

# Hemophilia Headlines

FALL 2001

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## Worldwide factor VIII shortage may last until mid-2002

*(From Hemophilia World, September 2001)*

DAVID PAGE

VICE PRESIDENT, WORLD FEDERATION OF HEMOPHILIA, CHAIRPERSON, WFH BLOOD PRODUCT SAFETY & SUPPLY COMMITTEE

The worldwide factor VIII shortage worsened over the summer and is now expected to last well into 2002. Manufacturing problems at Bayer's Berkeley, California facility have caused a shortfall in production of Kogenate and Helixate, an identical product manufactured by Bayer which is distributed by Aventis Behring. The shortfall has affected the supply of other factor VIII products, both recombinant and plasma-derived, as buyers around the world scramble to get enough treatment products.

In March, when Bayer stopped releasing Kogenate, it was hoped that normal shipments would start again in 90 days. However, on June 4, Alison Arter, Bayer's Senior Vice President, wrote to the world bleeding disorders community, "We feel it is in the best interest of patients to seek alternative sources of factor VIII treatment. We will continue to apply all available resources and efforts to return to full production and normal shipment schedules for Kogenate. In the meantime, we recommend that Bayer be viewed as a supplemental supplier rather than a primary provider of recombinant factor VIII. Any product that we are able to release into the marketplace should be treated as supplementary and used accordingly."

In June 2001, when asked to give supply projections to help the global hemophilia population plan usage, Ms. Arter replied, "If I were forced to make a prediction, I would have to say "No [product] releases for nine months. Don't count on Kogenate."

*[Editor's note: Now is the time for people in the hemophilia community to be in touch with their providers of clotting factor to develop a plan to work around this shortage.]*

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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

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BY LINDA CHARLES

I am absolutely excited by the direction the Foundation is taking, and want to fill you in on what this means to you in 2002 ...

- Our **Parents' Support Group** will continue to meet every other month, and is a chance for parents to support one another as they learn to live with bleeding disorders in their family.
- We'll have two **Family Outings** – a WinterHawks game in early 2002, and a baseball event in June.
- The HFO is planning a **Health Fair** this Spring, which will include a variety of educational speakers, breakout sessions, social time, and fun for all.
- Of course we'll continue our very popular **Summer Camp**, which is August 4-10 at Camp Tapawingo in Falls City, Oregon!
- We're adding a **Youth Raft Trip** next summer, which will be jointly organized by the Hemophilia Foundations of Oregon and Washington and the Oregon and Washington Hemophilia Treatment Centers.
- The **Annual Meeting** at the Oregon Zoo is one of our best-attended events, so you can count on it again next year!
- We're working on a new **HFO web site**, which we plan to have up and running in early to mid 2002.
- And we will continue publishing our **quarterly newsletter**, *Hemophilia Headlines*, which got a brand new look in 2001 and continues to be an excellent way to stay plugged in to the bleeding disorders community!

The Board of Directors had an all-day planning retreat in mid-October, and designed the 2002 programs based on the HFO's Mission Statement and your responses to the Questionnaire contained in the Summer 2001 newsletter. If you would like to be involved in the planning and implementation of any of the programs above, please contact us. We'd love to have you join the efforts to make these programs great!

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## In Memory

Gary Brant Morgan passed away Saturday, June 30 in his Salem home. He was 60 years old.

Gary grew up in Independence, Oregon and graduated from Central High School in 1959. He married Lucy in 1965. Gary earned his bachelor's degree at Oregon State University. Gary and Lucy lived in Salem, where he worked for the State of Oregon in the Urban/Rural Mapping & Aeronautics Division for 31 years until he retired.

Gary was a lifelong avid fisherman, and also enjoyed traveling, spending time with his wife and working around his home.

Memorial contributions may be given to the Northwest Medical Teams International or the Humane Society of the Willamette Valley.

# Traveling with factor supplies and new airline safety

October 1, 2001

## NHF Medical Advisory #388

Due to the tragic events of September 11, 2001, the Federal Aviation Administration (FAA) has increased security measures on all US commercial aircraft. NHF understands that this may cause some difficulty for people with bleeding disorders and their families.

