

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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Day at the Lake: July 31st, 2010

This past July, HFMD was thrilled to have a great turnout at our Canoe Fitness Event at Lake Calhoun. We had about 30 in attendance, which is more than we have had in previous years! We kicked off the event with some stretching to get loose before our excursion across Lake Calhoun. This was enthusiastically led on the beach by Cheryl Hansen, P.T.

Afterwards, the attendees were able to choose between two adventures: low-riding in a kayak (with the ability to stretch out their legs!) or coordination and teamwork in a canoe. Once a fabulous group picture was taken, we were given some instruction on how to maneuver the floating vessels in which we would be gliding across the water. John Schulte led the canoeists in paddling instruction and technique while



Kerry Hansen, RN, B.S. led the kayakers. Finally, it was time to head out on the lake.

We started the route off slowly, and picked up the pace a little as people got more comfortable with their kayak or canoe. Everyone enjoyed a nice leisurely pace while taking in some of the beauty of our surroundings. It was a perfect day to be out on the lake...not too hot and not too cold with some clouds overhead keeping the temperature down and visibility up.

Not far into the trip, we had our first and only scare when one of the canoes dumped its passengers, their two cameras, and the entire family's cell phones into the lake. They were both focused on capturing some great pictures from the same side of the canoe and leaned over a little too far. Luckily, this happened in an area in which they were able to climb out of the lake rather easily. With the help of John and Kerry, the canoe was emptied of its water content and ready to claim its next victims. Surprisingly, the cameras turned out okay!

I (Bethany) headed back early to pick up our lunch for the day while the rest of the group kept paddling a little farther before making their way back to the beach. At a perfect time, the sun made its appearance and brightened up the day. We all enjoyed an assortment of Subway sandwiches and socializing to start off our afternoon before heading back to the hustle and bustle of day-to-day life.

All in all, everyone had an excellent time at this event. We had a great workout and enjoyed fantastic company. HFMD hopes to see you all out next year!

By Bethany Pearson, HFMD Intern.

Summer Camp 2010

HFMD summer camp for kids and teens with bleeding disorders was held this year on July 11th-17th, 2010 at Camp Courage North in Lake George, MN. There were 50 campers at camp this year, and many other past campers working as C.I.T.'s (counselor in training), counselors, kitchen staff, and volunteers!

The theme of camp this year was a "Journey Around the World." Each cabin was assigned a country and they were given information about their country including what it's like to live with a bleeding disorder in that country. Campers decorated their cabins in the style of the countries. One of the cabins even looked up the names of things in the language of their country and labeled items (bed, dresser, door, etc). The campers did a great job of being creative and learning about their countries. The Courage North program staff and counselors created lots of fun "international" activities! The "Journey Around the World" ended with an "Amazing Race" game on the last day of camp where campers were challenged with a variety of activities relating to countries from all around the world. Special thanks to HFMD Intern Jenna Trisko for her creativity and hard work in planning the "Journey Around the World" program.

The campers also got to do many traditional camp activities in their clubs. Campers join clubs depending on their interest. There are many different clubs to choose from such as kayaking, cooking, photography, fishing, swimming, biking and the ever-popular "wild card" club!

Meanwhile in the medical cabin, the medical staff had two amazing former campers volunteer to help teach campers self-infusion. Special thanks to Matt Ouellette and Cody Morrow for providing one-on-one sessions each morning during prophylaxis to help campers achieve "The Big Stick"! Campers who learned self-infusion were given



awards during special mealtime ceremonies and earned a place in history by getting their names on "The Big Stick", a big walking stick (see picture), which now hangs in the King Building at Courage North.

As in past years, new campers were paired up with experienced campers for the Mentor Program. Thanks to the 14 and 15 year old campers who served as mentors to the new campers. Some great bonds were formed!

On the last day of camp Kerry Hansen, RN from the University of Minnesota Medical Center, Fairview, counselors from Courage North and a group of older teens from camp went on 4 day trip to the Boundary Waters Canoe Area. As always, that group had a great time while learning valuable camping and leadership lessons!

Thanks to the extraordinary staff at Courage North and all of the medical staff from the Hemophilia Treatment Centers around Minnesota, North and South Dakota and Wisconsin who helped plan camp and provided medical care to the campers! The HFMD and I would like to thank the following sponsors who helped to make this terrific experience possible: The Wasie Foundation, Buuck Foundation, Novo Nordisk, Baxter BioScience, Bayer HealthCare, Pfizer, and CSL Behring.

