

**NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
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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theHFMD



@theHFMD



**HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS**

Veinline

SUMMER

2024

THE NEED FOR YOUR SUPPORT IS REAL!

The **Hemophilia Foundation of Minnesota/Dakotas** invites you to join us at the 14th Annual



Step Out
for Bleeding Disorders
WALK FUNDRAISER

Saturday, August 10th, 2024

Central Park Roseville ✦ Jaycees Shelter
2540 Lexington Avenue N ✦ Roseville, MN 55113



Check-in: 10:00 a.m. Walk Start: 11:00 a.m. Lunch: 12:15 p.m.



Scan the QR Code
or visit our website at

WWW.HFMD.ORG



to register, donate, volunteer, or form a team.

Prizes Awarded to the Top 3 Fundraising Teams!



**BALLOON TWISTING, FACE PAINTER, MASCOTS,
SUB-WICHES, REFRESHMENTS, AND MORE!**



HFMD IS ACCEPTING NOMINATION APPLICATIONS FOR THE



The CSL Behring program, **Getting' in the Gamesm Junior National Championship** was the first national sporting competition designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to compete in baseball, basketball, golf or swimming and provides education and information-sharing opportunities for participants and their parents/caregivers.

Who is eligible: Children between 7–18 years of age with a bleeding disorder (*nominees must be accompanied by a caregiver 25 years of age or older at the event. Due to state and federal laws, CSL is unable to permit healthcare professionals to attend.*) Special consideration will be given to first time attendees, but all children who have attended in the past are welcome to apply again!

Cost: Free! CSL Behring will sponsor two chapter nominees and one accompanying caregiver for each nominee to participate in the program. This sponsorship will include the coordination and cost of airfare, ground transportation in Henderson, Nevada, and hotel arrangements (*attendees will be responsible for transportation to/from their hometown airport*).

**This event is limited to the nominee and one caregiver only. CSL is unable to accommodate additional family members at any JNC related events.*

During the program nominees will have the opportunity to:

- ◆ Take part in baseball, basketball, golf, or swimming activities to learn the fundamentals and enhance their skills in that sport.
- ◆ Learn about the importance of physical fitness and managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form.
- ◆ Show off their ability in the national competition with fellow nominees from around the country.
- ◆ Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.

Click [HERE](#) for the nomination application form or go to HFMD.org/events/

Return completed application form to: tammyw@hfmd.org

For more information about the JNC, visit www.csljnc.com

Pre-Camp Family Lunch!

July 14, 2024, 11:00 a.m.

Many campers have a long drive to Camp Not-A-Clot, so why not come and enjoy a free lunch before Camp registration starts. Get to know other campers and their families in a smaller setting.

There will also be a short education program:

Celebrating Connection in the Hemophilia & Bleeding Disorders Community!

This event is for all BDAND and HFMD Camper families.

Warren's Restaurant

115 Railway St W, | Loretto, MN 55357



BDAND
Bleeding Disorders Alliance of North Dakota



**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

PRE-CAMP FAMILY LUNCH

Meet other campers and their families!

Free lunch!

Short education program

Sponsored by Sanofi

JULY 14TH
11 AM - 1PM

WARREN'S
LORETTO, MN



RSVP:

< --Scan the QR code
or visit:
hfmd.org
bdand.org

Have questions or need help registering?
Email, call, or text Emily:
director@bdand.org | 701-381-0670





HFMD IMPORTANT ANNOUNCEMENT

As you may have seen in an announcement sent out to the HFMD Community on May 17th, 2024, long-time Executive Director, James Paist has left the Foundation to move on to new endeavors.

We wish to express our deepest appreciation for Jim's nearly 20 years of service to HFMD and our bleeding disorders community.

The office remains open. Tammy Ward is available to handle HFMD business.

