

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



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HFMD



HEMOPHILIA  
FOUNDATION  
OF MINNESOTA/DAKOTAS

# Veinline

**WINTER**

**2024**

## THE HFMD'S 24<sup>TH</sup> ANNUAL HEARTS OF HOPE GALA

*Please join us for an evening of fine dining, a cocktail hour, a silent auction  
and dancing to benefit the*

**Hemophilia Foundation of Minnesota/Dakotas**



HEMOPHILIA  
FOUNDATION  
OF MINNESOTA/DAKOTAS

**Saturday, February 10, 2024**

6:00 pm - 11:00 pm

***Metropolitan Ballroom & Clubroom***

5418 Wayzata Boulevard, Golden Valley, MN 55416

To register, visit our website at: [www.hfmd.org](http://www.hfmd.org)



HEMOPHILIA  
FOUNDATION  
OF MINNESOTA/DAKOTAS

## HFMD Symposium 2023

**W**e held our 5<sup>th</sup> annual Symposium back at the lovely community center of Eagan Minnesota. Registration opened with coffee, lemonade, muffins, and time to visit our exhibitors. Children were checked into HFMD Child-Life Programming with Vicki Neis and her wonderful Team where kids get to have a blast while learning about bleeding disorders.

Executive Director, Jim Paist shared an HFMD presentation looking back on 2023 highlighting our programs and services in action. Board Vice President Jean O'Connell

shared some motivating information and words of wisdom

in becoming an Advocate and in being an Advocate. Jean spoke to the importance of access to health care our community needs.



The Price Is Right theme song was a bold tell for a gift-card drawing before each company presentation (*must be present to win*). Each company exhibiting was given 10 minutes or less to share their presentation. An old-fashioned timer was in play to keep us on schedule for the day.

Tammy Ward of HFMD handled all of the slides and A/V for each presentation.

HFMD announced it will be changing its name, so we asked members in attendance to share new organization name suggestions in the "New Name" box. Members came up with some intriguing ideas. Stay tuned as HFMD is planning a rebranding campaign in 2024.

After some good sandwiches and fruit, it was time for a favorite part of this event for many; the Roundtable Member Discussions. We pushed tables together to make two big group discussion tables. The topic on Table #1 was "what is the most common challenge with your bleeding disorder, and how to you resolve it?" Table #2 was "what should HFMD's legislative priorities be for 2024.

To see our members engage each other in depth on some important topics is gratifying and beneficial for all involved. Overall the event was packed with information, good discussions, and fun for all. Thank you to our event exhibitors!

~ By Jim Paist

### Thank You!



#### Symposium Presenters/Exhibitors



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## HFMD Group Fitness Program Rolls Along

As bowling is a fun family fitness activity, we held an event at Pinstripes in Edina on December 9<sup>th</sup>.



Our group met in a nice meeting space at 11:00 a.m. with time to visit before some interesting presentations on gene therapy with bowling to follow.

While we enjoyed a nice lunch, some thoughtful questions were asked by our members during the presentations.

Then it was time to hit the lanes. While we have some skilled bowlers in our group, everyone had fun and got in some good exercise. The HFMD would like to thank the program sponsors of this event.

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Biotherapies for Life™

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## NAME CHANGE SUGGESTIONS

The HFMD will be changing our name to be more inclusive of bleeding disorders beyond hemophilia.

We ask for YOUR suggestions.

Email your ideas to [info@hfmd.org](mailto:info@hfmd.org)

# **SAVE THE DATE!**

## **HFMD/RARE DISEASE COALITION STATE ADVOCACY DAY**

### **March 5<sup>th</sup>, 2024**

### **STATE OFFICE BUILDING**

**100 REV. DR. MARTIN LUTHER KING JR. BOULEVARD  
SAINT PAUL, MN 55155**



## HFMD Education Dinner at the LEXINGTON

On Wednesday October 4<sup>th</sup>, a group of bleeding disorders community members joined the HFMD and our dinner sponsor, Lisa Cardarelli, from Takeda for a HELLO Talk titled “My Factor, My Body”. Lisa provided valuable information with comprehensive images and diagrams that helped us to understand the science behind bleeding disorders, as well as practical advice and helpful tips to help overcome the challenges bleeding disorder patients may face.

A big thank you to Lisa and Takeda for sponsoring this education dinner!



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## Women and Teen Girls Event

### Jonathan Padelford Riverboat Cruise

Saturday, Sept 30<sup>th</sup>, 2024

The weather was perfect for the group on this CSL Behring sponsored Women and Teen Girls Event aboard the Jonathan Padelford Riverboat Cruise on September 30<sup>th</sup>.

The event started with "Get to Know You Bingo" Icebreaker. The bingo cards had different "get to know you" items in each box and participants had to go around to the group and have them sign the box that corresponded with something about themselves. It was an interactive and fun activity.

After the icebreaker, while lunch was being set up, the group had a few minutes to head to the upper level of the Jonathan Padelford and enjoy the sunshine and scenic view.

After a light lunch of sandwiches and salad, Julia Colling, PA-C, from M Health Fairview gave a very informative presentation titled "All About Iron". She spoke of where iron is found in the body, symptoms of iron deficiency and how to treat it.

Julia also discussed the typical causes of iron deficiency and how to prevent it, as well as the best ways to increase your iron intake along with other strategies to do so, such as a lucky iron fish or leaf, which is used in cooking.

Next up to the microphone was CSL Behring advocate speaker, Kim Walsh, from Pittsburg, PA. Kim shared a compelling story of her own experiences growing up with heavy menstrual cycles for long periods of time, and being told it was normal. It wasn't until the age of 35



with the first three of her 5 children, that she finally learned she had a bleeding disorder. She spoke about being a mom, wife, friend, nurse and being more than her bleeding disorder". Kim's made an excellent point that a bleeding disorder is not what you are, it's something that you have.