It is advised that, when traveling with your clotting factor, bring a prescription from your physician with contact information, as well as a letter from your physician/Hemophilia Treatment Center providing a brief explanation of your condition and the need for this medication. In addition, when you bring needles onto an airplane in your hand luggage you must have the clotting factor with you as well. Check with your airline at least two days prior to departure to learn their specific regulations regarding the transport of medications. Each airline is developing regulations that are subject to change.

NHF has also requested that the FAA include hemophilia in any list of disorders that require the use of a needle.

To receive the full text of this document, call NHF at 800-424-2634 and ask for a copy of Medical Advisory #388, or visit the NHF website at [www.hemophilia.org](http://www.hemophilia.org).

*The Oregon Hemophilia Treatment Center would be glad to generate a letter for travelers with bleeding disorders to carry, or to assist other health care providers in preparing such a letter for travelers.*

## Promising new HIV drugs in development

*(From HIV Notebook, Hemophilia Association of New York, Fall 2001)*

As we know, the 18 or so antiretroviral agents now approved to treat HIV infection have serious limitations. At the top of the list of problems is toxicity for the body and the virus' ability to quickly mutate and develop resistance to the drugs. But researchers are coming up with new drug classes to stop HIV in its tracks.

Called fusion, or entry, inhibitors, these new drugs act on the cell targets that HIV covets but that the current classes of drugs (reverse transcriptase inhibitors and protease inhibitors) do not affect. This latest edition of drugs "should have activity even in patients who have cycled through all the current drugs and have developed resistance," says Trip Gulick, MD, of Cornell Medical Center in New York.

*(For full text of this article, contact the HFO office and ask for a reprint of the Fall 2001 HANY HIV Notebook.)*

## CONTACT THE EDITOR

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To contact Mike Charles, Editor of *Hemophilia Headlines*, his email address is [hemoheadlines@home.com](mailto:hemoheadlines@home.com)

# HFO Annual Meeting held at Oregon Zoo

HFO members, friends and supporters gathered Sunday, September 23 at the Oregon Zoo in Southwest Portland's Washington Park for the HFO's Annual Meeting.

Most people came early to check out the wonderful exhibits at the Zoo. The meeting room opened at 3:30 pm for the meeting's Trade Show, where companies that provide products to the bleeding disorders community had exhibit space. Attendees had the opportunity to ask questions directly to industry and find out about current products as well as possible products on the horizon.

At 4:30 pm, attendees gathered for our annual business meeting. President Linda Charles gave a brief talk to members, followed by the election of officers and trustees for 2002.

After enjoying a delicious picnic meal, the kids gathered in the foyer where the Zoo staff presented a great program about reptiles. (Kids were able to examine the critters up close, and even hold a few of the tamer ones!)

While the kids learned about reptiles, the adults gathered in the meeting room to hear Dr. Marion Koerper of the UC-San Francisco Hemophilia Treatment Center present a program on blood safety. In her program, Dr. Koerper paid particular attention to the role of Human Parvovirus (HPv) infection, particularly among persons with hemophilia who were



Dr. Marion Koerper, who heads the Hemophilia Treatment Center at UC-San Francisco, delivered the meeting's keynote address on "Blood Safety."

Dr. Marion Koerper's trip to Portland was sponsored by the Postgraduate Institute for Medicine and supported by an unrestricted educational grant from Wyeth/Genetics Institute.



While the adults attended the program on blood safety, staffers from The Oregon Zoo presented a program on reptiles to the kids, which proved extremely popular.

co-infected with both HIV and Hepatitis B/C. While she stressed there had been no documented instances of HPV being transmitted by recombinant clotting factor products, she urged everyone to talk with a physician experienced in hemophilia about Parvovirus.

At the conclusion of the meeting, a one-year Family Pass to the Oregon Zoo was raffled. Thanks to everyone who attended, and we hope to see you next year!



Genetics Institute was one of the many companies involved in the hemophilia industry who had an exhibit in the rear of the meeting room. Genetics Institute also sponsored Dr. Koerper's trip to Portland.



