NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS



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FALL 2022

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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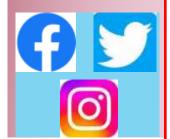
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The 2022 Step Out for Bleeding Disorders Walk was a big success! Thank you to all of the sponsors, exhibitors, donors and volunteers — and a huge shout out to the 106 people that signed up to Walk with us on Sunday.

It was an absolutely perfect Minnesota summer day, with blue skies and a beautiful setting at Harriet Island Regional Park in St. Paul.

The annual walk is HFMD's big fundraising event of the year, and it did not disappoint. We raised \$43,000 in sponsorships and exhibitor fees. Donations and registrations for the Walk came in at over \$9500.

Prizes were awarded to the three Team Captains raising the most in donations. The top teams were Team James (captain - Kris Rauenhorst) in 1st place; Team Carson (captain – Angie Klersy) in 2nd place; and Hit Me With Your Best Clot (captain – Kathleen Kubitschek) in 3rd place.

The Walk had a lot of fun elements this year. We had mascots Goldy Gopher, Mudonna from the St. Paul Saints and Twinkle from Children's MN. We also had Sir Skolt representing the MN Vikings and Mark Dreyer in his full firefighter's gear. This added a lot of energy to the event.

Mandana the Balloon Artist was a hit, with colorful balloon towers at the starting line and balloon twisting for the kids inside the pavilion.

Exhibit space was sold out, with a full house of our amazing industry representatives in pharmacy and home and health care, as well as providers from the local Hemophilia Treatment Centers.

Volunteers from M Health Fairview served up Firehouse subs and chips, granola bars and bottled water to the hungry crowd. We had other volunteers helping with t-shirts, registration and directional assistance.

There were also inspirational speakers, including some young adults that impressed the audience with their enthusiasm and heartwarming stories of friendship and living with bleeding disorders.

We appreciate the support of each and every one of you that contributed in any way. We couldn't do it without you.

(continued on page 3)









WALK 2022 (continued from page 2)

Our sponsors and exhibitors were a huge part of the success of this year's Walk. We appreciate the time, energy and financial support from all of these wonderful organizations:

Children's MN CSL Behring HEMA Biologics

Takeda M Health Fairview

Bayer Healthcare Novo Nordisk Octapharma Sanofi Mayo Clinic

Biomarin Genentech Grifols USA HealthPartners Infucare

Cub Foods CVS Pharmacy Firehouse Subs

Thank You Kim Baumann! Physical Therapist, M Health Fairview

Dear Kim, We are sad to hear you are leaving the clinic, but we understand.

You have done so much for the HFMD over two decades, and we are so grateful for all of the time, energy, and creativity you brought to this organization. You were such a thoughtful Board member, and impactful member and volunteer of several committees, including the Gala, Annual Meeting, and Group Fitness committees.

You went above and beyond on many occasions; and always brought your "A" game as a presenter and panelist. We can't thank you enough for all you did! You will be dearly missed by HFMD and so many patients you helped at clinic.

We wish you the best!
- Jim Paist and the staff at HFMD







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HFMD & Sanford Health at the Great Plains Zoo, Sioux Falls, SD By Jim Paist

We held our annual South Dakota Family Education Day near the bison area at the very lovely and lively Great Plains Zoo on Saturday, July 30th. HFMD Administrative Assistant Tammy Ward

and volunteer Lisa Cochran were a big help in setting up and coordinating our group event throughout the day.

Our event opened with wonderful acoustical music from Short Notice, a local band led by Nathan Anderson and his two talented band-mates Jodi & Dave. They played some of the best classics from the 1970's which energized our group, and perhaps some of the animals too!

HFMD shared some early announcements and organizational updates before introducing our keynote speaker ,Dr. Briana Murphy, Hematologist at Sanford Health Sioux Falls, fondly known as "the Castle". Dr. Murphy, also an HFMD Board Director, led with some clever Zoo humor before sharing a timely and thoughtful presentation on families



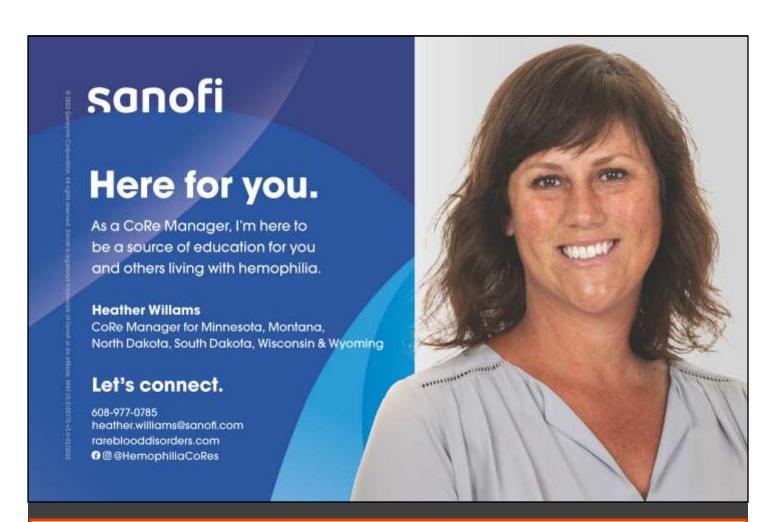
communicating with their child's school on preparedness and readiness in school if their child were to have a bleed.



