NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

HFMD
HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

Veinline

Spring 2015

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:

Minnesota Children's Family Event Held in January

After 2 years since our last Children's Hospital and Clinics of Minnesota Event at Arrowwood Resort & Conference Center in Alexandria, MN, the HFMD partnered once again to host the 2015 HFMD/Children's Family Education Event. This year we brought families together in Downtown St. Paul at the Doubletree by Hilton. Over a very cold winter weekend in January, Children's Healthcare families gathered on Saturday the 10th in the Doubletree's Grand Atrium for lunch. Though many enjoyed the feeling of family reunions, we were able to share the weekend with a number of new families too. Over lunch, several patients and parents learned about and tried venipuncture (self-infusion or parent infusion on their child) with the assistance of nurses from Children's Center for Bleeding and Clotting Disorders. The joy in the eyes of our kids that tried self-infusing was remarkable!

After lunch it was time for the kids to join our very own, highly anticipated Childcare Programming Team, lead by Vicki Neis, Child Life Specialist at Children's. Special thanks to Vicki's team: Patricia Cich Lee led the infant's room along with assistant, Chloe Crimmins. Betsy Brand, CCLS led the 3-4 year olds along with assistants Chris Neis and Evan Crimmins. Vicki Neis, CCLS and Deb Crimmins, CCLS led the 5-12 year olds along with their assistant, Sean Crimmins. Finally, thank you to our junior helpers and ping pong instructors, Wesley and Evan Brand. This year's theme was "Game Theme" – the kids had a blast playing get-to-know-you games, Medical Minute to Win It, Bleeding Disorder BINGO, learning ways to make needle pokes easier on Beanie Babies and bananas, arts'n'crafts, and just being silly together. In addition to Vicki's regular awesomeness with the kids, her team brought the older group of kids down to the hotel's "Sporting Parlour" where the kids got to play ball games, skee-ball, ping pong, and bubble hockey just to name a few activities.

Meanwhile, parents joined each other in the ballroom to hear HFMD Board Member and Key Note Speaker, Carson Ouellette. Carson is a senior at Concordia College at Moorhead studying political science, philosophy, and business. Carson was also our keynote speaker at our last family education event in Fargo – his session was so inspiring that we asked him to share his story with our Minnesota parents. He shared how living with severe hemophilia A has never held him back. Since the age of 6, Carson has grasped every opportunity to learn and grow from having hemophilia and becoming a member of the National Youth Leadership Institute to being a member of our HFMD board. Thank you, Carson, for sharing your inspiring story of determination with us!

Next up to bat was our patient panel, titled, "Sports & Bleeding Disorders". Our panel consisted of two HFMD Board Members, Carson Ouellette and Casey MacCallum, our Board President's son, Cole Schulte, and our sports nut member, Matt Jaworski. Special thanks to Joni Osip, NP at U of M Health for moderating the discussion. Our four panelists talked about what it was like growing up playing sports with hemophilia. Well, in Cole's case, we were able to hear a live and in action teenager's view on the subject matter. It was also great to have our Children's medical team in the audience helping answer questions as they arose.

continued on page 3....

