

# Hemophilia Headlines

S U M M E R 2 0 0 8

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## Team Hemophilia

BY ALEX ELL

Vrrroooooommmmm! The Andretti Green Racing (AGR) Team, Bayer Health-Care, and the National Hemophilia Foundation (NHF) worked together to foster awareness and education in the bleeding disorders community. They did so by developing a bus. A bus swamped with red and white colors along with the big bold words "Team Hemophilia". Their mission was to have young adults from the National Youth Leadership Institute (NYLI – the group under NHF that I belong to and explained in the last newsletter) on this bus and have them visit NHF chapters along the IndyCar Series Racing route. I had the privilege to volunteer during the second week of this five week long program.

Three of my friends (Barlen Matias – FL, Lily Bervis – FL, Brad Allain – MA) from NYLI along with Jen Crawford (NHF representative – NY) and I began our journey in the thriving capital of Louisiana, Baton Rouge. Together we designed and facilitated our own agenda structured around trust, teambuilding, and education. We had a blast with 12 young adults from all over the state!

Next, our bus took us to where everything is big, Texas. A whopping 100 people from the local chapter came to our barbeque! The families had interest in us because we told everyone that we each have a bleeding disorder, go to college, and stay involved in the community. I was able to meet with families and answer any of the questions they had for me. The majority of questions had the theme of physical activity and my response to each one was, "Stay active".

Oklahoma, where the wind comes sweeping down the plains!!! The bus arrived at the hemophilia summer camp on an early Oklahoma morning. Just enough time to tour the grounds and get acquainted with the campers before the big day. That afternoon we facilitated the same program we did in Louisiana, but the numbers doubled! Instead of 12, we had 24. The two oldest boys cabins and the oldest girl cabin learned some new things that day. In summary of their thoughts out loud: "If one person splits away from the group, the support is weakened and others need to step up", "having trust in your group/partner helps you cut through your fear", "precise communication is extremely important when giving instructions". After a hard day's work we slid back down to Texas.

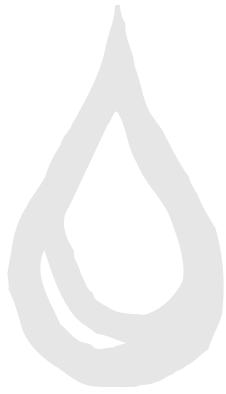


Team Hemophilia Bus

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# President's Message

School's out for summer! Congratulations everyone for making it through another school year. We have a lot of very exciting things going on this summer. Summer camp is coming soon, youth activities, Camp Superfly is underway, our major fundraiser is getting closer and bigger, and the annual meeting will be here before we know it.

I'd like to thank everyone that has played a role in the growth of the HFO's activities over the past few years. Monica Dickey is the primary reason that so many programs go from idea to reality and we are so grateful to have her. Thank you to Tom Dickey and all of our camp staff for all of their hard work at summer camp. Thank you to Pat Torrey for leading so many of our youth and adolescent programs that have become a ton of fun and a wonderful way to teach leadership and teamwork skills that will serve our youth for years to come. Thank you Patina Fieken for leading our parent support group, which provides a much needed and appreciated service to our families. Our fundraiser has become a huge success and has allowed for the growth of our services and the increased stability of the HFO. This could not be possible without the support from our industry sponsors. Personal thanks to Todd Moore, Sherwood Dudley and Beth Rankin from El Gaucho restaurant for their passionate support and efforts to make this event more successful each year. Thank you also to John Self from CSL Behring and Greg Jablonski from Wyeth for their time and energy in making this event so wonderful.

As I mentioned above this summer is going to be packed with fun activities. Summer camp will be our best ever with our theme of "Tapawingo Remix – Heatin' Up The Leftovers". To celebrate our 25th anniversary at Camp Tapawingo, we're taking the best from past summer camps and throwing it all into one week this year. Camp Superfly has started and is an incredible opportunity for the foundation to win funds for our summer camp program. Please be sure to participate in this program.

