

HFMD MISSION

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other bleeding disorders by providing a broad range of services and programs.

Inside this issue:

Annual Meeting	2
North Dakota	3
Family Get Together	
WALK Fundraisers	
World Congress	4
Australia	
Financial Assistance	5
Treatment Centers	8
Factor Concentrates	8
Are Here!!	
Contributions	10
Calendar	12

BUNKER BEACH

This year, our summer group fitness event was held at Bunker Beach on Saturday, June 21st. Bunker Beach is the largest outdoor water park in Minnesota and our HFMD families had the opportunity to explore this water park on a beautiful sunny day! We had 120 members come out and get the chance to meet other HFMD families. Everyone had such a great time and were so grateful to be part of an event where they could spend the day in the sun with their families.



We started the group fitness event with a few announcements from Kayla, a staff member from Bunker beach. She mentioned a few safety procedures and how to be careful around the water at such a large water park. Shortly after her announcements, it was time for lunch! Bunker Beach provided us with hamburgers, hotdogs, corn dogs, and salads as the main meal. The sides

included chips and a fountain pop as the beverage. As a little surprise, there was also some candy thrown in there as a treat after lunch time and it seemed to be a hit with the younger members! With their stomachs full and their minds fully aware, our families bolted for the water park for the rest of the day.

Many decided to take the time to relax and enjoy the 900 foot lazy river and the large sand area. Others took a more thrilling route and spent their day in the wave pool and going down the slides. There were so many attractions within Bunker Beach that you had to make an effort to be bored.

There was something fun for everyone to do and it appeared our families truly enjoyed their day in the sun as they exchanged personal experiences and stories. It was a great way for members to learn from one another about camp and other HFMD events that they have been to in the past or will be attending in the future. Bunker Beach was the perfect way to enjoy the warm weather and host our summer group fitness event!



By Ketrin Vinokur, HFMD Intern.

HFMD Annual Meeting 2014

Step right up, folks, to the 2014 HFMD Annual Meeting! This year's Annual brought in 170 attendees including HFMD members, Hemophilia Treatment Center staff, exhibitors and Pickles the Clown. We came together Friday night, May 2nd at the Crowne Plaza West in Plymouth to eat pasta and get our carnival on. This year's carnival consisted of a number of games for kids of all ages, including: a putting green, Big Top Hoops, Dino Dig, a fishing wall, ping pong/solo cup, a chicken wing fling, snow cones, Pickles the Clown and her impressive balloon twisting, and new to the HFMD Carnival, the inflatable Hot Potato! In the other half of the ballroom, adults and teens gathered to play BINGO where full sized candy bars went like hot cakes (or like hot potatoes, in our case).



On Saturday, May 3rd our group got down to business. After breakfast, parents dropped off the kids with our MVP, Vicki Neis and her childcare team. Dr. Nigel Key presented as our first keynote speaker. Dr. Key opened his presentation by talking about the contrast in weather between North Carolina and Minneapolis, his previous home. After a good laugh and everyone being reminded of the snowy and bitter cold Minnesota winters, Dr. Key shared news and information about hemophilia research at the University of North Carolina where he treats patients and is also deeply involved in hemophilia research. Our second keynote speaker, Kristen Brown came to us from outside of the bleeding disorders community. Kristen is a

Bestselling Author, Brand Strategist, Speaker, Widow Mom and founder of Happy Hour Effect LLC. By sharing her personal story about overcoming major challenges of her past, Kristen provided ways for the group to "create happy hour moments throughout the day". Many members lined up to talk to Kristen after she spoke and nearly a dozen of her books were purchased at the end of her address, she was a hit! The afternoon offered up 3 different breakout sessions. 1. "Ask the Doctors Panel" with Dr. Margaret Heisel Kurth, Dr. Rajiv Pruthi, Dr. Susan Kearney, and Dr. Nigel Key. 2. "Foods for Great Energy" presented by JoAnn Ridout



from Nutritional Weight and Wellness 3. Blood Brotherhood "Understanding the Knee-Joint Anatomy" presented by Kim Baumann, MPT of UoMN Fairview followed by a peer rap session moderated by HFMD member Chris Maddix.

For the kids, Vicki Neis brought in InnerCity Tennis, a nonprofit tennis group that provided innovative physical fun through tennis skills, billiard lessons and a tournament for the teens. A beach theme of continuous activities and arts'n'crafts were held throughout the day with an educational twist, and a morning teen session with social worker, Jill Swenson.