Kayla Berkey was the winner of the afternoon's raffle drawing, a one-year Family Pass to the Oregon Zoo. Kayla is shown receiving her pass from HFO President Linda Charles.

## A BIG THANK YOU!

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The HFO would like to thank the following companies for purchasing exhibit space to help defray the costs of the annual meeting:

- Alpha Therapeutics Corporation
- American Red Cross
- Aventis Behring
- Baxter Healthcare Corporation
- Care for Life
- Choice Source Pharmaceuticals
- Genetics Institute
- Gentiva Health Services
- Novo Nordisk
- Providence Home Infusion



## Family Focus

### Corey Parker played pro ball with the Detroit Tigers

(Reprinted from *Mis'n Factor [Hemophilia Resources of America]*, Fall 2001)

Corey Parker, who has mild hemophilia, played professional baseball for six years. He set a record for five consecutive home runs in five times at bat in 1996, while playing with the Bangor Blue Ox in Maine. (Even Babe Ruth and Mark McGwire didn't do that!)

His father was a teacher and a coach for track, baseball and basketball. Corey says that growing up with two brothers, one of whom also has hemophilia, in a family with so much enthusiasm for sports was an "awesome" experience.

Corey played Little League baseball and loved it. Baseball and basketball were his favorite sports in school. He tried football but had serious knee bleeds and gave up football.

Corey says that when he was trying out for the junior varsity basketball team in high school, a groin bleed started. He tried to ignore the bleed because he didn't want the coach to think he was "different" or "weaker" than other team members. The bleed went out of control and he spent 12 weeks in a wheelchair. "If I had treated at the outset, it wouldn't have been a problem," he says.

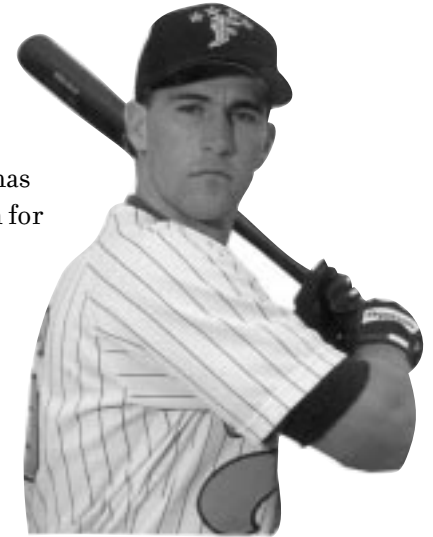
Corey attended Orange Coast College where he played baseball for two years. Then he won a baseball scholarship to the University of California at Irvine for his last two years.

When scouts for professional baseball started talking to Corey, he decided to sign with the Tigers. The contract specified that the Tigers would pay for him to complete the rest of his schooling. Corey knew that earning his college degree was important. The spring of his junior year, Corey began spring training. When he wasn't playing baseball, he was back in school studying. Corey earned a bachelor's degree in social science.

He says he loved playing baseball, traveling the country and meeting other people. While playing professional ball, Corey tried to hide his hemophilia. "This was a big mistake," he says. "If I had been up front about it, it would have been more manageable. I would have missed less time playing ball."

#### *Corey Parker shares tips for managing hemophilia:*

- Get to know other kids who have hemophilia. It's important to know other kids and other people with hemophilia. You will be able to talk with them about how you handle your hemophilia, how you explain it to your friends,



"If you have hemophilia and are playing a sport at the level of your teammates, you are not 'weaker,' you are superior. You are strong enough mentally, emotionally and physically to go out and play as well as the others do. You are facing a much greater challenge in the game than your teammates are," says Corey. "When you think this way, it is much easier to deal with hemophilia."

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your teachers, and your coaches. Just having a friend with hemophilia can ease some of the stress. Friends with hemophilia give you something that no one else can give you.

