

Outstanding Camper Named!

Three years ago the HFO Board of Directors initiated the "Mike Charles Outstanding Camper Award." This award includes a \$500 savings bond that is funded through the Doug McAllister Fund, as well as a continuous plaque and a plaque that the camper can have at home. The winner of this award is Three 7 T* [2(Mcnd r o)16.5(who most disntiysaque oles)] TJ -ined byqurecaco.1funi o at ho Director.r oS ca at



HEMOPHILIA FOUNDATION 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.

World AIDS Day Memorial Held

BY JAMIE DESSELLIER

The Oregon Regional Hemophilia Treatment Center (HTC) at OHSU, with the support of the Hemophilia Foundation of Oregon (HFO), held a brief but poignant memorial for the region’s people with bleeding disorders who have died of AIDS and HIV disease. The ceremony was held Saturday, December 4, to coincide with World AIDS Day.

A small group of family and friends of those with hemophilia who died from HIV/AIDS complications gathered in the Meditation Room at Doernbecher Children’s Hospital at OHSU for the memorial. The gathered group took turns reading aloud the first names of people in the hemophilia community who have died since the epidemic began over 20 years ago. A clergyperson from Doernbecher shared some brief words of comfort, and a vocalist sang while attendees reflected on the memories of those no longer with us.

After the ceremony, participants gathered in the HTC lobby for refreshments and to visit with friends. The HFO extends a very special thank you to the HTC staff for coordinating the ceremony and helping the community remember these special individuals.

Ladies Luncheon Enjoyable and Relaxing

Thirteen ladies in the bleeding disorders community gathered for lunch at The Historic Embassy Suites Hotel in downtown Portland on Saturday, November 6. One attendee came all the way from Pendleton, and several made the drive from Salem! The majority were dealing with von Willebrand Disease in their families, and several were dealing with hemophilia. Although the bleeding disorders were varied, the conversation was lively as similar issues were discussed and ideas were exchanged. Our thanks to Paul Gobel and Bayer for sponsoring this enjoyable event!



NHF 2004 Annual Meeting

BY MONICA GRUHER, BOARD TRUSTEE AND MOTHER OF FIVE-YEAR-OLD SON BENJAMIN

It was my honor to represent the HFO and our families in attending the Annual Meeting in Dallas this last November. While every aspect of the bleeding disorders community interests and concerns me, the volume of information and sessions at this event is almost overwhelming. Since I am the mother of a five-year-old son with severe hemophilia A, and a friend and resource for other families of young children, I focused my attention in the areas which provided the most information for those of us in that situation. In addition, as a symptomatic carrier and victim of the "just tough it out" advice from gynecologists and doctors unfamiliar with bleeding disorders in women, I also attended as many information sessions as possible for this topic. Following are a few excerpts from my attendance at the sessions. They were very involved and you should do your own research on the topics. The NHF website can also provide you with further details. Feel free to contact me directly as well.

Have a child under age 6? A "poster abstract" was presented at regarding the half-life and recovery of Factor VIII following infusion of factor in children under age 6. (Note: This study was conducted by Baxter Healthcare Corp., makers of "Advate"). "Half-life" is how long the factor stays in the body following an infusion. That is, how many hours does it take for the dose to be "used up." You may not be aware that very few studies that have been conducted in children with hemophilia. Therefore, the dosing approach has basically been the same for both adults and children—i.e. an assumption of a 12-hour half-life for all. This initial study provided information that the half-life for children can be anywhere from 3 to 5 hours LESS than adults. They indicate that the half-life increases as your child becomes older, possibly reaching the adult expected level of 12 hours sometime after age 10.