A huge thank you to our Annual Meeting Planning Committee: Co-Chairs: Amy Eckerman & Jim Paist and the committee: Angie Boyd, Carrie Kisson, David Moss, Nancy Golden, Steph Miller, Vicki Neis, and Vicky Hannemann

We would like to extend a special thank you to our event sponsors: Children's Hospitals and Clinics of Minnesota, Baxter BioScience, Sanford Health, and U of MN Medical Center, Fairview. We would also like to give our thanks to our exhibitors: ARJ Infusion Service, Baxter BioScience, Bayer HealthCare, Biogen Idec, Bio RX, CSL Behring, CVS Caremark, Grifols, Kedrion Biopharma, Mid-West Cornerstone Healthcare, Novo Nordisk, Octapharma, Pfizer, and Walgreens Infusion Services.



Please watch our website (www.hfmd.org) and your mailbox for plans for next year's Annual Meeting! We look forward to seeing you then for more networking, education, and FUN!

By Carrie Kisson, HFMD Event Coordinator

North Dakota - Family Get Together - June 7th

The North Dakota Hemostasis & Thrombosis Center (Sanford Health – Fargo, ND) and the HFMD “knocked it out of the park” with their family get together on Saturday, June 7th. The afternoon began at the Lonestar Steakhouse restaurant, where Bayer HealthCare (via Nancy Golden) sponsored a delicious lunch and education session. Unfortunately, the scheduled speaker was unable to make it due to airplane mechanical difficulties. Despite this unforeseen change in plans, there was no shortage of good food, fun, and laughter. Later that evening, over 50 friends and family members joined together to cheer on the local minor league baseball team, the FM RedHawks and celebrated their victory over the Winnepeg Goldeyes. Thanks to all who participated! Special thanks for Courtenay Misheski, Nurse Coordinator, for organizing such a fun event!

Step Out for Bleeding Disorders: Family Fun & Education Day

Please join us for the Hemophilia Foundation of Minnesota/Dakotas Family Education Event! It'll be an entertaining and educational day for the whole family. Registration form enclosed.

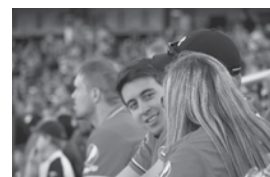
Saturday, Aug. 16

Holiday Inn, 3803 13th Ave. S., Fargo

- | | |
|----------------|--|
| 10:30-11 a.m. | Check-in & Vendor Fair
Visit with drug & home health vendors • Photobooth |
| 11 a.m.-Noon | Welcome & Social Hour
Group activities & games • Photobooth |
| Noon-1 p.m. | Lunch & Vendor Fair |
| 1 p.m.-2 p.m. | Keynote Speaker: Carson Ouellette |
| 2-2:30 p.m. | Chef Demonstration
Demonstration & preparation of an afternoon snack with nutrition discussion – Fun for kids! |
| 2:30-3 p.m. | Snack break & Vendor Fair |
| 3-4 p.m. | Patient Panel Discussion: Best Practices for Managing Hemophilia
Personal stories: Whitney Roske, mom of 2 year old with hemophilia
Adam Bohrer, Has hemophilia
Sherri Ouellette, mom of young adult with hemophilia
Bob Stone, Has hemophilia |
| 4-5 p.m. | Fun & Fitness: Physical Therapy & Fitness Discussion |
| 5:30-6:30 p.m. | Dinner |
| 7-9 p.m. | Thunder Road Family Fun Park • 2902 Thunder Rd. S., Fargo |



Blaine and Nicole McIvor



Carson Ouellette



Ethan Pochardt



Kellen Solem



Easton Roske



Beau Zeck

www.firstgiving.com/hfmd



**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

HFMD Walk Fundraisers
2 locations, 2 dates, 1 great cause!

SAVE the DATE

August 3, 2014:
St. Paul, MN
Como Park
Registration 10AM
Walk 11AM

August 17, 2014:
Fargo, ND
Lindenwood Park
Registration 10AM
Walk 11AM

The HFMD is proud to announce that there will be 2 Walk Fundraisers again, so “Step Out for Bleeding Disorders” in MN and ND! Join family, friends, form a team online, or be a team captain. Create your own fundraising page. People of all ages are encouraged to participate.

