

#### 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.

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## HFMD's 2nd Annual Walk

“Step Out for Bleeding Disorders!!!”

Thank you for participating in the 2nd Annual Walk Fundraiser for the HFMD! With the help of all of our sponsors, volunteers, committee members, fundraisers, and walkers, we raised a total of \$58,900! That is over a 15% increase from last year! What an accomplishment - congratulations to all!

We are so honored to have so many individuals that care so much about our mission. The funds you raised will continue to help us provide our programs and services for those living with a bleeding disorder in Minnesota and the Dakotas. Don't forget to watch for future Veinlines to browse through and see just how your hard work is helping others.

With July's record breaking temps, it's not a surprise that the HFMD's 2nd Annual Walk was another hot and steamy day. On Sunday, July 22nd, 2012, well over 300 dedicated and loyal people came together at Como Park in St. Paul, MN to walk, show their support, network, catch-up with one another, and unite for such an important cause. We had the honor of having local celebrity guest, KQRS's Brian Zepp as our Masters of Ceremonies. We'd like to thank Brian for returning and helping us bring laughs and motivation to our group! Along with Brian, we were also visited by local mascot celebrities Nordy from the MN Wild and Goldy Gopher from the University of Minnesota. Volunteer David Singer was brave enough to wear the Children's Hospital mascot Twinkle suit on a hot day. They were a all great addition to the team!



Fundraising efforts were again performed primarily through our Firstgiving website: [www.firstgiving.com/hfmd](http://www.firstgiving.com/hfmd). We increased our team count with a total of 22 teams and 54 individual fundraisers reaching out to their friends, family, co-workers, and neighbors to build awareness and gain support for the HFMD's important programs. A special congratulations to our top teams: 1) Team Romarheim 2) Wyatt's Walkers 3) Benji's Blood Squad 4) Red Hot Cole and 5) We Step for U.

*continued on page 3*



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*WALK...continued from cover page*

Again, we thank you! If you or someone you know would still like to donate, our Walk fundraising pages will continue running until October 22nd, 2012. Please visit: [www.firstgiving.com/hfmd](http://www.firstgiving.com/hfmd) and click on the 2nd Annual Walk link in the upper right corner.

On behalf of the HFMD, we want to thank Presenting Sponsor Baxter BioScience at the \$6,000 Power Walk Level. Next, we thank CSL Behring at the \$4,000 Long Strides Level. And at the \$2,000 First Step Sponsor level, we thank Bayer HealthCare, Biogen Idec Hemophilia, Children's Hospital & Clinics, CVS Caremark Specialty Pharmacy, Mayo Clinic Factor Program, Novo Nordisk, Pfizer, Sanford Health, University of Minnesota, Fairview and route sign sponsors BioRX and Coram.



We would also like to thank all of the companies helping to support this event through exhibiting: Accredo, Baxter BioScience, Bayer HealthCare, Biogen Idec Hemophilia, CSL Behring, CVS Caremark, Grifols, Novo Nordisk, and Walgreens Infusion Services. Thank you, CSL Behring for the highly anticipated photo booth, Lunds Market for the water and bananas, Culligan Water of Brooklyn Park for even more, well needed water, Subway Sandwiches of Brooklyn Park and Mark Wiener together providing lunch for all.

Thank you, again to EVERYONE! Please join us for the HFMD's 3rd Annual Walk next summer! Date, time, and location TBA. Hopefully at Como Park again. Fun had by all ages for a great cause!

By Carrie Kissoon





## Going Down Backwards

By Bob Newman

“Go ahead, try going down a flight of stairs the way you normally do but with one difference—keep both legs straight with no bend in the knees.” I said to Dave, the Physical Therapist at an extended care facility. I was there for many weeks because of a Staph infection in my knee prosthesis and pulled back muscles. I explained that staying mobile with severe Hemophilia is a major project, especially when you are 83 years old. During my therapy time, Dave warned me that he thought that descending a flight of steps backwards was dangerous. When I told him that when I was on crutches because of a foot, leg or a knee bruise, I learned how to also go down backwards on crutches. Dave turned pale, shuttered and pronounced that as a requirement in being released from extended care, I should try to have a chair lift installed between the upper and lower levels of my house. I found out that chair lifts don’t come cheap but thankfully, in times of trouble, a person finds out who his or her friends are. My Covenant Church found out about it and offered half the payment out of their benevolent fund for a reconditioned chair and the Hemophilia Foundation of Minnesota/Dakotas paid for the second half. The addition is saving me from having hundreds of painful steps going down and up my steps every month. Many thanks to all.



## CAMP 2012

Our Annual Summer Camp for kids and teens with Bleeding Disorders was held August 5th – 10th, 2012 at Camp Courage in Maple Lake, MN. A total of 60 kids between the ages of 7 – 17 attended camp this year. Campers came from all over Minnesota, North & South Dakota and Wisconsin. Camp is a collaborative program between Camp Courage, HFMD, Great Lakes Hemophilia Foundation (GLHF) in Wisconsin and many of the regional Hemophilia Treatment Centers. Camp is funded by HFMD, GLHF, and Children's Hospitals and Clinics of Minnesota.