What does this mean to you? If your child is having breakthrough bleeding or unexplained bleeds when he has been infused "recently," perhaps the dosing will need to be revisited for your child. It may not be high enough or frequent enough (for prophylaxis) to provide adequate levels of factor for their activity level. I personally experienced this when my son had an ankle bleed while under prophylactic treatment. We chose to have a factor recovery test performed using two different products. Our results mirrored the results obtained in the Baxter study—our son's half-life was 7-8 hours, not 12 as in adults. We found this test to be helpful so that we could time the infusions and the volume to reduce the risk of bleeding and allow our son to participate in normal activities and sports without a high risk of bleeding. Other patients may not share our experience, but I hope that it is helpful for you to be aware that this could be an issue for your child as he becomes more active.

Women. The sessions I attended for women with bleeding disorders were very informational and empowering. The HFO will be sponsoring an event later this year for the purpose of further educating women and their medical providers

CONTACT THE EDITOR

Do you have any suggestions or comments? Contact Jamie Dessellier, Editor of Hemophilia Headlines, at editor@hfo.info.

CONTINUED ON PAGE 4

HAPPY BIRTHDAY, CAMPER!

October

Mitchell Schoenheit

Josie Oleson

Jonathon Pool

Dakota Fieken

Ryan White

November

Janelle Heiner

Christina Cacouris

Zachary Pedersen

Amanda Wignall

Justin Williams

December

Kayla Schadle

Ricky Ramos

Tanner Siri

Chelsey Goshorn

Austin Keever

Daniel Diaz

Erin Oleson

Lizzy Nelson

Cody Holman

Christian DuBois

Alysha Wignall

January

Dimitri Cacouris

Alex Burden

Josh Hall

Tyler Hargett

CONTINUED FROM PAGE 3

about bleeding disorders and treatment.

Healthcare changes will impact you. The third most fascinating session I attended was the one on insurance choice and access, with author and advocate Laureen Kelley. Boy if this session didn't make you concerned, none would! Laureen conveyed her concerns that our freedom of choice is under attack, and we had better all be paying attention. Changes are happening before our very eyes and many of us are completely unaware. For example, topics on the table in many states for discussion are reduced Medicaid benefits and restricted eligibility. In addition, other scary things are being discussed by aggressive insurance providers and Medicaid, such as sole source providers and products which take away your treatment options; home audits; and prior authorization requirements. These decisions are being made by individuals and organizations having absolutely no knowledge of bleeding disorders and the impacts of their decisions on people's lives. She left us with several messages: 1) Know who your insurance company really is—is it really just an administrator and your company is actually "self-insured." 2) Advocacy and talking to your government representatives is critical. 3) Know how the hemophilia "business" works in America—the business model is changing every day and affects us all. 4) The federal government and private insurers are slashing reimbursement for what they will tolerate for drugs and many have targeted hemophilia. Your product choice, provider choice, and coverage are at risk.

I want to leave you with two take-aways from my meeting experience that I believe are imperative for parents of a child with hemophilia—knowledge is freedom and empowerment. Empowerment provides the capacity for advocacy.

Get educated and become KNOWLEDGEABLE of: the nature of the bleeding disorder; your options in treatment, products to use, where to get product, type of care; insurance benefits, limitations, and caps; and the body, especially veins and joints

ADVOCACY for your child—educate your child's teachers and schools often; ask as many questions as you need to of your health providers; if you do not get answers, go looking for them; and avail yourselves of other parents and this organization for support

NHF Annual Meeting

BY RHONDA BONI-BURDEN

At 3:00 a.m. November 4, my family and I loaded up and headed to the airport. We had eight suit cases, eight carry-ons, and four heavy coats. You would have thought we were going to move to Texas rather than just visit for four days.

The NHF Annual Meeting was such a great experience for me, as well as my children. The kids were able to participate in the children's program which involved breakfast, lunch, crafts, field trips, and bonding. This made it easier to attend all the opportunities that were available.

Each morning started with a breakfast meeting on various topics: Thursday I learned about inhibitors; Friday was "Mom's with Experience;" and Saturday

insurance problems/mapping out where you are going.

I visited the vendor fair Friday for lunch and gathered information from all the different booths. I asked questions, listened, visited with other parents and made new friends. For those considering attending a future meeting, my suggestion to you is take an extra empty suitcase for all the information that you receive plus all the goodies. It will be easier than UPS.