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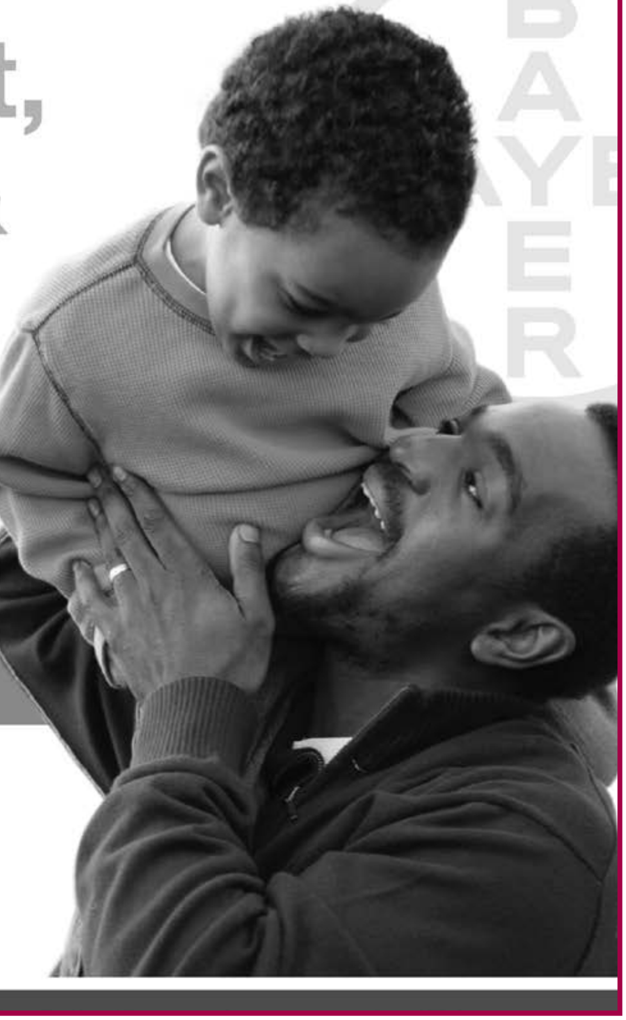

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Cover Story continued....

Thank you to our sports team for sharing your stories and knocking this session out of park!

This year's breakout sessions were sponsored by HFA through their Dad's in Action Programming led by Stanford Murry and their MomsConnect Programming led by Dave Robinson, PhD, LMFT. Stanford is a father of two sons with severe hemophilia and a daughter who is a carrier. Dave is a licensed and practicing marriage and family therapist and director of the marriage and family therapy program at Utah State University. He and his wife have 5 children, two of which have moderate Factor IX hemophilia. It was an honor to have both Stanford and Dave travel so far and speak for us!

After dinner it was time for some fun and action with the kids. We spent Saturday evening at the Minnesota Children's Museum! But, only after trying desperately to figure out the St. Paul skyway system beyond Saturday business hours. After putting 60-70 heads together, we managed to find our way!

After a busy day of education, networking and fun, we joined each other on Sunday for breakfast, more childcare programming, and reassembled in the ballroom, for HTC Updates – Research, StoryCorps, and Pharmacy Monitoring. Dr. Sue Kearney spoke about research projects going on at the center including the Centers for Disease Control and Prevention (CDC) Community Counts Surveillance Project for people with bleeding disorders started in 2014. Jill Swenson, Social Worker at Children's, introduced the StoryCorps® Legacy project, which is going on at Children's through June 2015. Jennifer Lissick, pharmacist at Children's, gave an overview of the new pharmacy monitoring of hemophilia/ bleeding disorders patients that she is working on. HTC Updates lead into our group's favorite session: "Ask the HTC Team", where Dr. Heisel-Kurth joined the panel and a lively discussion took place. The event was adjourned with a boxed lunch for families to eat together or take for the drive home.

The HFMD would like to thank Children's staff for helping to make this event a huge success! You are a genuinely caring team of healthcare professionals and we are all very lucky to have you in our lives! You are there from the start of our family's journeys and it is evident that you are one of the reasons this entire community truly feels like family.

Contributed by: Angie Boyd & Carrie Kissoon

Children's Healthcare StoryCorps Project

StoryCorps Legacy, a program of the national oral history project, StoryCorps, is partnering with Children's Hospitals and Clinics of Minnesota to record and preserve the stories of families of children with bleeding disorders and sickle cell disease.

StoryCorps interviews are conversations between two people who know one another. Participants talk about whatever they'd like and ask one another open-ended questions about their lives.