- Don't hide the hemophilia from your teachers or coaches. Explain the hemophilia in a way that won't make the coach or teacher apprehensive or too protective. Let them know that you have your product, you know how to infuse and how to take care of yourself. Give them your mom's pager or cell phone number.
- Learn from my biggest mistake. When I had an injury while playing professional ball, I would try to keep a low profile. I'd wait until I was back in my room to treat it. If I had been more up front, it would have been more manageable. The bleed would have been easier to control and I would have lost less playing time.
- Learn as much about hemophilia as you can. You need to be educated. Ask your doctor and the hemophilia treatment center to help you understand your hemophilia. Read about it.
- Make sure you always wear the proper equipment to protect yourself.
- If you have a chance to go to a summer camp with other kids with hemophilia, GO. Meet as many people with hemophilia as you can.

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## Is There a Future for Family Focus?

MIKE CHARLES, EDITOR

When we began Family Focus earlier this year, it was designed to provide an avenue for parents and caregivers to learn what others have done when questions arise regarding raising a child with a bleeding disorder (topics like organized sports, at what age should kids be encouraged to self-infuse, etc). We wanted to pose questions common to parents of children with bleeding disorders - questions that might come up, for example, if a group of parents meet informally and begin talking about their children. After all, who better to share challenges and successes than those who are living with it?

However, the response so far has been less than hoped for. We have only received one "volunteer" response for three issues; all other responses were as a result of our calling families and asking (all right...begging!) them to write a response as a favor to us.

If you would like to have a forum where you can talk about important, hemophilia-related issues in your life, drop me an e-mail ([hemoheadlines@home.com](mailto:hemoheadlines@home.com)) and let me know you would like the feature to remain. If you have ideas on how to improve this feature, or have suggested questions that are more targeted for your situation, please let me hear from you.

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### 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](mailto:hfo@easystreet.com).

# We heard you!

In the Summer 2001 newsletter, the HFO included a double-sided questionnaire asking each of you to tell us what you think! The questionnaires were also handed out at the Annual Meeting at the Oregon Zoo. Of the 500 questionnaires distributed, we received 38 responses. Here's what you had to say:

## HFO MISSION STATEMENT:

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"The Hemophilia Foundation of Oregon serves as an active force to enhance the quality of life for the genetic bleeding disorders community through advocacy, support, outreach, education, research and promotion of excellence in medical care."

### **The HFO can best meet your needs by providing:**

- *Hemophilia Headlines* newsletter
- Summer camp
- Family picnic
- Retreats for couples and families
- Health fair with educational speakers and workshops.

Answers that got fewer responses but still made the list are regular meetings with a speaker; support groups; educational workshops (on vWD and infusions); and Central Oregon activities.

### **The top issues you would like to see addressed in HFO publications and meetings are:**

- Factor products
- Familiarizing schools with bleeding disorders
- Gene therapy/research
- Factor/product shortages
- Parenting children with bleeding disorders
- Home treatment

### **You gave the HFO good to excellent ratings on its programs and services (thanks!):**

- *Hemophilia Headlines*
- Summer Camp
- Parent Support Group
- Annual Meeting at the Oregon Zoo
- Town Hall Meeting re Factor Shortage
- Family Events (WinterHawks, Baseball)
- Family Retreats
- Emergency Financial Assistance
- Resource for parents of a newly diagnosed child
- Oregon Hemophilia Assistance Program

The majority of respondents say all their needs are being met. However, you let us know you want more information on girls/women with bleeding disorders; dealing with schools; the transition to college and how to coordinate hemophilia care and insurance; new treatments; local homecare providers; and home health care nurses.

### **Services or support you would like?**

Again, the majority said nothing additional was needed. However, some items listed were dental care; survival/spouse support group; vWD information; help on weight training and physical education for young adults; information on preserving veins and taking care of joints; workshops; advocacy to

prevent discrimination in the workplace; and classes to learn more about home infusions.

**Information you would like to receive that you are not currently getting?**

While many said "none," there were a number of specific requests:

- More in-depth knowledge of gene therapy and its problems; more on factor development
- Family retreats
- New studies about joint replacements
- Legal rights of hemophiliacs with respect to insurance companies and employers
- More on hemophilia research

**Dues?**

The vast majority think the current annual dues of \$20 for an individual and \$35 for a family membership are reasonable. However, only 15% of the newsletter recipients have paid their dues for 2001. The HFO relies on dues to help pay for its programs and services (including this newsletter!) If you haven't already, we hope you'll send yours in soon.

