



WASHINGTON DAYS

CAN LITTLE OL' ME REALLY MAKE A DIFFERENCE?

By Denise Cadwell

HFMD MISSION

To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications.

Inside this issue:

Hearts of Hope	2-3
Washington continued	4-5
College & Hemophilia	6
Fitness	7
Contributions	8
HTC Listing	8
HFA News	9
HTC News	10
Retreats/ HTC News	10-11
HFMD FAQ'S	12
Editing Notes	13
Industry /Research News	13-15
Calendar	16

This was the underlying thought that kept looping through my mind when HFMD asked if I would be interested in attending this years' NHF Annual "Washington Days".

I had read NHF's email explanation of the event: Wednesday, March 7th – Friday, March 9th, 2007 NHF's annual Washington Days empowers individuals in the bleeding disorders community to affect the legislative process. Join us to: Become more informed on critical issues that affect your continued access to high quality care. Learn effective grass-roots advocacy techniques. Meet face-to-face with Legislators and Staff who shape National Healthcare Policy.

Well now... this doesn't seem too scary, I thought... and besides I can room with Theresa Fladager, (my Best Hemo-Mom Friend).

As it turned out Theresa could not attend, so I was on my own. I knew that once the meetings started I would see HFMD executive director, Jim Paist there and I would be able to reach out and speak with other Folks attending this function.

I had no idea what lay in store for me. Nor did I know that these three days would be the single most important, life changing and empowering days that I have ever spent within the Hemophilia Community.



Jim Paist, Congressman Jim Ramstad, Denise Cadwell & Eileen Bostwick

First let me say (if you are not aware yet) that I am the Mother of Nickolas Gamache who is 15 years old now. Nick was diagnosed with Von Willibrands Type 2A when he was 10 months old. I have been actively involved with HFMD and NHF functions including; Being a Parent Facilitator for the Parents Empowering Parents (PEP) Program, Member of the HFMD Annual Meeting Committee, Past Volunteer for Women With Bleeding Disorders Program, Volunteer for the NHF "On the Road" Program and a general Volunteer for several Annual Meetings. I have **ALWAYS** felt that because HFMD was there for me and my family when Nick was first diagnosed (and I was a lost and clueless Parent) and because they have provided years of support, knowledge and enhancement opportunities for our family, that I would like to pay-back my appreciation by volunteering as much as I can. Besides, what a great "show by example" opportunity to teach my children ... that you can volunteer and remain an active Member in your Support Group!

So when the Washington Days opportunity came up I looked at it as a way to tell my story and experiences as a Parent of a child with a bleeding disorder. So I packed my bags and headed to Washington D.C.

continued on page 4



Hearts of Hope Gala 2007

The HFMD held its 7th Annual Hearts of Hope Gala on February 17th, at the Hilton Hotel in downtown Minneapolis. The evening opened at 6:00 p.m. with our silent auction featuring a big selection of exciting items to bid on. Guests mingled and bid on everything from lawnmowers & snowblowers to jewelry, to weekend getaways. We had a solid display of quality items donated by so many generous people and businesses.

As the silent auction closed at 7:30, our guests settled in the ballroom for some fine dining, entertainment and a live-auction. We were thrilled to welcome the return of Joe Schmit as our Master of Ceremonies. Joe was charming and entertaining throughout the night sharing his great sense of humor and genuine support of the bleeding disorders community. Honorary Co-Chair, Mark Plencner, R.Ph, of the Roger Maris Center/MeritCare HTC in Fargo spoke for both he and Dr, Nathan Kobrinski who was the other Honorary Co-Chair and unable to attend. Mark also shared a lovely spiritual invocation just before dinner.



Joe Schmit

Glenn Fladeboe together with Joe Schmit led a thrilling live-auction that saw some intensely competitive bidding on five tremendous items and packages: an original oil painting by Bob Newman, One week in Hawaii, ten Twins tickets with two Sun Country airline tickets donated by Joe Schmit, and five racing slots to do eight laps at Raceway Park in Shakopee and an Orlando vacation. We took a moment to give awards of outstanding support to our Diamond and Platinum level sponsors.

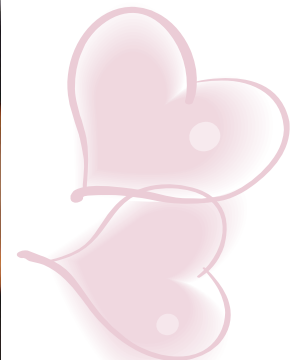
Just after the live-auction, Glenn Fladeboe led a pledge for HFMD post-secondary scholarships which raised \$7,500! Before the program ended, Del Pettis's name was drawn as the winner of the Caribbean cruise. After desert, the DJ opened up the dance floor with music and a light show. The food was terrific, the service was great, and our guests sure seemed to enjoy the evening's festivities. Over 250 people attended to support the work of the HFMD.

We would like to extend very special thanks to our Gala Planning Committee: Co-chairs Lisa Kallberg and Brett Schaumburg. Committee members: Nancy Golden, Liz Kallberg, Deb Melhado, Jessie Poundstone, Jessica Scofield, Deb Starling & Peggy Wier. The HFMD would like to thank all of our volunteers who helped get items donated and who volunteered at the event!

Send Us Your Email Address We like to stay in touch with our readers to share announcements of upcoming events and activities. We would also be happy to send you the Veinline electronically. Please send your email address (and name) to hemophiliafound@visi.com



Front row: Jeff Kallberg (CoaguLife), Peggy Wier (Baxter BioScience), Diane Sjolander (MeritCare), Nancy Golden (Bayer HealthCare), Deb Melhado (Wyeth). Back row: Jesper Ostergaard Jensen (Novo Nordisk, Inc.), Mark Wiener (CSL Behring)



Mark Plencner

We would like to thank our generous sponsors of the 2007 Hearts of Hope Gala!!!