The evenings were spent with social events where we met other people around the country with similar issues. We shared war stories and success stories which was quite rewarding. Friday evening a bus transported us to the Cowboy's stadium for a dinner party. I must say all the kids and adults had a great time and experienced more than enough Texas hospitality of more food than you can eat.

There were so many little workshops and informational meetings that it was hard to choose which ones to go to. I am going to have to go again, so I can attend the ones I did not get to go to.

Finally, there was a grand party of all Texas style. We were bused to an off-site western hall where we had a band, ribs and line dancing along with good fun family games.

Back at the hotel at the end of the weekend, we were very exhausted and ready for the early morning flight home (with more bags than we left with).

SIGN UP FOR HFO E-LINES

Simply send an email to hfo@easystreet.com, and in the body of the email give us your name and email address(es). Don't miss out on important information and events!

HFO Receives National Award for Web Site and eLines Program

NHF announced the Awards of Distinction and Awards of Excellence winners at its Annual Meeting in Dallas on November 6, 2004. The HFO received an Award of Distinction in Communications for our web site (www.hfo.info) and for our monthly "HFO eLines" email communications. Rhonda Boni-Burden and Monica Gruher accepted the award at the NHF awards luncheon, along with a \$1,000 check which will be used for future web site costs.

President Linda Charles has been working with web site designer Nicole Moles for the past year to revamp our existing web site. The new web site is easy to navigate, highlights relevant and timely information.

After launching the redesigned web site in June 2004, the HFO eLines email notifications were implemented in October 2004. These monthly emails let you know about upcoming activities, social events, fundraisers, and other time-sensitive information. These notification emails also let you know about volunteer opportunities and how you can be more involved.

We hope each of you is regularly receiving our quarterly newsletter, accessing our web site and receiving our HFO eLines emails. In order to make informed decisions, it is imperative that members of the bleeding disorders community have access to the most up-to-date information. What better way to advance the interests of our community than to empower you with the ability to make excellent decisions for your own families?



Family Focus

HFO Family Day and Annual Meeting 2004

ANNUAL MEETING SPONSORS

The HFO thanks these companies for their support of our Annual Meeting at the Zoo:

- American Homecare Federation
- Baxter
- Bayer
- Care for Life
- Caremark
- Coram
- Factor Health Management
- Hemophilia Health Services
- Novo Nordisk
- Wyeth
- ZLB Behring



On Sunday, September 12, over 200 individuals and families involved with HFO attended our Family Day and Annual Meeting at the Oregon Zoo. It was wonderful to see so many old friends of HFO and so many new faces.

Most people came early to check out what was new at the zoo. Prior to the meeting, an educational medical insurance session was held for those who wanted to learn about managing medical insurance benefits, insurance caps, COBRA, and accessing various programs. Speakers were Rosanne Combs and Susan Rasmussen with Regence Blue Cross/Blue Shield, Tom Jovick with the State of Oregon Medical Insurance Pool, and Tammy Vogel with the Oregon Hemophilia Treatment Center.

At 3:30 the meeting room opened for the meeting's Industry Trade Show. It was great to have so many bleeding disorder industry representatives there. Attendees had time to ask questions of industry and see what new products are on the horizon.



At 4:30 we gathered for our annual business meeting. President Linda Charles gave a brief talk to members, followed by the outcome of the election of officers and trustees for 2005. Next on the agenda was the presentation of the "Mike Charles Outstanding Camper Award" which went to Lizzy Nelson. Camp counselor Chris "Squirrel" Leland again put



together a fabulous slide show of the 2004 summer camp. Our thanks to Chris for a beautiful job. CDs and DVDs were made of this presentation and some are still available for \$20 at the HFO office, call Monica to get your copy.

The business meeting was followed by a delicious picnic dinner and plenty of time to visit with one another. We ended with a birds of prey show presented by volunteers from the Oregon Zoo. Thanks to everyone who participated. Hope you had a good time and will join us again next year.

