

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
DAKOTAS



HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

Veinline

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

Fall

2024

IMPORTANT NOTICE!

The HFMD website is temporarily down while we are making long overdue updates. Please contact the HFMD office at 651-406-8655 or info@hfmd.org with any needs.

A MESSAGE FROM THE HFMD BOARD PRESIDENT



HFMD is a registered non-profit corporation under the laws of the State of Minnesota and is a qualified charitable non-profit organization under Section 501 (c) (3) of the Internal Revenue Service. (Tax ID# 41-6032276)

Hello HFMD Community:

On behalf of the HFMD Board of Directors, I want to Thank You for your continued support of the HFMD and for your participation at recent events.

We are very excited for the **1st Annual Dinner Party on Saturday, February 15th, 2025**. This event will have a Vegas Night theme and be in Bloomington, MN at the Minnesota Masonic Heritage Center in the Dan Patch Hall.

Also scheduled is the **Annual Members' Meeting on May 2nd - 3rd, 2025**, again being held at the Mermaid Event and Entertainment Center in Mounds View, MN.

There will be more information forthcoming, but mark your calendars for these fun, educational and exciting events!

Significant progress has been made to place a new Executive Director, the Board has made great strides in narrowing the search for this position.

While we are striving to find the best candidate for the Executive Director, the Board has made the difficult decision to cancel the Symposium during this time of transition.

Please contact me with any questions.

Kris Rauenhorst
Board President
BoardPresident@hfmd.org
612-245-1828



CSL Behring

Biotherapies for Life™



THERE IS STILL TIME TO REGISTER FOR THE

Women and Teen Girls Event

Saturday, October 26th, 2024 from 11:30 a.m. - 5:00 p.m.

Woodlake Nature Center - Fireplace Room

6710 Lake Shore Drive S., Richfield, MN

A haven for migrating birds and waterfowl, this 150-acre cattail marsh, woodland and restored prairie has three miles of wheelchair accessible trails. This education event is for females age 13 and up with a bleeding disorder & one guest. Guest speakers include Dr. Jacob Cogan, and CSL Behring speaker Roberta Smith with *Telling the Patient's Story Through the Arts*. Check-in starts at 11:30 a.m.

RSVP to tammyw@hfmd.org or call: 612-242-9664. Please provide full name as well as your guest's full name.



Please Spread the Word!

Being the only resource of its kind in Minnesota & South Dakota, it is very important for the Veinline 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 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!



COME DRESSED IN YOUR VEGAS BEST
TO

Raise Awareness
FOR BLEEDING DISORDERS

Saturday, February 15th, 2025
5:00 p.m. - 10:00 p.m.

Dan Patch Hall
Minnesota Masonic Heritage Center
11411 Masonic Home Drive
Bloomington, MN 55437

DINNER ~ DRINKS ~ FOOD ~ GAMES
SILENT AUCTION ~ GIFT CARD WALL



FAMILY FUN!

At the 14th Annual HFMD Step Out for Bleeding Disorders Walk Fundraiser!



On Saturday, August 10th, 2024, the weather was perfect, and there was excitement in the air as HFMD staff, volunteers, board members and even exhibitors, all lending a helping hand to set up for the HFMD Annual Walk!



This year the HFMD found a great venue for the event. The Jaycee's Shelter at Roseville Central Park overlooks Lake Bennett, and is ideally located near trails and playgrounds. This was the perfect spot for our community to come together to socialize and have fun while raising awareness and support for the HFMD core programs.

Thus far in 2024, the HFMD Emergency Assistance Program been able to help 64 families with a financial hardship. Our free Medical ID Program has provided over 200 free medical ID's, and we helped to send 85 children to Camp Not-A-Clot at no cost to the families.

The event started at 10:00 a.m. and the St. Paul Saints mascot Mudonna was there entertaining our group along with the MN Gophers mascot, Goldie Gopher. The balloon artist, Mr. Twisty, returned this year and was kept busy making creative balloon animals, swords and hats, while his cohort, the Face Painter, created various designs of facial decorations on kids and adults, alike. This was a big hit with the kids!