This year camp had an Australian theme with several Australian-themed activities such as "Capture the Walaby" and the health center was even decorated like a huge crocodile!

As in past years, campers were free to choose an activity club to participate in throughout the week. Some popular clubs this year were the Fishing Club, Watersports Club, Movie-Making Club and of course the Wild Card Club. Campers meet with their Clubs every day, it gives them a chance to do fun activities and get to know more kids outside of those in their cabins.

"The Big Stick" self-infusion award program was a great success again this year with 14 kids successfully sticking themselves with an I.V. Congratulations and good work to all of those campers who achieved "The Big Stick" and got their name on the traveling stick trophy! Thanks to all of the nurses and medical staff who helped campers learn to infuse.



The main education program this year was presented by Cheryl Hansen, PT from Children's Hospitals and Clinics Center for Bleeding and Clotting Disorders. Cheryl engaged the campers in a fun, interactive session where the campers learned about all of the parts inside of a joint in the body. Through a series of experiments and hand-on activities the campers gained a better understanding of what it takes to keep their joints healthy. Special thanks to Cheryl for planning such a creative session!

This year the camp planning committee made an effort to formalize the leadership track of camp, starting with the Buddy/Mentor program for 12-14 year olds, then the Future Leaders ages 15-16, then the C.I.T.s (Counselor In Training) with the end goal of working at camp for summer as a counselor. As a part of this program we brought in three special guest speakers, Cody Morrow, Kelly Young and Jeff Kallberg. Each speaker talked with the older teens about taking control of their independence and how the choices they make as young adults can have a lasting impact on their lives. Thank you to the three guests, it was GREAT to have you visit camp!

As always, there are too many people and organizations to thank! Thanks to the Camp Planning Committee Members and HTC staff who worked at camp. Thanks to all of the pharmaceutical and homecare companies who provided giveaway items for the kids. Thanks to the staff and counselors at Camp Courage who always find new, creative ways to make camp the "best week ever"!! See you next year at Courage North!

By Angie Boyd



## SAVE THE DATE:

2013 camp will be held back at Courage North in Lake George, MN on July 14th-19th, 2013!

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# Blood Brotherhood

## Pain Management Teleconference & Twins Game

The HFMD has been a part of the Hemophilia Federation of America's Blood Brotherhood program since July 2010. Through the BB program, the HFMD organizes a number of events for our adult men living with bleeding disorders ranging from chat sessions via teleconference to Twins games and rib dinners. Each event is designed to offer a night out to reconnect with one another and to stay involved and active in our community. Through educational pieces and most importantly, a good time, Blood Brothers are able to share their experiences, offer ideas on how to cope, and always unite with a good laugh!



Through educational pieces and most importantly, a good time, Blood Brothers are able to share their experiences, offer ideas on how to cope, and always unite with a good laugh!

On Tuesday, July 17th, 2012 the guys met via teleconference to hear a presentation on Pain Management and to get some highly anticipated plans made for our upcoming Twins game. Our Pain Management discussion was lead by our own Joni Osip, RN, MS, NP-C, Program Manager, Center for Bleeding and Clotting Disorders (formerly the Hemophilia and Thrombosis Center). Joni covered the difference between acute and chronic pain, anxiety issues, and the importance of diet, exercise, and stretching. Thank you, Joni for taking the time to hang with us on the phone!

On Sunday, August 12th, 2012 our Blood Brothers gathered at the beautiful Target Field for a MN Twins game against the LA Angels. After our leisurely walk around the stadium to our gorgeous executive suite view, we began with an informative presentation on insurance issues by Frank Quentieri of Baxter BioScience. Thank you, Frank for making the flight out to MN to present. As Frank wrapped up his Q&A, the extraordinary service team at Target Field filled our suite with a plethora of food fit for kings...at a baseball game! We enjoyed food and root beers through to the end, when the game eventually went into overtime with an unfortunate loss by the Twins.

By Carrie Kissoon

*If you or someone you know would like more information about our Blood Brotherhood program, please contact the HFMD or visit: [www.hfmd.org](http://www.hfmd.org) and click on the Blood Brotherhood link.*

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**NEWSLETTER OF  
THE HEMOPHILIA  
FOUNDATION OF  
MINNESOTA AND  
THE DAKOTAS**

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## 2012-2013 Calendar of Events

- October 26-28.....Minnesota Family Retreat (Children's HTC)  
Arrowwood Resort & Conference Center  
Alexandria, MN
- February 9, 2013..... Heart of Hope Gala  
Embassy Suites - Airport  
Bloomington, MN
- April 5-6, 2013..... Annual Meeting  
Crowne Plaza  
Bloomington, MN
- July 14-19, 2013.....Camp at Courage North  
Lake George, MN
- August (Date TBA).....3rd Annual Walk Fundraiser  
"Step Out for Bleeding Disorders"

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

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