

Hemophilia Headlines

S U M M E R 2 0 0 2

The Hemophilia Foundation of Oregon
5319 SW Westgate Drive #126
Portland, Oregon 97221
VOICE 503 297 7207
FAX 503 297 0127
EMAIL hfo@easystreet.com
WEB www.hfo.info

Youth Whitewater Rafting Adventure a Big Success!

BY MITCH RENVILLE

On a day filled with sunny blue skies and temperatures over 100, sun-screen and swimming were major ingredients adding to a great river experience. In a combined effort of the Hemophilia Foundation of Oregon, Oregon Hemophilia Treatment Center, Bleeding Disorders Foundation of Washington, Puget Sound Blood Center, and Disabled Adventure Outfitters, through a financial grant from the NHF, the Youth Whitewater Rafting Adventure was a big success.



One of our rafts shooting the "gnarliest" rapid of the day!

The Deschutes River in central Oregon was the location of the event, which included two nights of camping next to the river, making swimming and river floating a constant way to stay cool. There was also a lot of good food and plenty of cool drinking water. Participants included seven youths from Oregon and Washington and seven adult volunteers.

The rafting part of the trip was an exciting 16-mile stretch of popular whitewater, which was filled with a variety of churning, rolling rapids, mixed with calm, slow-moving sections perfect for swimming. The rapids were pretty big and fast, but the guides were experienced and the rafts were brand new, which made for a safe ride.



Rafters pose for a group picture

The raft trip was a big success, and aside from a few bug bites and a bit of sunburn, the kids all said they had a great time!

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HFO Office

5319 SW Westgate Drive
Suite 126
Portland OR 97221
(503) 297-7207
fax (503) 297-0127
hfo@easystreet.com
www.hfo.info

Newsletter Editor

Mike Charles
hemoheadlines@attbi.com

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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.

World's First Book on von Willebrand Disease Released

"A Guide to Living With von Willebrand Disease," the first book on the world's most common bleeding disorder, was released on February 4, 2002. The book was written by Renee Paper, R.N. (Hemophilia Foundation of Nevada's Executive Director and a woman with von Willebrand Disease) and Lauren Kelley.

Aventis Behring provided complimentary copies to the HFO for distribution at our Health Fair, and we have extras available. To order a copy of this informative book, simply call Monica Dickey at the HFO office.



Renee Paper, author of "A Guide to Living With von Willebrand Disease"

Dennis' Seven Dees Landscaping Golf Tournament Benefits HFO's Summer Camp Program

BY DAVE WORTHINGTON

The HFO reaped the benefits of golf, food and fun on July 19 at the Oregon City Golf & Country Club. For the third consecutive year, Dennis' Seven Dees Landscaping generously donated the proceeds from their 12th Annual Golf Tournament to the HFO Summer Camp Program. After the tournament, Dave Snodgrass, President of Dennis' Seven Dees, presented the HFO with a check for \$1,371. "We are once again pleased to support the Hemophilia Foundation Summer Camp," Snodgrass said. "It makes us feel good to support such a great program."

The day gave us perfect summer golf weather and a flawlessly orchestrated tournament, which included an 18-hole "best ball" competition. The afternoon concluded with a banquet dinner and raffle drawing for over 120 golfers and non-golfers alike.

Raffle prizes were generously donated by Aventis Behring, Wyeth/Genetics Institute, Hemophilia Health Services (formerly Gentiva), and Bill Thoroughman, among others.

The HFO would like to thank Dave Snodgrass and Dennis' Seven Dees Landscaping for their continued support.

Mike Charles "Outstanding Camper Award" Established

BY JIM MCALLISTER

At the February 2002 meeting of the HFO Board of Directors, Mike Charles submitted his letter of resignation as a member of the Board of Trustees. After a long discussion about the valuable contributions Mike has made on behalf of the bleeding disorders community, the Board unanimously passed a motion setting up a method of honoring him.

