

NEWSLETTER OF
THE
HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

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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HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

Veinline

WINTER

2023

YOU ARE INVITED

Please join us for the HFMD's 23rd Annual

HEARTS OF HOPE GALA

*Enjoy an evening of fine dining, drinks,
a silent auction, and dancing to benefit the*

Hemophilia Foundation of Minnesota/Dakotas



Saturday, February 11, 2023

6:00 pm - 11:00 pm

Metropolitan Ballroom & Clubroom

5418 Wayzata Boulevard, Golden Valley, MN 55416

This year's Hearts of Hope Gala is shaping up to be a wonderful, festive event.

We've shortened the program, and extended the social hour and silent auction. A lot of fantastic items will be included in the silent auction, such as dining gift cards, various family experiences, sporting events and more.

The Metropolitan Ballroom & Clubroom is an elegant venue, and the food will be delicious.

Singles, couples or tables of eight are welcome. Register today!

With the event's timing of February 11, it could be a great way to celebrate Valentine's Day while supporting an important cause.

We'll be dancing to tunes spun by official Minnesota Vikings DJ Ray Mills.
We Hope to see you there!

[**CLICK HERE TO REGISTER**](#)

A Successful 2022 HFMD Symposium

The HFMD's 4th Annual Symposium was held on November 19, 2022 at the Eagan Community Center. The feedback from the exhibitors and attendees was that the event was all that we could have hoped for.

The Symposium started at 9:45a.m., with muffins and coffee and a chance for the community members to visit with the exhibitors at their tables in a spacious and bright conference room.

Families with kids were welcome to take the youngsters to one of two Child Programming areas, where Vicki Neis, Child Life expert from Children's Minnesota, organizes a team of fun-loving colleagues to do age-appropriate activities, such as music, arts and crafts and some supervised time in The Blast, an indoor play area inside the community center. A big thank you to Vicki and her staff for doing such a great job. We saw a few kids this year that didn't want to leave when the event was over!

At 10:30, the adults moved to the big ballroom, next door to the exhibitors' area. Jim Paist gave updates on all of the things that HFMD has been up to over the past few months. He filled the participants in on the efforts that will be made to get some important legislation passed in 2023. The legislation is all focused on making insurance more fair and helping people with bleeding disorders manage their health care costs.

After Jim's updates, there was a short and silly special visit from "Violet and Daisy." Those that were at the Symposium know the inside story – Violet and Daisy were really the two HFMD admin assistants, Tammy Ward and Peggy Nasby. They performed a little skit in which Violet tries (and succeeds!) to cheat Daisy out of \$20. Luckily for Tammy and Peggy, there is no video evidence of this.

Next on the agenda was the first of many drawings for MasterCard gift cards. Fun game show music was queued up, and that theme continued before each drawing.

This is the only event throughout the year in which our pharmaceutical and home care partners come together to meet with the community and do presentations to the attendees, so that we can all get to know more about their specific products and services. At this year's event, there were 8 exhibitors doing presentations.

We heard from Bayer, CSL Behring, Genentech and InfuCare Rx before breaking for a delicious pizza party, featuring pizza and salad from Carbone's. The kids and exhibitors joined us in the ballroom for lunch.

After lunch, reps from Novo Nordisk, Pfizer, Sanofi and Takeda each had a chance to address the audience for ten minutes. There was brief Q&A after most of the presentations.

The last segment of the Symposium was the Member Roundtable Discussions. This portion of HFMD's events is always well-received by those that participate. The topics at the roundtables vary, and members are welcome to share ideas, experiences, ask for advice and talk about things that may be affecting them or their families.

When the event adjourned around 3:00p.m., everyone seemed to have enjoyed the day and got a lot out of it. That was our goal, and we're happy to hear that we achieved it.

Thanks to all that attended, and we hope to see you all back at the next Symposium in 2023.

And, once again, thank you to our wonderful presenters:

Mya Anderson, Bayer Healthcare
Jason Clarin, CSL Behring
Kaitlyn Eliason, Genentech
Ali Crochet, InfuCare Rx

Craig Price, Novo Nordisk
Joe Schuch, Pfizer
Heather Williams, Sanofi
Lisa Cardarelli, Takeda

See fun photos from the Symposium on the next page!

- By Peggy Nasby

(2022 HFMD Symposium, continued from the previous page.)

*Here are a few fun pictures from the
2022 HFMD Symposium.
We hope to see you at next year's event!*



In Memoriam

Dr. William Lawrence Nichols, Jr. (Bill) passed away suddenly September 7th at the home he shared with his wife of 59 years, Sharon Nichols (Moore).

