

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 Walk Fundraiser 2

Cover Story *continued* 3

“Walk” Photos 4
Save the Date - Gala

Women’s Retreat 5
Camper Reunion

Gettin’ In the Game 7

Contributions 8

Summer Fitness 9
Blood Brotherhood

Treatment Centers 10

Contributions 11
continued

Calendar 12

Never Pass Up a Chance ...

In a small community such as the Hemophilia community we all have to remember to never pass up the chance to share our story. Most people do not know much, if anything, about bleeding disorders so it is important for us to share our stories when we get the opportunity. My example of never missing a chance to share our story is a pretty unique one.

As the City Administrator in Cannon Falls I was given a very special chance that I did not pass up. On a recent Wednesday morning I received a phone call from my Public Works Director telling me that someone called him saying they were with the White House and wanted to meet in

twenty minutes. We knew from newspaper stories that the President was coming to Minnesota as part of a three state bus tour, but we both assumed it was someone playing a joke on us. To be safe, we showed up and within a few minutes about ten White House advance team members arrived and introduced themselves. Cannon Falls had been chosen to host the President’s Minnesota speech and Town Hall discussion.

A few weeks earlier, another advance team had been scouting locations in southern Minnesota and had stopped in Cannon Falls on their way back to the airport to have lunch. They loved our historic and vibrant downtown, the rivers that run through the community, and our beautiful parks.

Five days before the President’s speech, the final advance team was in town to pick the actual site and get things ready. We drove White House staff members to our various

parks and waited while they discussed camera views, lighting, backdrops, etc. While we were at the final location, a group of five very large black SUV’s pulled up. About twenty Secret Service agents introduced themselves and started doing their evaluations of the sites. Most of my day was spent sitting and watching as all this happened and answering the occasional question.



Isaiah Reeves and President Barack Obama

While the Secret Service was reviewing one of the parks, I had a chance to talk with one of the White House staff members. I took the opportunity to mention that my son Isaiah had Severe Hemophilia and that I served on our regional Hemophilia Foundation Board. I told him how

much we appreciated the new Health Care legislation that provided so many benefits to our community such as the elimination of lifetime caps, the ability to continue on the parents plan until the age of 26, and the elimination of the pre-existing conditions clause when switching plans. I explained how this was not only good for my family but for our Community as a whole. I finally asked if he could thank the President on behalf of my family and our Community the next time he saw him. The White House staffer then said, “Well maybe your son can thank him in person. I’ll see what I can do.” I had been listening to how tight the schedule was going to be and how things had to be timed out to the minute so I really didn’t think it would happen but I thanked him for the opportunity if possible.

continued on page 3

Step Out for Bleeding Disorders!

It was a warm and muggy August morning at Como Park in St. Paul, MN, but that didn't stop over 300 people from coming together to Step Out for Bleeding Disorders! On August 6th, 2011, HFMD hosted our 1st Annual Walk Fundraiser – “Step Out for Bleeding Disorders”, and it was a huge success! Fundraising efforts began via the Internet on HFMD's new fundraising site: www.firstgiving.com/hfmd. We had 20 teams and 55 individual fundraisers reaching out to their friends, family, co-workers, and neighbors to build awareness and gain support for HFMD's important programs. Thank you to all of the individuals, team captains, and team members who worked so hard for our community!



Local celebrities, Dick Bremer and Brian Zepp, motivated, entertained, and cheered on the group to finish-line victory. Brian Zepp, a member of the KQRS Morning Show, was so kind with his words about our cause, and he also shared his great sense of humor. Dick Bremer, Minnesota Twins & FSN Television Broadcaster, shared his personal family connection to hemophilia and talked about our strong and resilient community. As our Masters of Ceremonies, Dick also spoke about HFMD's programs and the importance of coming together like this, for a Walk. As the count down began, Dick announced the cutting of the tape ceremony. Our oldest Minnesota hemophiliac, Bob Newman, had the honor of cutting the ribbon at our gigantic red and white balloon arch starting-line. Thank you, Bob, for taking part in such an important part of the day.