Tammy can be reached by any of the following:

Email: tammyw@hfmd.org

Office: 651-406-8655

Cell: 612-242-9664

The Board of Directors will keep you updated on our transition plans. If you would like to contact the Board President, Kris Rauenhorst, please email:

BoardPresident@hfmd.org

2024-2025 SCHOLARSHIP WINNERS ANNOUNCED

Mendota Heights, Minnesota, July 3, 2024 - The Hemophilia Foundation of Minnesota/Dakotas is excited to announce the scholarship recipients for the 2023-2024 academic school year. Congratulations to the HFMD 2023-2024 scholarship winners, each who exemplify a strong commitment to their education and communities. We are proud to provide scholarships to students from our hemophilia community each year, to support their education journey, gain independence and help them establish strong and secure financial futures.



Congratulations & Good Luck!

TO THE FOLLOWING SCHOLARSHIP AWARD RECIPIENTS:



Lindsay Daschner

University of Sioux Falls

Nicholas Hanson

Minnesota State Colleges, Winona

Carson Klersy

North Dakota State University

Alyssa Persell

Century College, White Bear Lake

The HFMD commends these students for their academic accomplishments, and wish them the best of luck in attaining their educational goals. The HFMD scholarship application for the 2025-2026 academic school year can be found on the Hemophilia Foundation of Minnesota/Dakotas website at www.hfmd.org.

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Annual Meeting, April 19-20, 2024

On Friday, April 19th, our group settled in for a fun and casual evening of dinner music and mingling to start off the 2024 Annual Meeting, held once again at the Mermaid Entertainment Center in Mounds View, MN. We saw new and familiar faces in attendance and had a warm welcome for all.

The buffet dinner was opened at 5:30 and while meals were enjoyed, we entertained by one of our very own community members, the lovely and talented Annelise Carlson.

Annelise drew curiosity, awe, and wonder with her musical talent. When I asked for background on her musical journey, mom, Lydia shared: *“She plays an instrument called the guzheng, or Chinese Zither. The instrument is a Chinese traditional instrument several thousand years old (she plays a modern one, but the instrument has been around that long). The instrument has a very traditional sound, and its pentatonic scale is especially soothing, so she has enjoyed sharing her talents with patients at the Mayo Clinic, Camp Not a Clot, and of course, the Annual Meeting. Annelise has studied the instrument for 6 years with a teacher here in Minnesota and another teacher in Arizona. She has competed in a number of international competitions and has won top prizes including one on Chinese TV, another in Shenzhen, China, and one in Hong Kong.”*

We hope Annelise will be back to perform for us again in the near future!

After dinner the HFMD group hit the bowling lanes. We reserved 6 lanes from 6:30-8:30. We broke this into two 1-hour bowling sessions. When Members check in at the registration table, they sign up for the preferred bowling session.

Once bowling got underway, we observed a lot of laughter, joking, light hearted teasing, with high-fives and fist bumps from our group. Bowling wrapped up at 8:30 and all adjourned for the evening.



SATURDAY, APRIL 20th:

Bright and early Saturday morning, as 19 exhibitors lined the perimeter of the Atlantis Ballroom, breakfast was served to our hungry bunch. HFMD Board Vice President, Jean O’Connell opened with a Group Action project. Teens were encouraged to stay for this part of the session, as it is important that they learn to advocate for themselves, as well as others. Members looked up the number to their

local state representative, calls were made and messages left asking the representatives to support these three bills:

- ◆ Full Funding for Rare Disease Advisory Council – HF 3841
- ◆ Medical Bill Debt Relief – HF 4100
- ◆ Prior Authorization Reform Bill – HF 3578.



(Continued on next page)

After this important opening Group Action, Amy Wilson, MSW, LICSW, ACM, from M Health Fairview presented on Mental Health and Wellness. There interactive stations that provided helpful suggestions on what one can do to help with their own mental health and wellness. These stations were a big hit and they included affirmation cards, aromatherapy, journaling, acupressure and more.



After the health and wellness presentation our group had a break to spend time with exhibitors and check out of their hotel rooms.