To this end, the Mike Charles "Outstanding Camper Award" has been established. Mike has had a 25-year involvement with the HFO summer camp, beginning as a camper in 1970. This award will be given annually to a camper selected by the Camp Director and Staff who exemplifies the attributes Mike has modeled for so many years:



Mike Charles accepts his award from board member Jim McAllister at the HFO Health Fair.

leader, teacher, encourager, mentor, friend. In addition to a full sponsorship to attend camp the following summer, a \$500 U.S. Savings Bond will be awarded to the camper receiving the award. (Maybe your child will be the next to receive this worthy award!)

Mike has served on the Foundation's Board of Directors for over 20 years. He has persevered in the need to bring reform and change to the care provided to all with bleeding disorders. During the Hemophilia/HIV epidemic, Mike met with politicians and news reporters, both local-

ly and nationally, to advocate for those in the bleeding disorders community. His work on the class action lawsuit and the Ricky Ray Hemophilia Relief Fund Act has positively impacted our community. He has been a beacon of light during the storms of controversy that have impacted the lives of children and adults with bleeding disorders.

During the most difficult times, Mike has been a model of the American Volunteer. His ever-present smile and calm determination have given hope and encouragement to us all. His ability to see a problem and seek solutions in a rational manner has been a gift to the HFO, and the Board has flourished with his thoughtful leadership.

While Mike has stepped down from the HFO Board, he will continue to be active in our events and activities, and will continue as editor of the HFO's quarterly newsletter, *Hemophilia Headlines*. His leadership skills will still be utilized, and his list of contributions will no doubt continue to grow. Please join us in thanking Mike for his many years of contributions to our community.

CONTACT THE EDITOR

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

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

Educational Health Fair a Great Success!

On June 1, 115 people from the bleeding disorders community took an entire Saturday out of their busy lives to attend the HFO's Health Fair, and from the feedback we received decided it was a very worthwhile use of their time. Thanks to everyone who participated!

The day started off with parents getting their children registered for the kids' programs, a light breakfast, and welcoming remarks from HFO President Linda Charles. Rob Dash with Aventis Behring was first on the agenda to speak on insurance reimbursement issues, a subject that touches many of our lives.



Attendees socialize in the main meeting room

The group then had the choice of four morning breakout sessions—Jan Goldman with the Oregon HTC facilitated a Parent-to-Parent session, Sandy Puckett with the Oregon HTC spoke on Educating and Working With Your School Personnel, two speakers from Cascade AIDS Project talked about Living Options, Working Choices—Living with HIV, and Renee Paper educated her group on von Willebrand Disease.

The entire group reconvened in the main meeting room and shared lunch, got reacquainted with old friends and met new people. Jim McAllister announced the establishment of the "Mike Charles Outstanding Camper Award," and a very surprised Mike shared a few thoughts (*see article on page 3*).

The participants then had the choice of four more breakout sessions in the afternoon—Sandy Puckett spoke on Navigating the Emergency Room, Renee Paper shared ways to Minimize the Impact of Bleeding Disorders on Your Life, Dr. Ken Flora with The Oregon Clinic educated his group on New Hepatitis Therapies, and Mitch Renville, person with hemophilia, motivated his group by sharing his Trek on the Appalachian Trail.

The group reconvened for the final group session, where Dr. Anne Neff of Vanderbilt University's Hemophilia Treatment Center spoke about Gene Therapy for Hemophilia. Thanks to Wyeth/Genetics Institute for sponsoring her trip to Portland.

The majority of funding for the HFO Health Fair was provided through a generous grant from the Aventis Behring Foundation for Research and Advancement of Patient Health, a non-profit 501(c)(3) corporation dedicated exclusively to charitable, scientific and educational purposes designed to advance the needs and interests of the bleeding disorders community.

