficient quantities. Genetics Institute has begun selling Refacto, its recombinant factor VIII in the United States earlier this year, but the amount of product being sold in the US is low and is not alleviating the supply shortage. The company's new plant in St. Louis, Missouri, is not expected to be online until early 2002.

The three manufacturers of recombinant factor VIII sell product worldwide and have contracts and demands from many countries; consequently, this impacts supplies available to the US market. As in the US, factor VIII demand from the rest of the world continues to increase, and this puts a further strain on the supply. With the resumption of Baxter and Bayer production this spring, the severe supply shortage is expected to be alleviated by midyear.

# Membership Dues, Memorials and Contributions

The Hemophilia Foundation of Oregon thanks the following individuals and companies for dues payments and other donations. This list reflects donations received as of April 30, 2001.

Fred and Patty Adams  
Don and Rowena Aina  
Richard Ames and Or Mizuho  
Mike and Sharon Amos  
MaryLou Anderson  
Rose Buckley  
Donny and Rhonda Burden  
Theodore and Kathleen Cacouris  
Mike and Linda Charles  
Dave Chvatal and Marci Kociemba  
Richard DeNeffe  
Bruce and Jamie Dessellier  
Gaye Di Pasquale  
Tom and Monica Dickey  
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Tom and Andrea Dieringer  
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Edward Wagner  
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Wesley Wolf  
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#### **IN MEMORY OF:**

*In Memory of Dave Anthony:*  
Anne Pagenstecher  
*In Memory of Larkey DeNeffe:*  
Richard DeNeffe  
*In Memory of Eric Dutson:*  
Tom and Andrea Dieringer  
*In Memory of Jacqueline Husen:*  
Jim and Sylvia Kurilo

*In Memory of Barry Kurath:*  
Amy Pool  
Marshall and Joan Turner

*In Memory of Barry and Shirley Kurath:*  
Carl Kurath

*In Memory of Mark Laam:*  
Mary Laam

*In Memory of Douglas McAllister:*  
Catharine Collins

*In Memory of Lon Ochs:*  
Anne Pagenstecher

*In Memory of George Tester, Sr.:*  
George (Jr.) and Debbie Tester

*In Memory of Bruce Wildrick:*  
Ashmun, Raymond and Mary

#### **HONORING:**

*Honoring Nancy and Bill Worthington:*  
Anne Pagenstecher  
John and Mary Pelton

#### **CORPORATE CONTRIBUTIONS:**

Aventis Behring  
Bayer Corporation  
Wyeth-Ayerst Pharmaceuticals

It's not too late to pay your  
2001 dues!

- \$20 Single
- \$35 Family

Checks should be made  
payable to "The Hemophilia  
Foundation of Oregon"

## PATIENT NOTIFICATION SYSTEM

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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](http://www.notify1.com).

*The following is the latest Community Alert from the National Hemophilia Foundation's web page ([www.hemophilia.org](http://www.hemophilia.org)) regarding the current shortage of recombinant clotting factor products. For copies of the referenced Medical Advisory Bulletins, access the NHF web site or contact the HFO office and ask for a copy of NHF Medical Advisory Bulletins #377, #379 and #380.)*

## The Shortage of Recombinant Factor VIII

BY GLENN PIERCE, MD, PHD

Recombinant factor VIII remains in extremely short supply. The reasons for our present situation are multiple and have been detailed in a series of NHF Medical Advisories (Medical Advisory 377 – March 16, 2001; Medical Advisory 379 – March 29, 2001; and Medical Advisory 380 – May 2, 2001).

Despite the addition of new plant capacity from Baxter and Genetics Institute at the end of last year, we are facing the worst supply crisis since monoclonal purified products were introduced in 1987. This is directly due to the fact that Bayer Corporation and Aventis Behring have stopped shipping product at the end of 2000.

NHF's Medical and Scientific Advisory Council (MASAC) met on March 29 to review the supply situation and is making treatment recommendations separately (MASAC Recommendation 114). The treatment recommendations suggest strategies for treatment with recombinant and monoclonal purified products during this crisis.

*continued on page 10*



The Hemophilia Foundation of Oregon  
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*Address correction requested*