The day proceeded with Miranda Solem from BDSUMHAC (*Bleeding Disorder Substance Use and Mental Health Access Coalition*) speaking on

the issues that affect and surround access to substance abuse and mental health programs for those who have a bleeding disorder and the policy intervention areas when there is a treatment facility denial.

After the break for lunch, the afternoon started with Jeff Amond, from Hemophilia Alliance giving us helpful information on Navigating Health Insurance. Jeff spoke on how to navigate the common problems that arise with health insurance companies while trying to treat your bleeding disorder.



For the adults, the event wrapped up with a fun and exciting game of Hemophilia Jeopardy. Melinda Otto and Dawn Rusk from Mayo Clinic in Rochester hosted this competitive and fun game of bleeding disorder information based game. Prizes were given to members at the winning table.

While the adults were playing Hemophilia Jeopardy, the teens (*including all the children in the children's program*) went to the arcade to enjoy an hour of unlimited games. This event concluded the Annual Meeting, goodbyes were said and the group adjourned.



The HFMD would like to thank our Annual Meeting Sponsors!



Just for Fun!

WORD SEARCH

Disney Animated Movies

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N	C	D	O	I	O	U	I	R	L	B	C	E	D
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D	N	I	E	O	H	T	M	T	C	N	C	P	R
E	I	N	L	S	E	A	A	S	R	H	F	A	E
L	P	T	G	A	R	R	B	N	E	O	O	N	L
G	M	L	N	U	B	Z	I	O	H	O	A	E	L
N	O	O	U	R	E	A	T	M	E	D	A	S	A
A	A	B	J	U	A	N	O	B	M	U	D	M	A
T	A	D	C	L	R	A	I	S	A	T	N	A	F
L	U	B	T	S	W	A	L	L	E	R	B	L	E

WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com



EDUCATION DINNER AT THE TAP HOUSE

On June 13th, HFMD along with Sanofi, hosted our first education dinner program in Rochester in years. Folks met at The Tap House for a discussion on Big Goals, Small Steps (and tons of fried pickles!).



Participants were guided through identifying their top goals, breaking them down into steps, and identifying actions they can take right away.

Regardless of age/life stage, participants were so encouraging to each other! A great reminder of why getting the community together is so important. HFMD looks forward to offering more outreach programs like this in the future!

~by Jess Hutchison



Mom's Group is Back!

On Thursday, May 16th the M-Powered Mom's Group was reintroduced to the HFMD Community with an Education Dinner at Axel's Restaurant in Roseville. Jennifer Laughlin with Soleo Health presented a Bayer sponsored M-Powered Inspiration Exchange program where hemophilia Mom's get together to share experiences and strengths while achieving balance and empowerment while sharing gratitude and staying connected. We hope to add another Mom's Group event to our calendar soon!





2024 REMAINING CALENDAR OF EVENTS

July 14, 2024: Pre-Camp Family Education Lunch. Warren's Restaurant, Loretto, MN **REGISTER NOW!**

July 14-19, 2024: Summer Camp Not-A-Clot. **REGISTRATION CLOSED.**

July 27, 2024: South Dakota Family Education Day. Thunder Road Family Fun Park. **REGISTER NOW!**

August 10, 2024: Step Out for Bleeding Disorders Walk Fundraiser, Central Park Roseville. **REGISTER NOW!**

September 20-22: Getting' in the Gamesm Junior National Championship.

NOW Accepting JNC Nomination Applications! Deadline is July 10th!

October 26, 2024: Women and Teen Girls Event. **SAVE THE DATE!**

November 23, 2024: HFMD Industry Symposium. **SAVE THE DATE!**



To register for an event, for more information, or to see what's new, visit the [HFMD Events Calendar](#).

The HFMD needs your help in spreading the news!

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 is especially important that everyone has an 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 for your support of the HFMD!



The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1 - June 30, 2024.

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IT'S ABOUT
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