Industry representatives also purchased exhibit space, and the fees received will be used to fund future HFO programs. Having the representa-



Mitch Renville talks about his Trek



Michael Hargett shares his experiences about camp

tives present also gave attendees a great opportunity to learn about various products, services, and companies from which to choose when deciding the best options for themselves and their families.

The Aventis Behring Foundation funding also enabled us to offer additional education—a raffle drawing for three trips for two to attend the NHF’s annual meeting in Orlando this Fall. The lucky winners are Ken and Ingrid Harper, Cathy Coatney, and Mitch Renville! Congratulations, and we’re looking forward to hearing about your experiences!

We would especially like to recognize the hard work of the Health Fair Committee for organizing this program: Linda Charles (chair), Gloria Brogan and Patina Fieken (von Willebrand program), Gail Liberman (event site and food), Jim and Marj McAllister (child care program), and Scott Torrey (school-aged kids and youth programs). We also had a wonderful group of volunteers for the day of the event. Thanks to everyone for attending, participating, speaking, volunteering, and sharing your day with us!

DATES TO REMEMBER

Parents’ Support Group

September 10, 2002

**HFO Annual Meeting
at the Oregon Zoo**

September 15, 2002

**National Hemophilia
Foundation’s
54th Annual Meeting**

Orlando, Florida

www.hemophilia.org

Oct. 31 – Nov. 2, 2002



Kids enjoy the play equipment



NHF raffle trip winners chosen



Family Focus

Parents' Support Group

BY PATINA FIEKEN

Our last Parents' Support Group was July 2, and we had a great turnout of about 20 people. Even though our group has remained relatively small, the relationships we have formed remain close for us all. I enjoy seeing each family and discussing their ups and downs for the past two months. And hopefully nobody has had any problems, but if they occur at least we have others who may have gone through similar issues, or we may become more knowledgeable when it does happen to us. I know I have learned a lot from the similar experiences, good and bad, of other families. It is a very relaxing atmosphere, and the children always have a lot of fun—sometimes it's hard to get them to leave!

Our next meeting is Tuesday, September 10, 2002 at 6:30 pm at the Rainbow Play Systems in Tigard. If you have questions or comments, please call or email Patina Fieken, 503-625-6508, patinaf@aol.com.

I would also like to formally thank Rainbow Play Systems for allowing us to continue to use their wonderful facility for our meetings. The area we use features completely rubberized floors, and we usually have the whole area to ourselves! As of June 1, 2002, Rainbow no longer holds evening parties during the week. However, our group has made such an impact on their staff that they will make a special exception for our meetings! Thank you, Rainbow Play Systems!

HAPPY BIRTHDAY, CAMPERS!

July

Christina Diaz 07/06

Flossy Marchese 07/07

August

Michael Brassel 08/08

Racheal Dagenais 08/21

Mitch Dickey 08/04

Natasha Singler 08/17

September

Travis Davenport 09/09

Kyler Hoskins 09/04

Ryan Hoskins 09/04

Shantell Moffit 09/05

Jesse Winn 09/27

Community Member Update

Stewart Worthington has completed his athletic season as a Class IV Gymnast for the Multnomah Athletic Club Gymnastics Team. He qualified for and participated in the regional competition in Washington (Oregon, Washington, Idaho, Alaska and Montana). He was also voted the "Most Inspirational Class IV Gymnast for Oregon" by the coaches and judges in this region. Congratulations, Stewart!

Regional Prevention Conference and NHF on the Road 2002

BY DAVE WORTHINGTON

“Do the Five” has been the message of the NHF Prevention Program for the past three years. The goal for this five-year program is to get the message out to the bleeding disorders population to encourage better health.

Each year the NHF sponsors regional prevention program conferences throughout the country to update chapters and HTC's on the program's progress, listen to the community response to the program and to present new tools to support the program goals. The Western Region conference this year was held in Scottsdale, Arizona on June 21-23. Our region, Region X, was well represented with Robi Ingram and Jan Goldman from the Oregon Regional HTC, Ryan Yokum as the youth representative and me as the consumer/chapter board representative.

