

Hemophilia Headlines

SPRING 2006

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NHF Annual Meeting: National Youth Leadership Institute

BY ALEXANDER ELL

Throughout my young life I have only associated with hemophiliacs from the Northwest. However this past October, I was given the opportunity to make new friendships and share my ideas with an amazing group of affected young men and women spread throughout the country. The participants in The National Youth Leadership Institute (NYLI) ranged in age from 17 to 25, were both male and female, and were all in some way connected to the bleeding disorders community (i.e. ourselves, sibling, or parent). All 26 of us signified a strong symbol of diversity as we educated each other on our own unique stories and lessons we had learned along the way.

For three days, we attended programs at the NHF Annual Meeting in San Diego. Leadership was the predominant theme in most of our activities, as was responsibility. A presentation that stood out in particular was very "camp-like," with fun games that each had a hidden meaning or taught a certain lesson. For instance, we learned how to play and facilitate an ice-breaker game called "Water Pistols" that involved squirting each other with imaginary squirt guns. The game brought everyone out of their shells as we interacted together, laughed, and become more comfortable with these friends we had just met the day before. At the end of our training we learned our mission: to facilitate education games representing NHF's "Do the Five" to the children and adolescents present at the Annual Meeting. The NYLI was split into five teams, and each team was responsible for instructing one of the "Five." The kids had a blast and many didn't even realize they were learning about how to keep themselves healthier in the process.

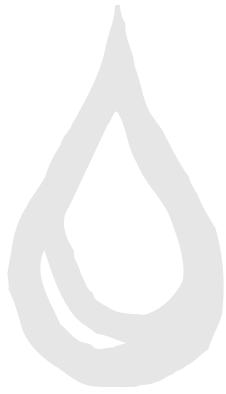
One factor that stood out beyond any other on my journey was the stories. I am a local Oregonian living in the city and take for granted the extraordinary treatment I receive. Listening to others tell stories of having a bleed out in the Midwest and having to travel sometimes hundreds of miles to get to the nearest HTC made me feel uneasy. One thing I learned is the importance of making a personal health treatment log with all my medical history and contacts, so if



Alexander Ell

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President's Message

BY LINDA CHARLES

Here it is the beginning of 2006 and planning is already in full swing for this year's programs! One significant change I want to share is the addition of "suggested donations" for many of our programs and events. We remain a relatively small nonprofit with limited funding, and with our program costs increasing each year, we think it's time to ask those in the bleeding disorders community to help pay a small amount to help offset costs.

Beginning in 2006, there will be a "suggested donation" amount for you and your guests when you attend an event. We ask that you send your suggested donation check to the HFO when you RSVP for events. If you cannot afford the suggested donation, please contact Monica Dickey in the HFO office and arrangements will be made for admission at no additional cost. However, we anticipate the cost will be reasonable enough that most will be able to manage it.

Read on for the great programs being planned for this year!

Our Parents' Support Group will continue to meet every other month. This is a great chance for parents to support one another while learning to deal with the issues that come with bleeding disorders.

We'll have two Family Outings this year—likely a Winter Hawks game in early 2006 and a second event later in the year.

We'll also have three Youth and Adolescent events, the first of which is a Blazer game in late February.

An Educational Insurance Symposium will be held in early 2006. The insurance climate is changing rapidly and we need to remain up-to-date on issues to best advocate for each family's needs.

Of course we'll continue our very popular Summer Camp, which is July 29 to August 5 at Camp Tapawingo in Falls City, Oregon.

The Annual Meeting at the Oregon Zoo in September is one of our best attended events, so you can count on it again this year.

Our web site (www.hfo.info) continues to be updated regularly – check it out!

If you have provided us with your email address, you will receive periodic HFO eLines emails, designed to keep you informed about upcoming events, fundraisers and volunteer opportunities.

And we will continue publishing our quarterly newsletter, "Hemophilia Headlines," which continues to be an excellent way to stay plugged in to the bleeding disorders community.

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!

HEMOPHILIA FOUNDATION OF OREGON

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NHF Annual Meeting 2005 San Diego

BY CHRIS LELAND

Thank you to HFO for the opportunity to attend the Annual NHF Conference this year. It was a wonderful and very educational experience that I believe will have a huge impact on my ability to support and grow HFO.

The most interesting meeting that I participated in was on grant writing. There was discussion on what makes a successful grant, and numerous resources for anyone without a ton of experience on how to write a great grant proposal.

