

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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OF MINNESOTA/DAKOTAS

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FALL

2023

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5th Annual

SYMPOSIUM

Saturday, November 18th, 2023

Eagan Community Center

1501 Central Pkwy, Eagan, MN 55121

10:00 am - 3:00 pm

Registration Opens at 9:30 am



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Camp Not-a-Clot 2023 was a week to remember! In our second year at YMCA Camp Ihduhapi in Loretto, MN, we got to see our partnership blossom. Ihduhapi staff recognize and get excited about Camp Not-A-Clot traditions, and it is great to be a part of Ihduhapi's many fun traditions as well.

The mission of the Camp Not-A-Clot is "to foster community among bleeding disorder patients and promote a transition to independence. Campers will enjoy all the fun of an outdoor summer camp in a medically safe environment." We try hard to hit each piece of our camp mission statement:



Community. It is so cool to see the connections that are made between campers (and staff!) from the 5 participating HTC's: Children's MN, Mayo Clinic, M Health Fairview, Sanford Health ND, and Sanford Health SD. We welcomed new campers of all ages this year and were amazed by the friendships and supportive communities that emerged by the end of the week. Ihduhapi has a community-building theme this summer and incorporated team-building programming throughout the week. Tuesday night was declared "Cabin Magic" night, and cabins got to decide on special activities to do together as just a

cabin. Many chose to include sunset swims and campfires with s'mores in their evening plans.

Our community of girls is strong and growing! We always look forward to our fun girl's educational session each camp, and had 21 girls in attendance this year! These campers built a welcoming community full of strong leaders, and we could not be prouder.



Independence. We promote independence at camp in many ways. For some, the first step to independence is staying at an overnight camp, a huge milestone! Independence also comes through learning and doing. It may be learning how to mix medication; self-infusing; or practicing one's bleeding disorder 'elevator speech'. We had a lot of campers demonstrate steps to independence by poking themselves for the first time, earning their well-deserved spot on The Big Stick!!





This year we introduced "The Big Branch." Campers who have continued branching out towards independence can work to achieve this award by demonstrating advanced bleeding disorder knowledge and skills. For example, roleplaying phone calls with a pharmacist, demonstrating how to self-advocate at school/work with a social worker, walking through their medication routine (or emergency bleed plans) with a nurse, and more. We were so proud to announce our 3 first ever Big Branch awardees during our final lunch.

Summer Camp Fun. Ihduhapi has a beautiful camp space and a lot to offer. As cabins, campers learned about nature

and outdoor skills; and then split off into different choice activities. Archery, sports, arts and crafts, rock climbing, and more. While we didn't have a record-breaking hot week like last year, Lake Independence remained a popular spot. Whether swimming, hanging out on the lily pad, paddling boarding, or canoeing- the waterfront was always active. Each day, cabins performed funny skits for the group,



campers had opportunities to showcase their talents, and everyone participated in all-camp activities. Capture the Flag remains the ruling all-camp game!

Camp is a great group effort between HFMD, the 5 HTC's, Camp Ihduhapi, and all of the campers and families who participate. It means the world to us staff to see skills built, knowledge gained, friendships made, and fun being had. Thanks to all who brought their great energy to camp this year. We hope to see you next summer!

~ By Becca Shaheen,
Children's MN
HTC Program Coordinator



What Females Need to Know About Bleeding Disorders

This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Please speak to your treatment team if you have any questions about your/your child's care.

This content is brought to you by Pfizer.



Women of all ages, but particularly teenagers, with bleeding disorders may not be receiving all the information and care they need.¹ Educational materials that were originally made for males may not be as relevant for females, especially around bleeding as it relates to menstruation. For this reason, women and girls, along with close family and caregivers, could find it important to learn how to advocate for themselves in order to get the correct diagnosis and treatment.

Recognizing Heavy Periods

Between 75% and 80% of adolescent girls who have an inherited bleeding disorder also have heavy or prolonged periods.² It's important to know that pain and heavy bleeding around menstruation isn't something that needs to be endured. There are treatments available that can help reduce symptoms and avoid problems like missing school and activities. A trained medical provider can describe all the treatment options and help find the one that will be most helpful.¹

Staying Ahead of the Possibilities

Girls and women who are symptomatic carriers or who are living with hemophilia may also experience other complications due to their bleeding disorder. It's important to know about these potential issues in order to watch for them and bring them to the attention of health care providers.

Some of the gynecological health issues girls and women might experience include³:

- **Corpus luteum cyst.** A cyst that forms after bleeding during ovulation. These cysts have a risk of causing abdominal pain or of rupturing.
- **Dysmenorrhea.** Moderate to severe pain, which could be associated with heavier blood flow.
- **Menorrhagia.** A menstrual period that includes heavy bleeding or bleeding that goes on for more than 7 days. This could lead to iron deficiency, anemia, and a decreased quality of life.