**Volunteers!**

Quite a few of you signed up to volunteer in specific areas – thanks! We'll definitely be calling on you as projects and needs arise. If you didn't volunteer but would like to, we're still looking for people to help out in the following areas:

- Being a resource to other parents
- Camp
- Foreign Language Interpretive Services (written or oral)
- Fundraising
- Grant Writing
- Graphic Design
- Legal Advice (pro bono)
- Legislative Issues
- Office Assistance
- Special Events
- Volunteer Coordination (contacting volunteers, training, scheduling, etc.)
- Web Page Support
- Youth Programs
- Other? (please specify)

**Bottom Line? We heard you.**

Your responses were top of mind during the HFO's Board Planning Retreat in October, and we think you'll find the programs and services offered in 2002 will be responsive to your requests. If you have needs or requests that are not reflected above, simply email them to [hemoheadlines@home.com](mailto:hemoheadlines@home.com). We're still listening!

**DATES TO REMEMBER:**

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**Summer Camp!**

August 4-10, 2002

**HAPPY BIRTHDAY,  
CAMPER!**

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**October**

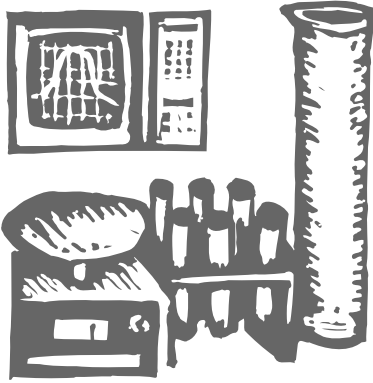
John Cutter	10/23
Daniel Gutierrez Hart	10/18
Josie Oleson	10/6
Jonathon Marquez Pool	10/20
Ryan White	10/30
Stewart Worthington	10/24

**November**

Michael Hargett	11/6
Eddie Pfaff	11/20
Justin Williams	11/28

**December**

Daniel Diaz	12/16
Lizzy Nelson	12/23
Erin Oleson	12/22
Ricky Ramos	12/1
Kayla Schadle	12/1
Tanner Siri	12/2
Eric Tschida	12/2



## News from Industry

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*(The following contains excerpts from a September 10, 2001 news release by Baxter Healthcare. It has been edited for length and clarity.)*

DEERFIELD, ILL. - Baxter Healthcare Corporation (NYSE:BAX) announced today that it has received U.S. Food and Drug Administration approval for a third production suite at its BioScience facility in Thousand Oaks, California. This facility is the manufacturing site for Baxter's recombinant Factor VIII therapy, Recombinate Antihemophilic Factor (rAHF), which is a clotting factor produced by recombinant DNA technology as a therapy for treating hemophilia.

The approval will not affect overall U.S. supply because Suite C is already operating at full capacity for global customers since receiving European regulatory approval last year. However, it will allow Baxter greater flexibility in providing therapy to its U.S. customers.

Baxter continues to invest in future capacity with construction of a fourth processing suite (Suite D), also underway at its Thousand Oaks facility, at a cost in excess of \$50 million dollars. The company anticipates regulatory approval by late 2004 and projects that Suite D will increase capacity significantly. Additionally, Baxter is investing \$131 million in a multi-purpose plant in Neuchâtel, Switzerland, for the processing of recombinant therapies. In total, by 2005, Baxter will have production capacity to provide in excess of two billion units of recombinant Factor VIII, with four suites in Neuchâtel and four suites at Thousand Oaks.

*Editor's Note: Full text of this article can be found on Baxter Healthcare Corporation's website, [www.baxter.com](http://www.baxter.com).*

### DUES PAYMENTS

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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."

*See the newsletter insert for  
more details!*

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## Red Cross announces the Red Cross CARE 2001 Art Contest

What happens when people care about one another? When families care? When doctors care? When friends care? Now, individuals with hemophilia can show the world what it means to care.