At the end of your conversation, you'll receive a free CD recording to share with family and friends. With your permission, another copy will be archived in the American Folklife Center at the Library of Congress and at Children's Hospitals and Clinics of Minnesota. StoryCorps is an audio project only—no video will be taken.

How do I participate? Recordings will begin in March 2015. Contact Stephanie Davis at stephanie.davis@childrensmn.org and/or (612) 813-7483 to schedule your interview today!
To learn more about StoryCorps Legacy go to: storycorps.org/initiatives/legacy.

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HFMD 15th Annual Hearts of Hope Gala

Back by popular demand, the HFMD returned to the Radisson Blu for our Gala fundraiser on February 21st. With a substantial increase in sponsorship, we had 260 attendees join us for an evening of auctions, mingling, fine dining, and a meaningful program led by Dick Bremer (our Master of Ceremonies). We had a fantastic silent auction thanks to so many of our Gala committee members and supporters securing a wide range of quality donated items from local businesses and pro-sports teams, and even tickets to a Chicago Cubs game at Wrigley Field donated by Paula & Ron Coomer (former Minnesota Twin).

There was competitive bidding on nice hotel stays, restaurant gift certificates, birthday parties, book baskets, and a wheel barrel full of craft beer. We had items ranging from Wild hockey tickets to childrens' toys. Our Diamond Drop raffle sponsored by Continental Diamond was another big hit! And U of M Medical Center HTC staff volunteered to run a wine wall raffle where they had secured over 70 bottles of nice wine. It was a great silent auction and our guests had plenty of time to schmooze before our dinner program.

Our program opened with a heart-felt invocation from HFMD Board President John Schulte. Then back for his third consecutive year hosting our Gala, Minnesota Broadcasting Hall of Famer, Dick Bremer opened our evening program sharing some stories as a Fox Sports North Television Broadcaster. Dick also shared his personal connection to our bleeding disorders community.

During dinner, Auctioneer Dave Nelson and Dick Bremer opened an exciting silent auction that featured a fully stocked liquor cabinet, group dinner class from Chef Antonio, a Disney World package, and ½ inning in the Fox Sports North booth with Dick and Bert during a Twins game this summer. The live-auction led into our Fund-a-Need which raised over $14,000 for our Patient Financial Assistance program & Camp from our generous guests. Time was taken to recognize all of our event sponsors who came through in a big way to support the HFMD. At the end of the program, the half-carat diamond raffle winner was drawn just before the Total Entertainment DJ started the music.

With the increase in sponsorship, wonderful auctions, raffles, and a very strong Fund-a-Need, we raised $111,500 (gross), a record Gala for the HFMD!!! While HFMD has just 3 staff, we have a very strong base of volunteers and supporters who help to make this event such a huge success. Our Gala Planning committee was extremely productive and we would like to thank each of them! Stacie Cowen (Co Chair), Jim Paist (Co-Chair), Dena Ianello-Zimmer, Carrie Kissoon, Stacy Pike, Kristy Heer, Dan Tinklenberg, Nancy Golden, Jessica Hutchison, and Troy Gleason. We are so grateful to the following sponsors:

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Tri to Change the World TM 2015

Tri to Change the World TM is a non-profit corporation, whose mission is to empower children to live healthier lives by encouraging activities that stress the importance of exercise.

Tri to Change the World TM will host its third annual youth triathlon on Saturday, June 6, 2015 at the Hudson, WI YMCA. This year Andreas (7) and Lukas Romarheim (4) will be the honorary grand marshals for the event, which is great for our hemophilia community. Andreas and Lukas have severe hemophilia A, and this event will increase hemophilia awareness in the area. Also, TCWTM will donate raised funds split 50% between HFMD and the Children's Hospital in honor of Andreas and Lukas.

This event is a partnership between TCWTM and the Hudson YMCA. Youth can compete in three age groups: 5-8, 9-12 and 13-16. The swim course is indoors in the YMCA lap pool, the bike course is a 2-mile loop that includes a scenic trail, and the run course is a trail run all on YMCA property for children under the age of 13. The run for participants 13 and up is down the city running path on Vine Street.