By Angie Boyd



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SAVE THE DATE



Walk for the HFMD

The Hemophilia Foundation of Minnesota/Dakotas is pleased to announce that we will be having our first walk fundraiser in 2011. The Walk will take place on Saturday, August 6th, 2011, at Como Park in St. Paul. Join us and many others as we raise money to support HFMD's mission of advancing the quality of life of individuals and families affected by hemophilia and other bleeding disorders by providing a broad range of services and programs.

Form a team, walk by yourself, or be a virtual walker -- support the cause without actually walking! Bring your children, friends, co-workers, relatives; people of all ages are encouraged to join. There will be entertainment, prizes, food, and fun for everyone. After the walk, you could stay and enjoy a day at the zoo.

For more information about this event, contact HFMD at 651-406-8655,
or hemophiliafound@visi.com.

HFMD Golf Tournament 2010

On Monday, August 16th the HFMD held our 14th consecutive golf tournament fundraiser. This year it was held at the Minnetonka Country Club in Shorewood, MN. The weather was beautiful as nearly 100 golfers participated in an 18 hole scramble. Just before the shotgun start, the drawing was held for a chance to win \$10,000 for a lucky golfer to sink a 60 foot putt. Joe Gorman's name was drawn. With a courageous effort, Joe hit a putt just a little wide of the hole. Our four-somes then took to the course to test their skills on the fast greens of this well kept golf course.



After the rounds, Fox 9 weekend new anchor Tom Halden welcomed our guests and spoke about the programs and services HFMD provides for the bleeding disorders community. He then awarded a trophy to the winning foursome of Jeff Kandt, Barry Vaughan, John Nelson, and Evan Stoltz. Closest to the pin winners were Sue Curoe and Kendall Bos. Longest drives were held by Chris Paulson and Steph Anderson, and the longest putt was from Mike Zabel.

Attendees enjoyed our silent auction before settling in for a prime rib dinner. HFMD volunteer and golf planning committee co-chair Mark Wiener led the live auction which featured Vikings game tickets, Minnesota Twins tickets, and a lawnmower donated by Toro. So many volunteers put their hearts into getting quality items donated for the live and silent auction. We would like to give a special thanks to the event planning committee volunteers: Mark Wiener, Dick Bone, Kert Seversen, Deb Melhado, Nancy Golden, Jenna Trisko, Bethany Pearson, and Deb Starling. The HFMD would like to thank all of the companies who donated such terrific items to support our cause. We extend our deepest appreciation to the sponsors of this event: Double Eagle Sponsor: Baxter BioScience, Eagle Sponsors: CSL Behring, CVS Carmark, Pfizer; Birdie Sponsors: Bayer HealthCare, Novo Nordisk, and Walgreens.

Fargo Event in July

Redhawks baseball "Facts First" program was held in Fargo on July 21, 2010. There were 35 people who attended this event. It turned out to be a perfect day for a baseball game. The program started with Dr. Nathan Kobrinsky talking about the community involvement and support that has been very important for the families with bleeding disorders. This was followed by Kathy Kirkeby, Hemophilia Coordinator, presenting the importance of logging, treatments, and options soon to be available.

It was great seeing everyone get together for a fun evening. There was an added bonus that night, free green bats were being given away and all our young and old kids got bats. One of our youngsters' won a chance to sit up in the scoring box and help out. He did a great job. We had several new families participate. They really felt welcomed and appreciated the family and staff involvement. Six HTC staff members attended the event.

I would especially like to thank Stacie Cowen from Baxter, Thomas Hyland from HomeTech Therapies and the HFMD because without their support this program would not have been made possible.

By Kathy Kirkeby



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IS A CADI WAIVER RIGHT FOR YOU?

by Stephen E. Calvit, LICSW
Center & Bleeding and Clotting Disorders, FUMC

The acronym CADI stands for **Community Alternatives for Disabled Individuals**. The word WAIVER refers to waiving or putting aside the established rules on how Medical Assistance (MA) money can be spent. Think of the CADI WAIVER as a county bank account containing funds that are granted to a disabled individual who's at risk of needing nursing home level of care. The CADI WAIVER funds are used to purchase services (e.g., in-home nursing, medical equipment, home-makers, etc.) that are designed to increase a disabled person's ability to live as independently as possible.

Here's an example of a hypothetical CADI waiver recipient to help you better understand what the Waiver is and how it can be used. John Smith has severe hemophilia and has bleeds mainly in his knees and ankle joints, making it difficult to get around in his home and in the community. He receives Social Security Disability benefits and has Medical Assistance health insurance. A county public health nurse recently came out to John's home and conducted an assessment to determine if he might qualify for a CADI waiver.

Based on a complex formula, the nurse determines that John qualifies for the Waiver and needs the following services to remain independent in his home: 1) Modifications to his home and car; 2) Medical equipment which will help him transfer independently; and, 3) a home-maker who can do chores around the home that John is no longer capable of. The total cost of these services comes to \$35,000. With this money, John also gets a case manager who meets with him periodically to coordinate his services.

