

7th Annual Walk Fundraiser Recap



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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Over 250 attendees joined the HFMD, beat the looming rain and walked at Como Park on Sunday, August 13th for our 7th Annual "Step Out for Bleeding Disorders" Walk fundraiser. Thank you to all of our amazing Walk teams and supporters who supported this event!

Walk registration and festivities started up at 10am and guests enjoyed time with exhibitors, balloon making with Doodles the Clown, photos in the Memories and More Photo Booth sponsored by CSL Behring, fun with Timberwolves' mascot, Crunch and face painting with Jennifer Paist. Walk teams gathered in the pavilion for treats and refreshments courtesy of General Mills and David Singer. After grabbing neon yellow Walk t-shirts, participants headed for the starting line for the 11am start. HFMD Executive Director, Jim Paist and Crunch kicked off the Walk with a countdown and a horn start!

Walkers enjoyed a 2.5 mile stroll around Como Lake and returned to the finish line to high fives from U of M mascot, Goldy and St. Paul Saints mascot, Mudonna. Everyone then enjoyed a delicious lunch of Subway sandwiches and more fun on the plaza.

Thanks to the incredible efforts of our 20 Walk teams and support of our sponsors, exhibitors and fundraisers over \$62,000 was raised for HFMD programs and services. THANK YOU to all of the teams, families, individuals, virtual walkers and donors who supported the 2017 Walk – without you none of this would be possible! HFMD honored the top three Walk teams for their fundraising efforts at the end of the Walk program. Our first place team, D'Valle Blood Brothers, raised \$2,489 and won a travel reimbursement to the 2018 NHF Conference.

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Our second place team, Team Naumann, raised \$2,140 and won a one-night weekend stay at the Hyatt Regency Bloomington with Regency Club access; four general admission passes to FlyOver America; four passes to Moose Mountain Adventure Golf; and four Community Passes to AMC Theatres. Our third place team, Team James, raised \$1,540 and won a bag toss yard game; four general admission tickets to SEA LIFE Aquarium at the Mall of America; two general admission tickets to the Crayola Experience; two all-day unlimited ride passes to Nickelodeon Universe; and a Mall of America Coupon Book. Thank you to the top three and all of our Walk teams for your amazing fundraising and recruiting efforts!



We look forward to our 8th Annual "Step Out for Bleeding Disorders" Walk next year! We hope that you will join us!

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Hello Talk

HFMD partnered with Shire on September 14th at the Timber Lodge Steakhouse in Bloomington to host this education dinner for members of our community. The keynote speaker was Skye Peltier, PA who treats patients at both MHealth and Children's Hospital (HTC) clinics.

Skye shared a creative presentation entitled "No Sweat"; which focused on the benefits of regular exercise, and recommended time to strive for each day and each week. Skye also shared handouts of NHF's Playing It Safe. This is the National Hemophilia Foundations guide which rates a wide range of sporting activities on a scale of 1-3 with 3 being the most high risk activity for injury, and 1 being the lowest risk activity for injury. She then asked attendees what kinds of activities they participate in. We were pleased to hear most in our group are doing fun and safe sporting activities and exercises. Our group of nearly 30 included both families and individuals affected by bleeding disorders. The food and service at the Timber Lodge Steakhouse was terrific! HFMD would like to thank Shire for sponsoring and we thank Skye Peltier for presenting!



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Thunder Road Event a Hit in Sioux Falls!

July 29th dawned as a beautiful, sunny day in Sioux Falls, SD. Is it any wonder that over 70 community members and exhibitors joined together for a day of education, great food and exciting family fun at Thunder Road?

As the group arrived our exhibitors were on hand to welcome them. While the group waited for the food to be delivered Nathan Anderson, LSW, from Sanford introduced Physical Therapist, Dan Steventon. Dan educated the group on physical activities and sports that are safe for those with bleeding disorders. He presented information from the National Hemophilia Foundation's *Playing It Safe* publications through the Steps for Living Program. For more information and to access the *Playing It Safe* booklet for activity overviews, risks and safety measures visit www.stepsforliving.hemophilia.org.

While the group enjoyed a wonderful meal of grilled chicken and beef brisket with all the fixin's from Famous Dave's of Sioux Falls, Jim Paist, provided an overview of the programs and events provided by the Hemophilia Foundation of MN/Dakotas throughout the year.

Finally it was time for everyone to get their wristbands and enjoy a fun-filled afternoon at the Thunder Road Family Fun Amusement Park.

This event marked the first time Pharmacy and Specialty Pharmacy representatives had a presence

at an HFMD event in South Dakota. Community members were very appreciative of the opportunity to meet with the exhibitors and took full advantage of the information they had to offer.

