

HFMD MISSION
To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications.

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Dakotas Retreat 2008 – Our Youth Really Shined

This year our Dakotas family education retreat was held in Casselton, North Dakota at the Governor’s Inn Hotel and Water-park. 85 people attended. This education event was held on Saturday, August 2nd, beginning with lunch at 12 noon. Registration opened at 10:00 a.m. with time to visit exhibitor booths before lunch. Our education programming began at 1 p.m. with a presentation from HFMD.

Our medical panel featured Dr. Nathan Kobrinsky, Kathy Kirkeby PA, and Erin Tobin RN. Dr. Kobrinsky shared a riveting presentation which included a historical background of hemophilia leading into contemporary treatment approaches.

Then the panel opened the floor for Q & A. Our Dakota families took the opportunity to ask some very good questions. Following the medical panel, Mark Plencner RPh. and HFMD executive director Jim Paist led a panel discussion on patient advocacy. Mark gave an outstanding presentation on insurance and cost related issues associated with treating hemophilia. Jim presented on public policy advocacy emphasizing how people really can make a difference when they get involved.

One of the day’s highlights was our youth panel which truly captivated and

impressed our audience. Each panelist shared such well-prepared and thoughtful presentations. Taylor and Morgan Wray dazzled us by sharing their personal stories of excelling in sports as hemophiliacs. They closed their section showing an amazing video with highlights of the “bruise brothers” in action running track and field, playing basketball and baseball. Adam

Pietruszewski spoke about his compelling experience playing high school football (running back) and setting a new school record for rushing yards in a season. It was inspirational to say the least.

Carson Ouellette presented on his exciting experience going to Washington Days with his mother Sherri as they were a part of the HFMD delegation in March. As someone with interest in government and history, Carson’s passion was reflected in his outstanding presentation.

At the conclusion of our education programming, there was more time to visit exhibitors to learn more about the factor medication and services they offer. After dinner our group had the option of going to a local musical, an amusement park, or jumping in the pool at the hotel. The event



Left to Right: Morgan Wray, Taylor Wray, Adam Pietruszewski, and Carson Ouellette

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ended after a buffet breakfast on Sunday morning. HFMD received some very positive feedback from attendees on the quality of the programming and the facility. The food was terrific at the Governors Inn! The event went so well because Bob Stone, Kathy Kirkeby, Courtenay Misheski and Pam Cella did such a good job of planning it. Months of meticulous planning went into this and it turned out well.

The HFMD would like to thank our sponsors of the retreat: MeritCare, Baxter BioScience, Bayer HealthCare and CSL Behring. We would also like to thank all of our exhibitors for supporting and participating in this HFMD annual gathering: BIOMED, Baxter BioScience, Bayer HealthCare, CSL Behring, CVS Caremark, Grifols, Hemophilia Health Services, Mid-West Cornerstone, New Life Home Care, Novo Nordisk, Talecris, and Wyeth.



Youth Panelists - Left to Right: Morgan Wray, Taylor Wray, Adam Pietruszewski, Carson Ouellette



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SUMMER CAMP 2008

Once again we had a fantastic week in the north woods at Courage North. Our week was filled with “Hemo-Olympics”, good friends, education and lots of good food. Hopefully you have talked with your camper about their week at camp and know how much fun we had.

Our week started out with the more experienced campers meeting with the new campers as part of the camp mentoring program run by our HTC social workers, Jim Langworthy & Terry Hammink. The mentors spend time throughout the week with the new campers, go on an outing and help the campers adjust to camp. This is a wonderful opportunity for our older, more experienced campers to become involved at a different level in the community. (We are always grooming the kids to become leaders in the community).

As always, we had self-infusion education. This year the campers received edible awards for each step of the self-infusion process. If your camper was working on self-infusion at camp, please encourage him to continue to participate in the infusion process at home. Self-infusion is so important for your child(ren) to learn as they start the transition into a more independent life. This year at camp we had more campers in the health center learning self infusion than in other years. Congratulations Campers!!