Diamond level \$10,000

- Bayer HealthCare
- Baxter BioScience
- MeritCare
- Wyeth

Platinum level \$5,000

- CoaguLife
- CSL Behring
- Novo Nodisk Inc.

Silver Level \$1,200

- Caremark
- Maguire Agency
- Grifols
- HHS
- OptionCare Hemophilia Services

Patron \$500

- American Bank
- Jon & Beth Andersen
- ARJ Infusion



Del Pettis & Barb Schaumburg



Gayle & Bob Newman



Washington - continued from page 1

Wednesday evening was the first “get – together” meeting. We met as a group and Dr. Alan Kinniburgh, CEO, of NHF and its president Paul Haas, introduced themselves and both spoke about the importance of Advocacy amongst the Hemophilia Community. Glen Mones, then spoke about advocacy and really pointed out that we (as a Community) are the only ones that can speak for the rights and legislative issues both nationally and locally for the Hemophilia Community. NHF doesn’t have any Lobbyists that have the sole duty to advocate for us. We need to be the voices that are heard. He pretty much summed it up when he said, “The Hemophilia Community may be small in numbers (estimated: 20,000 nationally), but we are large in Voice!” This really hit home with me. If no one else is advocating and lobbying for the protection of my Sons future... I better step up to the plate. Why? Because I have a LARGE voice. Glen went on to inform us all of the current National Advocacy issues.

- Access to Adequate Healthcare Coverage:
In a nutshell, to get several health reform initiatives currently being discussed on Capitol Hill going and to act on these initiatives. As Advocates we were to discuss with our Government Representatives;
 1. What Bleeding Disorders really are
 2. Insurance issues and trying to make it easier to keep private health insurance for those of us in the bleeding community
 3. Lifetime Caps... (My Major Issue), and to eliminate them from all policies
 4. Access to products and services without jumping through insurance hoops
- Increased Access to Medigap Policies:
To discuss with our Representatives the importance of opening up the Medicare enrollment to folks 65 and under and to look at eliminating the 20% co-payment (which is out of pocket expenses) on us high-costing, chronic condition Members.
- Addressing Needs of Women with Bleeding Disorders
To address the importance of increased funding for our HTC's. One huge reason is because of the growing population of women diagnosed with or at risk for a bleeding disorder... the funds are currently being spread too thin.

· The Genetic Information Nondiscrimination Act

This one floored me. I never knew it existed. Evidently at this time any Health Insurer or employer can request that a person has to undergo a genetic test and consequently deny employment or health insurance based on obtained genetic information. Did I want my son’s future employers to deny him a job or medical insurance because of his inherited bleeding disorder? NO WAY... and I had NO idea that this was still going on! This bill was almost passed last legislative session but was set aside. We had to bring this bill up again and remind our Representatives that we needed their support to get this passed this time!

After Glen spoke a NHF representative explained the ins and outs... and the dos and don’ts of Capitol Hill and the protocol that is to be expected when we head to Capitol Hill the next day. Pretty simple... be respectful... but be heard. We then had a Pizza Buffet and sat with the Folks that we would be pairing up with. I officially met Eileen Bostwick from Minnesota... and realized that she is the current Secretary for the NHF Board... How impressive! Jim, Eileen and I met two lovely Mothers of Hemophiliacs from Missouri and we discussed who we were set up to visit on Capitol Hill the next morning. We discussed our backgrounds and some of the Advocacy issues this little get-together really gave me a strong sense of security. Jim Paist was extremely helpful because Advocacy is his background. He gave our Group so much support... but he really had a strong sense of selling our issues and knowing how this complicated process really worked!

Thursday morning after breakfast we jumped on a bus and headed for Capitol Hill. “WATCH OUT CAPITOL HILL CAUSE DENISE FROM HASTINGS MINNESOTA WAS LOADED FOR BEAR AND KNEW... JUST KNEW... THAT SHE WOULD MAKE A DIFFERENCE!”

All of the NHF state advocates met for a Legislative Briefing before their respective appointments with their own State Representatives. It further got us excited to talk about these pending issues... and how these issues affected our daily lives and how as their Constituents we need their support and their understanding to represent us and our Bleeding Disorder Community.



Rep. Jim Ramstad and Dr. Alan Kinniburgh say goodbye after meeting with the Minnesota and Missouri delegation.

After the briefing ... we had appointments with Representative Staffers from Missouri and from Minnesota... and even paused long enough to take a picture with Jim Ramstad. Dr. Alan Kinniburgh joined our meeting to thank Congressman Ramstad for his support. Jim Ramstad is and has been a big supporter for HFMD.

We all packed together and hit one appointment after another... we each had our own important aspects to share. I was able to explain to them that even though my Son does not have frequent bleeding episodes (we had a break of 5 years) that when he did have an episode like this November when he ruptured a vein in his Septum... that the hospitalization cost, Physician costs, Factor and pharmaceutical costs combined with Home Health Care and follow up care ended up costing nearly \$800,000 from November 19th until December 20th. This caused our family to switch insurance carriers because my Medical Insurance through my Employer had a 1 million dollar life-time cap. We were forced to switch to my Husbands coverage because of this. And this was the cost of only 1 bleeding episode!

After our appointments we headed back to the Hotel via bus and each sat down with members of the NHF staff to share our experiences! I couldn't help it... ideas just spewed out of me... and I was so excited that I called my Son Nick and told him that next year he was going to tell his own story! Let me tell you... he is all ready excited and ready to share away!

Thursday evening we had a reception to wind down from all of the excitement of the day. My feet hurt... and I was exhausted! I took off early and headed for bed!

Friday morning everyone from all of the States gathered and NHF discussed State Advocacy. They spoke about how to find out and how to jump in and

let your voice be heard on a state level. They talked about the successful attempts of other Hemophilia Chapters success at changing or preventing their own state legislative issues. This was pretty empowering... it was great to get an over view. It was great to meet other Parents... other Chapter Members. It was great to see old and new faces.