A big thank you to Julia Colling and Kim Walsh for speaking to this great group of women and teen girls.



This event is sponsored by:

**CSL Behring**  
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# A BIG THANK YOU! TO ALL OF OUR 2023 SPONSORS







## 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](https://bleedingdisorders.com)**





# CHRISTMAS Word Search

S	O	G	I	N	G	E	R	B	R	E	A	D	A	T
N	H	C	V	X	M	A	S	T	R	E	E	L	M	T
O	U	D	L	K	P	R	E	S	E	N	T	S	S	U
W	N	M	I	E	L	F	Y	S	A	N	T	A	M	S
F	R	O	S	T	Y	H	T	O	B	L	Y	C	T	S
O	E	H	R	D	W	R	E	A	T	H	S	O	S	O
W	I	C	W	R	N	U	T	C	R	A	C	K	E	R
S	N	E	H	R	W	R	T	W	G	K	R	S	E	N
A	D	L	I	R	A	N	T	T	I	I	E	K	A	A
L	E	L	L	J	I	O	C	N	A	E	A	S	D	M
I	E	U	E	U	S	S	G	D	T	E	A	L	J	E
G	R	E	E	N	T	S	T	N	E	T	S	L	I	N
H	O	L	L	Y	E	D	C	M	N	D	Y	E	Q	T
T	P	N	C	A	N	D	Y	C	A	N	E	B	E	S
S	A	L	K	R	E	O	L	L	J	S	H	E	O	X



CHRISTMAS  
STOCKINGS  
BELLS  
CANDY CANE  
SNOW

WREATHS  
NUTCRACKER  
FROSTY  
GINGERBREAD  
HOLLY

PRESENTS  
SANTA  
REINDEER  
TREE  
ORNAMENTS



## Group Fitness Event in Rochester

We had a full house on October 14<sup>th</sup> at the HFMD hosted group fitness event at the Bowlocity Entertainment Center in Rochester. This event had limited spots and filled quickly.

After checking in at the registration table, this group of mostly Mayo Clinic patients and families, spent time chatting and getting to know one another.

**Dr. Rajiv Pruthi, MBBS**, Medical Director of Mayo Clinic Comprehensive Hemophilia Treatment Center in Rochester, MN, shared a few words with the group before lunch. Also attending from Mayo HTC staff were Anja Arend, Amy Eckerman and Melinda Otto.

There was no educational component to this fitness event. We wanted everyone to unwind, socialize and get to know other families in the bleeding disorder communities.



After a pizza lunch buffet, the group settled into the private eight-lane suite area for bowling fun.

For many of the participants, this group fitness event was their very first HFMD event. We welcome and encourage all new bleeding disorder families to join the HFMD community, where there is understanding and support for those just learning to navigate a bleeding disorder.

The HFMD would like to thank the Mayo Clinic and HTC staff for supporting and participating in this event!



## HEMOPHILIA FOUNDATION OF MINNESOTA/DAKOTAS

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# CAMP UPDATES

Please mark your calendars for these Camp Events.

## ANNUAL WINTER TEEN RETREAT

**WHEN:** MARCH 9-10, 2024

**WHERE:** YMCA Camp Ihduhapi, Loretto, MN

FOR TEENS, AGES 13-17, WITH A BLEEDING DISORDER

*Connect with other teens while enjoying fun indoor and outdoor winter activities while gaining independence!*

**Registration Now Open!**



## SUMMER CAMP NOT A CLOT

**WHEN:** JULY 14-19, 2024 *(to be officially confirmed soon)*

**WHERE:** YMCA Camp Ihduhapi, Loretto, MN

FOR CHILDREN AND TEENS AGES 8-17 WITH A BLEEDING DISORDER



The Hemophilia Foundation of Minnesota/Dakotas is once again collaborating with YMCA Camp Ihduhapi to host a 6 day traditional summer camp experience for campers with chronic bleeding disorders. The mission of camp is to foster community among patients with bleeding disorders and promote transition to independence. Campers enjoy all the fun of summer camp, with the support of a specialized healthcare team. The cost of camp is covered by HFMD. Registration for Camp Not a Clot will be open soon!



## HFMD 2024 UPCOMING CALENDAR OF EVENTS

January 27, 2024: Teen Event at ProKart Indoor Racing, Burnsville, **Registration Now Open!**

February 10, 2024: 24<sup>th</sup> Annual Hearts of Hope Gala Fundraiser at the Metropolitan Ballroom. **Registration Now Open!**

March 5, 2024: HFMD/Rare Disease Advocacy Day, State Capitol, St. Paul, MN. **SAVE THE DATE!**

March 6-7, 2024: Washington Days, National Bleeding Disorders Foundation, Washington DC. **SEE NBDF WEBSITE**

March 9-10, 2024: Teen Winter Retreat at Camp Ihduhapi, Loretto, MN. **Registration Now Open!**

April 19-20, 2024: Annual Members' Meeting at Mermaid Entertainment Center. **Registration Now Open!**

June 13, 2024: Education Dinner at the Tap House West End in Rochester, MN. **SAVE THE DATE!**

July 14-19, 2024: Summer Camp Not-A-Clot. **YMCA Registration Opening Soon!**

July 27, 2024: South Dakota Family Education Day. **SAVE THE DATE!**

August 10, 2024: Step Out for Bleeding Disorders Walk Fundraiser, Central Park Roseville. **SAVE THE DATE**

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

Check the [HFMD Events Calendar](#) for more information or to register for the events listed above.

### 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 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](mailto: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 - December 31, 2023.**

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**Contributors:**

**\$45,000 and Up**

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Mayo Foundation for Medical  
Education & Research  
M Health Fairview

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