We will be posting our new website very soon, with a new layout and expanded resources. Keep checking back at [www.hfo.info](http://www.hfo.info). Plus, you'll be able to buy tickets online for the raffle of a 2008 BMW M3 at this year's third annual fundraiser, Shooting For The Stars! Watch your mailbox for more information on this exciting opportunity to share with your friends and family members.

I hope you all have a fun and safe summer!

## HEMOPHILIA FOUNDATION OF OREGON

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Monica Dickey and Alex Ell  
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The Hemophilia Foundation of Oregon is a 501(c)3, not-for-profit corporation and an equal opportunity employer. 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.

# Fight Stress – Just Breathe!

Breathing exercises are an ideal way to relieve stress. They're fast, simple, free, can be performed by just about anyone, and can be done anywhere at virtually any time.

Symptoms of anxiety or stress are actually worsened by shallow breathing, which doesn't allow your lungs to adequately remove carbon dioxide...ultimately making you feel more short of breath. Deep breathing removes carbon dioxide and helps you gain some control over your muscles.

To perform deep-breathing exercises, lie face down on the floor. Breathe deeply and slowly, with your hands resting under your face. Do this for five minutes. Or sit in a reclining chair. Put a hand on your abdomen and a hand on your chest. As you breathe deeply and slowly, make sure the hand on your abdomen is moving up and down rather than the hand on your chest.

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## Let's Get Moving!

Why keep putting off exercise? Working out is a sure path to a healthy body, including preventing joint disease. Try a couple of the different techniques below if you haven't already.

First, help increase your internal motivation. Examine how you think about the change. Challenge your beliefs that "exercise" is a pain-filled process. For example, remind yourself any physical activity is beneficial – whether it's a neighborhood walk, an hour of swimming, an afternoon of golf or a night of dancing. Focus on the positive. Make a list of all the possible positive outcomes of making the change. For example, instead of focusing on your weight notice if your clothes fit better. Make it personal. Choose an approach that works for your personality. If counting calories doesn't appeal to you, focus on choosing appropriate foods and portion sizes. Set realistic goals. Pick one achievable action that takes you toward your goal. If you want to build up your bad leg, start focusing your energy on that leg slowly but steadily. Remember, if you don't use it, you lose it.

Lastly, step up your external motivation. Develop a support system. Yes, you are responsible for changing. But as with any important project, don't you want a strong team working with you? So enlist support: a co-worker, friend, significant other or your health care provider. Having others to encourage you can help you stay inspired. Reward yourself with something that matters to you each time you reach a goal. It might be anything from getting a massage after a good week's workout to seeing a movie in the theater after you've worked those joints and muscles.

You'll probably have days when your best intentions go out the window. Don't feel guilty or blame yourself if that happens. Recognize it as part of making a change, and use the strategies above to return to your desired healthy behaviors.

# Family Support Group

BY PATINA FIEKEN

Family Support group at Bullwinkles Family Fun Center in Wilsonville, Oregon! Come join us July 8, September 9 and November 4.

A support group meeting is a great way to get to know the other families in the bleeding disorder community. Whether you're a Mom, Dad, Aunt, Uncle or grandparent we'd love for you to come. We are able to discuss our positive as well as negative experiences with other parents or people affected with a bleeding disorder to help ourselves cope. It is also a great way for our kids to meet one another and build long lasting friendships.

Bullwinkles has over 6 acres filled with fun and exciting attractions for all ages. Included for the children are tokens for Bullwinkles 80+ video games and prize redemption games, admission to Kidopolis Playland, Bumper boats, miniature golf and the Frog Hopper! Please contact Event Coordinator Patina Fieken at 503-625-6508 or [patinaf@verizon.net](mailto:patinaf@verizon.net) for more information

## PARENTS SUPPORT GROUP MEETING FOR 2008

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Meetings are held every other month at 6:30 p.m. at Bullwinkle's Family Fun Center in Wilsonville. Contact Patina Fieken at 503-625-6508 or [patinaf@verizon.net](mailto:patinaf@verizon.net) for further information.