Thank you to our exhibitors: Accredo Specialty Pharmacy, Aptevo, ARJ Infusion Services, Bayer Healthcare, CSL Behring, CVS Specialty, Diplomat Specialty Infusion Group, Factor One Source FAST, Octapharma, and Shire.



Return To the Jonathan Padelford

In a second consecutive year, the HFMD partnered with Octapharma to host an education dinner cruise excursion on the historic Jonathan Padelford docked at Harriet Island in St. Paul. On a sunny evening June 18th, our education presentation featured Dietician LeeAnne Graveaux from HealthEast, who shared What's on the Mind Diet for healthier eating habits for our group of just over 50 members.



LeeAnne made this an interactive presentation engaging children and parents with dietary questions. She also distributed handouts for all; as we enjoyed a well-balanced grilled chicken dinner on the boat. The second part of our dinner cruise included a narrated tour from the Padelford boat captain. The HFMD would like to thank Cory Muller and Octapharma for sponsoring this exciting education dinner down the mighty Mississippi River.



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These are donations received from January 1, 2017 through September 30, 2017.

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HFMD Board & Staff News

We are pleased to welcome Kristina Rauenhurst to the HFMD Board. Kris has been a successful fundraiser and dedicated volunteer for this organization. Her experience and commitment to our cause will be a nice addition to the Board.

We also welcome our two new industry representatives (non-voting) to the Board. Todd Hedlund and Dan Kallberg were nominated to the HFMD Board by their peers on our Industry Relations Committee. The HFMD Board meets six times per year, including an all-day Board Business Meeting coming up on November 18th.



CONGRATULATIONS to HFMD Event Coordinator Brianna Hager, husband Matt, and daughter Alice, on the birth of Arlo Hager on September 12th! Brianna will be on maternity leave until the first of the year.

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Campfires, capture the flag, swimming, smores... greeting old friends and making new ones...

those are just a few of the great memories that our campers took from the 2017 HFMD Hemophilia Summer Camp. Kids from Minnesota, Wisconsin and the Dakotas got together for a week of activities, crafts, and learning about hemophilia.

Camp Courage North on Lake George was the setting for this year's camp, held July 9th – 14th.

Camp started out with a campfire and sing-along. Days were filled with tubing, fishing, and games by the lakeside. Kids age 8 – 17 got to do what kids do best – be a kid! And they got to do it with other kids who know what it's like to handle a bleeding disorder. Every new camper was paired with an older buddy who could help as a mentor and friend. They got to compete in a series of fun challenges that taught kids about bleeding disorders and the best ways to manage their conditions. They learned how bleeding disorders worked, what factors they need to use, and what to do if they have a bleed.

Teaching self-infusion is one of the goals of the camp. Kids who can self-infuse gain confidence and independence. The health care team included Hematologist/Oncologists, physician assistants, nurses, physical therapists, and social workers from around the region. These medical professionals taught the campers how to do self-infusions. Older campers took the younger ones



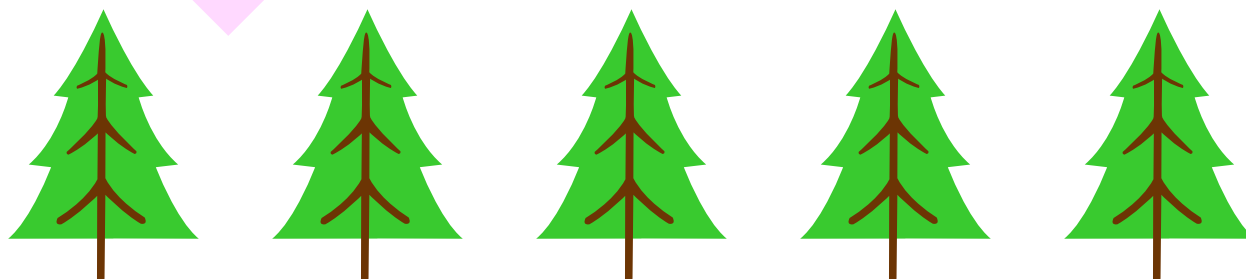
under their wings to show them that infusions can be just another part of the day. These mentors gave the young campers lots of encouragement and support. One of the highlights of camp is getting to put your name on the “big stick” after making that first self-infusion attempt!

Peer support is an important aspect of the camping program. Many of the campers don’t know other kids with a bleeding disorder. They may be the only one in their school with their condition; kids from small towns may not have met anyone else with a bleeding disorder. “As a camper, the connection to others with

hemophilia, same strives and struggles, pains and frustrations, was a very new and exciting aspect,” said former camper and current volunteer Cody Morrow. These kids serve as role models to each other, and help to normalize the experience of coping with the daily issues of a bleeding condition.