After six months, John reports to his CADI waiver case manager that he is having difficulty preparing his own meals. She contacts a community meals-on-wheels program which has a contract with the county. The service is set up and the cost is added to John's service plan. Fortunately, he has enough money left over in his CADI waiver account to pay for it.

In sum, the overall objective of the CADI waiver is a "win-win" for everyone; it's a "win" for the recipient who can stay in their own home and, it's a "win" for the State which saves a ton of money by NOT paying for someone to live in a nursing home.

To meet the requirements for the CADI waiver, one must meet all of the following conditions:

- Require the level of care provided in a nursing facility
- Be certified disabled by the Social Security Administration or the State Medical Review Team (SMRT)
- Be under age 65 at the time of opening to the waiver
- Have an assessed need for supports and services over and above those available through the MA state plan

If you would like to be considered for a CADI waiver, please call Steve Calvit at 612-625-8955. He will schedule an appointment with you to discuss whether you qualify, and if so, how to get the process going.

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A Program for Men

The HFMD recently became a Blood Brotherhood site sponsored by the Hemophilia Federation of America (HFA). We are now one of nine Blood Brotherhood sites in the United States. This exciting new program is designed for adult men with hemophilia and other genetic bleeding disorders. The goal of the program is to create opportunities for men to get together through their local chapter to learn from medical professionals about various topics relating to their bleeding disorder.

There is also a social networking aspect with the program, including an online chat-room available to Blood Brothers across the country. Physical therapy and regular exercise are other important elements of the Blood Brotherhood.

The program is designed to hold six events per year and to get more men active in local chapter activities. These events will feature information seminars followed by a recreational activity. The Blood Brotherhood currently has over 250 active members nationwide.

HFMD held our first Blood Brotherhood (BB) event on September 4th at Target Field in Minneapolis. Our group of fourteen met at 1:30 p.m. in front of gate 29, then made our way to a third level suite where attendees filled out BB enrollment forms and settled in to hear Joni Osip, RN, speak about the impact of good nutrition in maintaining your health. Joni's presentation was well received. The University of Minnesota HTC's new Social Worker Steve Calvit had an opportunity to introduce himself and talk about his passion for helping those in need.

For most of our attendees, it was their first visit to the new Twins ballpark and it was a great time had by all as the Minnesota Twins beat the Texas Rangers 12 to 4. We encourage men in our community to watch for upcoming Blood Brotherhood events.

We extend our deepest appreciation to the HFA and their Blood Brotherhood program for sponsoring this terrific event!



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LIGHTS, CAMERAS ... SAY "VICTORY!"

Rosie Geer recently celebrated the National Hemophilia Foundation's new "Victory for Women with Blood Disorders" program by participating in a photo shoot in New York City.

Nineteen women from across the country met in New York City in August to smile and say "victory" as they posed for famed fashion and society photographer Patrick McMullan. Patrick, whose sister Doreen died at age 25 from complications of von Willebrand's disease, generously donated his services to produce a calendar as a promotional piece for the Victory for Women program. The calendar is intended to raise awareness of, honor, and empower women with blood disorders, and raise funds for women's programs.

An awareness campaign promoting Victory for Women will be launched at the 2010 NHF Annual Meeting in November. At that time, NHF will host a reception to unveil the 2011 calendar featuring Rosie and her colleagues from the photo shoot.

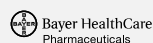
Victory for Women with Blood Disorders will incorporate education, advocacy, and support for women diagnosed with blood disorders, and raise public awareness of the issue so undiagnosed women with symptoms can seek care. Providing accurate information about signs, symptoms, and treatment for women's blood disorders is a priority for the staff and volunteers partnering together to carry out the program. For more information, click on the Women tab at www.hemophilia.org

The HFMD is proud to have Rosie Geer represent our chapter as we work to provide services for women in this area. Rosie has been an active member of HFMD's Women's Outreach Program for several years. Stay tuned for more information about the calendar release! Submitted By NHF.



Rosie Geer

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2010-2011 Calendar

November 11-13, 2010.....	NHF's 62nd Annual Meet New Orleans, LA
November & December.....	HFMD Poinsettia Sales
April 1 & 2, 2011.....	HFMD Annual Meeting Minneapolis Airport Marriott Bloomington, MN
May 21, 2011.....	Hearts of Hope Gala Minneapolis Airport Marriott Bloomington, MN
July, 2011.....	Summer Camp, Courage North Lake George, MN
August 6, 2011.....	HFMD Walk Como Park Pavilion St. Paul, MN

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

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