The American Red Cross is sponsoring the CARE 2001 Art Contest. Contest kits complete with art supplies are now available, and individuals are invited to create pictures that show what caring looks like to them.

**Prizes:** American Express Gift Cheques worth up to \$500 dollars!

**Deadline:** December 31, 2001. Winners will be announced in May 2002 at the World Federation of Hemophilia Congress in Seville, Spain. To order CARE Contest Kits, contact Lauren Safian at (703) 312-8483, or e-mail at [safianl@usa.redcross.org](mailto:safianl@usa.redcross.org).

# Membership dues, memorials and contributions

The Hemophilia Foundation of Oregon thanks the following individuals and companies for 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 October 15, 2001.

Fred and Patty Adams  
Don and Rowena Aina  
Richard Ames and Or Mizuho  
Mike and Sharon Amos  
MaryLou Anderson  
Donny and Rhonda Boni-Burden  
Gloria Brogan  
Rose Buckley  
Theodore and Kathleen Cacouris  
Mike and Linda Charles  
Dave Chvatal and Marci Kociemba  
Tekle Debesay  
Richard DeNeffe  
Bruce and Jamie Dessellier  
Gaye Di Pasquale  
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Forbes and Carol Lapp  
Art and Gail Liberman  
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James McDermott  
Jason McDermott and Sonya Karanjia  
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Merlyn and Rose Mitchell  
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Nicholas Wade  
Edward Wagner  
Winthrop and Betty Wells  
Ellen Wood Wells  
Michael Wile  
Dave and Pam Worthington  
William and Nancy Worthington

#### **DONATIONS/GIFTS:**

Jeffrey Anderson  
Robert Beal  
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Anthony Dolan  
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Tracey Sherwood  
Ethel Strong  
Dave and Ann Taylor  
Eric Velander  
Nicholas Wade  
Chris Walton  
Wesley Wolf  
William and Nancy Worthington  
Juan Young Trust

#### **IN MEMORY OF:**

*In Memory of Dave Anthony:*  
Anne Pagenstecher  
*In Memory of Lawrence Joseph Churchman:*  
Nancy and Bill Worthington  
*In Memory of Larkey DeNeffe:*  
Richard DeNeffe  
*In Memory of Janet Duffield:*  
Jim and Sylvia Kurilo  
*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 Stanley Kurilo:*  
Jim and Sylvia Kurilo  
*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 Corey Morrison:*  
Rosalie Morrison  
*Honoring Nancy and Bill Worthington:*  
Anne Pagenstecher

#### **CORPORATE CONTRIBUTIONS:**

American Legion Auxiliary Department of Oregon  
Aventis Behring, Inc.  
Bayer Laboratories  
Baxter Healthcare Corporation  
Choice Source Northwest, Inc.  
Employee's Community Fund of Boeing Portland  
Louisiana-Pacific Corporation  
Novo Nordisk Pharmaceuticals  
Oregon Iron Works  
Stockamp and Associates  
Wyeth-Ayerst Pharmaceuticals

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

MARK YOUR  
CALENDARS!

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2002 Parent Support Group

meetings:

- January 8
- March 5
- May 7
- July 2
- September 10
- November 5

# Parent Support Group

BY PATINA FIEKEN

Our last Support Group meeting was scheduled for September 11. Although there was a national tragedy, we decided it was more important than ever to get together with our families and offer one another support. The evening was a great way for the parents to come together and the kids to play the night away.

However, it is primarily the same group of people attending each meeting, and we would like to extend an invitation to families who have not yet attended our group. We would love to hear your experiences! If you have questions or comments, please call me at 503-625-6508 or email [patinaf@aol.com](mailto:patinaf@aol.com).

Also, if you would like to be included on the HFO Parent Support Group Mailing List and receive all meeting notices, you can contact the HFO office at 503-297-7207 or [hfo@easystreet.com](mailto:hfo@easystreet.com).

Our next get-together is Tuesday, January 8, 2002, at the Rainbow Play Systems in Tigard. I hope to see lots of new faces!



The Hemophilia Foundation of Oregon  
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Portland, Oregon 97221

*Address correction requested*