Hudson, WI is only 20 minutes from St Paul, MN, so we are hoping other families from the hemophilia community will participate in this exciting experience, joining forces with Andreas and Lukas to raise hemophilia awareness.

Please visit their webpage http://www.tritochangetheworld.org/register.html or their facebookTM page for registration and more information about the event.

Contributed By Vidar Romarheim

NHF Grant for Fist Time Attendees to their Annual Meeting

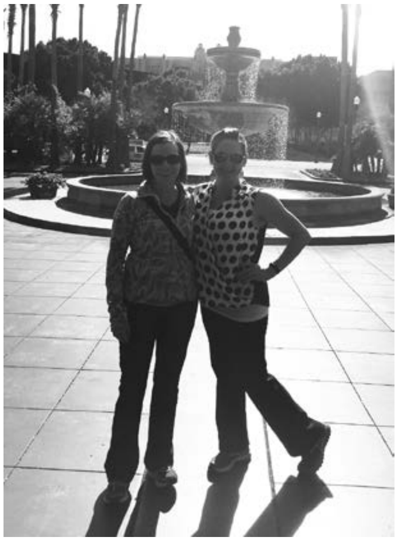
The National Hemophilia Foundation (NHF) is pleased to offer **Connections for Learning Grants** for those who want to attend its 67th Annual Meeting in Dallas, TX, August 13-15, 2015.

To provide a more inclusive Annual Meeting, NHF offers a limited number of **Connections for Learning Grants** to individuals and/or families with bleeding disorders who wish to attend the Annual Meeting *for the first time*, and returning families who have not attended NHF's Annual Meeting *for the past three years*. NHF would especially like to provide assistance to those unable to attend due to personal obstacles or other barriers. Awards will be based on these factors, and on need.

The grant may be used to cover airfare or mileage and/or hotel expenses. Applicants may apply for grants in one or more of these categories, for a maximum of three nights and four days. To apply visit the NHF website at: http://www.hemophilia.org/Events-Educational-Programs/Annual-Meeting/Connections-for-Learning.

HFMD Staff Member attends NACCHO Conference

NACCHO typical conference. HaHa! Get it? Oh…no? OK, OK, let me explain…



As the Event Coordinator for the HFMD, one event that I haven't had the chance to be a part of yet, is Camp. I was lucky enough to visit Camp Courage in Maple Lake a couple of years ago, but only for a few hours. During those few hours, I saw some of the happiest kids in the world – swimming, medical ed breakout fun, and lunch! Lunch was complete with cheers, chants, and a delicious camp feast. The memories of my own time at camp through the Boys and Girls Club became this overwhelming sensation of pure joy! Camp, for me, was my favorite time of year, so when I was asked if I wanted to get involved in our Hemophilia Camp, I jumped on the opportunity. Literally, I jumped…I jumped on a plane and flew to Arizona to attend the North American Camping Conference of Hemophilia Organizations – NACCHO!

Along with Angie Boyd from Children's and Dawn Olive from Mayo plus hundreds of other bleeding disorder camp planners from not only North America, but from around the world, I got to experience one of the most unique, fun, and essential conferences. Through grant support from Biogen Idec and Pfizer, NACCHO is a conference where bleeding disorder camp staff unite for 3 days to learn and share ways to make our camps the very best that they can be. Sessions ranged from what kind of world our children are growing up in today, to learning how to help parents decide if their child is camp-ready, to health professional's roles and camp guidelines, to the inspirational session lead by Chris Bombardier. Chris has severe hemophilia B and is in pursuit of climbing the Seven Summits of the world. While traveling, Chris also works with hemophilia organizations along his path to help raise money and build awareness for bleeding disorders. He just returned from his climb in Papua Indonesia! Read his story here: http://adventuresofahemophiliac.com/ Chris also inspired this year's NACCHO theme: Reaching for New Heights. And wow, did our speakers stay true to the theme! While combining crazy, interactive activities such that you would see at camp, NACCHO speakers had us interlocking elbows and ears with strangers, dancing to hip hop around the ballroom to start the next small group discussion, and racing to finish jars of chicken flavored baby food!