I also attended a session on family social and educational activities. Events like hikes and bike rides focusing on safety, nutrition and the importance of exercise.

The summer camp session was insightful and focused a lot on counselor-to-camper interaction. In hearing the session leaders description of a great interaction and other camps share their experiences, it was wonderful to have it validated that we really do have an excellent camp program.

Overall it was a very beneficial experience, and I am excited for the year(s) ahead to see what I can make come from it.

CONTACT THE EDITOR

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

Announcing the Creation of the Hemophilia Federation of America Hemophilia Disaster Relief Fund

In response to numerous calls for assistance from Hurricane Katrina evacuees, the Hemophilia Federation of America (HFA) announces the creation of the Hemophilia Disaster Relief Fund to help support families with blood clotting disorder who have been affected by natural disasters. Your donations are tax deductible and can be made by check, credit card or money order.

Please make donations to the HFA Hemophilia Disaster Relief Fund by going to www.hemophiliafed.org and clicking on the "Donate" link at the bottom of the page or by mailing a check or money order made out to HFA Hemophilia Disaster Relief Fund to the address below:

Hemophilia Federation of America
1405 W. Pinhook Road, Suite 101
Lafayette, LA 70503

Additional information can be found on the web site or by e-mailing info@hemophiliafed.org.



Woman-to-Woman

Like Mixing Oil and Water? Women with Bleeding Disorders in Emergency Departments

BY RENEE PAPER, RN, CCRN
CONDENSED FROM AN ARTICLE IN HEMAWARE,
VOL 3 ISSUE 3, JULY 1998

When I was asked to write this article, I thought about the irony of having to write such a specialized article. The fact that such an article is even needed is a sad example of the care many women with bleeding disorders have reported receiving in emergency departments (ERs) throughout the country. Accounts such as "physician didn't believe a woman could have a bleeding disorder" or "the doctor had never heard of von Willebrand disease" are all too common. In fact, reports about mistreatment at the hands of ER personnel throughout the country when managing males with hemophilia continue to abound, so one is not surprised to hear that women with bleeding disorders face the same mismanagement. For a woman, however, the issue of gender bias enters the picture.

Obviously such behavior and ignorance are unacceptable, but the cold, grim reality is that they still persist. So what can a woman with a bleeding disorder do to increase her chances of adequate and appropriate management at the hands of ER personnel? The following are some steps I propose every woman or caregiver of a girl with a bleeding disorder think about prior to having to utilize ER services. Be realistic about your expectations for care in the ER.

Why are you seeking ER care?

Is it for the usual emergent conditions such as broken bones, lacerations, burns or are you looking to the ER personnel to figure out why you keep having excessive menstrual bleeding and prescribe therapy to stop it? Such complaints are more appropriately handled by your hematologist in consultation with your gynecologist. ER personnel are not specialized in either. ER personnel are truly "jacks of all trades, but masters of few."

Look for alternatives whenever possible

Hemophilia, vWD, and related bleeding disorders are chronic, lifelong disorders, just like diabetes. People affected by these disorders should learn early on how to manage them on a day-to-day basis. Do not become dependent of ERs to do so. Diabetics do not go to the ER for their daily insulin injection and likewise, people with bleeding disorders should not count on ERs to manage their clotting factor or DDAVP infusion needs.

Be prepared to educate the staff about your disorder and its management

Most people with bleeding disorders who have had to utilize an ER can recount the infamous question by an ER physician, "so how long have you had hemophilia?" That is your first warning sign that you are in trouble. If the physician does not know that hemophilia and von Willebrand disease are inherited

disorders and that you were born with it, do not expect him or her to know how to treat it. Know enough about your disorder and its treatment to be able to explain it to the personnel. Make it short and sweet. ERs are busy places, and the ER staff will not have time to listen to the basics of hemostasis and the differences between intermediate purity and recombinant factor concentrates. Just tell them what they need to know to care for you. Be sure to wear a Medic Alert bracelet that lists your disorder for those situations in which you may be unable to speak.

Bring your own factor or DDAVP

If your treatment requires infusion of factor concentrate or DDAVP, it is best to bring it with you to avoid delays in obtaining it. If you do not have factor with you, know where to obtain it in your community. If you are traveling to rural areas, it is best to carry factor with you because it may be completely unobtainable in a reasonable period of time in small rural communities. Know how to mix and administer the product.