I have been lucky over the years to be able to give some of my time for volunteerism of our local chapter. I figured I had more time on my hands than the Parents who are dealing with bleeds daily, weekly or even monthly. I have been lucky and I have been blessed. But I know it is time (now that Nick is getting older) for me to expand my horizons with-in the Community. Don't be surprise to see my name ... running for our HFMD Board someday.... Soon!

All in all, I can honestly say that "LITTLE OL' ME... DID MAKE A DIFFERENCE... A HUGE, LOUD AND BOISTERIOUS DIFFERENCE!"

Thank you Jim Paist for your guidance and thank you Eileen Bostwick for your human touch and Parental support!

A heritage of caring. For over 60 years Grifols has been dedicated to quality, safety, efficacy and purity in the products we manufacture.

Andrew, an actual patient with his son.

Alphanate®
Antihemophilic Factor (Human)

AlphaNine®SD
Coagulation Factor IX (Human)

Profilnine®SD
Factor IX Complex

As with all plasma-derived products, the risk of transmission of infectious agents, including viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

Grifols Biologicals Inc. 5555 Valley Boulevard, Los Angeles, CA 90032
(888) GRIFOLS www.grifolsusa.com

Working for health since 1940

GRIFOLS

COLLEGE AND HEMOPHILIA

by Jeff Bostwick

Parents worry. It's a simple statement, but one that bears repeating: Parents worry. It doesn't matter if the kid is two or 22, wherever something can go wrong, there's a parent worrying about it. So when you take a teenager (already a great source of anxiety for the average family) and send them off on their own into the vast unknown we call "College", there's bound to be some excessive nail-biting. Add hemophilia into the mix, and there's a serious potential for panic. Luckily, a lot of the anxiety can be soothed with a bit of planning.

For the most part, hemophilia shouldn't play much of a role in deciding which school to attend - that's an entirely different conversation! Still, there are a couple things to consider:

- College tends to involve a lot more walking from class to class than high school. For students (like me) who tend to get knee or ankle bleeds, the size and layout of the campus can become a factor. Some of the schools I looked at had very nice, open campuses - but the daily walks from dorm to class and back would have put more strain on my ankles than I was willing to endure.
- Though the student health centers on campus are better than the average high school nurse's office, it was important to me to have a well-qualified staff. If there's a problem with an infusion, or I need extra assistance with anything, it's good to know that I have easy-to-contact, competent help right on campus.
- If you know that you spend a lot of time on crutches or in a wheelchair, make sure that you get a good feel for how handicap-accessible the campus is. From what I've heard, this isn't usually a problem with larger universities, but smaller colleges often have older, less accessible buildings. Campus tours are always encouraged, but if you know you'll have mobility problems they're almost a must.

Once you've found your school, the work really begins. Since I'm going to an out-of-state school, the first thing I did was talk to my current

hemophilia treatment center and get details for the closest HTC to the campus. They helped transfer paperwork to the new center, and sent them a "head's up" that I would be moving into the area. Along with alerting the HTC, they put together a set of standing orders for the local emergency room. My next step was to call up the health specialist at my school and ask her about my factor shipments, infusions, and supplies storage. She talked to the people in the mail room for me, to let them know that they should refrigerate the boxes and call my dorm when they arrived. As for the infusions, I was happy to learn that the school has no problem with me doing my shots in my dorm room, as long as I informed my roommate and the RA for the floor. In fact, with my RA's permission, during the first few weeks of school I left my door open during infusions, so the other guys on my floor could stop by and ask questions. Other schools might have other policies, however, so be sure to check that out before school starts.

Still, all the paperwork and policies can only get you so far. In the end, there are still some adjustments that have to be made. The two biggest things I had to deal with were doing the whole infusion myself and remembering to keep on schedule with my prophylaxis treatment. The first one I dealt with in steps, so that by the time I left home, I could routinely do the entire infusion sequence unassisted. To me, it was important not to be tied down to the nurse's schedule if I needed to do an infusion, so I wanted to be sure I could handle it myself. As for remembering to do the shots, the easiest way I've found is to mentally just tie the infusion to a set day (or days) in my class schedule. I find a couple of days where I'll have a good chunk of time (so I don't have to feel rushed), and then I just plan the infusions in like any other class.

No amount of planning can really take all the worry out of leaving for college, just like no amount of preparation can guarantee that you'll never run into problems once you get there. Still, by thinking ahead and practicing your routine at home, while you can still get input and help if you need it, the whole experience can be made just a bit more tolerable, for both the teen *and* the parent. There's just one last tip I have, and it's one you'll hear a lot, but it will really help: every so often, maybe just once every couple weeks, call your parents! A few minutes are all it takes to help set their minds (temporarily) at ease, and a phone call makes the perfect opportunity to ask for more spending money. ~ Jeff

Family Fitness Program Update

Because everyone had so much fun with our basketball event in December, we held another one on Saturday February 3rd at the Hancock Recreation Center in St. Paul. This time, we decided to offer basketball and floor hockey (a highly supervised style of floor hockey with rules of no contact, no checking or high sticks). Some of our HTC volunteers for the event were still a bit concerned as this is technically a level 3 sport according to NHF "Playing It Safe" guidelines.

Two dads with hockey backgrounds; Paul Hansen and HFMD board member John Shulte coached and played a scrimmage game with about ten young kids in our group. Most of the older kids and adults stuck with basketball and had a great time doing lay-ups, shooting free throws and long range shots. Everybody got a good workout in and enjoyed the warm gym on a bitter cold day. Once again, we ended our fitness activity with a low calorie lunch of submarine sandwiches. It was another successful family fitness event. Please contact the HFMD to find out about our Spring and Summer fitness event dates, or check our website calendar at www.hfmd.org.



member of
**Community
 Health Charities**
 M i n n e s o t a

Shift to the fast lane...