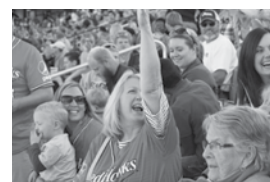


Please register on our Walk web-site: www.firstgiving.com/hfmd

For more information contact
the HFMD at: 651-406-8655 or
hemophiliafound@visi.com



Carson Ouellette



Blaine and Nicole McIvor, Sherri Ouellette,
Whitney Roske, Sarah Viseth



2014 World Hemophilia Congress in Land Down Under

Besides being home to the world's deadliest insects and snakes, Melbourne Australia hosted the 2014 World Federation of Hemophilia (WFH) Congress May 11-15th. Over 4000 delegates from over 130 countries were in attendance. The Congress included a full lineup of sessions, free papers, plenaries, crossfires, and workshops.

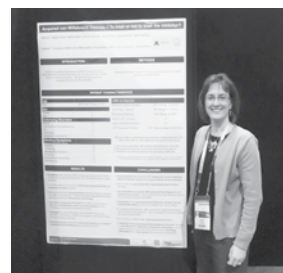
Some of the sessions included: discussion of new long-acting products, remaining challenges to Hemophilia gene transfer, and the successes and future of WFH.

CEO's of Biogen Idec and Sobi pharmaceuticals announced that they will donate 500 million IU's of factor VIII and IX over the next 5 years to WFH's Humanitarian Aid Program. They join CSL Behring and Grifols who have made multiyear donation commitments to WFH.

Dr. Mark Reding, from the University of Minnesota, Center for Bleeding & Clotting Disorders, presented at the meeting. He discussed a paper titled, "Safety and efficacy of prophylaxis and on-demand treatment with BAY 94-9027; Results of phase 2/3 multicentre, partially randomized, open-label trial." BAY 94-9027 is a Bayer study of a longer acting factor VIII product.

The Hemophilia Treatment Centers at University of Minnesota and Mayo collaborated on developing a poster about diagnosis, treatment, and prognosis of acquired von Willebrand disease. Acquired von Willebrand disease is a rare bleeding disorder that is not inherited. Sue Curoe, RN, Nurse Coordinator, and Surbhi Shah, Hematology Fellow, both from the University of Minnesota, presented the poster at the meeting.

We had a beautiful fall week along the Yarra River. Besides attending a great meeting, we were able to see some of the tallest trees in the world, spot a koala bear with its eyes open, and view some wonderful scenery along the Great Ocean Road. *By Sue Curoe*



INTRODUCING

Grifols Factor Savings Card Programs

Apply for a card and start reducing your out-of-pocket factor costs today:



Call



855-355-2574

AlphaNine SD Savings Card Program
Help Desk

OR

Visit



www.alphaninecard.com
AlphaNine SD Savings Card Program
Website

AlphaNine® SD
Coagulation Factor IX (Human)



Call



855-831-2090
ALPHANATE Savings Card Program
Help Desk

OR

Visit



www.alphanatecard.com
ALPHANATE Savings Card Program
Website

Alphanate®
Antihemophilic Factor/von Willebrand
Factor Complex (Human)

COA11-0214

GRIFOLS

www.grifolsusa.com

When “Life” Happens, HFMD’s Financial Assistance Program is There to Help!

By Stephen Calvit, LICSW

Tim and Donna live in rural Minnesota, way up north near the Iron Range. April 1st was just like any other day...wake up, let the dog out and start the coffee. Then moments later, without warning, Tim dropped to the floor, complaining of a throbbing headache. It quickly became obvious to Donna that something was dreadfully wrong! She dialed 911 and began to collect vials of Tim’s factor for the ambulance ride to the Emergency Room in the next town.

Tim had suffered a life-threatening cerebral hemorrhage. The ER physician contacted the Hemophilia Treatment Center (HTC) and spoke to a physician assistant who instructed the ER doctor to immediately have Tim transported to the U of M Medical Center. The HTC team developed a factor infusion plan for Tim’s pending emergency neurosurgery which occurred after his arrival.

The HFMD provides financial assistance to families who, like Tim and Donna, face sudden emergencies requiring out-of-town hospitalizations. The HFMD and HTC partner together and work as a team to reduce, as much as possible, some of the financial stress of lengthy hospitalizations, requiring hotel stays, eating out and parking. The HFMD even assists with transportation costs, including follow-up medical appointments months after the original hospital admission.