Stay informed and in charge

Be careful about consenting to invasive procedures unless you fully understand them, are sure of their necessity, and pre-treat ahead of time. Again, I am not expecting you to know the alternatives, just to ask if there are any, and fully understand the risks and benefits of a procedure before you consent to it. If ultimately you feel the procedure is warranted, be sure to pre-treat if the likelihood for bleeding post-procedure exists. If at any time you are unsure of what to do, insist that your hematologist or the nearest HTC be consulted prior to proceeding.

Do not consent to unnecessary testing

This includes unnecessary blood testing. The same goes for X-rays of routine joint bleeds. In the absence of some sort of traumatic event preceding the bleed, there is little information the ER physician will garner from X-rays of the joint.

Remember you can catch more flies with honey than vinegar

Always treat ER personnel with the same respect and dignity you wish to be treated with. Behaving in a threatening or adversarial manner will not help the situation, it will only worsen it. You are in a crisis, and these professionals are there to help. You will need to understand and accept the fact that they will not have the expertise in managing bleeding disorders that you may desire. What they do possess, however, is the knowledge and skill to help you in a true emergency.

Go in prepared to help explain the bleeding disorder and its treatment so that they can proceed to deliver the necessary care. ER visits need not be horrible, frightening, powerless experiences. The power truly does rest with the patients if they will just assume that role. But remember, if you can avoid the ER in the first place, that is always best.

The full text of this article can be found at www.hfo.info



Family Focus

“We’re all Winners” at the ZLB Jr. National Championships

BY MONICA DICKEY

PARENT SUPPORT GROUP

New start time for the Parent Support Group: Meetings will now begin at 6:00 p.m.

Meetings are held at Bullwinkle’s Family Fun Center in Wilsonville. Contact: Patina Fieken at 503-625-6508 or PatinaF@verizon.net for further information.

Upcoming meetings for 2006:

- March 7
- May 2
- July 11
- September 12
- November 7

When our son Mitch was born 11 years ago with severe hemophilia, we never imagined that he would be able to play competitive sports. Thanks to his prophylactic treatment, our education about his disorder, and his willingness to learn to play sports safely, he has been fortunate enough to be able to participate in many of the activities that he enjoys. His biggest passion however is baseball, and he had the opportunity this past summer to attend and eventually win the baseball competition in the western regional ZLB Jr. National Championship competition in Salt Lake City, Utah.

When we arrived at the competition, we could not believe the level of athletes that had turned out to participate that day. It was hard to imagine that our son could have a shot at winning against kids who actually compete at the high school level. However, because of how the competition is structured, kids under 13 can fairly compete with kids over 13 on a level playing field.

The day begins with some basic instruction in golf or baseball, the kids are taught how to do proper stretching to prepare for their athletic events and after lunch the actual competition begins. At the competition in Utah, about 40 kids competed in the baseball event ranging in age from 8 – 18.

The baseball competition challenges the kids skills in pitching, hitting and fielding. To make the competition fair for all of the participants, there are different distances that the players compete from depending on their ages. Points are scored based on pitching accuracy, hitting distance and fielding ability. At the Utah competition, Mitch was in the top half of the scoring range throughout the day, however in the final round, two of the top competitors missed catching their fly balls and Mitch caught all of his scoring enough points to take over the lead and win the regional competition.

In winning the regional event, Mitch won a trip for our family to go to Orlando, Florida so that he could compete against the other regional winners in the National Championship. For a child who dreams to play baseball professionally some day, it was magical to see him be able to play on an actual professional baseball field. Participating in these events this past year has had an amazing impact on our son. Most of his creative writing choices have been about participating in these events and of his hero, Corey Parker.

As a parent watching these events, the greatest part was not only seeing our son compete, but in watching the friendships and bonds develop between our son and the other competitors—kids who are just like him! What an amazing opportunity for our son to be able to interact



Mitch Dickey proudly displays his winning trophy and certificate.

with others from around the country who not only have a bleeding disorder, but who share a love of baseball as well, they instantly had things in common.

We would just like to thank ZLB, NHF and the Utah and Florida chapters for sponsoring and hosting these events this past year. Not only does it give kids a chance to compete in a friendly, non-threatening venue, but it is such a great opportunity for families to connect, network and support one another.

Beginning Home Infusion: Karter Gives His Mom a Lesson

BY LINDA ZWETSCHKE

For all the new parents out there and parents who haven't started home infusion yet, here is a story for you.