Bill served as an esteemed hematologist at Mayo Clinic in Rochester, Minnesota. His career began with both BA ('63) and MD ('68) degrees at the University of Kansas. He served 2 years of required military service with the Navy at Camp Pendleton, CA, and then completed his residency and hematology fellowships with the Mayo Clinic. His career there spanned from 1977 to 2022. Bill was dedicated to the science of medicine, pursuing decades of research in the field of hematology, while also training subsequent generations of physicians. He was known within the Mayo hematology community for his generous manner... and his

trendy socks and colorful neckties.

Bill furthered his scientific study through frequent international conferences. He and Sharon cultivated many friends and colleagues around the globe and often hosted international physicians visiting Mayo. The trips were too numerous to count, but Bill was sure to document every place traveled with photos of art museums and new cuisines they tried.

Bill was instrumental in establishing and incorporating two professional scientific organizations. He worked with special coagulation laboratory professionals to establish the North American Specialized Coagulation Laboratories Association (NASCOLA) to improve the quality of coagulation laboratory testing and create a network of education and learning. Bill served as NASCOLA president as well as undertaking several other offices and committee assignments. His latest endeavor is the External Quality Assurance in Thrombosis and Hemostasis (EQATH) organization whose mission it is to assess existing external quality assessment programs and enhance communication among the different programs. Bill served as the inaugural secretary/treasurer and worked again with colleagues to create the organizational framework.

For Bill's complete obituary and an opportunity to share a special memory or condolence, please [click here](#).

Women's Educational Day Held October 8th

The Annual Women's Educational Day was held on Al & Alma's Charter Cruise at the Port of Wayzata this fall on Saturday October 8th.

Our day started with an icebreaker titled *Unique & Grateful* led by Sue Curoe, RN, Center for Bleeding & Clotting Disorders, M Health Fairview. Everyone was able to share what made them unique and what they were grateful for and then pick out a gift of appreciation for their participation.

Our keynote speaker, Dr. Brianna Murphy, hematologist from Sanford Health, gave a session, "*This isn't normal, period.*" She made the topic easy to understand and was available for any questions the group had.

We had a wonderful lunch buffet and were able to enjoy the beautiful sunny day and gorgeous views from the boat. We even got some highlights from the captain about the various homes on the lake.

Our afternoon speaker, Shonda Joshua, a CSL Behring patient advocate speaker, then gave a presentation titled, F.O.C.U.S.: Strategies for keeping a positive perspective." She gave a personal perspective from that of a patient and caregiver.

Thanks to all the speakers, Hemophilia Treatment Centers' staff, and the women's outreach group from the HFMD who helped make this event possible. A special thanks to Jason Clarin, from CSL Behring, for his help and financial support with the event.

~ by Sue Curoe





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AsBR=annualized spontaneous bleed rate.

[‡] Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤ 40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

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“Hello Talk” Dinner at the Lexington - Sponsored by Takeda

On October 20, 2022, the HFMD Community was invited to the Lexington Restaurant in Saint Paul. The restaurant and the food were fabulous!

Our dinner sponsor was Lisa Cardarelli from Takeda, who presented a very informative Hello Talk program topic: **Do What Moves You: Staying Active**.

Lisa provided important information on choosing safe sports and exercising activities for those with Hemophilia and other bleeding disorders.

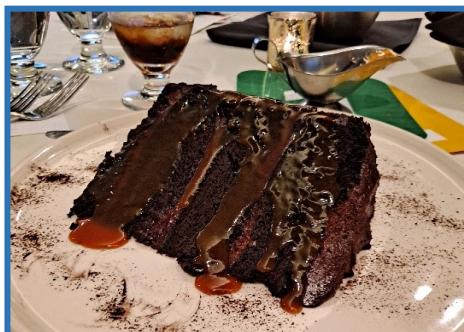
Did you know that swimming is one of the safest ways to exercise? You do now!

Staying active is imperative for people with bleeding disorders, it helps you retain and regain joint health, prevent mobility issues and lead to a better quality of life.

For more information on safe sports and activities, you can download your own “Playing it Safe” book from the National Hemophilia Foundation here:

https://www.hemophilia.org/sites/default/files/document/files/playing-it-safe_0.pdf

Thanks again to Lisa and Takeda, and to all of those that joined us for this enjoyable and educational evening!



Group Fitness Day at Pinz Entertainment

Saturday, November 5th, 2022 was a fun filled day for those who attended the HFMD Group Fitness event, at Pinz Bowling & Entertainment Center in Oakdale This event was sponsored by Bayer and InfuCare Rx.

HFMD Executive Director, Jim Paist welcomed everyone and shared some dates for upcoming organization events. Ali Crochet then shared an introduction herself and her company to everyone. Ali is fairly new to InfuCare Rx and doing a great job getting to know the HFMD community.

Mya Anderson had an audience engaged presentation about being prepared for an emergency when not at home. Some of the community members shared their experiences with trips to the emergency room while on a trip away from home.