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## First Step Program

BY PATINA FIEKEN

First Step is a large program designed for new parents and families of children newly diagnosed with bleeding disorders. Early education about bleeding disorders and prevention starting from the first years of life is highly effective.

This past March, NHF Task Force member Sonji Wilkes, Joann Deutsche, Lori Evans and I took a portion of this program and adapted it to fit our community of all age groups and had our first training for Peer Support. With peers identified from all over Oregon, including adults with hemophilia and parents of children affected by a bleeding disorder, we got together for a full day of training in Portland.

New Peer Support participants were trained on everything from grief and loss, cultural awareness, and effective empowerment to active listening and their roles and responsibilities.

If you are interested in having a Peer Support contact you, please contact Joann Deutsche at the HTC, 503-494-8716 for more information. We look forward hearing from you!



# 2008 “Camper Connection” Program!

Each summer, the HFO sponsors a fabulous camp program for our youngsters living with bleeding disorders! The costs associated with the camp have skyrocketed, and we need your financial support to be able to continue offering this great camp. This year’s session is August 3 – August 9, and we expect over 60 campers will participate.

## What’s A “Camper Connection”?

Sponsor a camper for as little as one-half day or as much as the entire week – it’s up to you! Simply write your tax-deductible check to the HFO and get connected to your camper. Each donor will receive a personal note from their camper sharing their camp experience. That way you’ll know how much your contribution means to these special kids, and they will know their week at camp has been made possible by your generous donation!

## What Are The Costs?

Very little, when you consider what this experience means to each camper. For many campers, this is the highlight of their year and a chance for them to be “just like everyone else.” (Many former campers who are now adults still talk about their own camp experience, and how it was always the highlight of their summer.)

- \$50 sponsors your camper for one-half day
- \$100 sponsors your camper for a full day
- \$350 sponsors your camper for one-half week
- \$700 sponsors your camper for the entire week

## How Is My Money Used?

The Camp Program Fund pays for the facilities at Camp Tapawingo in Falls City, Oregon, as well as a varied schedule of activities for our campers throughout the week. The kids have a wide range of activities including a rock climbing wall, horse back riding, archery, swimming, hiking, canoeing, arts and crafts and much more. Campers participate as they are capable, each setting his or her own pace.

## How Do I Participate?

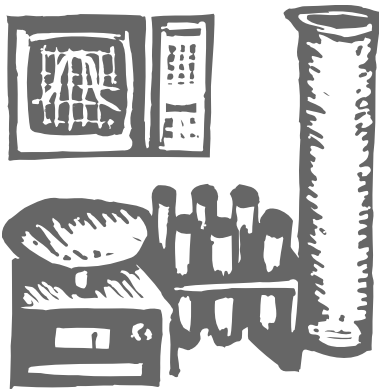
Simply write your tax-deductible check to the “HFO,” mark it for the Camper Connection program, and mail it to the Hemophilia Foundation of Oregon, PO Box 2259, Clackamas, OR 97015. You will receive a tax receipt right away, and your camper thank-you note in August!

*Sponsor Your Camper Today!*

## GOODSEARCH.COM BENEFITS HFO

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www.GoodSearch.com is an internet search engine that can benefit the HFO. For every search performed, HFO receives one cent. That may not sound like much, but consider how many times you currently use Google or Yahoo! Just go to www.GoodSearch.com, enter “Hemophilia Foundation of Oregon” in the space labeled “Who Do You GoodSearch For?” and start earning pennies for the HFO!



# News from Industry

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## Game On!

The wait is over! Camp SuperFly Next is underway. Inspired by the community, Baxter introduced Camp SuperFly in 2005 to bring the spirit of summer camp right into our homes through a unique system of mail-in challenges.