Team Carson provided the carnival style popcorn machine and we were all able to enjoy delicious, buttered popcorn and other snacks throughout the day.

At 11:00, our group gathered at the starting line and the count-down began and the Step Out for Bleeding Disorders Walk got underway. While participants walked around Lake Bennett, the Team of M Health Fairview kitchen volunteers prepared for distributing Subway sandwiches to our hungry walkers.

A few announcements were made and then it was time to declare the top three fundraising teams and award prizes to the Captains of these amazing teams. 1st Place, for a \$300 gift card, was Charlie's Gardians. Winning 2nd Place and a \$200 gift card was Team Carson, and 3rd Place was Emmett's Clot Crushers, winning a \$100 gift card. We thank you for all your hard work and efforts!

We big thank you to our exhibitors and to everyone who participated and donated to our 14th Annual Walk fundraiser. The collective efforts of this community coming together, raised nearly \$38,000 in donations to help keep the HFMD going strong!



~ by Tammy Ward



HFMD

Step Out

for Bleeding Disorders
WALK FUNDRAISER



THANK YOU TO OUR WALK SPONSORS AND EXHIBITORS!

LONG STRIDES



FIRST STEPS



The Kid Experts™



EXHIBITORS



ADVATE
[Antihemophilic Factor
(Recombinant)]

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

YOUR LIFE IS YOUR CANVAS

Whether it's **ADVATE** or **ADYNOVATE**, look to the **TAKEDA** family to be there with you wherever life takes you.

Keep Painting Your Story



Patient Portrayal



Get access to
Takeda Patient Support





CAMP NOT-A-CLOT 2024 RECAP

By Becca Shaheen, Children's MN Program Coordinator



Another spectacular year of Camp Not-a-Clot has been completed! 2024 was our third year holding the HFMD Bleeding Disorder Camp at YMCA Camp Ihduhapi in Loretto, MN. Within year three, we are truly seeing an amazing synthesis of Camp Ihduhapi and Camp Not-a-Clot traditions. 2024 was our biggest year yet, with 83 campers from Children's Minnesota, Mayo Clinic, Sanford South Dakota, and Sanford North Dakota.



Some of the broad goals of camp include building community, gaining self-confidence, learning more about bleeding disorders, and working towards developing independence in managing one's bleeding disorder. This all occurs while enjoying summer camp games and activities and experiencing nature.

This is what Not-a-Clot 2024 looked like:

In true summer camp fashion, the week started out HOT and sunny (nothing that a dip in Lake Independence couldn't fix) and then settled into absolutely gorgeous summer weather the rest of the week.

After getting all settled in and oriented on Sunday, we started out Monday full speed ahead with a number of campers enjoying morning run club and waking up with a polar plunge. Monday marks the start of camp "achievements" or the rotation of 4 activities that campers select. This year's achievements included swimming, boating, archery, arts and crafts, sports, nature club, and more.



Monday also marked the beginning of our weeklong Olympics theme.

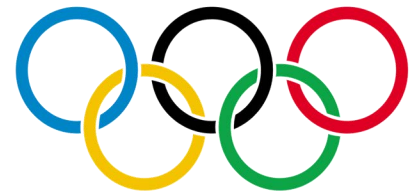
HTC staff ran the all camp game in which cabins received a big score sheet with a list of stations and challenges to complete for points. Stations included games like "discus," "shotput", and "volley ball," and fun educational stations like a physical therapy equipment safety relay race, a station to choose the best course of action for an injured Olympic athlete, and a station to learn about medication half-life.



Tuesday evening tradition at camp Ihduhapi includes cabins hiking out to different camp sites to cook over a fire, bond as a cabin, and enjoy Ihduhapi's beautiful acreage. This year, the two oldest cabins canoed out to the island within Lake Independence for their cookouts! These cabins had surprise guests from the nationally renowned "Gut Monkey" facilitation and programming group. The Gut Monkeys led the older teens in great conversation and activities related to transitioning to independence while out on the island.