Corey Pierce – National Golf Champion

JANET REIMUND, ZLB BEHRING

The excitement was mounting as all the families from the four regional events arrived in southern California to compete for the Junior National Champion Titles in Golf and Baseball. The NHF and ZLB Behring hosted a welcome dinner on Friday evening, where the families became acquainted with one another, shared so many common experiences and enjoyed a slide show of the many photos taken throughout this exciting championship.

The weather was beautiful, however the competition was tough as a total of 46 children competed in golf at the Tustin Ranch Golf Course and in baseball at Beckman High School.

For a second year in a row, Corey Pierce, representing the Hemophilia Foundation of Oregon was the Regional Winner from the state of Oregon. He just missed the 2003 Junior National Title in Golf by a slim margin, so he was determined to do his best at this year's competition. His perseverance paid off! Corey won this year by one stroke! He loves the game of golf and was determined to compete despite an ankle bleed. Congratulations, Corey!

His father, Douglas, stated that this was an incredible program and allowed parents to interact and learn from each other.

In closing, this Junior National Championship was designed to inspire children, but a by-product of this tremendous championship was the inspiration it gave to everyone involved.

The NHF and ZLBB would like to thank all the Chapters, the many dedicated volunteers, the children who gave it their all, their families who took time from their busy schedules in order for their children to be involved in this competition, the companies who supported us in this effort and most importantly Perry and Corey Parker for their untiring commitment and insight into the needs of the bleeding disorders community. Thank you both for being great role models for the hundreds of children we met this year! We will always remember the fond memories and the people we touched through our 2004 circuit!



From left to right: Corey Parker - Gettin' in the Game athlete, Corey Pierce - Junior National Golf Champion, Perry Parker - Gettin' in the Game athlete.



News from the Treatment Center

COX-2 Inhibitor Medications: Are They Safe?

BY JOANN DEUTSCHE, RN, MS, FNP
FAMILY NURSE PRACTITIONER

The Hemophilia Treatment Center has been getting a lot of calls about pain medicine recommendations since the recall of Vioxx, a "COX-2, selective" anti-inflammatory medication that was pulled off the market in late September of 2004. Many of our patients take COX-2 medication for debilitating chronic pain related to joint arthritis. Other COX-2 medicines that are currently available include Celebrex and Bextra.

Nonsteroidal anti-inflammatory drugs (NSAIDs) are especially effective with arthritic-type pain. These medications are widely prescribed for people with hemophilia because of their ability to selectively inhibit an enzyme (cyclooxygenase-2) that is induced during an inflammatory reaction, and, at the same time, NOT inhibit another enzyme that is responsible for protecting the stomach lining, platelets, and renal function. In other words, people taking these medications have a reduced risk of stomach discomfort, stomach bleeding, or having their platelet function affected while still getting pain relief.

As mentioned earlier, Vioxx is no longer an option. Merck & Co., Inc. announced in September 2004 that it is taking Vioxx off the market because of "an increased relative risk for confirmed cardiovascular events, such as heart attack and stroke, beginning after 18 months of treatment." Additionally, higher doses of Celebrex made the news in December when the National Institute of Health (NIH) announced it was halting a three-year colorectal cancer prevention study where participants were taking either 200 mg or 400 mg of Celebrex twice a day. Early analysis showed a "2.5-fold increased risk of major fatal and non-fatal cardiovascular events for participants taking the drug as compared to placebo" according to NIH.

At this time, the Food and Drug Administration (FDA) is keeping Celebrex and Bextra on the market. The cardiac risks identified seem to affect a small number of subjects participating in studies. Scientists need time to understand the full meaning rather than jump to quick conclusions. The FDA is collecting and analyzing available information from the most recent studies of Vioxx, Celebrex, Bextra and other NSAIDs to determine whether additional regulatory action is needed.