This year's program has exciting, new ways for our team, the Oregon Tapawingos, to play, have fun and learn more about healthy behaviors. The HFO had our 2008 Superfly Kickoff Party on Sunday, June 1st at the North Clackamas Aquatic Park. This was a chance to get signed up early to help our team compete for first place. Last year, the HFO received \$5,000 for receiving third place in this nationwide competition. We're going for first this year and with your help we can do it! To make things even easier this year, you can download your challenges online at [www.CampSuperFly.com](http://www.CampSuperFly.com). Contact Monica Dickey at the HFO office at (503) 297-7207 or at [hfo@easystreet.net](mailto:hfo@easystreet.net) to get signed up for this year's competition.



The first challenge is due on July 15th, so don't delay! Get your challenges turned in and help earn points for Camp Tapawingo! If you have questions about Camp SuperFly Next, contact HealthInfo at [info@healthinfodirect.com](mailto:info@healthinfodirect.com) or 1-866-383-8166.

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## iPod Touch Media Player Drawing!

Hemophilia Treatment Centers (HTCs) provide a comprehensive care assessment to help maximize treatment. For a limited time, Bayer HealthCare is offering a chance to win an iPod Touch Media Player upon completion of your regular comprehensive HTC visit. For this contest, you must be a hemophilia patient. It does not matter what factor product you are infusing. Proof of your regular HTC visit qualifies you to enter this drawing. Go to the internet link below to learn more, and how to download the pdf form to take to your annual HTC visit. You then mail your completed entry form to Leverte Associates, their address is noted on the form you download. Completed entry forms must be received by November 7th, 2008. 10 iPod Touch Media Player entries will be drawn at random by current HTC nurses, and given away at this year's 2008 National Hemophilia Foundation annual meeting in Denver, Colorado, November 13-15. You do not need to be present to win! Leverte Associates will contact winners by phone within 10 days of the NHF drawing. No matter what, you win when you visit your HTC!

For entry forms, go to: [http://www.kogenatefs.com/Promo\\_ipod.cfm](http://www.kogenatefs.com/Promo_ipod.cfm)

## New Third Generation Factor VIII Product: Xyntha

On February 21, 2008 Wyeth Pharmaceuticals received FDA approval for Xyntha (ZIN-tha), its new recombinant factor VIII product for patients with hemophilia A. Xyntha is designed for both the control and prevention of bleeding episodes, and for surgical prophylaxis. Xyntha is the only recombinant factor VIII product to use an entirely synthetic (non-human and non-animal-based) purification process in its manufacture. Until now, the purification process for all recombinant factor VIII products used monoclonal antibodies derived from mouse cell lines. In Xyntha's manufacture, the mouse monoclonal antibody is replaced by a synthetic peptide ligand, invented by Wyeth scientists. Xyntha should be available to patients later in the year. For more information: [www.xyntha.com](http://www.xyntha.com)



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## CSL Behring cordially invites you to attend a Special Mom2Mom Event!

Join us for a relaxing morning cruise on the Willamette to nurture your mind and spirit. CSL Behring created this exclusive Mom2Mom event with food, fun, and socializing especially for you, the mother of a child with hemophilia.

This is a valuable opportunity to meet other moms who live with the daily joys and challenges of raising a child with hemophilia. Meeting other moms is a great way to make you feel less alone and help you rise to the challenges you face. Share your triumphs and concerns, and broaden your knowledge by learning about other moms' stories and experiences.

Besides enjoying a stress-free morning brunch while cruising the Willamette from the falls to the Columbia and exchanging valuable information with other moms, you'll get to meet one of our featured moms on [www.HemophiliaMoms.com](http://www.HemophiliaMoms.com), Rhonda Boni-Burton. Rhonda will share her own personal challenges and achievements in parenting a child with hemophilia.

Enjoy this unique chance to take time for yourself, relax, enjoy meeting other moms, and—did we mention relax? Give yourself a break: come join us!