Wednesday was a busy day! We hosted a number of special healthcare guests including RN's, Genetic Counselors, Hematologists, and an Adolescent Gynecologist, to run our annual girl's group and period program. This is a great way for girls of all ages to learn what to expect when it comes to menstruation, and an opportunity to ask the experts questions, and even learn from one another.

Wednesday tradition at camp is Theme Day, and Ihduhapi had additional Olympic games programming and contests. Wednesday afternoon a group of campers went to the horse barn, and group of campers completed the incredible high ropes course, and other groups of campers





played in special sports tournaments. We ended the day with the campers' all-time favorite game Capture the Flag! There is BIG energy during this game and campers look forward to it all week long.

Thursday after achievements, it's already time for closing campfire! Closing campfire is always fun and emotional. After a torch-led procession through the woods, each camper adds a stick to the fire and shares with the group kind words, shout outs, and good memories from the week.

The Health Center:

The health center at camp is a busy place full of lots of learning opportunities. Campers can work with their team to learn the steps of self-infusion (and can be celebrated on "The Big Stick" if they poke themselves for the first time) and self-injection. Campers are hugely encouraging and supportive of one another while learning these skills.

Campers continue to earn bracelets (bronze, silver, and gold this year!) for completing bleeding disorder questionnaires with health center staff. 2024 was our second year of "The Big Branch" challenge which is earned for showing significant independence in understanding and managing one's own bleeding disorder. It is a huge feat!

It is so great to see a clinical space transform into a vibrant place to learn and develop, and we are so proud of what campers learn each year!



Camp Not-a-Clot is an incredible special place for children and teens with bleeding disorders to relate to one another, learn from another, and grow together. This year, many moments of camp were well documented by an amazing videographer (more information to come soon!!) and we are so excited to share some more of the magic of camp with you later this year.

Thank you HTC staff, volunteers, HFMD Staff, Ilduhapi staff, families, community members, and campers who make this week possible!



It's Your Move

Making Health Insurance Work For You

SANOFI HEM STREAM

It's Your Move: Making Health Insurance Work For You

When it comes to health insurance, it's all about knowing how to play your cards right to get the most out of your plan.

In this live webinar, participants will explore different types of health insurance plans, learn how to determine coverage for bleeding disorder care and treatments, and get tips and strategies on how to make their insurance plans work harder for them.

Everyone will leave with game-changing insurance knowledge and the confidence to successfully navigate their plans.

Webinar in English: Saturday, November 23rd 12:30 PM EST

Webinar in Spanish: Saturday, November 23rd 3:30 PM EST

Register at:

<https://www.rareblooddisorders.com/patient/events/>



Join us.

Reach out to your CoRe or visit
RedefiningHemophilia.com.

sanofi

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MAT-US-2409948v1.0-10/2024



BDAND and HFMD collaborated on two education events this year and we to continue this partnership moving forward.

GUT MONKEY **BDAND**
Bleeding Disorders Alliance of North Dakota

PATHFINDERS

The great outdoors is for everyone in this with this accessible invitation to a local nature spot. For individuals, friends, and families, Pathfinders events are specially crafted to bring together folks affected by all bleeding disorders.

We invite families and folks from all walks of life to discover the beauty of the outdoors while forging lasting connections with others who understand the journey.

Saturday, September 21

Itasca State Park, MN

Register: BDAND.ORG/EVENTS

Questions? Contact Emily
director@bdand.org | 701-381-0670



CAMP NOT-A-CLOT
OLYMPIC GAMES 2024

BDAND **HEMOPHILIA FOUNDATION**
Bleeding Disorders Alliance of North Dakota 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