After the presentation, the food and fun started. Everyone had their bowling shoes on and were ready to bowl (and eat). It didn't take long for the sounds of laughter and bowling balls rolling and pins being knocked down to fill the private 10-Pin Alley. There was plenty of pizza, salad and more. Nobody went home hungry.

A big thank you to all who attended and a special thank you to our sponsors of this event, Bayer and InfuCare Rx.

~ By Tammy Ward





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**Comprehensive
Hemophilia
Treatment Center
Family Event**

MAYO HTC FAMILY EVENT

On the weekend of November 11-13, 2022, Mayo Hemophilia Treatment Center held their Family Event at Embassy Suites in Bloomington, MN. All Mayo HTC families were invited to come together to Live, Learn and Imagine.

Friday evening started off with a hearty buffet dinner, introductions of staff, announcements, and an ice breaker game. Afterwards, families could choose to swim, gather, or play games in the hospitality room.

Saturday morning after breakfast, kids 4-11 attended activities lead by our excellent Mayo Child Life team, while childcare was provided by nannies for ages 3 and under.

We were very excited to have Patrick Lynch as our featured keynote speaker. In his captivating and talented storytelling fashion, he shared what his life was like growing up with hemophilia. He shared hardships as well as highpoints in his life. He held everyone's attention for 90 minutes by using a mixture of speaking, photos, and video. He is a wonderful speaker and we were thankful to have him come share.

Our second presentation for the morning was a Tai-Chi experience with Tai-Chi and Qigong by Ellen. Focus was on using these methods for mindfulness, relaxation, and a sense of well-being. Attendees had the opportunity to participate and learn under Ellen's instruction and guidance with take-away tips for using some of the methods/movements at home.

Our final presentation of the morning was an "Ask-the-Provider" Panel featuring Dr. Rajiv Pruthi, Dr. Ahmad Al-Huniti, Amy Eckerman, RN and Melinda Otto, LSW, and moderated by Dawn Rusk, RN. The physicians each shared a short presentation followed by an hour of great questions and answers.

The final event of the day, after a lunch buffet of tacos and some rest and relaxation in the early afternoon, was a trip to the Science Museum. Attendees gathered on 2 buses headed to the museum to Explore and Learn! Everyone also received 1 ticket to the Omni theater presentation of their choice. Dinner was catered in to the museum private banquet room and included some delicious pizza, salad and desserts.

Guests checked out Sunday morning after breakfast after sharing their evaluations for the weekend with us. The overall consensus was a great weekend! Mayo hosts an HTC family event every other year. We'd like to thank all those who participated in and attended the event!

By Dawn Rusk



Photos from this wonderful event are on the next page!

MAYO HTC FAMILY EVENT PHOTOS
(continued from the article on previous page)



**HFMD 2023 ANNUAL
MEMBERS' MEETING
APRIL 21 & 22, 2023
MERMAID EVENT CENTER
MOUNDS VIEW, MN**

Join us for Good Info, Food and Fun!

**Friday 5:30 –8:00pm
Saturday 8:00am-3:00pm
2200 Mounds View Blvd.
Mounds View, MN 55112**



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**HEMOPHILIA
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Upcoming Calendar of Events

- February 11, 2023 HFMD Hearts of Hope Gala
Metropolitan Clubroom, Golden Valley, MN
[Click HERE to Register](#)
- April 21-22, 2023 HFMD Annual Meeting
Mermaid Event Center, Mounds View, MN
[Click HERE to Register](#)
- July 29, 2023 South Dakota Family/Education Day
Sioux Falls Canaries Baseball, Sioux Falls, SD
- August 19, 2023 HFMD Annual Step Out for Bleeding Disorders Walk
Time: 2:30 p.m.-5:30 p.m. Como Park Pavilion (near Como Zoo)
1199 Midway Parkway
St. Paul, MN 55117
- November 18, 2023..... HFMD 5th Annual Symposium
Eagan Community Center, Eagan, MN

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



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The HFMD needs your help in spreading the news!

Like many organizations, HFMD went paperless in 2021.

As the only resource of its kind in Minnesota & South Dakota, it is very important for us to reach any and all patients/families, supporters & friends of the HFMD. It's especially important that everyone has an opportunity to know about all of the events available to them.



For this reason, we need your help in expanding our Veinline circulation. We are very guarded with our member email lists. However, since going paperless, we have been hearing that some members, patients and supporters are no longer receiving the Veinline and other communications from the HFMD.

Please check your spam folders each quarter, as our quarterly newsletter is emailed out in early January, April, July, and October.

Also, if you know of someone that may benefit from our programs, services and events, please ask them to reach out to us at info@hfmd.org to be added to the email lists.

We have been told the Veinline is informative, uplifting and fun to read. Hopefully, you agree and are willing to spread the word to your family, friends and others in the bleeding disorders community.

Thank you in advance, and we wish you a happy and healthy year ahead!



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