With planning for this year's Camp Courage North already underway, I'm honored and excited to be a part of our camp planning committee. But, don't you worry, we won't make your children eat chicken flavored baby food…we're thinking chicken flavored baby food with green beans might be more tasty!

Contributed by Carrie Kissoon

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WHAT IS XYNTHA?

XYNTHA® Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for 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, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, 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
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea
- 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 for XYNTHA and XYNTHA SOLOFUSE on the next page.

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.

*You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer's RxPathways program. For questions about the XYNTHA Trial Prescription Program, please call 1-800-710-1379 or write us at XYNTHA Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736.

†The chemically defined cell culture medium in which the Chinese hamster ovary (CHO) cells are grown contains recombinant insulin but does not contain any materials derived from human or added animal sources.

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xyntha® Antihemophilic Factor (Recombinant) xyntha® solofuse® Antihemophilic Factor (Recombinant)

Rx 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 Pfizer Inc toll-free at 1-800-879-3477.

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. Your healthcare provider may give you XYNTHA when you have surgery.

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:

- have any allergies, including allergies to hamsters.
- 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.

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

Common side effects of XYNTHA are

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

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)] Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0500-9.0, revised 10/14.

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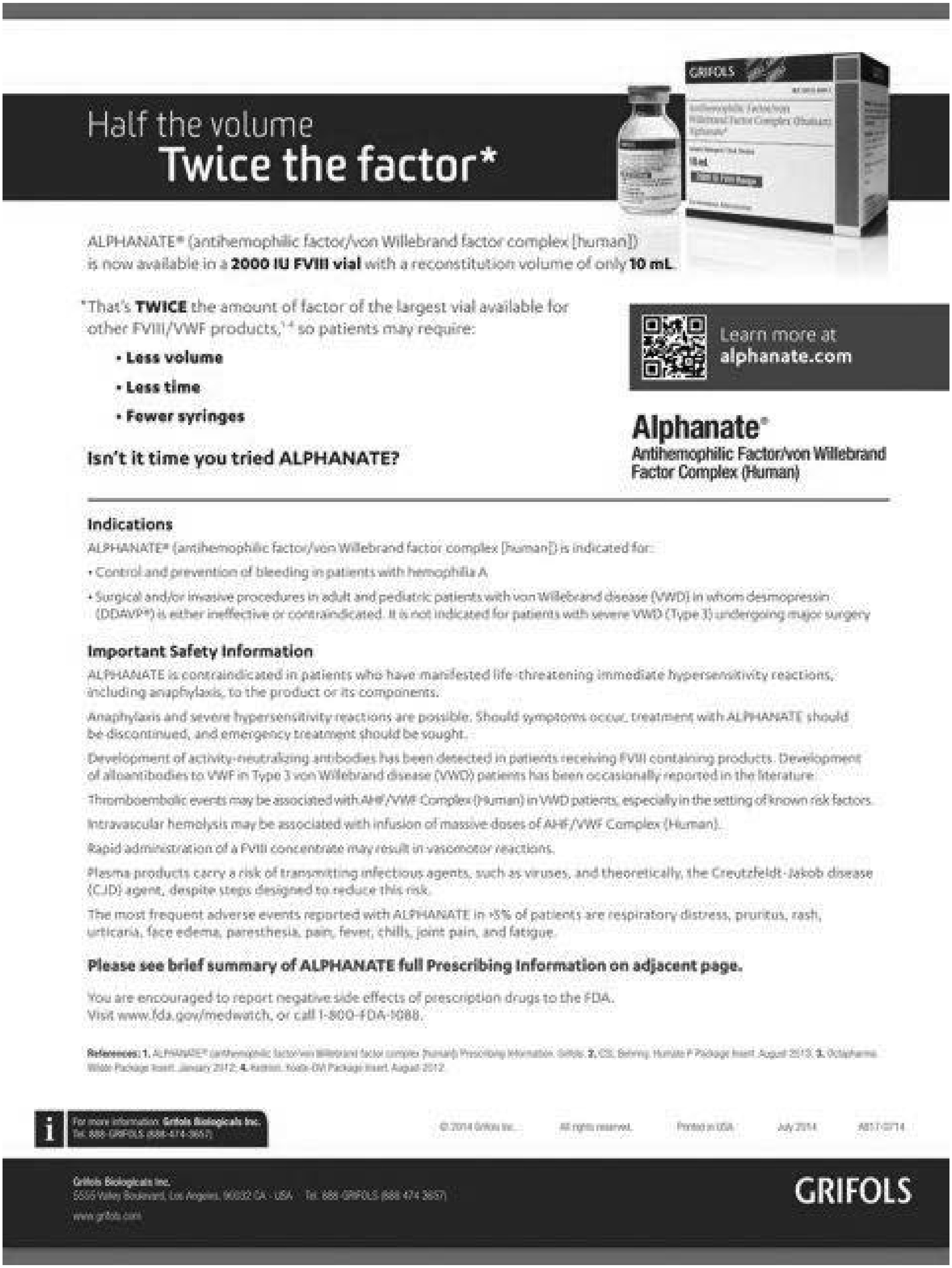