In addition to regular patient support duties, the HTC Social Worker makes initial contact with the patient’s family to explain the HFMD’s financial assistance program. The Social Worker’s message is simple and straightforward: you are on “auto-pilot” now and are under tremendous physical and emotional stress. This HFMD financial assistance is available for you to take care of yourself, to remain strong and clear headed. It enables you to support your loved one who requires your presence and advocacy! You can get some well deserved rest, take a hot shower, and have a few good meals to help prepare you for this emotionally difficult journey.

After the patient is discharged, the lodging, food and parking receipts are handed off to the HTC SW, who reviews everything and submits a report to the HFMD Executive Director, James Paist.

Of course, there are limits to the HFMD’s generosity. The assistance is needs-based so a family’s ability to pay for food and lodging is taken under consideration. To ensure fairness, strict guidelines and procedures have been developed by the HFMD’s Executive Director and HTC SWs (and approved by the HFMD board of directors). In addition to financial assistance for medical emergencies, the HFMD also provides one-time assistance to patients with bleeding disorders who experience a non-recurring financial hardship. Therefore, if you are a patient (or the family member of a patient) and believe you may qualify for financial assistance from the HFMD, please contact the HTC SW who will gladly walk you through the process.



Biotherapies for Life™

CSL Behring is committed to saving lives and improving the quality of life for people with rare and serious diseases worldwide.

Through our continued focus on innovation, we are leaders in developing new and enhanced plasma-derived and recombinant biotherapies, with a 100-year heritage of quality and safety. We offer the industry’s most robust product portfolio delivering “Biotherapies for Life.”

CSL Behring

Prefilled for fast and easy ALL-IN-ONE reconstitution.

Available in:



250 IU



500 IU



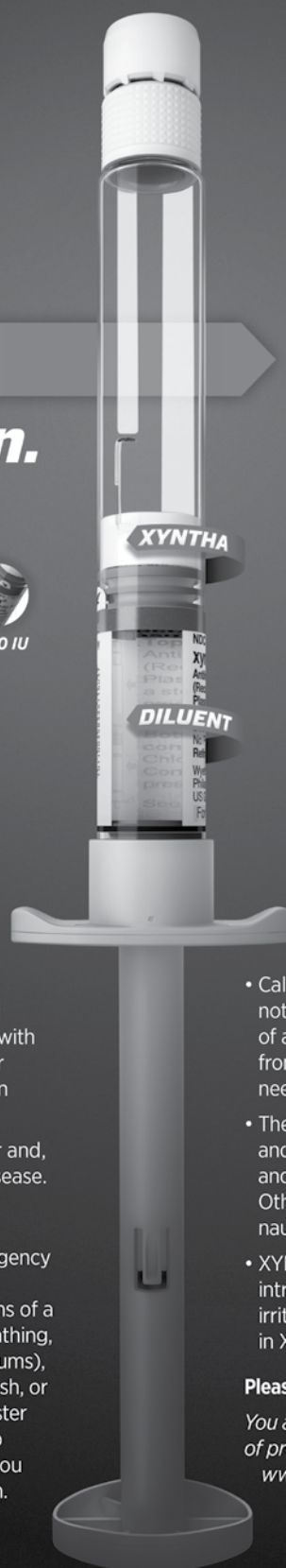
1000 IU



2000 IU



3000 IU



xynthasolofuse

Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free

***Get a 1-month supply up
to 20,000 IU of XYNTHA
at no cost to you—***

talk to your health care provider to see if
XYNTHA® SOLOFUSE® is right for you.
One-time offer.*

**Terms and Conditions can be found at
FreeTrialXyntha.com**

* You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the XYNTHA Trial Prescription Program, you may find help accessing Pfizer medicines by contacting Pfizer's RSVP program at 1-888-327-RSVP (7787).

What Is XYNTHA?

Xyntha® Antihemophilic Factor (Recombinant), Plasma/Albumin-Free is indicated for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for surgical prophylaxis in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated in von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, trouble breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein.

- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors.
- The most common adverse reaction in the safety and efficacy study is headache (24% of subjects) and in the surgery study is fever (43% of subjects). Other common side effects of XYNTHA include nausea, vomiting, diarrhea, or weakness.
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA® SOLOFUSE®.

Please see brief summary of full Prescribing Information.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Wyeth® Manufactured by Wyeth Pharmaceuticals Inc.
RUS481505-01 © 2012 Pfizer Inc. All rights reserved.