In between presentations, our group had time to visit with company exhibitors who set up in the perimeter of a circus-like tent we rented from the Zoo. Families also had time to visit with each other during the festivities and a group lunch. Important information and fun was had by all before everyone got to enjoy the Zoo and admire all of the amazing animals.

HFMD Would like to extend a special thanks to all of our event exhibitors:

ARJ Infusion
Bayer
CSL Behring
CVS Specialty Pharmacy
InfuCare Rx
Novo Nordisk
Optum
Sanofi



HFMD is getting more social!

This past summer, HFMD hired a consultant to help us step up our social media presence and reach more people. Lexi Dunn of Get Work Dunn worked with the HFMD staff to set up pages and improve our use of the HFMD accounts on Facebook, Instagram and Twitter.

Lexi spent time with HFMD staff, training us in the nuances of the various social media platforms. We were already doing some Facebook posts, but we have transitioned to a more appropriate "business page" so that we can reach more people and gain followers.

It was fun to share pictures and stories from the Summer Camp in June and from the South Dakota Family Day in July. At the Step Out for Bleeding Disorders Walk in August, we did a Facebook Live event, streaming video of the participants at the starting line for the Walk.

Staff at HFMD did a fun little promotional video leading up to the Walk, and we've been doing general informational posts about upcoming events and bleeding disorders.

Lexi has been doing some Twitter posts on our behalf, and helping us create a strategic plan for continuing to expand on our social media activity.

Check us out! Follow Us and Join the Conversations at:



Facebook.com/theHFMD





twitter.com/HFMD

An Important Change Regarding Medical ID Bracelets & Pendants

We know a lot of members of our community use medical ID bracelets or pendants as an important way to communicate information about your bleeding disorder to first responders and medical personnel in case of an emergency.

HFMD is pleased to be able to help our community members cover the cost of these.

Effective immediately, HFMD and your Hemophilia Treatment Center will be purchasing these medical IDs through a company called American Medical ID. (We are no longer using MedicAlert.)

You do not need to replace your current medical ID right away, but if you need a new one for any reason, please contact your HTC social worker. They will help you with the details, and HFMD will cover the cost up to \$50 per item along with engraving and shipping costs, per patient, per year.



Current Calendar of Events

October 8, 2022..... Women & Teen Girls Boat Cruise

Al & Alma's Charter Cruises, Wayzata, MN

October 20, 2022...... Hello Talk Education Dinner, sponsored by Takeda

The Lexington Restaurant, St. Paul, MN

November 5, 2022..... HFMD Group Fitness— Family Bowling Day, sponsored by

Bayer & InfuCare Rx Pinz, Oakdale, MN

November 11-13, 2022..... Mayo Clinic Family Event

Embassy Suites, Bloomington, MN & Science Museum of MN

November 19, 2022..... HFMD Symposium

Eagan Community Center, Eagan, MN

February II, 2023..... HFMD Hearts of Hope Gala (SAVE THE DATE!)

Metropolitan Club, Golden Valley, MN

Visit our website at www.hfmd.org/events/ for more information and to register!



Hemophilia Foundation of Minnesota/Dakotas and CSL Behring invites you to join us for our annual



Women and Teen Girls Event

Al & Alma's Charter Cruises

aboard the Isabella

Saturday, October 8th, 2022 10:00 a.m.-2:00 p.m. Leaving from the Port of Wayzata 402 Lake St E, Wayzata, MN 55391

Enjoy a spectacular view, good food and informative programming.

This event is for females age 13 and up with a bleeding disorder & one guest.

Seating is limited so get your completed registration form returned today!

Check-in starts at 9:30 am. We will depart promptly at 10:00 a.m. so don't be late.

Each patient may bring one guest.

Visit our website at www.HFMD.org to register.











The HFMD gratefully acknowledges our donors who have given so generously. These are donations received from January 1 - September 30, 2022

Organizational & Business Contributors:

\$40,000 and Up

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of Minnesota Mayo Foundation for Medical Education & Research M Health Fairview

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Osip, Joni

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