Our activities this summer consisted of Olympic events: canoeing, kayaking, fishing, swimming, tubing (with a glass of Kool aid), synchronized swimming, biking, drama, photography, nature and others. It is always fun to see the campers interact with each other and try new things – the boys did a fabulous job with the synchronized swimming!

For those of you who like to plan ahead, hemophilia/bleeding disorder camp is scheduled for July 19 – 25. Those of you old enough to work at camp for the summer, you can find a job application on the camp web site; http://www.couragecamps.org/cn_staff_information.html.

Staff Qualifications: To qualify as a counselor at Courage North, you must be at least 18 years of age. Students who have completed their junior year of High School may qualify for a food service position. Program area directors need specialized education in an appropriate field. Applicants who have specialized skills, such as fluency in American Sign Language or experience as a Personal Care Attendant, will be given additional consideration.

We would like to thank all who support camp with donations of time and money. It is was a successful week once again. A special thank you goes to our medical director, Dr. Margaret Heisel-Kurth.

by Kirstin Schmidt, RN



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HFMD Awards Post Secondary Scholarships

Knowing that an education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation was delighted to receive ten applications for post-secondary school this year from members within our community. During the month of July, the Scholarship Committee reviewed all applications, the recipients were named, and all applicants were notified by mail. Scholarship checks were awarded to the recipients and mailed to the school of their choice during the second week of July.



The Center for Bleeding and Clotting Disorders at the University of Minnesota Medical Center, Fairview is happy to announce a scholarship through the University of Minnesota! This scholarship is available to students attending any of the 4 U of M campuses.

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

The Minneapolis Bleeding Disorders Scholarship

The Minneapolis Bleeding Disorders Scholarship was established in 2007 by the Center for Bleeding and Clotting Disorders- Minneapolis to support new full-time students enrolling in for the first time in an undergraduate program or professional school. This scholarship assures that students with bleeding disorders will be given the opportunity to seek excellence in education, and preference will be given to those who have an inherited bleeding disorder. If no such student applies, scholarship can be offered to a student with systemic or other medical condition who is served by the office of Disability Services.

To apply for the scholarship please contact Disability Services at the U of M 612-626-1333 or www.ds.umn.edu. Feel free to contact the Center for Bleeding and Clotting Disorders with any questions 612-626-6455.

by Pam Cella

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NEW WAYS FOR FUNDRAISING



On July 23, 2008 The “Children’s Miracle Network”, Mandan Dairy Queen and the Legion baseball team the “Mandan Chief’s”, teamed together for a fundraising event for MeritCare’s Children’s Hospital. The event pre-sold Blizzard treat certificates for the main event on August 7th “Miracle Treat Day”. The event donates the proceeds of all Blizzard sales on August 7th, directly to the MeritCare Children’s Hospital.

Ben Delzer was asked to be present as a child who has benefited from the services of MeritCares’ Children’s Hospital in Fargo North Dakota, on many occasions, for treatment of Hemophilia A, by Dr. Nathan Kobrinsky and the HTC staff. Ben was excited to hang out with the team in the dugout of the Chief’s prior to the game. The members of the Chief’s took Ben in as part of the team for the short period just prior to the game, was given a team hat and was honored with throwing the first pitch of the game. Ben also walked away with the game ball and some new friends.

The main fund raising begins on August 7th at the Dairy Queen restaurant located on Main Street in Mandan, North Dakota. Ben has been asked to attend this event where he will learn to make Blizzard treats and assist in serving the customers of the day. Mike Wieland, owner of the Mandan DQ store and his staff, are dedicated to raising funds for the “Children’s Miracle Network”, last year raising 6,000 dollars in the one day event.

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TEEING OFF for the HFMD

Our 12th annual golf fundraising event was held on Monday September 8th, 2008 at the Indian Hills Golf Club in Stillwater, MN. We had nearly 90 golfers with a total of 110 people who showed up in support. Fox 9 Weekend News anchor Tom Halden participated as our celebrity golfer for the tournament. After a buffet style lunch and time for pictures with Tom, the shotgun started kicked off the tournament at 1:00 p.m. sharp.