Marketed by Pfizer Inc.
Printed in USA/July 2012





Antihemophilic Factor (Recombinant), Plasma/Albumin-Free



Antihemophilic Factor (Recombinant), Plasma/Albumin-Free

R_x only

Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Wyeth Pharmaceuticals toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using XYNTHA and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your healthcare provider about your medical problems or your treatment.

What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia.

XYNTHA is not used to treat von Willebrand's disease.

What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

XYNTHA contains trace amounts of hamster proteins. You should not use XYNTHA if you are allergic to hamster protein.

How should I infuse XYNTHA?

Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet. The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

Call your healthcare provider right away if bleeding is not controlled after using XYNTHA. Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

What are the possible or reasonably likely side effects of XYNTHA?

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:

- wheezing
- difficulty breathing
- chest tightness
- turning blue (look at lips and gums)
- fast heartbeat
- swelling of the face
- faintness
- rash
- hives

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it, immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free] Prescribing Information LAB-0516-3.0, revised 06/12, and LAB-0500-7.0, revised 06/12.



Manufactured by Wyeth Pharmaceuticals Inc.

RUS477227-01 © 2012 Pfizer Inc. All rights reserved.

Marketed by Pfizer Inc.



Printed in USA/June 2012

Mayo Comprehensive Hemophilia Center**Mayo Clinic**

Mayo 10-75E
200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726
Ward.debra1@mayo.edu

Rajiv Pruthi, MBBS
Vilmarie Rodriguez, MD
Amy Eckerman, RN
Aubrey Manahan, RN
Dawn Olive, RN
Melinda Otto, LSW
Lyndsey Vandenberg, PT, DPT
Michelle Kluge, Genetics Counselor
Ivy Akogyeram, Pharm.D
Deb Ward, Secretary

North Dakota Hemostasis & Thrombosis Center**Sanford Health, Fargo, ND Region**

820 Fourth Street North
Fargo, ND 58122
701-234-2757
jana.suder@sanfordhealth.org

Nathan Kobrinsky, MD
Samuel Odame Anim, MD
Jana Suder, DNP, NP-C, Program Coordinator
Courtenay Misheski, RN Nurse Coordinator
Nicole Bogrud, RN
Tanya Ramacher, RN
Kimberly Rasmussen, RN
Cynthia Vingelen, RN, BSN
Linda Thorseth, PT
Diane Sjolander, CCRP Clinical Research Coordinator
Kate Syverson, MSW, LCSW
Mark Plencner, RPh Pharmacy Supervisor

Hemophilia Treatment Centers (Tri-State Area)

**Hemophilia and Thrombosis Center
Children's Hospital and Clinics of Minnesota
(CHCMN)**

2525 Chicago Avenue, CSC-175
Minneapolis, MN 55404
612-813-5940
angela.boyd@childrensmn.org

Margaret Heisel Kurth, MD
Susan Kearney, MD
Steve Nelson, MD
Michael Sprehe, MD, MPH
Skye Peltier, PA-C, MPH
Kim Jacobson, RN, CPNP
Jocelyn Gorlin, RN, CPNP
Jane Hennessy, RN, CPNP, MPH
Kristen Appert, RN, CPNP
Linda Litecky, RN
Sue Purdie, RN, BSN
Nicole Leonard, RN, BS
Cheryl Hansen, PT, CLT
Jill Swenson, LICSW
Beau Crabb, Genetics Counselor
Jennifer Lissick, PharmD
Angie Boyd, HTC Program Coordinator
Stephanie Davis, Administrative Assistant

Center for Bleeding and Clotting Disorders**University of Minnesota Medical Center, Fairview**

420 Delaware Street SE - MMC 713
B549 Mayo Building
Minneapolis, MN 55455
612-626-6455
htc@fairview.org

Mark Reding, MD
Helen McIntyre, MBA Program Manager
Ricky Chan, PA-C
Joni Osip, RN, MS NP-C
Vicky Hannemann, RN, BSN
Susan Curoe, RN, MS
Kerry Hansen, RN, BS
Kim Baumann, MPT
Stephen Calvit, MSW, M.Ed, LICSW
Maggie Dreon, Genetics Counselor
Sheryl Raygor, Administrative Secretary,
Data Coordinator