The group followed Bob's lead, walked through the starting line, and marched down the path into Como Park together, side-by-side, “Stepping Out for Bleeding Disorders”. We witnessed a sense of unity and strength as our group walked around Como Lake. As individuals, families, and teams crossed the finished line we saw new friendships made, community families reunite

for a great cause, and watched our walkers line up for cold water and Subway sandwiches. Under the tent, a balloon artist Pumpkin the Clown made animals and Viking horns for the kids, while Jocelyn Gorlin and Jennifer Paist did face-painting for many. Fun was had by all ages! The HFMD Walk planning committee

and volunteers did a fantastic job in putting together a well-run event with a carnival atmosphere featuring food, fun and exercise for a truly good cause. We thank Walk committee members Stacie Cowen, George Paul, Mike Neubert, Deb Starling, David Singer, Deb Melhado, Dee Dee Johnson, Claudette Lyng, Aaron Reeves, Amy Eckerman, Angie Boyd, Danielle Flores, Mark wiener and Vicky Hannemann.

On behalf of the HFMD, we want to thank Presenting Sponsor Baxter BioScience at the \$6,000 Power Walk Level. Next, we thank Pfizer at the \$4,000 Long Strides Level. And at the \$2,000 First Step Sponsor level, we thank Bayer HealthCare, CSL Behring, CVS Caremark, Novo Nordisk, and \$500 Route Sign sponsor Coram.

We would also like to thank all of the companies helping to support this event through exhibiting: Accredo HHS, ARJ Infusion, Baxter BioScience, Bayer HealthCare, Bio Rx, CSL Behring, CVS Caremark, Kedrion Biopharma, Novo Nordisk, Pfizer, and Walgreens. Thank you, CSL Behring for the ever popular photo booth, Lunds for the water and bananas, Mayo Clinic for even more, much needed water, and Subway Restaurant of Brooklyn Park and Mark Wiener for sponsoring lunch.



Finally, thanks again to Dick Bremer, KQRS, and Brian Zepp. We are excited to announce that if schedules work out, Dick and Brian would both like to join us again next year, at our 2nd Annual Walk in 2012! By Carrie Kissoon, Event Coordinator.

Never Pass Up a Chance continued from page 1

On Saturday afternoon I received an email from the White House asking for a long list of information on my son and I for background checks. We were going to meet President Obama! Monday couldn't come soon enough.

On a beautiful summer day with the Cannon River as a back drop, my family and I went through tight security to be seated in the front row to watch President Obama give his speech. As we sat next to many State and Federal Legislators waiting for the President to arrive, I received a text from the White House asking us to come to the back of the seating area. From there, we were taken to a tent along with a number of our area elected officials to wait for the President to arrive. The White House staffer who I had talked to originally about the new Health Care legislation came in and made sure we were last in line to meet the President so we would have more time with him. As we sat and waited my son and I chatted with Senator's Franken and Klobuchar about why we were there and Health Care legislation. Again, never pass up the chance to spread our story.

Soon the ground began to literally vibrate under our feet and an all black bus pulled up. This was the brand new bus purchased by the Secret Service for transporting the President. They say it can withstand a direct rocket attack and I believe it. It was a very impressive thing to see. The President came bounding into the tent just giving off energy and excitement. We waited in line for about five minutes as the twenty or so people ahead of us moved through and got their picture taken with the President. As we came up at the end, my son Isaiah confidently stuck out his hand and shook President Obama's hand. I stepped up to do the same and said that we were there to personally thank him for all of his work in getting the new Health Care legislation passed. I explained that Isaiah had Severe Hemophilia and how much it meant to my family and our Community as a whole. Isaiah then personally thanked him for the elimination of lifetime caps and the other positive things the bill would provide for him. President

Obama then told Isaiah that young men like him are our future and to keep fighting for his Community, to stay involved, and to keep sharing his story. We then took a few quick pictures and we were ushered back to



our seats. The speech started and towards the end someone asked about the "Obamacare" Health Care legislation. As part of his response President Obama said this pointing right at Isaiah:

So part of the Affordable Care Act health care reform, also known as "Obamacare" -- by the way, you know what? Let me tell you, I have no problem with folks saying "Obama cares." I do care. (Applause.) If the other side wants to be the folks who don't care, that's fine with me.