**Where:** Portland Crystal Dolphin

**When:** July 12, 2008

**Time:** 8:30am - 12pm

**RSVP to:** CSL Behring Consumer Affairs  
1-888-508-6978

**Boarding:** 8:45am sharp, sails at 9am

# HFA Blood Brotherhood Event

## HAPPY BIRTHDAY CAMPERS

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### May

Dylan Kirsch  
Reed Thurber  
Marissa Cosgrove

### June

Marilyn Walker  
Tylor Groling  
Mario Huenergardt  
Jennifer Marquez  
Aaron Schoenheit  
Jakob Fieken  
Marcus Huenergardt  
Brian Schoenheit  
Ryan Groling

### July

Julian Fernandez  
Alli Dickey

### August

Mitch Dickey  
Michael Brassel  
Steven Harper  
Tyler Pulley  
Henry Schechter  
Brittney Groling  
Christian Sanders  
Husani Jackson Scott  
Ryan Bernstein  
Jaydra Thurber

Many guys with bleeding disorders have become disconnected from the community. They don't go to treatment centers, and have trouble finding people who understand their problems. They need to connect with others who have been where they are—people who can share their experiences, suggest a coping skill, or just crack a joke when things are tough.

The HFA Blood Brotherhood Program provides opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. Our website, available at [www.hemophiliafed.org](http://www.hemophiliafed.org), covers everything from meds to motor sports, surviving to "Survivor".

Through a generous grant provided by the Hemophilia Federation of America, the Hemophilia Foundation of Oregon is pleased to present the following event for men 21 and older with bleeding disorders.

### Event Details

Please join us for our inaugural Hemophilia Foundation of Oregon Blood Brotherhood event on Saturday, July 19th at McMenamin's Edgefield for golfing and dinner. The 32-hole, par-3 pitch-and-putt Pub Course meanders throughout the McMenamin's Edgefield property, offering stunning views while you work on your short game. Featuring holes from 40 to 80 yards in length, the Pub Course was modeled after Burningbush, the fantasy fairways from Michael Murphy's *Golf in the Kingdom* (a must-read for golfers). The HFO will be providing travel and lodging scholarships for those who may need assistance in attending this event. All greens fees and dinner are provided by the HFO.

Golfing tee times start at 2:00 pm with dinner to follow at 6:30 pm. If you have any questions or are interested in attending this event, please contact Monica Dickey at the HFO office at (503) 297-7207 or at [hfo@easystreet.net](mailto:hfo@easystreet.net).

# Scholarships Available

## **Applications due Friday, July 25th for scholarship to NHF Annual Meeting in Denver, Colorado, November 13 – 15, 2008!**

The HFO is pleased to offer two scholarships to attend the National Hemophilia Foundation's (NHF's) 60TH Annual Meeting in Denver, Colorado on November 13 - 15, 2008! We are not limiting the number of people who can attend with the scholarship recipient (i.e., could be an individual, a couple, or a family with children), but the reimbursement limit cannot exceed \$2,500 for travel and meeting expenses.

Qualification Requirements: Must be directly affected by a bleeding disorder (i.e., self, parent, sibling, carrier, caregiver, etc.), and have not attended the NHF Annual Meeting in at least 3 years. Financial need is a consideration but not a requirement.

This year promises new, exciting offerings along with the tried and true. Consumers and families are urged to attend two preconference symposia this year: "Empowerment at Every Life Stage" and "Insurance—Playing the Game to Win." Providers will be treated to a plenary session by Harvey Alter, MD, premier NIH researcher who identified the hepatitis C marker. The two-day medical track will provide substantive sessions for physicians and researchers.

Consumers and physical therapists can try their hand, or feet, in the new kung fu session. Other sessions include ports, prophylaxis and inhibitors for parents; interpreting the national presidential election results for the community; and for women, how to talk about your period and life as a carrier.

To be considered for this scholarship, complete and return the application page to the HFO's PO Box by Friday, July 25, 2008.

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## **Congratulations!**

Congratulations to Corey Pierce for being chosen to participate in the Bayer HealthCare 2008 Hemophilia Leadership Development Program. This is an exciting educational opportunity for a sophomore, junior, or senior year college student, touched by hemophilia, who has demonstrated potential and a strong interest in becoming a future leader in the hemophilia community. Corey will be a senior at Oregon State University, majoring in business marketing and health management and policy.