Sanford Health, Sioux Falls, SD Region

1600 West 22nd Street
P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

Mustafa Barbour, MD, Program Coordinator
KayeLyn Wagner, MD
George Maher, MD
Jerilyn Moore, RN
Grant Boltjes, PT
Wendy Jensen, CCLS
Quinn Stein, Genetics Counselor
Nathan Anderson, MA, LSW
Kay Schroeder, RD
Melissa Kruce, Dietician

Hemophilia Foundation of Minnesota/Dakotas Board of Directors 2014

John Schulte, President Woodbury, MN	Casey MacCallum Minneapolis, MN
Mike Neubert, Vice President Lakeville, MN	Carson Ouellette Devils Lake, ND
Elizabeth Myers, Secretary Mellette, SD	Ignacio Ramos Chaska, MN
Kris Manns, Treasurer Hudson, WI	Aaron Reeves Rochester, MN
Janell Badami Omaha, NE	David Moss Overland Park, KS
Donald Glascock Rochester, MN	Staff: Jim Paist Executive Director
Vicky Hannemann Minneapolis, MN	Carrie Kissoon Event Coordinator
Margaret Heisel Kurth, MD Minneapolis, MN	Ketrin Vinokur Intern
Brian Benke St. Paul, MN	

The New Tools:

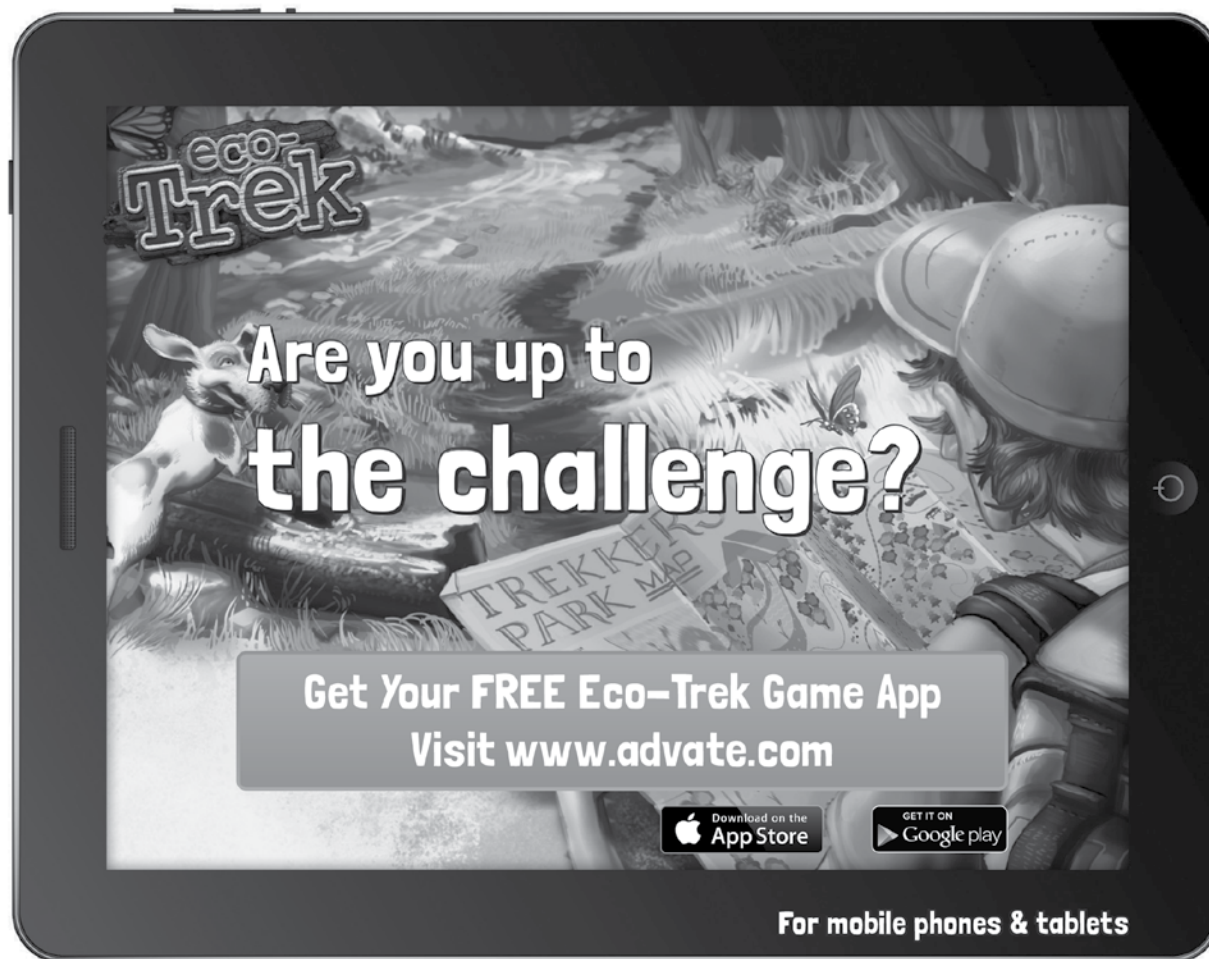
“Long Lasting” / “Longer Circulating” factor concentrates are here!