Less than half the steps*
 for quick reconstitution†

Use Kogenate® FS
 with BIO-SET®

Reduce your steps

Speed up your
 reconstitution

Get on with your day!

For more information, please contact your local Bayer HealthCare Account Executive, Nancy Golden, at (651) 407-6028, or by e-mail at nancy.golden.b@bayer.com.

Please consult with your healthcare provider to determine if Kogenate® FS is appropriate for you.

Kogenate® FS is a recombinant Factor VIII treatment indicated for the treatment of hemophilia A. The most frequently reported adverse events were local injection site reactions, dizziness, and rash. Known intolerance or allergic reactions to constituents of the preparation is a contraindication to the use of Kogenate® FS. Known hypersensitivity to mouse or hamster protein may be a contraindication to the use of Kogenate® FS.

For important safety and use information, please see full Prescribing Information at www.kogenatefs.com.

*Compared with conventional vial-to-vial reconstitution
 †Butler R, Larson P, Mannix S, et al. *J Outcomes Res.* 2004;8:63-78.

Kogenate® FS

Antihemophilic Factor
 (Recombinant)
 Formulated with Sucrose

with **BIO-SET®**
 Needleless Reconstitution System



Bayer HealthCare
 Pharmaceuticals

BAYER, the Bayer Cross, and Kogenate are trademarks of Bayer.
 BIO-SET is a trademark of Biodome SAS.

©2007 Bayer HealthCare LLC

All rights reserved

Printed in USA

2/07

09047Y

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2007 through March 31, 2007.

Organizational Contributors:

\$40,000 and Up
MeritCare

\$20,000 - \$39,999
Fairview Foundation

\$9,000 - \$19,999
Baxter BioScience
Bayer HealthCare
Novo Nordisk
Wyeth Pharmaceuticals

\$3,000 - \$8,999
ARJ Infusion Services
CoaguLife
CSL Behring
Mid-West Cornerstone Healthcare

\$1,000 - \$2,999
American Homecare Federation
BioRx
Community Health Charities-Minnesota
Factor Health Management
Grifols
Hemophilia Health Services
OptionCare Hemophilia Services

Individual Contributors:

\$1,000 +
Anonymous
John & Nancy Golden
Dan & Sarah Kallberg
William & Elisabeth Kallberg
Frank and Dr. Margaret Kurth
Maguire Agency
James & Stephanie Miller
Richard & Tracy Noble
Del Pettis
Catherine Roeder
John & Barbie Schulte

\$500 - \$999
American Bank
Jon & Beth Andersen
Abe & Kristen Appert
Timothy & Diann Boonstra
Alfred & Vicky Hannemann
Greg MacCallum
Pat McDonnell
Dr. Mark & Laurie Reding
Brett & Lynda Schaumburg
Linda Swanson
Patrick & Peggy Wier

\$200 - \$499
Jed & Vanessa Adams
Brad & Kim Baumann
Michael Beckman
Susan Bickmore
John & Angela Boyd
Gordon & Dr. Judith Campbell
Joseph Cella, MD
Steve & Marty Chamberlain

Phil & Susan Curoe
Thomas & Mimi Fogarty
John and Becky Fredericksen
Gregory & Rhonda Gilmer
Shawn & Mary Goettl
Dr. Jed & Jocelyn Gorlin
Glenn Kelley
Joe & Lori Kunkel
Mark & Dottie Larson
Jay & Shannon Lotthammer
John Malich & Joni Osip
Dave & Deborah Melhado
Bob & Gayle Newman
David Norris
Timothy & Patti O'Brien
Richard & Clare Pilon
Michael & Shirley Propp
Nicole Pulsifer
Susan Purdie
Shirley Wilson-Oslund

\$100 - \$199
Mr. & Mrs. Robert Braff
John & Cheryl Daniels
Dr. Larry Deal & Lisa Simonsen
Richard Dillon
Harold & Carol Farley
Theresa Fladager
Katherine Frey, MD
Mary Isabell Goettl
Steve & Deirdre Gollinger
Michael & Patricia Gorman
Dr. Robert & Kristi Gorman
Jeffery & Linda Graves
Kerry & Rachelle Hansen
Michael & Jackie Hellendrung
Andy & Pam Joe

Ricky & DeeDee Johnson
Jeff & Roxanne Kallberg
Lisa Kallberg & Laura Baird
Kent & Julie Krabbenhoft
Sean & Dawn Krauss
James Langworthy
Henry Lano
Dennis Lash
Craig Looney
Dean Mieseler & Assoc.
Mike & Heidi Neubert
LaVonne Propp
Thomas & Carrie Recker
James & Kathleen Reding
Mitchell & Barbara Rucks
Barbara Schaumburg
Joe & Laura Schmit
Dean & Katie Senne
Dr. Lowell & Judy Sorenson
Ernie & Mary Stelzer
Marie Storhaug
Dan Tinklenberg
Wenck Associates, Inc.
Dr. Blair & Joanne Woolsey
Kathy Wussow

Up to \$99
Carol Bistodeau
Connie Brown
Jim & Barbara Brown
Karen Everson
Shannon Fabick
Thomas & Pamela Flood
Rollie & Marilyn Gates
David & Alice Griffin
Jody Gronberg
Al & Karen Haugstad
Jason Hutchison
Jesper Ostergaard Jensen
& Carolyn Stein
Bill Kallberg
Rolland & Jean Krauss
Bill & Vera Laughlin
Patrick & Adrienne Lenling
Todd & Pebbles Lescarbneau
Peter & Kathryn Louis
James & Amber Manfred
Scott & Melissa Moran
Stephen Nelson, MD
George Noble & Joyce Daugaard
John & Anne Nolan
Mary Ollhoff
Karen Pedersen
Skye Peltier
John & Ruth Quast
Maureen Reeder
Janice Rossbach
Jessica Scofield
Doug & Diane Sjolander
Dr. Thomas & Robin Slack
Betty Stone
Robert & JoAnn Stone
Katherine & Timothy Treichel
Martin & Jill Weber
Steve & Dawn Witcraft