But, yes, I do care about families who have been struggling because of crushing health care costs. I met a young man here who -- right here -- who, as a consequence of health care reform -- he's got a blood disorder that, if it weren't for the health care reform act, his family would have been capped out and he wouldn't have the help that he needs. (Applause.) So -- and you can tell he's an outstanding young man and he's going to do great things, and his family is not going bankrupt as a consequence of it.

It was an amazing end to a very amazing experience for my family that really would not have happened if I would not have taken the opportunity to spread the word about the bleeding disorders community when the chance presented itself. Not everyone will have a chance like this to share our story with the President but you will have chances with your elected officials, potential donors to our Foundation, and others. When that chance presents itself don't miss your opportunity. Share your

story, spread the word about our cause, and advocate for our Community.

By Aaron Reeves



"WALK" PHOTOS



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Women's Retreat 2011

The Women's Retreat at the Oakridge Conference Center in Chaska was held October 1st and 2nd. We had a good turnout of women and teens with bleeding disorders, and the colors and weather were spectacular.

Saturday began with Dr. Mark Reding, Director of the Center for Bleeding and Clotting Disorders at the University of Minnesota. He recapped, in David Letterman style, the Top -10 Countdown of what he's learned from women about bleeding disorders. Barbara Forss from the LadyBugs Foundation spoke on how to be empowered with your bleeding disorder. The women then got advice from Alexandra Gregg, RD, LD, a dietician from the Healthy Living Center at the Mayo Clinic, on Eating Right to Look and Feel Your Best. After a wonderful lunch, Nancy Saslow spoke about acupuncture and how she uses these methods to help cope with bleeding disorders. She also led a session on yoga. The women and teens also were able to share their story and offer advice about what they have learned. These share sessions were led by Skye Peltier, PA; Kirstin Schmidt, RN; and Angie Boyd.

Besides providing educational content to women with bleeding disorders, the retreat also provided plenty of fun activities. Breakout sessions this year

zumba (led by Joni Osip, RN), manicures (MelisSalon, Chaska), and card making (led by Kirstin Schmidt, RN). The evening was filled with a little bingo (led by Sue Curoe, RN) and lots of connecting time.

On Sunday, Jean Haley, from the University of Minnesota Center for Spirituality and Healing presented an experiential on Mindfulness-Based Stress Reduction. She shared a personal story of close neighbors with hemophilia and then her father's involvement with the National Hemophilia Foundation. Dr. Margaret Heisel-Kurth, pediatric hematologist at Children's Minneapolis Hemophilia Center and also NHF Physician of the Year, was the final speaker. She talked about Ehlers-Danlos Syndrome and why "bendy people" sometimes bleed. The women loved having Dr. Heisel there in a non-formal setting to answer questions that they had about their bleeding disorders.



The retreat ended with a fabulous brunch, and the women and teens revitalized. Thanks to all the speakers, HTC staff, and the women's outreach group from HFMD who helped make this event possible. A special thanks to Mark Wiener, from CSL Behring, for all his help and financial support with the event. By Sue Curoe, RN, University of Minnesota Medical Center, Fairview.