My son is four now, but due to a severe ankle bleed and a new baby in the house, we decided to start home infusion shortly after he turned two. With the help of our HTC and a wonderful home care company, we tackled the task. Karter, of course, had veins that were hard to find, and he is also a very regimented young man. Everything had to be done the same every single time. The hardest battle was getting him to let someone other than me to hold him while we infused. Then we went on to him sitting by himself while I infused him. Once we got to that point, we were able to start infusing without the home nurse there. Which was good and bad - what if I couldn't find a vein?

One morning I was trying to find the vein, and at 6 a.m. his hands are cold, his blood seems to be in a resting state and of course he won't let me use a heat pack on the hand to bring the veins out. I missed the first time, and I was irritated with myself. I said "Karter, I am so sorry, but I have to try again." And as he sat there eating his candy, he calmly says "Not, not sorry. Try again." He was about 2 1/2. He amazes me daily, and I will always remember that poke. Sometimes it is harder on the poker than the poked.

If you have an anecdote that you'd like to share, please e-mail the editor@hfo.info. We love personal stories!

Fundraiser DVD Still Available

The 2005 Camp Tapawingo DVD features the Mike Charles tribute, the slideshow of this year's camp photos, as well as video from this year's camp. Each DVD is \$25, and the proceeds benefit our summer camp. Please contact Monica Dickey at the HFO office if you'd like to purchase your own DVD.

HAPPY BIRTHDAY, CAMPERS!

JANUARY

Alex Burden

Tyler Hargett

FEBRUARY

Michael Glenzer

Samantha Teague

Joseph Ransom

Crayson Neeley

Taylor Stuckey

Rafael Ramos

Nathan Oleson

Christian Heiner

Lindsey Groling

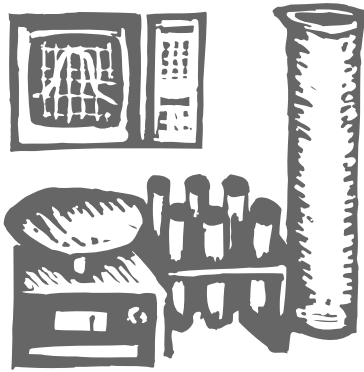
Caitlin Kirsch

MARCH

Josh Bulfinch

Gabriel Polo

Ray Winn



News from Industry

Wyeth Launches New Insurance Gap Program

Continuing its support of the hemophilia community, Wyeth Pharmaceuticals has introduced the Factor Resource Program, which consists of three individual programs, which are the Insurance-Coverage Program, the Patient Assistance Program and the Reimbursement-Information Line.

Insurance-Coverage Program participants will receive assistance tracking their insurance cap usage and identifying alternate sources of insurance. In the event of a lapse in their insurance, they can receive up to 12 months of free product.

The Insurance-Coverage program is available to individuals with either private or government health insurance and who have been using a Wyeth hemophilia product for at least three consecutive months at the time of application.

Program enrollment information is available from the Wyeth website at www.hemophiliavillage.com, the Wyeth Hemophilia Hotline at (888) 999-2349, or from a local Wyeth representative.

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

Over-The Counter Powder To Treat Nose Bleeds

“Nosebleed QR” is a topical powder that bonds with blood to halt a nosebleed quickly. It is a product of Biolife, a Florida-based company.

The powder is a mixture of a hydrophilic (water-loving) polymer and potassium salt. The polymer swells with absorption of fluids from the blood and binds with the blood to form a strong, artificial scab that falls off naturally.

Samples are available by calling 1-800-722-7559.



Contact Us To Schedule Educational Visits

Treatment Center staff are available for educational visits to schools, local emergency departments, fire departments, physicians' offices, county health departments, or wherever you think more education about bleeding disorders is needed. And we are always available for phone consultation for you or your providers. Our toll-free number is 1-800-452-3563.

Don't hesitate to ask for our assistance...we are here to serve you.

New HTC Website!

The HTC will have a new website up and running by Feb 1. It may be accessed at www.oregonbleedingdisorders.org. It will include options to order supplies and, eventually, factor. We will have educational offerings and ongoing information about Center activities. We are very excited about it and look forward to hearing how patients like it.

“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

In Memory

William "Bill" Harrison, 81, of Nampa, Idaho, passed away on June 8, 2005. Bill, a hemophiliac, was born in Twin Falls, Idaho on February 11, 1924. His life was always a challenge because of his hemophilia. In spite of this, he was always upbeat, planning how to cope if he were "laid-up" the next day. It was during one of the "laid-up" situations, as a patient in old Mercy Hospital, that he met the love of his life, Esther Henrickson. A year later she became his wife, establishing a special companionship for 60 years. With the Lord as his pilot, he established a successful insurance/real estate agency. Not being blessed with natural children, God gave them two daughters to call their own, Rebecca and Donna.