**Hemophilia Treatment Centers
(Tri-State Area)**

Hemophilia and Thrombosis Center
University of Minnesota Medical Center, Fairview
420 Delaware Street SE - MMC 713
Minneapolis, MN 55455
612-626-6455
htc@fairview.org

Mark Reding, MD
Raj Kasthuri, MD
Margaret Heisel Kurth, MD*
Christopher Moertel, MD*
Joni Osip, RN, MS
Skye Peltier, PA-C
Vicky Hannemann, RN, BSN
Susan Curoe, RN, MS
Kerry Hansen, RN, BS
Sue Purdie, RN, BSN*
Jocelyn Gorlin, RN, CPNP*

Jane Hennessy, RN, CPNP*
Kristen Appert, RN, CPNP*
Nicole Leonard, RN, BS*
Kim Jacobson, RN, CPNP*
Linda Litecky, RN, CPNP*

Kim Baumann, MPT
Jenni Sullivan, PT
Terry Hammink, MSW

Meg Eilers, Genetics Counselor
Shannon Fabick, Admin. Secretary
*Pediatrics at Children's in Minneapolis

**South Dakota Center
for Blood Disorders**
1305 West 18th Street
Sioux Falls, SD 57117
605-333-7171

Linda Stout, MD
Michael Sprehe, MD
LeAnn Schneider, PT
Carrie Kindopp, CCLS
Quinn Stein, Genetics Counselor
Jan Grogan, MSW
Kay Schroeder, RD

**Mayo Comprehensive
Hemophilia Center**
Mayo Clinic
Hilton 106
200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726
schmidt.kirstin@mayo.edu
slaby.jeffrey@mayo.edu

Rajiv Pruthi, MD
Vilmarie Rodriguez, MD
Kirstin Schmidt, RN
Jeff Slaby, RN
Jim Langworthy, MS, LICSW

**North Dakota Hemophilia/
Thrombosis Treatment Center**
MeritCare Hospital
820 Fourth Street North
Fargo, ND 58122
701-234-7544

Nathan Kobrinsky, MD
Kathy Wussow, PA-C
Kristin Odden, SW
Courtenay Misheski, RN
Linda Thorseth, PT
Diane Sjolander, CCRP
Mark Plencner, RPh



HFA Symposium 2007

The Hemophilia Federation of America (HFA) held its annual symposium in Albuquerque New Mexico, March 1st – 4th. Members of the bleeding disorders community came from all parts of the country to attend this exciting education event.

The exhibitor's hall opened on Thursday evening from 5:30 – 7:30 p.m. The programming began Friday at 12 noon with opening remarks from HFA President Carl Wexler, who delivered his speech in shorts. Carl shared his deep passion for the community and talked about what we can accomplish together. It was a very casual and welcoming atmosphere, featuring some terrific program sessions with dynamic speakers and panels.

I attended this event along with our board Treasurer, Dan Tinklenberg, who is also on the HFA board representing the HFMD. Nearly two years ago the Hemophilia Foundation of Minnesota/Dakotas joined the HFA as a member organization. The HFA has demonstrated an impressive ability to mobilize the bleeding disorders community, and has played a key role in recent progress on related legislation at our nation's capitol.

They have established a strong working relationship with the National Hemophilia Foundation (NHF) and the Committee of Ten Thousand (COTT), by working together and speaking with one voice. HFA understands that this community is small in numbers on a national scale, and therefore must maximize every possible resource to make our voice heard in Washington D.C., and in local Congressional offices across the country.

The HFA has an amazing Legislative Action Center on their website which they have generously shared as an internal resource for our HFMD website. Through their Legislative Action Center, you can send a letter to your state & U.S. representatives in a matter of minutes. Their sophisticated system also monitors any state legislation around the country which may affect the bleeding disorders community.

Since they were formed 11 years ago, their legislative policy efforts have been led by Jan Hamilton, who was honored in a farewell ceremony (a roast) on Saturday evening. After driving hundreds of miles up and down the corridors of Capitol Hill on her electric scooter, Jan is leaving the HFA as its Legislative Policy Director. The HFA is doing a great job in educating, organizing and motivating the hemophilia community. We applaud the HFA for their outstanding efforts in advocating for the bleeding disorders community, and we are very proud to be a member organization!

By Jim Paist



When you need us, Baxter will be there.

Through Therapies

Providing innovative recombinant factor, plasma-derived, and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

Through Participation

Offering initiatives for patients, families, physicians, and nurses and supporting local and national organizations and community events, in addition to volunteering.

Through Progress

Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs
and services, visit www.thereforyou.com

There when you need us

Baxter

Baxter, Advoy, Camp SuperFly, Factor Assist, and www.thereforyou.com are trademarks of Baxter International Inc.
©Copyright (January 2007), Baxter Healthcare Corporation. All rights reserved. HYL2652

SE MN FAMILY RETREAT



The SE MN Family Retreat was held February 10 – 12, 2007 at the Grand Lodge Hotel (Water Park of America). We had a very successful retreat with 76 people attending and all reported having a great time.

Our weekend started with registration and lunch on Saturday followed by three educational choices during two break out sessions:

- Yoga – presented by Holly Hunt, was offered during both breakout sessions. Holly provided a background and instructed participants on easy stretch moves as well as breathing techniques and the meditation aspects of yoga.

- Stress Management – presented by Jim Langworthy & Lori Kunkel

- Transition: What's it All About? – presented by Jeff Slaby & Kirstin Schmidt, the going process of transitions was discussed with much group discussion from our center experts; the patients, parents and family members, who shared experiences, concerns and advice.

Child care was provided for 16 children during the break out sessions by some of our teens; Sam & Kelsey Slaby, Tessah Schmidt and Kelsey Wigham.

After some swimming & free time we gathered on Saturday evening for a taco buffet at the “Tree House” and then had more time for swimming, visiting and even some self - infusion instruction.