So what to do now? There is not just one right answer. Each person is different in terms of how pain affects his/her ability to do the things that make them feel okay about their life. The risks and benefits of taking these medications need to be taken into account, particularly any cardiac risk factors that may already be present. For example, in a young person without risk factors for heart

disease, continuing a COX-2 inhibitor to treat severe arthritic pain may be reasonable. On the other hand, in an older person with other risk factors for heart disease such as high blood pressure, a family history, smoking, or diabetes, it may be better to switch to an alternative pain medication, especially if the joint pain is not severe.

Don't hesitate to call the Treatment Center (503.494.8716) to discuss your particular situation. We will make recommendations and will continue to keep you informed about current drug developments and medication alternatives.

NW Home Care

Northwest Home Care has gone out of business effective January 6, 2005. The Hemophilia Treatment Center now has an agreement with Legacy Infusion Services to provide nursing services to patients needing assistance with home therapy. Legacy nurses are available on short notice to providing home nursing. Please contact the Hemophilia Center if you have questions or would like to be referred to Legacy Infusion Services.

NHF On-the-Road

The next NHF On-the-Road meeting will be held April 15-16, 2005 in Santa Fe, NM. The hemophilia bi-regional meeting for Region X (our region) and Region VIII will precede this on April 14. NHF On-the-Road is an interactive event for:

- Individuals with Bleeding Disorders and their families/friends
- Treatment professionals
- Chapter and association leaders
- Industry representatives

It is sponsored by NHF's National Prevention Program in collaboration with the CDC. The topic of this meeting will be family relationships. Discussions will include specific issues pertaining to single parents, siblings, fathers, and more.

For further information visit <http://www.hemophilia.org/events/ontheroad/home.htm>.

"DO THE FIVE"

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

In Memory

Richard Wagner

A Mass of Christian burial was held November 22 for longtime Portland-area resident Richard James “Dick” Wagner. Mr. Wagner died November 17, 2004 at the age of 47.

Dick was born in Portland on October 14, 1957. He was a graduate of Lake Oswego High School and lived in the Lake Grove area his entire life.

While he had many diverse interests, Mr. Wagner was perhaps best known within Portland’s musical circles as an expert piano technician and tuner. Over the years, he used his piano-tuning abilities as a fundraiser for the Hemophilia Foundation of Oregon and other charitable causes.

Survivors include his father, Ed; a companion, Claire Cunningham; three brothers and two sisters. Remembrances are suggested as donations to the Hemophilia Treatment Center at OHSU.

Jeffrey Leppaluoto

Vancouver resident Jeffrey A. “Jeff” Leppaluoto passed away October 24, 2004 at the age of 42.

A Memorial Service for Jeff was held at Vancouver’s Memorial Garden Funeral Home. As part of the service, attendees were able to share their favorite memories of Jeff, many involving hobbies he especially loved—among them, camping, fishing and golf.

As a youth, Jeff particularly enjoyed the outdoors. He was a regular participant in the Hemophilia Foundation of Oregon’s summer camp program. He grew up living along the Columbia River and loved to fish in his spare moments. He also enjoyed deep sea fishing with his grandfather in California, and as an adult, Jeff lived in California and worked as a commercial fisherman aboard his grandfather’s boat.

Jeff Leppaluoto is survived by his wife, Tina of Vancouver; his father, Keith Leppaluoto of Vancouver; and mother, Toni Herrin of Portland.

Membership Dues, Memorials and Contributions

Dues, memorials and contributions as of January 15, 2005

SUSTAINING (\$500 AND GREATER)

Heffernan, Robert

BENEFACTOR (\$250)

Jones, Alan & Jill

Oregon Hemophilia Treatment Center

PATRON (\$100)

Franklin Contracting, Inc.