A milestone in the treatment of Hemophilia was reached on March 28th, 2014 when the FDA approved the first “long acting” factor concentrate. Bioengineers have been working for years to design Factor VIII and IX proteins that would last longer in the blood. Several different protein designs showed promise in the laboratory and animal models but failed to extend the factor activity time in human trials. Fortunately, recent clinical trials in patients with Hemophilia have demonstrated that some of these engineered proteins do last longer, work well to prevent and stop bleeds, and are safe. As of this writing, one long acting Factor IX product and one Factor VIII product have been FDA approved for use with more approvals on the horizon.




How will these new factor concentrates effect Hemophilia treatment and who should use them? This turns out to be a complicated question in the era of “personalized” hemophilia care. Each person has a different bleed pattern and life style that influences hemophilia care decisions. The goal of preventing and controlling bleeds doesn't change but the plan of how to achieve it varies significantly. These exciting new products increase treatment options, but they will not be the best fit for everybody.

To understand who might benefit from the “longer acting” factor products requires detailed information about a person's bleed pattern (where, how often, when it occurs) and current factor infusions. Evaluating this documentation will then allow you and your hemophilia care team to determine if the new concentrates may benefit you. Let's work together to understand and make the most out of these new tools! Call your treatment center with any questions.

By Kerry Hansen, RN, Nurse Coordinator, Center for Bleeding & Clotting Disorders



Eco-Trek is a one-player, multi-level game package that tests your outdoor survival skills

-  3 outdoor adventure games in 1
-  An online leaderboard for nationwide competition
-  Answer educational questions about ADVATE for bonus scoring

Bring your A-game to www.advate.com for your free download!



[Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free Method]

For more information, contact your Baxter representative today:

Stacie Cowen

Phone: (612) 701-5880

Email: stacie_cowen@baxter.com

Baxter and Advate are registered trademarks of Baxter International Inc.
All other trademarks, logos, or product brands appearing herein are the property of their respective owners. USBS/34/14-0031

Baxter

DONORS

Organizational Contributors:**\$40,000 and Up**

Fairview Health
Sanford Health Fargo

\$20,000 - \$39,999

Baxter BioScience

\$14,000 - \$19,999

Novo Nordisk Pharmaceutical

\$9,000 - \$13,999

Bayer HealthCare
Children's Hospital
CSL Behring
CVS Corporation
Express Scripts Inc
Mayo Clinic Factor Program
Pfizer

\$3,000 - \$8,999

BioRx
Buuck Family Foundation
Grifols
HFA
Octapharma
United Way Greater Twin Cities

\$1,000 - \$2,999

Accredo
ARJ Infusion Services
Biogen Idec
Community Health Charities MN
Maguire Agency
Mid-West Cornerstone HC
Walgreens

\$500 to \$999

Deano's Collision Specialists
The Park Tavern

Up to \$499

Aegis Foundation, Inc & Sanctuary Restaurant
Big Thrill Factory
Breadsmith
Chanhassen Dinner Theater
City of SLP
Community Health
CRAVE & Ignite Models, Inc.
Crowne Plaza Plymouth
Dakota Supply Group
FirstGiving
Foss Swim School
Grand Casino Mille Lacs - Hinkley
Guthrie Theater
Haskell's of Minnetonka
Kid Create
Little Feet
MN Swarm
MN Vikings
MSP Hilton
Mars Chocolate
Maynards & Old Log Theater
Mystic Lake Casino
Nascar Wallhauer, Jeff gordon
No Name Steaks
Ordway Center for the Performing Arts
PedalPub, Inc
Prime Therapeutics
Renaissance Festival
River Pines Dental
Saint Paul Orchestra
Saint Paul Saints
Sheraton Hotel
Stages Theatre Company
Surly Brewing Company
Trader Joe's Minnetonka
Truist
US Bank
Walker Art Center
Wells Fargo Community Support Campaign

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2014 through June 31, 2014.