Along with breakfast Sunday morning, Jim Langworthy and Jeff Slaby held a HTC Advisory Board meeting.

We had a great weekend and would like to thank all that participated!



Transition Ignition

The Hemophilia and Thrombosis Center at the University of Minnesota Medical Center recently held a “Transition Ignition”™ program at the Hilton Garden View in Shoreview March 10th. Twelve teenagers ages 14-17 joined us in the day long program that focused on the ‘what next’ as they learn to take increasing responsibility for their bleeding disorder. Our center was the second in the country to host this event.

The program was sponsored by a grant from Bayer HealthCare. The program developer, Mike Rosenthal from Hemophilia Innovations was there to facilitate. Mike Stinson, a 22-year old with hemophilia was the youth mentor. Joni Osip and Skye Peltier and Margaret Heisel Kurth from the Hemophilia Center were also present.

The objectives of the program were:

1. To promote a comfort level with hemophilia among teens.
2. Reach an agreement with teens to increase their responsibility for their own care.
3. Teach and practice skills that help teens and parents manage hemophilia treatment in school and social settings.
4. Build relationships with the providers at the HTC .
5. Build parental support and opportunities for guidance.

After the program the group went bowling and had dinner together. It was a long day but most agreed it was worth the time.

By Joni Osip, MS, RN

EIGHTH MN ANNUAL FAMILY RETREAT



The 8th Annual Family Retreat was held January 19-21, 2007 at the Grand Lodge at Brainerd Lakes in Baxter, MN. This event, coordinated through the University of MN Hemophilia Center and the Hemophilia Foundation of MN/Dakotas, was attended by ~ 120 people. The group was made up of families with children with bleeding disorders, their siblings and parents and HTC and HFMD staff. The Lodge was a beautiful, comfortable setting, with a great water park! We hope to have the retreat there again some time!

Dan Tinklenberg, an adult with hemophilia and a HFMD board member, started off the event at the Friday evening Italian buffet. The time allowed families to introduce themselves and begin connecting with similar life experiences. On Saturday, Joni Osip, RN gave an interactive presentation on *Living With Hemophilia*. This was followed by families gathering in small groups to *Tell Your Story*. Judging by the positive response, these opportunities will certainly be offered at future events. Dan Tinklenberg had a special breakout with a group of teens focusing on growing up with a bleeding disorder and approaching adulthood. It was so valuable for kids to be able to talk with someone who has been there and knows their experiences first hand.



After lunch, Mark Kay Thrower, RN gave a presentation on *Navigating the ER* during which, families gained insights on how to be the best advocates for themselves and their children. This was followed by an open session with all the gathered medical staff called *Everything You Have Always Wanted to Know – Ask the Providers*.



During the morning and afternoon sessions, children were together with teenage babysitters. Thanks to Beth Andersen who coordinates this and brings a troop of kids for this purpose. Next year we hope to expand the space allotted for this as the quarters were a little tight.

In the time in between and after sessions, there was time for families to connect with each other and also to enjoy the great facilities. The evaluations were overwhelmingly positive and we got many good suggestions on how to make the 9th Annual Family Retreat even better. If you are interested in planning or helping with next year's event, please call the Hemophilia Center at the University of MN at 612-626-6455.



By Vicky Hannemann, RN
Nurse Clinician

HFMD FAQ'S

(FREQUENTLY ASKED QUESTIONS)

- Can you explain how HFMD works with or interacts with Hemophilia Treatment Centers (HTC), and Pediatric Hospitals? We partner with the four regional HTCs in our area to carry out most of our programs for the community. HTC staff frequently volunteer on HFMD committees to help plan and coordinate our programs. Our four regional HTCs are a vital part of who we are, and they are four of the very best Hemophilia Treatment Centers in the country! See HTC list on page 8.
- If I want to volunteer for HFMD who do I call? Call Jim Paist at the office (651) 406-8655, or email to jamesp@hfmd.org
- How do I find out about the different outreach programs through HFMD? Read the Veinline, check out our website at www.hfmd.org, or call the office.
- If we pay for our Family to attend the HFMD Annual meeting, does this mean we are Members with HFMD for the year? No. You need to register as a member separately. Just contact HFMD for a membership form.
- How long is my HFMD Membership good for? Can I join at any time of the year or is there a specific time that Membership monies are due? What is the current Membership fee? Membership is for one year and can be easily renewed one year after you have joined. Member fees are \$20 for an individual & \$35 for a family membership. We will also waive the fee for anyone who requests it. General donations are not automatically processed into memberships, unless you specify such on a check or payment.
- Is a Membership with HFMD the same as a Membership with NHF? No. Although we are a proud chapter of the NHF, we are an independent non-profit organization. NHF has their own membership form and membership process.
- How does the HFMD decide who it sends to the NHF Annual Meeting? We ask our four regional HTCs to each recommend one family or individual to send. Priority is given to families or individuals who have not previously attended the NHF Annual Meeting. *The Mayo Clinic prefers to have HFMD make the recommendation.*
- If I am interested in joining the HFMD Board... what do I need to do? Who do I need to talk too? Attending the HFMD Annual Meeting and talking to HFMD staff or board members about your interest is a great place to start. You could also contact the HFMD anytime of the year to express your interest in joining the board.
- Does HFMD currently know of (or have) any locally regional scholarships available? Yes. We have a Post-Secondary scholarship program available to students with a bleeding disorder in our tri-state area. The deadline for applications is June 1st, 2007. Last year the HFMD awarded 7 students with education scholarships in the amount of \$2,000 each.

Alphanate® Receives FDA Approval for Some VWD Patients

The U.S. Food and Drug Administration (FDA) recently approved Alphanate®, a plasma-derived factor VIII/von Willebrand factor product, to treat specific patients with von Willebrand disease (VWD) undergoing surgery or invasive procedures. It is also approved for VWD patients in whom the synthetic hormone desmopressin is either ineffective or contraindicated. However, it is not approved for type 3 severe VWD patients undergoing major surgery.