This is an 8 week internship program based at the Bayer facility in Wayne, New Jersey. The program is designed to help the intern see firsthand how a product is manufactured and promoted to the healthcare community treating hemophilia. A robust schedule is planned, including a visit to the manufacturing facility in Berkeley, California to better understand how recombinant factor VIII (rFVIII) is made, a review of state and federal legislative activities, classes on leadership skills, and an introduction to reimbursement and marketing. The experience will culminate with an independent project.

Corey has been involved in numerous programs with the HFO over the years, including camper, counselor, volunteer and even a NW regional winner in golf for the ZLB/NHF Junior National Championship. Way to go Corey, we look forward to your future leadership with our community!



Team Hemophilia

## Team Hemophilia, cont'd.

Off to the race we went. The Texas Motor Speedway filled the surrounding desolate land with a glow of light. My friends from NYLI and I were able to tour Marco Andretti's pit and garage and also managed to relax in his suite before the big race. I've never been a racing fan but watching these cars go over 200 mph for 200+ laps got me hooked. The roar of the engines around the track is enough to sweep one of their feet. I thought it was absolutely amazing the way the cars passed each other with such careful but dangerous maneuvers. Sadly, Marco Andretti crashed with another car with only five laps to go in the race. He was in 2nd place.

The final lap of the race marked the end of our trip. This week was only one of more to come. After August, the Team Hemophilia bus will have met with a total of twelve NHF chapters! If you wish to donate or just follow along, you can do so at [teamhemophilia.org](http://teamhemophilia.org). Go TEAM HEMOPHILIA!!!

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## Upcoming HFO Events

<b>July 8</b>	Family Support Group Meeting
<b>July 12</b>	CSL Behring Mom 2 Mom Event
<b>July 19</b>	HFA Blood Brotherhood Event
<b>July 25</b>	Deadline for NHF Annual Meeting Scholarship Application – see page 9 for details
<b>August 3 – 9</b>	Summer Camp
<b>August 24</b>	Shooting For The Stars Fundraiser
<b>September 27</b>	Family Health Information Day
<b>September 28</b>	HFO Annual Meeting at the Oregon Zoo

# Membership Dues, Memorials and Contributions

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## **BENEFACTORS**

Angell, Shirley & Tom  
Heffernan, Bob & Franci  
Jones, Alan & Jill  
McClure, Lester & Wanda

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Koepke, Don & Dona  
Pierce, Doug & Cindy Secrest  
Schechter, Howie & Leslie Hunt  
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Harrison, Esther  
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Keohokalole-Kam, Jeanine & Rory Kam  
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Nelson, Cliff, Kristy & Liz

Ruff, Lola  
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Schuff, Louise & William  
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From Amal VanWagenberg  
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*George Dinsmore Hansen*  
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Hemophilia Alliance Group

## **CAMPER CONNECTION**

Sandy Cunningham

## **GENERAL FUNDS**

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## **AUCTION**

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Novo Nordisk

# Bleeding Disorders Legal Hotline

The Hemophilia Foundation of Oregon has been selected to participate in a unique program funded by a grant from Baxter and recognized by the National Hemophilia Foundation. It's the Bleeding Disorders Legal Hotline.

This program was initiated by the Lone Star Chapter of the NHF in 2006. It is a legal advocacy source for people with hemophilia and von Willebrand disease, created to help those with a chronic illness get information quickly and easily from respected attorneys. The hotline is designed to bridge the gap between the laws and the people who need to know about them.

A team of two attorneys and two paralegals answer each free, confidential hotline question. Beth Sufian of Sufian & Passamano, LLP, in Houston is the main contact for the hotline. She has more than 17 years' experience helping people with chronic conditions understand the laws intended to protect them. Sufian provides information on legal topics that relate to people with bleeding disorders, such as health insurance caps, education or workplace discrimination and medical equipment costs. The hotline, however is not designed to represent patients in legal disputes related to insurance.

If you would like a magnet for yourself, contact Monica Dickey at the chapter office (503) 297-7207 or at [hfo@easystreet.net](mailto:hfo@easystreet.net).



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*Address correction requested*