This was the 28th year for the summer camp, sponsored by the Hemophilia Foundation of Minnesota/Dakotas, regional Hemophilia Treatment Centers, at Camp Courage North/True Friends.

by Amity Carlson, MS, PA-S2



ADULT MENTOR PROJECT

Last year, the HFMD's Adult Mentor Project was rejuvenated by a special grant from Aptevo (formerly Emergent). Thank you Aptevo! The program is designed to help young adults (ages 17-25) who are at a cross-roads in life and struggling with personal and career decisions. Through this program, HFMD has connected two young adults with Life Coach Jeremiah Rangel.

One of the two young men just finished his program during a six-month period which included the 20 hour maximum of Life Coach time; paid for by HFMD. "I have benefitted from the program in ways I could never imagine" is just one of the statements shared by this HFMD member. He is back in college making school his number one priority, while being a reliable employee with his part-time job. The other participant is just getting started in the program. Like many HFMD programs, this project includes collaboration from our affiliated Hemophilia Treatment Centers.

HELP HFMD REDUCE OUR CARBON FOOTPRINT

The HFMD is asking for your help in an effort to go paperless!

The Veinline is one of the ways we keep our community informed of our programs and events. However, each year as our community grows we are printing and mailing more. In an attempt to save printing and postage costs, as well as reduce our paper and ink usage we're asking community members to provide an email address where we can send the quarterly Veinline electronically. If you'd like to help us out and receive future issues of the Veinline via email instead of hard copy, please email us at info@hfmd.org and let us know the email address(es) where you would like to receive future newsletters?

National Hemophilia Foundation (NHF) Annual Meeting 2017

The NHF conference was a GREAT experience and exactly what we needed as parents of a 3 year old with hemophilia/VWD.

Evan has been very well managed by Children's Hospital but we are still missing the family/human piece of things. How or will our son want to share his diagnosis with his friends, teachers, potential girlfriends (gulp), sports coaches, potential employers? These were questions about his future that no doctor or nurse could answer for us. At the NHF conference we finally had the opportunity to speak with families, couples, and individuals who were further down this path than we are. We met active men in their 20's and 30's that gave us piece of mind and hope that Evan will be able to do whatever he DECIDES to do, not just what is the safest.

The conference also gave us a great history of hemophilia/bleeding disorders in this country, how insurance coverage has changed and will continue to change, potential new "game changer" medications that won't cure but will change his quality of life. Also a great deal of hope overall for future generations of our little family as well as this amazing community of people who have become such an amazing support system to us.

Hemophilia CAN feel normal and now after this conference we are that much closer! Thank you HFMD for affording us this opportunity and experience! We will be forever grateful!!

Abby and Dylan Naumann

2017-2018 Calendar of Events

October 19, 2017.....Tucci Benucch and Nickelodeon Universe
Mall of America, Bloomington, MN
(This event is full)

October 28, 2017.....HealthEast Ways to Wellness
Ways to Wellness, Woodbury, MN

February 17, 2017Hearts of Hope Gala
Radisson Blu, Bloomington, MN

April 21-22, 2018.....HFMD Annual Member Meeting
Marriott Airport, Bloomington, MN

****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 more exciting news and updates!

Veinline

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

HFMD

750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363

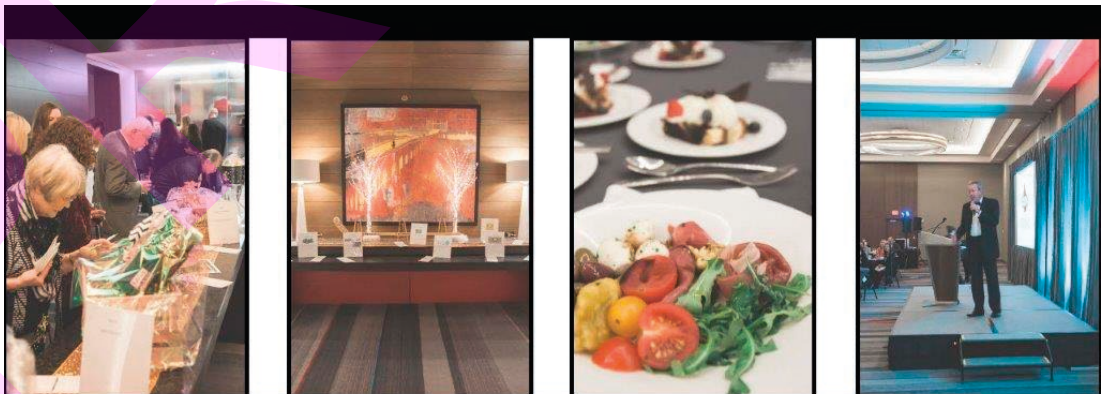
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18th Annual Hearts of Hope Gala Fundraiser

February 17, 2018
Radisson Blu, Mall of America
Bloomington, Minnesota


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