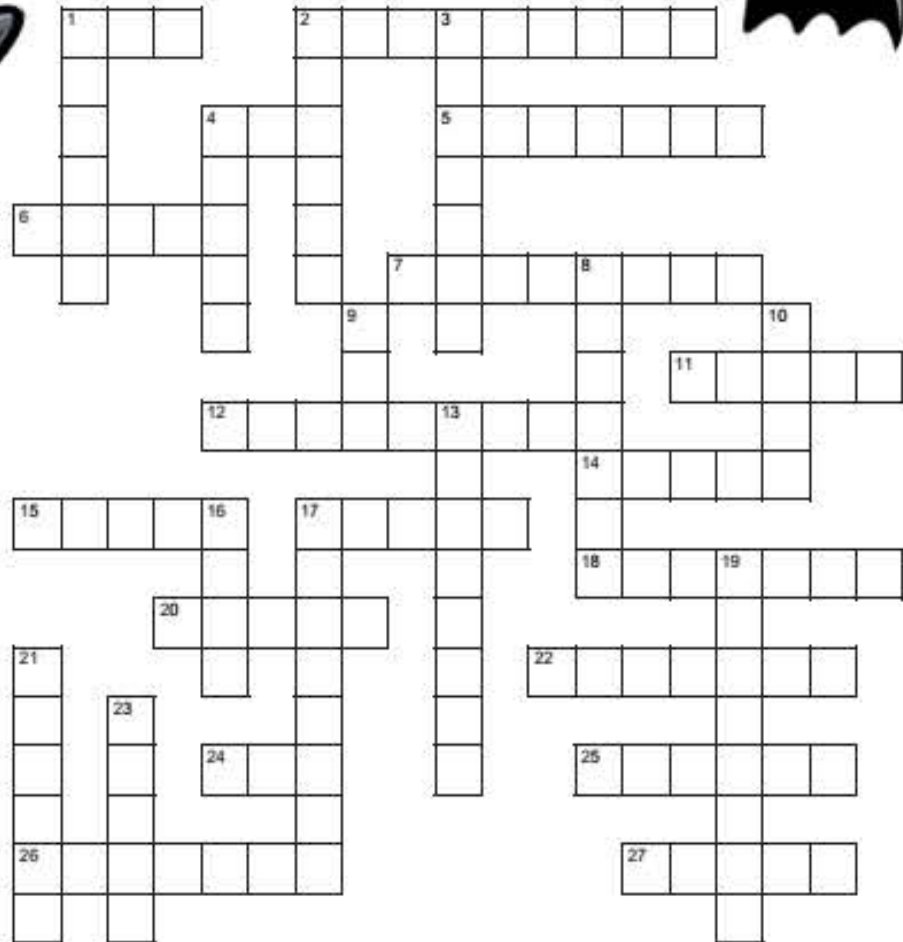
Have questions or need help registering?
Email, call, or text Emily:
director@bdand.org | 701-381-0670

Just for Fun!



WORD SEARCH

Halloween



Across

- 1. He swallowed the canary.
- 2. Playground for ghosts.
- 4. What a spider spins.
- 5. Frankenstein has one.
- 6. When ghosts come out to play.
- 7. Scare.
- 11. What the pot might call the kettle.
- 12. October 31st.
- 14. _____ or treat.
- 15. Witch transportation.
- 17. Frightening.
- 18. The Count.
- 20. A skeleton is just a bunch of these.
- 22. Disguise.
- 24. Lives in the belfry.
- 25. Incey wincey is one of these.
- 26. Main ingredient in a popular pie.
- 27. _____ stories.