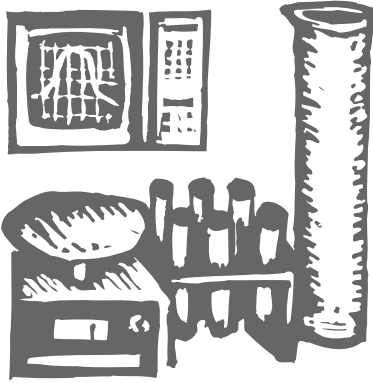
The focus at this conference was how to communicate the “Do the Five” message to youth. There were at least 30 youth participants from various western regions in attendance to provide insight. The meetings were lively and informative and provided a valuable opportunity to hear what other hemophilia groups were doing to communicate the “Do the Five” message. Our region recently completed a successful youth raft trip under this program. (See page 1). Other foundations and chapters have printed brochures, made summer camp videos and have organized fitness programs to promote this universally beneficial message.

The prevention program was coupled with the “NHF on the Road 2002” Conference, which is an opportunity for NHF to update our region about their current activities. NHF has assembled an extensive collection of materials for the “Project Red Flag” program (support for women with bleeding disorders). NHF has assembled an impressive “tool kit” of printed information and video for volunteers from chapters to present to their communities and local physicians to raise the level of awareness of bleeding disorders. Coupled with the national attention, the timing is right for a grassroots push in our region. NHF also announced a youth website that is fun, interactive and informative: www.nhfyouthworld.org.

Both the prevention program and the NHF on the Road 2002 provide a great opportunity to get a glimpse of what is happening in the bleeding disorder community nationwide. The greatest benefit, however, is the opportunity to exchange ideas with other foundations and individuals and to communicate more closely with HTC's. After witnessing the tremendous dedication of talented individuals and groups throughout the country, I feel our region is strong and can provide a considerable contribution to these programs.

“DO THE FIVE”

1. Get a comprehensive check-up at the Hemophilia Treatment Center
2. Get vaccinated for hepatitis A and B
3. Treat bleeds early and adequately
4. Exercise
5. Get tested regularly for blood-borne infections



News from Industry

Win a Trip to Orlando!

Baxter is sponsoring trips for five families to Orlando, Florida, for the National Hemophilia Foundation Annual Meeting, October 31 - November 2, 2002. For your chance to win, enter monthly online at www.hemophilia-galaxy.com/trip.

Specialty Pharmaceutical Division of Gentiva Purchased by Hemophilia Health Services (HHS)

DONNA ELLIOTT, HHS

On June 13, 2002, Gentiva Health Services Specialty Pharmaceutical Division was purchased by Hemophilia Health Services. Although this division of Gentiva is now known as Hemophilia Health Services, patients and health care providers will continue to see many familiar faces in addition to meeting more professionals serving the bleeding disorders community.

Hemophilia Health Services, Inc. is a wholly owned subsidiary of Accredo Health, Incorporated, www.accredohealth.com, a Memphis-based parent organization for a family of companies providing specialized contract pharmacy and related services beneficial to patients with certain chronic diseases.

Thanks For Your Support!

The following companies purchased exhibit table space at the HFO's Health Fair on June 1, and the fees received will fund future HFO programs:

- Alpha Therapeutic
- American Red Cross
- Aventis Behring
- Baxter
- Care for Life – NCS Health Care
- Coram, Inc.
- Gentiva Health Services (now HHS)
- Wyeth/Genetics Institute

The majority of funding for the Health Fair was provided through a generous grant from the Aventis Behring Foundation for Research and Advancement of Patient Health.

We sincerely thank these companies and their representatives for their support of and involvement with the HFO.