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Indications

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

- Control and prevention of bleeding in patients with hemophilia A
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand disease (VWD) in whom desmopressin (DDAVP®) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery

Important Safety Information

ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

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Please see brief summary of ALPHANATE full Prescribing Information on adjacent page.

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.

References: 1. ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) Prescribing Information. Grifols. **2.** CSL Behring. Humate-P Package Insert. August 2013. **3.** Octapharma. Wilate Package Insert. January 2012. **4.** Kedrion. Koate-DVI Package Insert. August 2012.

For more information: **Grifols Biologicals Inc.**
Tel. 888-GRIFOLS (888-474-3657)

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Washington Days

Snow drifted slowly around my feet as I stepped onto the sidewalk, quickening my pace as I desired to escape the cold. I was one of about fifty others on the bus, each making our way to the nation's capitol to address members of Congress. About three hundred were present this year at Washington Days, and I am incredibly pleased with the opportunity to participate and the experience I had. While there were families from around the country, I was given the fortune of being placed in a group with Carson Ouellette and Casey MacCallum, members of the local hemophilia community. Together we represented Minnesota and North Dakota and were privileged with having a total of six different meetings with Congressional staff. It was a spectacular time and one I hope to repeat.

Our asks were simple: maintain funding for Hemophilia Treatment Centers (HTCs), increase availability of Medicare funds to cover the cost of hemophilia drugs at skilled nursing facilities, and move hemophilia medications from Tier IV to Tier III insurance coverage. For some background, HTCs receive $4.9 million in funding from the federal government, an amount which has not changed in years but remains a reliable source of support for the hemophilia community. With regards to skilled nursing facilities, they currently shoulder hemophilia-related medications when giving treatment and, due to their cost, often turn away hemophiliacs to prevent massive financial losses. Finally, hemophilia medications have been placed within the "specialty tier" for insurance policies, which means that most are required to pay large amounts ($6,600/individual or $13,200/family) in order to reach the copay maximum under the Affordable Care Act. Instead of pressuring hemophiliacs to use off-brand or lower cost medications (which we don't have), this policy forces them and their families to pay exorbitant amounts simply to receive a basic level of treatment.