Laam, Mary

Porter, Don & Clara

Schuyler, Bill DMD

Smith, Donald

INDIVIDUAL & FAMILY MEMBERSHIP DUES (\$20 INDIVIDUAL, \$35 FAMILY)

Adams, Fred & Patty

Aina, Don & Rowena

Amos, Mike & Sharon

Anderson, Mary Lou

Bernstein, Michael & Tina Marie Baskin

Cameron, PJ

Cannizzaro, Santo & Shirley

Carpenter, E. Powell

Charles, Mike & Linda

Cook, Tom & Jean

Dessellier, Jamie

Dickey, Jim & Sharon

DiPasquale, Gaye

Evans, Lori & Philip

Fisher, Lisa

Gibson, David & Sharon

Greenfield, Doris

Gruher, Jim & Monica

Harrison, Bill & Esther

Heffernan, Kevin & Jana

Heffernan, Pat & Tricia

Holmes, Steven & Lynne

Koepke, Don & Dona

Lapp, Carol

Lindemann, Sally & James

Lofland, Joan

Malek, William

McAlpin, Jim & Esther

McCartney, Robert & Margaret

Morrison, Tami & Larry

Nelson, Cliff & Kristy

Pagenstecher, Stewart & Deborah

Petrick, Frankie

Pierce, Doug & Cindy Secrest

Ruff, Lola

Sherwood, Neil & Nancy

Wagner, Edward

Zwetschke, Linda

DONATION IN HONOR

Mike & Sharon Amos

From Jim & Sharon Dickey

Mike & Linda Charles

From Doris Greenfield

Judie & Dave Cox

From Mike & Sharon Amos

Sharon & Jim Dickey

From Mike & Sharon Amos

Kellie Dowell

From Dr. Oscar Polo

Karen Fernandez

From Dr. Oscar Polo

Ann & Gary Linn

From Mike & Sharon Amos

The Steve Olson Family

From Mike & Sharon Amos

Pat & Mike Stone

From Mike & Sharon Amos

Gail & Dick Taylor

From Mike & Sharon Amos

Nancy & Bill Worthington

From John & Mary Pelton

MEMORIAL DONATION

Charles B. Ames

From Bill & Nancy Worthington

Katharine Howard Glass Coates

From Bill & Nancy Worthington

Bruce Dessellier

From Jamie Dessellier

Dorothy Hilligoss

From Chris & George Van Biber

From Russell & Lucille Harwood

Nathaniel Kurilo

From Tom & Jean Cook

Jeff Leppaluoto

From John & Toni Herrin

From Myles & Sylvia Kaye

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Lola Taylor

From Clyde & Emily Robinson

From J.D. & Gweneth Bane

William Worthington

From Mr. & Mrs. Robert Grether

From Jay & Faye Lindsey

DONATIONS/GIFTS

Allen, Harriet & Earl

Employees of Adventist Medical Center

Hilligoss, Barbara

Nelson, Doug

DONOR CHOICE FUNDS

United Way of the Columbia- Willamette

Scholarships Available

PARENT SUPPORT GROUP MEETINGS

Meetings are held at 6:30 p.m.

at Bullwinkle's Family Fun
Center in Wilsonville

- March 1, 2005
- May 3, 2005
- July 12, 2005
- September 13, 2005

Contact: Patina Fieken
at 503-625-6508 or
PatinaF@verizon.net for
further information.

Factor Support Network is pleased to offer two educational scholarship opportunities this year:

- The Mike Hylton & Ron Niederman Memorial Scholarship for men with Hemophilia or von Willebrand Disease and their immediate family members offers ten \$1000 awards.
- The Millie Gonzalez Memorial Scholarship for women with hemophilia and von Willebrand Disease offers five \$1000 awards.

All the necessary instructions and application forms can be downloaded from FSN's website, www.FactorSupport.com. Applicants are encouraged to submit their application online to: Scholarships@FactorSupport.com. All forms must be completed and emailed or postmarked by April 30th. Incomplete or late applications will not be eligible for consideration. Scholarship recipients will be announced and notified July 1st.

If you have any questions or would prefer a hard copy of the application to be mailed to you, please contact Linda Leigh Sulser, (877) 376-4968 or e-mail LindaLeighSulser@FactorSupport.com



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Address correction requested