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

News from the Treatment Center

BY DR. GREGORY THOMAS, OREGON HTC DIRECTOR

The Universal Data Collection Program (UDC) is a voluntary program conducted by hemophilia treatment centers (HTCs) with support from the Centers for Disease Control and Prevention (CDC). The goal of the UDC is to improve the health of people with bleeding disorders by monitoring and developing prevention strategies for two major health complications of bleeding disorders: blood borne diseases and joint disease. Any person who has an inherited bleeding disorder or an acquired inhibitor can participate. The program is confidential.

What We Have Learned So Far In Oregon

UDC participation began nationally in 1998; the Oregon HTC first began participation in 1999 with five patients. Through mid-2002, 95 HTC patients over the age of 2 have participated and have completed data entered in the national database.

Oregon participants:	2-10 years old	29.5%
	11 - 19	51.6%
	20 -44	24.2%
	45-64	10.5%
	Over 65	1 person

	Region X	All U.S. HTCs <i>(Includes Oregon)</i>	Oregon HTC <i>(Includes Region X)</i>
Types of Bleeding Disorders:			
Hemophilia A	75	233	6,816
Hemophilia B	12	46	1,821
Von Willebrand Disease	6	13	1,924
Other Bleeding Disorders	2	10	330
Hepatitis A Immunity:			
Hemophilia A	41%	51.2%	62.2%
Hemophilia B	25%	50.0%	59.7%
Hepatitis C Positive:			
Hemophilia A	38.2%	45.3%	46.4%
Hemophilia B	66.7%	43.2%	45.0%
Factor Use in Hemophilia A:			
Home Infusion	77.3%	81.5%	72.3%
Prophylaxis	34.7%	31.8%	25.4%
Inhibitors	5.3%	3.9%	7.0%
No Factor Use in Previous Year	9.3%	9.0%	12.6%
Recombinant Factor Used	64.7% of those using factor	60.4% of those using factor	69.3% of those using factor



UPCOMING CLINIC DATES:

Annual Eastern

Oregon Clinic:

September 26

Malheur County Health Dept

September 27

Good Shepard Community
Hospital

Portland Clinics:

Doernbecher Children's
Hospital, 7th Floor.

2nd Wednesdays

(adult and pediatric patients)

Drs. Kujovich, Noall, Ey and
Thomas are available

4th Wednesdays

(pediatric patients)

Dr. Thomas available

If you or your child has not been seen at the HTC in more than a year, contact Theresa Garrett at the Oregon Hemophilia Treatment Center at 503-494-8716 or 1-800-452-3563 to schedule an evaluation.



Positive Page

Lab Work 101

You Don't Need An Advanced Degree in Chemistry to Read and Understand your Blood Test Results!

CONDENSED FROM POZ MAGAZINE, SUMMER 2002

The report is in...all three, five, seven pages of it. How in the world do you make sense of it? So many numbers, so many big words—it might as well be secret code! Well, why worry when you have your doctor right there to explain it all to you? Snap out of it! It's your blood, and you have every reason to understand everything that's going on with it. Remember, with HIV, ignorance is not bliss!

This article will focus on the most common lab test: the CBC (Complete Blood Count) and what its resulting numbers can indicate.

PATIENT NOTIFICATION SYSTEM

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

COMPLETE BLOOD COUNT (CBC) – Sample Readings

Test name	Results	Units	Reference Range
White blood cells (WBC)	3.5	cc x10 ⁹ /9th	(4.0 – 10.5)
Hemoglobin (HGB)	14.3	g/dL	(13.0 – 17.0)
Hematocrit (HCT)	39.4	%	(38.0 – 50.0)
Platelets (PLT)	185	cc x10 ⁹ /9th	(140 – 375)

White Blood Cell (WBC) count. White blood cells (or leukocytes) help defend the body against infection. A healthy WBC count ranges widely, from 4,000 to 11,000 per cubic milliliter of blood. A high WBC count may mean the body is fighting an infection. A low count might be due to a bone marrow problem, HIV itself or the effect of HIV meds.