Overall, our day on the hill was productive. Senators Klobuchar (D-MN), Franken (D-MN), and Heitkamp (D-ND), and Representative Ellison's (D-MN) staff all displayed strong support for our legislative agendas and I believe they will be backing our community for some time to come. All of the staff members we spoke with showed support for the first two asks, although there was some pushback on the third. While generally understanding, Representative Kramer's (R-ND) staff seemed reluctant to back the Tier III switch, as he viewed it as a tax on the American public. This was due to the effect it would have on copays, raising them by three dollars per person, and is an understandable approach to take on the matter. However, this stance was an outlier on the hill, and the proposal was met with wide endorsement not only from the members we visited but also from other members of Congress. Last year a similar bill was proposed which did not pass but received 142 co-sponsors, indicating the broad support of the legislation and that it will likely become law in the near future.

While the venture was met with general success, I can't help but wonder how different the outcome might have been if more of our community from the Minnesota/Dakotas area had been present. Democratic government grants us the means to express our needs and have them heard, and as members of the hemophilia community we have been given a special opportunity to voice those needs.

continued next page...

...Washington Days continued

Over three hundred people attended the event, yet Casey and I were the only hemophiliacs to attend from Minnesota. Ours is an important, vibrant, and influential community, and I hope to see more of you attend in the future. It is not often that we are given the opportunity to connect with those who act on our behalf, and even one story from the smallest of individuals can make a lasting difference in all of our lives. I hope to hear yours next year in Washington, DC, the home of our democracy and the birthplace of our future.

Contributed by Adam Alver

HFMD
HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

NATIONAL HEMOPHILIA FOUNDATION'S ANNUAL MEETING

NHF'S ANNUAL MEETING
67TH
Boots on the Ground
DALLAS, TX · AUGUST 13-15, 2015 · #NHF2015

It's that time again--time to register for the National Hemophilia Foundation's (NHF's) 67th Annual Meeting, "Boots on the Ground," August 13-15, 2015, in Dallas, Texas.

Whether you're a first timer or an old timer, NHF's annual gathering of the entire bleeding disorders community in the US offers participants three key elements: an array of educational sessions, a hands-on Exhibit Hall with fun for all ages and social events where you can unwind each day.

Every year families and individuals with bleeding disorders look forward to dozens of sessions on everything from parenting issues, dealing with inhibitors and transition stages to hepatitis C advancements, advocacy updates, research breakthroughs and other timely topics. Programs for children, teens and young adults mean the next generation of people with bleeding disorders is nurtured, encouraged and emboldened to represent the community.

And our hotel is Texas-style, welcoming visitors in a big way. Where else can you walk through a lush indoor garden, shop at fabulous boutiques, enjoy a nearby water park or dance the night away to live music?

So y'all better take a few minutes to register because you don't want to miss out on NHF's 67th Annual Meeting in the great state of Texas! See y'all there!

For more information and to register visit NHF's website at: http://www.hemophilia.org/Events-Educational-Programs/Annual-Meeting.

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
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angela.boyd@childrensmn.org

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2015 HFMD Scholarship Applications

The Hemophilia Foundation is accepting scholarship applications for post-secondary education from now until June 1st.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota or South Dakota, or being a patient of one of the Hemophilia Treatment Centers in these states, and be a participant in HFMD programs and services, and (3) be accepted into a post-secondary educational program.

More information and forms for this scholarship and information on additional scholarships is available online at www.hfmd.org or by calling the HFMD office at 651-406-8655 or 1-800-994-4363.

THE VEINLINE IS MOVING TOWARD *PAPERLESS!!!*

If you would like to receive future issues of the Veinline via email instead of hard copy, please email us at hemophilia-found@visi.com and let us know the email address(es) where you would like to receive future newsletters?

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Faculty & Staff Dept of Laboratory Medicine and Pathology, Univerity of MN

Registration Begins for Camp Courage!