Camper Reunion

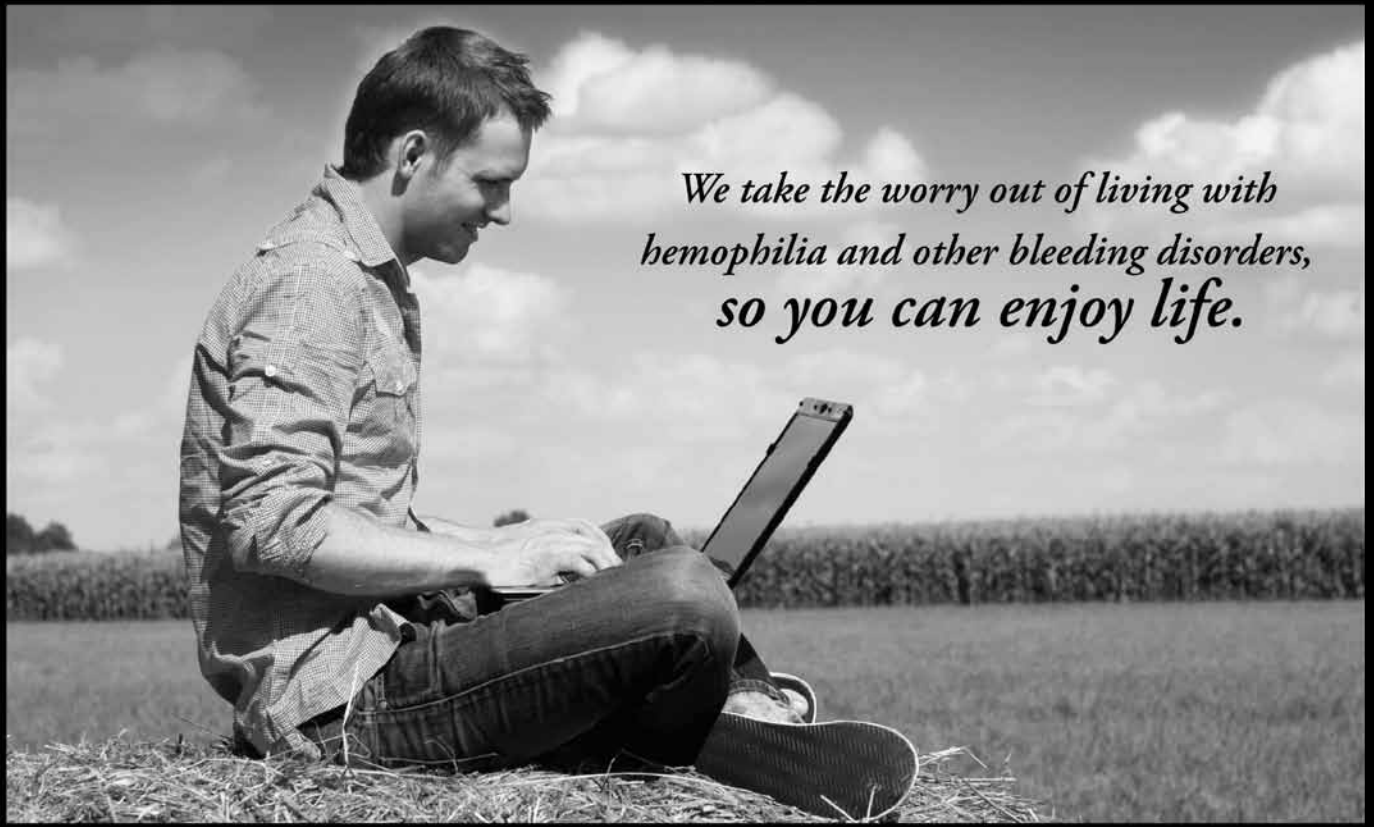
On August 27th, the HFMD and the University of Minnesota Medical Center Fairview held our first Camper Reunion for adult alumni and HTC staff who volunteer at camp. In the spirit of a woodsy atmosphere, this dinner was held at the Timberlodge in Bloomington.

The evening began with a wonderful slide-show put together by Joni Osip. It included camp pictures from twenty years ago to the present. It was fun for everyone to look back and see pictures from years ago. Seeing the pictures was a perfect prelude to reminisce and share stories about our camp's illustrious history. Dr. Heisel and husband Frank told the fascinating story about how they discovered Courage North in 1991 after Frank spotted the blue sign off of highway 71 while driving through Lake George, Minnesota. After they turned in to learn more; they met with Tom & Mimi Fogerty and the rest is history.

During the story-telling over dinner, the laughter was intense as campers and HTC staff remembered the past together. Because the turnout was relatively small, we decided to plan another reunion for next year earlier in the summer when more people will be available to attend. The food was good and the camp conversation was so much fun.