Alphanate® is manufactured by Grifols, a global healthcare and pharmaceutical company headquartered in Barcelona, Spain. The product is approved to prevent and control bleeding in patients with hemophilia A (factor VIII deficiency) or acquired hemophilia A (factor VIII deficiency).

“This approval is an important advance for patients and their surgeons, providing them access to a proven preventive therapy that can make needed surgery possible and safer,” said Jesse L. Goodman, MD, MPH, director of FDA’s Center for Biologics Evaluation and Research.

SUPPLY NOTE: A Grifols representative has reported that because of increased use of Alphanate®, the company is contacting hemophilia treatment centers (HTCs) to obtain information about their utilization patterns so that the needs of specific providers and large-volume consumers can be met on an ongoing basis. For more information, please see www.grifols.com

Editing Notes



We would like to extend a sincere thank you to the following companies for their \$1,200 Silver Level sponsorship of the HFMD Gala on February 17th: Caremark, HHS, Grifols, Maguire Agency and OptionCare Hemophilia Services. Their sponsorship was not verbally recognized at the event as it was unintentionally omitted from the announcements.

Interested in writing an article for the Veinline?

We encourage members of our bleeding disorders community to submit articles, personal stories (& pictures), or general comments about HFMD and our programs. The deadline to submit an article for consideration in the next issue is June 27th. Please contact HFMD for more information about writing an article for the Veinline (651) 406-8655, or email to: hemophiliafound@visi.com



Finally, there's someone to look out for you.
Because you've got enough on your mind.

We take the worry out of living with hemophilia and other bleeding disorders, so you can enjoy life. We handle prescription fulfillment and product delivery, with a full

line of factor products and custom foil-wrap packaging that maintains the recommended temperature in all weather. We also handle insurance reimbursement and care provider issues. You'll have an individual case manager to assist you, advise you and negotiate for you. Finally, you'll have the reassuring feeling of someone always looking out for you. Finally, you'll have peace of mind.

Call us so we can start serving you today.

Craig MacDonald - 888-522-3681 ♦ Jim Brown - 888-550-1597



MID-WEST
CORNERSTONE HEALTHCARE
Peace of mind for your healthcare needs.

The American Thrombosis and Hemostasis Network Receives Five-Year Grant From Novo Nordisk

Riverwoods, ILL.

-- The American Thrombosis and Hemostasis Network (ATHN) announced today that Novo Nordisk will provide start-up funding through a significant unrestricted grant over the course of five years to help establish and grow the organizational leadership and operational infrastructure of the network. Founded in July 2006, ATHN provides stewardship of a secure national database, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the thrombosis and hemostasis community.

"Novo Nordisk has a steadfast dedication to social responsibility and we are honored by this investment in ATHN's future," said Diane Aschman, President and CEO of ATHN. "This unrestricted grant will allow us to truly begin defining and standardizing a secure, national database, and the processes surrounding it, to benefit patients and providers throughout our community."

In a joint effort with the Centers for Disease Control and Prevention (CDC) Division of Blood Disorders, ATHN will create a formal coalition with the 140 federally funded hemophilia treatment centers (HTCs) across the U.S. with the goal to conserve resources through use of a common information infrastructure so precious data will no longer be at risk for loss or fragmentation.

ATHN will facilitate the reuse of common data elements thereby reducing the need to collect the same data repeatedly for different purposes using different formats. At the local level, patients and providers will benefit from having access to more structured individual and aggregate patient data as needed to support the continuum of care.

"We are proud to support ATHN with their innovative work which will lead to better insight into treatments for people with hemophilia," said Martin Soeters, president of Novo Nordisk. "As part of our social responsibility, Novo Nordisk is committed to addressing the significant need for improving hemophilia care and we are confident that the ATHN clinical database will help answer the many questions that exist about bleeding and thrombosis conditions and care."

To see the rest of the story visit [novonordisk-us.com](http://www.novonordisk-us.com)
<http://www.novonordisk-us.com/>
<http://www.novonordisk-us.com/>

Bayer HealthCare and CSL Behring Extend Agreement for Supply of Recombinant Factor VIII

Global distribution deal extended through 2017

BERKELEY, Calif. (February 1, 2007) — Bayer HealthCare LLC., announced today the extension of an agreement with CSL Behring to distribute Bayer's Recombinant Factor VIII Kogenate® FS under the trade name Helixate®. This agreement, effective through 2017, extends the long-standing relationship between Bayer and CSL. CSL Behring is a subsidiary of CSL Limited, a biopharmaceutical company with headquarters in Melbourne, Australia.

As part of the agreement, Bayer was granted a license to intellectual property related to formulations of recombinant Factor VIII. The two companies have had a long and productive collaboration. "We strongly believe that this agreement can further develop our factor VIII franchise and that the new deal terms are attractive for both companies. It also solves all outstanding litigations," said Dr. Gunnar Riemann, Board Member Bayer HealthCare AG. "This is also a collaboration that has served the global hemophilia community through expanded distribution of our reliable Kogenate® and Helixate® line of products; reliability demonstrated by nearly two decades of clinical experience and more than 6 billion units infused," added Riemann.

"Securing the long-term supply of this life-saving therapy is significant for the patient communities we serve," said Peter Turner, president of CSL Behring. "Under this agreement, we will have the ability to increase the supply of Helixate® available for our customers. We highly value our long-term relationship with Bayer and look forward to continuing it through the next decade." To read the rest of the story, please see: www.cslobehring.com, or www.hemophiliabayer.com

Wyeth Pharmaceuticals and Nautilus Biotech Announce Collaboration to Develop Hemophilia Therapies

Wyeth — world's fourth largest biopharmaceutical company — builds on commitment to innovation in hemophilia

Madison, N.J., February 5, 2007

Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), and Nautilus Biotech in Every, France, today announced the signing of a research collaboration and license agreement to discover and develop novel recombinant Factor IX proteins for the treatment of hemophilia B. These extended half-life proteins will be designed to enhance patient convenience as they will reduce the number and frequency of treatments needed. As part of the agreement, Nautilus Biotech will apply its proprietary technology to improve the duration of action of recombinant hemophilia B therapy. The Nautilus Biotech technology makes minimal and specific changes to amino acids sequences in order to slow the breakdown of the protein in the body. To read the rest of this story, please see: www.wyeth.com.