Registration is now open for the 25th Annual Hemophilia/Bleeding Disorder Camp at Camp Courage North! Camp will be held for kids and teens with bleeding disorders ages 7-17 on July 12-17, 2015 at Courage North in Lake George, MN.

Camp is a great opportunity for kids to:

- connect with other kids with bleeding disorders
- learn more about their bleeding disorder
- learn self infusion
- Have a great time!

Activities include: swimming, boating, camp outs, fishing, canoeing, kayaking, biking, hiking, ropes course, arts & crafts, cooking, photography, games (including camper favorite Ga Ga Ball) and much more!

Contact your local HTC or Angie Boyd at 612-813-7064 or angela.boyd@childrensmn.org for more information.

In Memory of Dr. J. Rodger Edson

J. Roger Edson, M.D. aged 88 died 3/9/15. Dr. Edson was the Director of the University of Minnesota Hemophilia Treatment Center from 1974 until 1992 and Director of the University of Minnesota Special Coagulation lab from 1968 until 2000.

Dr. Edson came to Minnesota in the mid 1960's following completion of medical school and residency at UCLA. He founded and became the director of the Special Coagulation Lab at the University of Minnesota in 1968. He continued as its director until his retirement in 2000. He developed it into one of the regions premier coagulation labs specializing in tests for the diagnosis of patients with bleeding disorders. In addition he was very active in the teaching of medical technologists at the University of Minnesota over the years.

In 1974 he applied for and was awarded a NIH grant as one of the original Hemophilia Treatment Centers in the US. He cared for both children and adults with hemophilia and other inherited bleeding disorders until 1992. At that time he passed on the Directorship of the HTC but continued his work in the Special Coagulation Laboratory until his retirement.

During his time at the HTC he consolidated and standardized the care of both children and adults with hemophilia and other inherited bleeding disorders. He greatly improved the lab support for the diagnosis of patients with bleeding disorders. In the 1979 he developed a cryoprecipitate program for children and teenagers with hemophilia A. His objective at that time was to decrease the incidence of hepatitis in children with hemophilia A. This program, which was started just before the outbreak of HIV infections from factor concentrate, saved many children with hemophilia in Minnesota from hepatitis but also from HIV. This program gradually changed into a director-donor cryoprecipitate program that continued until the introduction of recombinant factor concentrate in1992.

Doctor Edson taught countless physicians, medical students, residents, fellows and medical technologists over a span of 35 years about coagulation testing, bleeding disorders and their treatment. There are hematologists and medical technologists around the country who have benefitted from his incredible knowledge and experience.

Roger has touched many lives over the years and will be missed by his wife, Jean Gorman, his children Eileen Baker, Craig Edson, Ezra Gorman and Stuart Gorman, grandchildren Bryce Edson-Kiley and Flynn Gorman, his sister Margaret Spencer and many other family members and friends. The medical community that he helped to educate will also miss him greatly. Donations may be made to the Hemophilia Foundation Minnesota/Dakotas in his honor. Reprint credit to the Edson family, Dr. Margaret Heisel-Kurth, & Star Tribune.

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2015 Calendar of Events

May 3, 2015	Camp Courage & Friendship Open House Camp Courage: 1:00 - 3:00 p.m. Camp Friendship: 2:00 - 4:00 p.m.
May 17, 2015	Camp Courage & Friendship Open House Camp Eden Wood: 1:30 p.m. - 4:00 p.m. Camp Courage North: 2:00 p.m. - 4:00 p.m. RSVP: 952-852-0110 x6 Camp New Hope: 2:00 p.m. - 4:00 p.m. RSVP: 952-852-0110 x3
May 17, 2015	Blood Brotherhood Event at Target Field
Summer 2015	Group Fitness Bunker Beach (Date TBA)
July 12-17, 2015	Camp Courage North (True Friends)
August 13 - 15, 2015	NHF's 67th Annual Meeting Dallas, TX
October 3, 2015	Step Out for Bleeding Disorders Walk Como Park, St. Paul

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

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