If you have made a donation and your name is not listed, please contact HFMD.

\$1,000 and Up

Beth & Jon Anderson
Dick Bremer
Tim & Patti O'Brien
Mark Weiner

\$500 - \$999

Susan Bickmore
Tim Boonstra
Dusty Diekmann
Jed Gorlin
Barbara Griffin
Randy & Laura Halter
Susan Kearney & Robert Rothaar
Jai & Carrie Kissoon
Andy Lawrence
Mike Neubert
Joni Osip
Skye Peltier
Stacy Pike
Sue Purdie
Jon Schlosser
Judith & Dave Wegner
Mike Wheeler & Bridget Hegeman
Jane Zulueta

\$200 - \$499

Brian Benke
Dawn Bina
Gail & Mark Borchard
Dan Fremont
Vicky Hanneman
Jane & Mike Hutchens
Dena Ianello-Zimmerman
Paul & Nancy Jaworski
Jim & Stephanie Miller
Julieta Naranjo
Gary Newhouse
Bob & Gale Newman
Jim Paist
Jennifer Paist & Tom Tiegan
Mark & Stacy Plencner
Scott Rappa
Vidar Romarheim
Theresa Schneider
John Schulte
Dan Tinklenberg
Steven Younstedt

\$100 - \$199

Janell Badami
Brad & Kim Baumann
Joan & Nathan Boyer
Perry Cowen
Sue Curoe
Randy Frahm
Ron Frye
Nancy & John Golden
Jodi Gronberg
Kristy Heer
Natalie & Courtney Heer
David Jordan
Dan Kallberg
Gayle Kvenvold & Chuck Gould
Dave & Kathy Lundin
Kris & Joel Manns
JR Martinez
Josh & Beth Maus

Deb Melhado
Chris Moquist
David Moss
Sean Nugent
Lois Nyman
Kelly O'Hara
Ben Olson
Monica Parks
Shirley Propp
Jill Riley
Kirstin Schmidt
Mark Simpson
Lark Weller

\$50 - \$99

Janell Badami
Marlene Broin-Strong
Ricky Chan
Richard Daniels
Stacy Gleason
Nancy & John Golden
Ellyn Janski
Rich Lanz
Kris & Joel Manns
JR Martinez
Casey McCallum
Cheryl Peterson
Mindy Stewart
Amy Thie

Up to \$49

Patricia Alver
Nathan Anderson
Paula & Bruce Andrews
DeLon & Karen Bohrer
Carol Bistodeau
Chip Davis
Amy Eckerman
Teresa Fladager
Sharold Friedrich
Matthew & Teresa Germain
Amy Gilbertson
Don Glascock
Andy Hamilton
Dayna Hansen
Greg Hjelm
Sharbeen Hoskins
Dan & Carolyn Janski
Erick Johnson
Jill Johnson
Michael Johnson
Caleb Klersy
Claudette Lyng
Elizabeth Myers
Carson Ouellette
Jessie Poundstone
Julie Ramos
Kim Rasmussen
Teri Rehmann
June Schatz
Barbara Schulte
Sharon Slavic
Robert Stone, Jr
Jennifer VanPelt
Laura Young



Having issues with co-pays or gaps in coverage for your **hemophilia A** treatment???

We may be able to help.

Bayer offers a range of programs that can help you **navigate insurance questions about your hemophilia A treatment**. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call **1-800-288-8374** and press 1 to speak to a trained **insurance specialist!**

Venline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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



Donations can be made by sending them to the HFMD office or on our website www.hfmd.org using the PayPal donate button.



**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

Prsrt Std
U S Postage
PAID
Permit #1146
Twin Cities MN

Calendar

- August 3rd Step Out for Bleeding Disorders Walk
Como Park East Picnic Pavilion, St. Paul
10:00 am – 1:00 pm
- August 16th Dakota's Family Education Event
Holiday Inn of Fargo
- August 17th Step Out for Bleeding Disorders Walk Fargo
Lindenwood Park, Main Shelter
10:00 am – 1:00 pm
- Sept 18 - 20..... NHF 66th Annual Meeting
- October 11th -12..... Women's Education Weekend
Oakridge Conference Center, Chaska, MN

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****

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