Bill is survived by Esther, his wife of sixty years; daughters Rebecca Griffin and Donna Clason; and grandchildren Brian and Erik Talbert and Jill, Kate and Lindsay Clason.

World AIDS Day Memorial Held

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 Thursday, December 1 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 first names were read aloud 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 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.

National Youth Leadership Institute, cont'd.

anything out of the ordinary does happens to me, the local emergency room will know exactly what steps to take and who to reach.

The NYLI is filled with young voices and shows great potential for role models for the bleeding disorders community in the future. We are eager to get many projects organized so we may branch out with our diversity and educate our peers and the younger generation. By doing this, not only are we helping others, but we ourselves are learning about how to lead a healthier lifestyle and discovering leadership within us. It is a long journey ahead, and the NYLI is helping pave the way for the future of living with a bleeding disorder.

Membership Dues, Memorials and Contributions

Dues, memorials and contributions as of January 15, 2006.

BENEFACTOR (\$250)

Jones, Alan & Jill
McClure, Wanda

PATRON (\$100)

Aina, Don & Rowena
Franklin Contracting, Inc.
Heffernan, Dr. Robert & Francy
Heffernan, Kevin & Jana
Pierce, Doug & Cindy Secrest
Schechter, Mr. & Mrs. Howie
Schuyler, Dr. Bill DMD, PC

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

Adams, Patty & Fred
Allen, Earl & Harriet
Amos, Mike & Sharon
Anderson, Mary Lou
Angell, Charles & Shirley
Berstein, Michael & Tina Marie
Baskin
Boni-Burden, Rhonda & Family
Bruce, Doris
Cameron, Phyllis
Carpenter, E. Powell
Charles, Linda
Chvatal, Dave & Marci Kociemba
Dessellier, Jamie
Dickey, Tom & Monica
Ell, John
Evans, Phil & Lori
Gassaway, Lee & Linda
Harrison, Esther
Hilligoss, C. Adair
Ingram-Rich, Robi & Tim
Koepke, Don & Dona
Lavelle Family
Lieberman, Art & Gail

Lindemann, Dr. James
Lofland, Joan
Malek, William
McAlpin, Jim & Esther
Nelson, Cliff & Kristy
Oleson, Dave & Family
Pagenstecher, Anne
Petrick, Frankie & Colton Norton
Pool, Amy
Potwara, Tamara & Paul
Ruff, Lola
Schuff, William & Louise
Sherwood, Neil & Nancy
Smith, Donald
Stanley, Jess
Stanley, Jess
Wagner, Edward
Worthington, Nancy
Zwetschke, Christopher & Linda

DONATION IN HONOR

Judie & Dave Cox
From Mike & Sharon Amos
Sharon & Jim Dickey
From Mike & Sharon Amos
Alex Ell
From John Ell
Ann & Gary Linn
From Mike & Sharon Amos
The Steve Olson Family
From Mike & Sharon Amos
Anne Pagenstecher
From Nancy Worthington
Cindy Secrest
From Over the Fence Brand Strategy
Pat & Mike Stone
From Mike & Sharon Amos
Gail & Dick Taylor
From Mike & Sharon Amos
Nancy Worthington
From John & Mary Pelton

MEMORIAL DONATION

Mike Charles
From Doris Bruce
From Earl & Harriet Allen
From Barrie Handy & Michael Handy
Bruce Dessellier
From Jamie Dessellier
Bill Harrison
From Esther Harrison
Barry Kurath
From Amy Pool
James Neville
From Nancy Worthington
Danny & John O'Brien
From Art & Gail Liberman
William R. Schuff
From Mitch & Marty Mitchell
From Jeanne Wilcox
From Charles & Shirley Angell
From Phil & Lori Evans

DONATIONS/GIFTS

Sandy Cunningham
Sandy Duncan
Jan Goldman
Doug Pierce & Cindy Secrest

Watch for information for these upcoming events!

March 4: Family event at the Rose Garden to watch the Portland Winterhawks tear up the ice. Come and join the fun!!!

March 18: "Facts First" Insurance Symposium – Red Lion Hotel on the River
– Jantzen Beach



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Address correction requested