Down

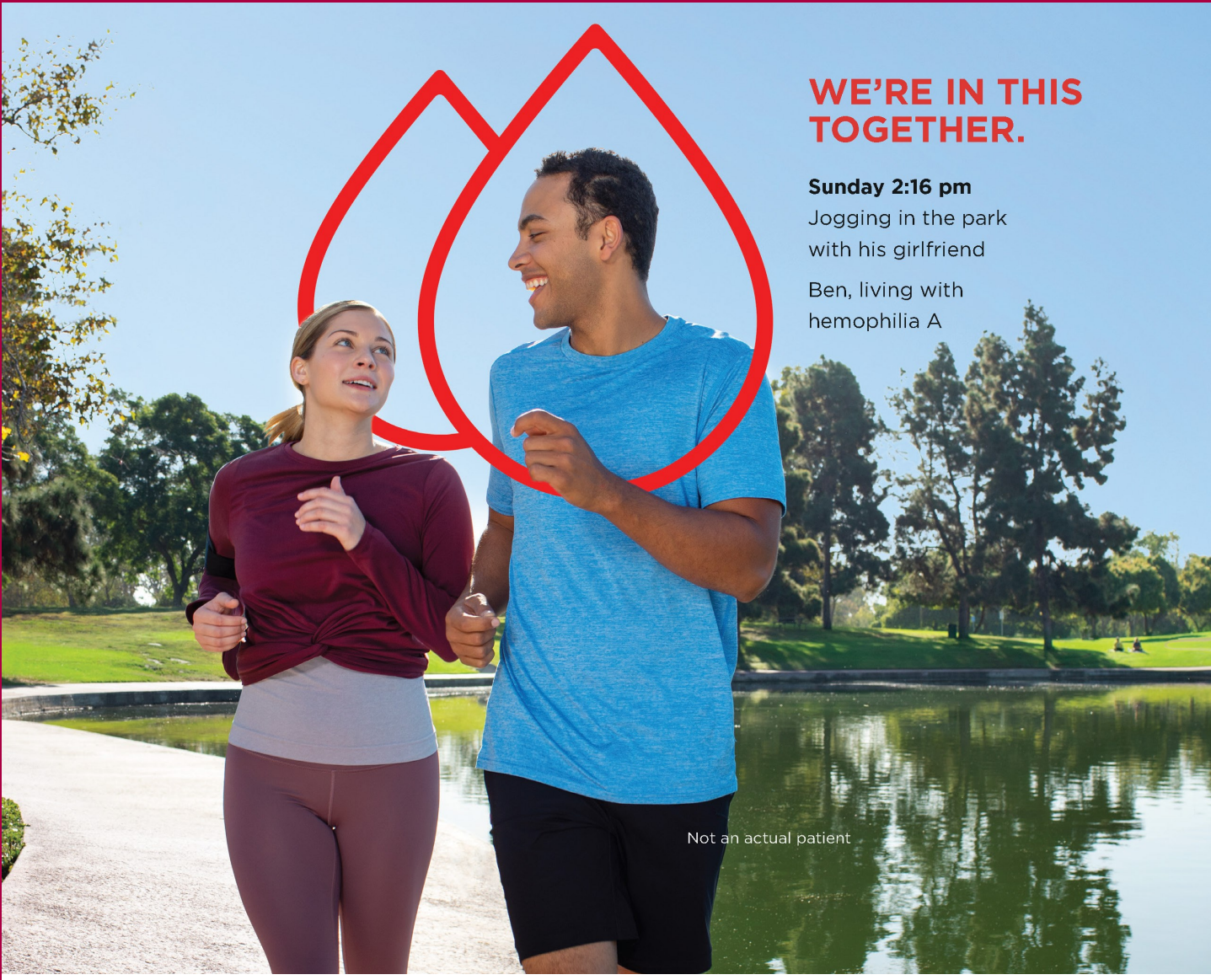
- 1. Where a vampire sleeps.
- 2. Evil or mischievous creature.
- 3. He hates garlic.
- 4. Samantha for example.
- 8. _____ house.

- 9. Who? Who?
- 10. Mr. O'Lantern.
- 13. Comes out on full moon nights.
- 16. Might be full, half, or new.
- 17. A boney sort of fellow.
- 19. Fire burn, and _____ bubble.
- 21. When something makes our skin crawl, it's this.
- 23. Found in Egypt.



Halloween Coloring





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



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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\$50,000+

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Mayo
M Health

\$10,000-\$20,000

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Children's Minnesota
CSL Behring
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MAKING A DONATION.
IT'S ABOUT
MAKING A DIFFERENCE.

Thank you

FOR MAKING A DIFFERENCE!

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Rochester, MN 55905
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