By Jim Paist

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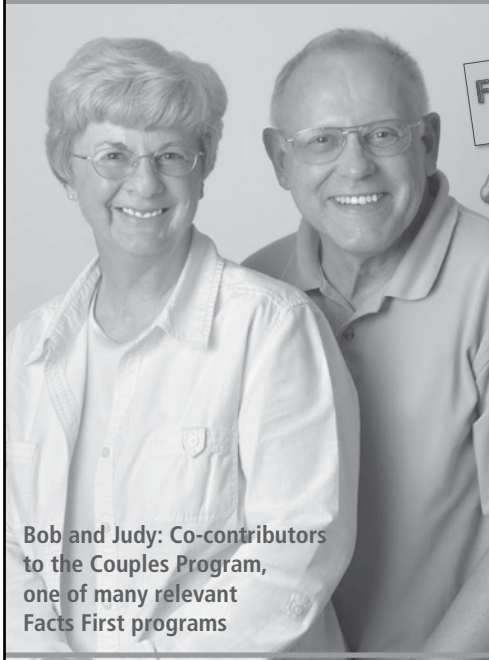
Gettin' In the Game

Fargo, ND hosted their first Gettin' In the Game event on August 13, 2011. This baseball clinic and gathering to watch the local team was sponsored by CSL Behring. Jesse Schrader, former minor league pro baseball player, had a baseball clinic which took place on the Redhawks' stadium outfield. It was a great sunny day with temps in the 80's. We had 12 boys ages 6-18 participate in the event. We had a total of 10 families participate in the outing to watch the ballgame after the clinic.



It was a great time for families to get together and visit. We had several new families participate which was great. The food was great and we had plenty of it and even more exciting was the Redhawks won their game. We would like to thank CSL Behring and Mark Wiener for doing such a great job organizing this event. By Kathy Kirkeby, PA, Sanford Health HTC, Fargo.

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continued on page 11

Summer Fitness Event

On Saturday, August 20th, the HFMD held another canoe outing at lovely Lake Calhoun in Minneapolis. With a picture perfect summer day, our small group met at 10:00 a.m. in front of the Wheel Fun boat rental station. After a brief stretch and a little time to mingle, our paddlers set out on a course that took us through a scenic tour over to Lake of the Isles, then along a shady channel to Brownie Lake where we drifted for a while before heading back. There was plenty of sun and exercise with this summer event. After returning the canoes, we called Jimmy John's for submarine sandwich delivery which arrived surprisingly fast. The HFMD plans to hold a canoe outing once again next summer. Please watch for the announcement in the 2012 spring issue of the Vein-line.

By Jim Paist

Blood Brotherhood at the Ballpark

On Sunday, May 29th, the HFMD held a Blood Brotherhood event at Target Field in a game suite. This event began with a physical therapy session led by Jeff Kallberg, PT. Jeff shared important information about maintaining good joint health and did demonstrations on range of motion. Our 14 attendees (adult men with hemophilia) were engaged in the presentation, and they asked some thoughtful questions during the session discussion.

Then it was time to settle in to watch the Minnesota Twins take on the Los Angeles Angels. For some of our Blood Brothers, it was their first time at spectacular Target Field. Everyone enjoyed the game and had some time to visit with each other. Although the Twins lost, it was an exciting ballgame. We extend a special thank you to Jeff Kallberg, the Hemophilia Federation of America & Baxter BioScience for sponsoring this event!

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NEWSLETTER OF
THE HEMOPHILIA
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Email: hemophiliafound@visi.com

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www.hfmd.org

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



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2011/2012 Calendar of Events

- November 4, 2011.....Blood Brotherhood Event
Chanhassen Dinner Theater & Comedy Club
7:00 p.m.
Chanhassen, MN
- November 5, 2011.....Viewing of Bad Blood PBS Documentary
10:00 a.m. Children's Hospitals & Clinics
2525 Chicago Avenue S., Mpls
- November 19, 2011.....HFMD Board Retreat
Hilton Minneapolis/Bloomington Hotel
Bloomington, MN
- February 11, 2012.....Hearts of Hope Gala
Minneapolis Airport Marriott
Bloomington, MN
- February 24-26, 2012.....Mayo Family Retreat
Metropolis Resort
Eau Claire, WI
- April 20-21, 2012.....HFMD Annual Meeting
Minneapolis Airport Marriott
Bloomington, MN
- August 5-10.....HFMD Summer Camp
Camp Courage, Maple Lake, 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!

If you wish to continue receiving the Veinline newsletter via regular mail, you need not respond to this. Otherwise, please see below to contact the HFMD at hemophiliafound@visi.com, or call (651) 406-8655. Thank you.

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