Wyeth Receives FDA Approval for New BeneFIX Features That Provide Hemophilia B Patients a Simpler and More Convenient Preparation Process for Recombinant Factor IX

Collegeville, Pa., March 26, 2007

Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced today that it has received approval from the U.S. Food and Drug Administration (FDA) for new product enhancements for BeneFIX® Coagulation Factor IX (Recombinant) that will offer patients a simpler and more convenient preparation process compared with the original BeneFIX preparation process. BeneFIX is a coagulation factor created using recombinant DNA technology to replace clotting factor IX to stop or prevent bleeding in people with hemophilia B who do not have enough factor IX of their own. A new BeneFIX feature allows patients currently using the most common dosage strength — 1000 international units (IU) — to use a lower volume of diluent to administer the product, leading to a lower total volume of infused product. BeneFIX also offers a new needleless preparation process, eliminating the risk of needle sticks during reconstitution. . *To read the rest of this story, please see: www.wyeth.com.*

Hemophilia Foundation of Minnesota/Dakotas Board of Directors 2006-2007

Aaron Reeves, President
Rochester, MN

Bob Stone, Vice President
Fargo, ND

Sharold Friedrich, Secretary
Fergus Falls, MN

Dan Tinklenberg, Treasurer
St. Louis Park, MN

Jim Brown
Lincoln, NE

Judith Campbell, MD
Thief River Falls, MN

Nancy Golden
Centerville, MN

Bill Kallberg
Prior Lake, MN

Jim Langworthy
Rochester, MN

Stephanie Miller
Savage, MN

Elizabeth Myers
Mollette, SD

Brenda Neubauer
Bismarck, ND

Joni Osip, MS, RN
Minneapolis, MN

John Schulte
Woodbury, MN

Staff:

Jim Paist
Executive Director

Pam Cella
Office Manager

U.S. Weighs Blood Safety and Supply Concerns

Emerging threats to the U.S. blood supply posed by new disease pathogens have compelled blood banks and government health officials to implement more aggressive donor screening measures. Consequently, by increasing the number of donor deferrals and introducing new screening tests approved by the U.S. Food and Drug Administration (FDA), blood bankers are growing concerned about significant reductions in the overall volume of blood donations. As reported in last month's eNotes, the FDA approved the use of a new screening test for Chagas disease. The U.S. blood supply currently receives an adequate, though hardly robust, number of donations per year—only five percent of the eligible donor population actually gives blood.

Over the years, donor deferrals have continued to increase due to added restrictions and more thorough screening based on risky behaviors, new infectious diseases and travel to countries where blood-borne infectious disease agents are prominent. For instance, despite growing pressure from AABB (formerly American Association of Blood Banks), America's Blood Centers and the American Red Cross to modify current regulations that prevent men who have had sex with men (MSM) since 1977 from donating blood, the FDA has kept this ban in place. The FDA has also enforced donor deferral policies among all blood donations from people who lived or visited the United Kingdom for three months or more between 1980 and 1996. The ban has been in place since 1999, in an effort to prevent variant Creutzfeldt-Jakob disease (vCJD) from entering the U.S. blood supply.

Most recently, the emergence of transfusion-related acute lung injury (TRALI) linked to particular antibodies found in the blood of women who have previously been pregnant, has necessitated caution. Deferring this segment of the population would affect 10% to 20% of female donors, up to one million women. AABB is recommending that blood collection centers institute procedures to reduce the risk of TRALI from plasma donations by November 2007 and from platelet donations by November 2008. Implementing these changes will undoubtedly shrink the donor pool.

Many in the field are forced to balance two often divergent, though equally important, needs—the need to maintain a sufficient number of donors while limiting risks to the blood supply. “There’s an endless barrage of emerging or expanding pathogens, and it’s a constant juggling act,” said Michael Busch, a transfusion medicine specialist and director of the nonprofit Blood Systems Research Institute in San Francisco. While blood supply viability remains a concern for the foreseeable future, the FDA continues to take a vigilant approach to donations. “For every deferral we put into place, we do a very careful consideration of how it will impact the donor pool,” said Alan Williams, PhD head of the Division of Blood Applications at FDA’s Center for Biologics Evaluation and Research.

Source: Pittsburgh Post Gazette online (post-gazette.com), January 10, 2007

Venline

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS
(HFMD)

HFMD
750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363

Email: hemophiliafound@visi.com

We're on the web!
www.hfmd.org

Presorted
First-Class
U S Postage
PAID
Lone Oak
Mailing Services

2007 Calendar

- April 13 –14, 2007.....HFMD Annual Meeting
Ramada-MOA (formerly the Thunderbird)
Bloomington, MN
Saturday Evening Activity: The Grand Lodge &
Water Park
- May 19, 2007..... 30 Year Anniversary, U of MN, Fairview
Hemophilia & Thrombosis Center
(*contact HTC for more information*)
- July 14 – 20, 2007.....Summer Camp, Courage North
Lake George, MN
- July 27 – 29, 2007.....Dakota's Retreat
Black Hills, SD
- September 10, 2007.....HFMD Golf Tournament
Indian Hills Golf Club
Stillwater, MN
- November & December.....Poinsettia Sales begin at HFMD

****The HFMD Board of Directors meets every other month on the third
Tuesday at 7:00 p.m.****

Visit our web site, hfmd.org, for exciting news and updates!