Hemoglobin (HGB). Hemoglobin is a protein that enables red blood cells to carry oxygen from the lungs to the rest of the body. Normal hemoglobin levels for men (13 to 17 grams per deciliter) are somewhat higher than for women (12 to 16). Hemoglobin levels often run low in HIVers, especially those on meds. Iron supplements or the hormone erythropoietin (Procrit) can help boost them. (As always, check with your physician before beginning any new over-the-counter drug therapies.)

Hematocrit (HCT). Hematocrit measures red blood cells as a percentage of the total number of all blood cells. For men a healthy range is 39 to 50 percent; for women it's 37 to 47 percent. Hematocrit can tell you if your blood is too thick or too thin. The hematocrit value is typically three times the hemoglobin value. Both are used to diagnose anemia.

Platelets. These are small, round disks that enable blood to clot (as when a scab forms on a cut to stop the bleeding). HIVers may have a low platelet count (thrombocytopenia)—drug reactions or HIV itself may be responsible. The average platelet count is 140,000 to 400,000, with greater risk of bleeding as the count drops below 40,000.

In the next issue of *Hemophilia Headlines*, we'll look at the more updated tests, including the HIV Viral Load test, the HIV Genotype and Phenotype tests, as well as the Liver Function panel tests.

Membership Dues, Memorials and Contributions

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

Fred and Patty Adams
Mike and Sharon Amos
MaryLou Anderson
Michael Bernstein and Tina Baskin
Gloria Brogan
The Burden Family
Mike and Linda Charles
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Eileen Ruth
William and Louise Schuff
Steven and Theresa Schuman
Bill Schuyler
Neil and Nancy Sherwood
Dave and Pam Worthington

IN MEMORY OF

*In Memory of Richard Steadman
Hambleton*
Bill and Nancy Worthington
In Memory of Marianne Huntsinger
Bill and Nancy Worthington
In Memory of Barry Kurath
Amy Pool
In Memory of Mark Laam
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Lyla Eddy
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In Memory of Bertha St. Pierre
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CORPORATE CONTRIBUTIONS

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Franklin Contracting
Gentiva Health Services
Novo Nordisk
Bill Schuyler, DMD, P.C.
United Way of Columbia-Willamette
Wyeth-Ayerst Pharmaceuticals
Juan Young Trust

HEALTH FAIR SUPPORT

Alpha Therapeutic
American Red Cross
Aventis Behring
Aventis Behring Foundation
Baxter
Care for Life – NCS Health Care
Coram, Inc.
Gentiva Health Services (now HHS)
Wyeth-Ayerst Pharmaceuticals

CAMPER CONNECTION

Santo and Shirley Cannizzaro
Mike and Linda Charles
Dave and Jeanette Dansie
Tom Dieringer
Gaye Di Pasquale
Susan Emery
John Hammar, Don and Wilma Evans
Kevin and Jana Heffernan
Robert Heffernan
Corey and Mindy Hill
Charles and Diane Marshall
Ann Taylor

Don't Miss the HFO's Annual Meeting at the Oregon Zoo!

Be sure to complete and return the enclosed registration form for the Hemophilia Foundation of Oregon's Annual Meeting at the Oregon Zoo on Sunday, September 15, from 1:00-6:30 pm!

Once again, meeting attendees will be able to come early and enjoy the Oregon Zoo, with its award winning exhibits and family fun for all ages! Starting at 3:30 pm, we'll socialize and have the opportunity to meet with industry representatives, followed by our short annual meeting and a great picnic dinner. Afterwards, the Zoo staff will present a Birds of Prey show for everyone to enjoy.

To reserve your space at the Annual Meeting, the enclosed registration form must be received at the HFO office by Monday, September 9. Questions? Call Monica Dickey, 503-297-7207.

**Check out our
new Web Site!**

www.hfo.info



The Hemophilia Foundation of Oregon
5319 SW Westgate Drive #126
Portland, Oregon 97221

Address correction requested