After our group finished 18 rounds of golf, people began filing in the clubhouse shortly after 5 p.m. where the silent auction began. There was an array of exciting auction items to bid on from weekend getaways, to golf items, and a Vikings jersey and signed picture from star running back Adrian Peterson. Just before dinner it was time to pick the lucky person who got to take a shot at a \$10,000 sixty foot putt. Scott Georman was drawn and a gallery of onlookers followed him out onto the putting green. After taking a deep breath and measuring his shot, Scott hit what appeared to be a winning shot. Just as the ball was headed toward the hole with just the right velocity, it vered just inches to the left. It made for a very entertaining moment as Scott came oh so close.

Once the salads were served HFMD executive director Jim Paist welcome everyone and shared updates on organization accomplishments in 2008. Jim also went on to thank all of our sponsors and volunteers. Our Master of Ceremonies Kert Severson called the raffle and kept our audience laughing throughout with his clever jokes and light ribbing of fellow golfers. As no stranger to a microphone, Kert was a real treat for this event! Mark Wiener then finished the second half of the raffle and did a fantastic job leading our live-auction. Mark used his wit and charm to get the highest bids possible for our 5 exciting live-auction items. Together the silent and live auctions raised over \$3,000.

This year's golf event turned out to be a well balanced support from all segments of our community. Our planning committee composed of consumer, industry and HTC volunteers did an absolutely amazing job in planning the event and getting so many quality items donated from various local businesses. Our Chair of the committee Jeff Kandt brought leadership and golf expertise to see that everything flowed well for the tournament, and HFMD office manager Pam Cella once again did a terrific job in coordinating registration and the silent auction. So many people put their hearts and time into making the event a success. It was a truly collaborative effort which helped to raise important funding for HFMD's programs and services. We would like to thank everyone on the golf planning committee: Jeff Kandt, Stacy Pike, Angie Klersy, Paige Reeves, Linda Litecky, Deb Melhado, Dick Bone, Steve Oas, Deb Starling, Mark Wiener, Mark Hunter, Kert Severson, and Nancy Golden. And thanks to all the volunteers who helped at the event: Gayle Kretman, Angie Boyd, Rita Shepherd, Kirstin Schmidt, and Cheryl Wistrom.

The HFMD would like to extend a very special thanks to our generous sponsors. First our Double Eagle Sponsor Novo Nordisk, Eagle level sponsors Baxter BioScience and CSL Behring, Birdie Level sponsors BIOMED, Hemophilia Health Services, Walgreens-Option Care, and Wyeth Pharmaceuticals, Par level Bayer HealthCare and CARQUEST Automotive Finishes, and Hole sponsor Grifols.

The 2008 HFMD Golf Tournament was a big success and we are very grateful to all who golfed and all who helped.

FAMILY FITNESS DAY

What a day to be on the river! Saturday, August 2nd, the HFMD Family Fitness program took a ride down the Cannon River. It was a perfect summer day for fun and fitness. Over twenty participants arrived in Cannon Falls and had their choice to canoe or kayak on the river or to bike down the beautiful adjacent trail. We began the day with a picnic in the park, then headed down the river for a two hour ride. Treatment centers from both Rochester and the Twin Cities were represented, canoes and kayaks were provided on site and a few people brought their own bikes. Once we got on the river, it was like we had the world to ourselves. The wilderness was beautiful and never could a car be heard. It was also surprising that even paddling with the current of the river could be a great workout. I think most of us agreed we couldn't wait to do it again.

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2008/2009 Calendar

November 13 – 15, 2008	NHF's 60th Annual Meeting Denver, CO
November /December	Poinsettia Sales begin at HFMD
January 24, 2009	Hearts of Hope Gala "Back to the 50's Theme" Minneapolis Hilton Downtown Minneapolis
January 2009	There will be no Minnesota Family Retreat this year
April 2009	HFMD Annual Meeting (Date and Location to be announced)
July 19th thru 25th, 2009	Summer Camp, Courage North Lake George, MN
August 7th & 8th, 2009	Dakota's Retreat Detroit Lakes, MN
September 14, 2009	HFMD Golf Tournament Indian Hills Golf Club Stillwater, 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!