- **Metrorrhagia.** Abnormal or irregular vaginal bleeding that occurs between periods. Heavy bleeding could lead to bed rest or hospitalization.
- **Mittelschmerz.** Abdominal pain that occurs during ovulation (when an egg is released from an ovary into the fallopian tube), which may be a result of bleeding during ovulation.

Voicing Your Questions

Talking to doctors about topics that seem personal can be challenging and may seem embarrassing. It's important to know that doctors who work with patients with bleeding disorders are trained in addressing these issues. When something doesn't seem right, being honest and open about symptoms is key to getting treatment and feeling better. It might be helpful to try one or more of these options:

- Speaking to someone you trust about problems or symptoms prior to an appointment
- Bringing a friend or family member to appointments to offer emotional support, to listen, and to ask questions
- Discussing your questions or concerns about conception, child birth, and surgery with your care team
- Using a patient portal to send messages ahead of appointments

Looking to the Future

Growing up includes a series of changes, and knowing how they may be affected by a bleeding disorder is important. Girls and women who live with bleeding disorders can find that they need to raise their voices and tell their story to get what they need.

Learning how to better express feelings and concerns with family, especially parents, health care providers, and other caregivers will help in getting the right treatment at the right time. Living well with a bleeding disorder may mean owning the journey to advocate for your best quality of life.

References: 1. Khair K, Holland M, Pollard D. The experience of girls and young women with inherited bleeding disorders. *Haemophilia*. 2013;19(5):e276-281. doi:10.1111/hae.12155 2. Screening and management of bleeding disorders in adolescents with heavy menstrual bleeding: ACOG Committee Opinion, Number 785. *Obstet Gynecol*. 2019;134:e71-e83. doi:10.1097/AOG.0000000000003411 3. Winikoff R, Brownlow M, Stewart P. Symptomatic carriers of hemophilia. *All About Hemophilia: A Guide for Families*. Canadian Hemophilia Society; 2010:14-1-14-26. <https://www.hemophilia.ca/files/Chapter%2014.pdf>



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

Visit www.pfizerpal.com to connect with your Patient Affairs Liaison.

South Dakota Family Education Day

Hot dogs, peanuts, & cracker jack were on the table for a day at the Canaries ballpark known as the Birdcage in Sioux Falls, SD. The HFMD South Dakota area member/family group came together on Saturday, July 29th, to watch the home town minor league baseball team.

We were thrilled to have the dynamic trio of Short Notice return with their musical talent to entertain our group throughout the event. Thank you, Nate, Jodi, & Dave!



We had a group of well over 50 together to enjoy the presentation, great music from Short Notice, a Canaries baseball game, and lots of good ballpark food. Nine companies sponsored the event as exhibitors. After some good snacks and time to visit our exhibitors, RN Alyssa Johannsen RN, Sanford Health shared a presentation on a new app designed for their patients. Kris Rauenhorst shared some welcoming comments for the group, then Jim outlined our Patient Financial Assistance Program and how HFMD helps patient/families going through an unexpected financial crisis. We further added that our program will also cover American Medical ID bracelets or pendant for any of our members who need one. After the presentation, our group of 50+ was ready to watch the Canaries game in the charming Birdcage with a well-groomed playing field.

A special thanks to our exhibitors: ARJ Infusion, Bayer, BioMarin, CSL Behring, CVS, InfuCare Rx, Medexus, Novo Nordisk, Sanofi, & Takeda.



Shortly after the event, we received a number of Medical ID orders from SD patients, and two families were helped by HFMD to get through a serious personal financial crisis.

~ By Jim Paist

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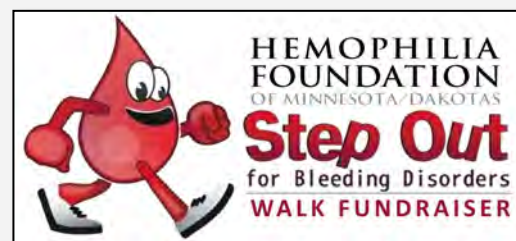
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Step Out for Bleeding Disorders 2023

The HFMD returned to Como Park in St. Paul for our 13th Annual Walk Fundraiser to “Step Out for Bleeding Disorders. After a few years at another location going back to scenic pavilion area walk path of Como was exciting.

This event begins and ends with HFMD Walk Teams. It is inspiring to see so many member/families banding together to reach out to raise donations for the HFMD to help support our core programs such as our summer camp and Emergency Assistance. Collectively HFMD Walk teams raised over \$11,000 in personal donations.



With a nimble group of dedicated volunteers in place, the event began at 3:00 p.m. with time for everyone to visit and mingle with each other and our sponsor exhibitors. After our group settled in, HFMD shared some announcements about the event, our cause, and the plan for the day. HFMD

Board Vice President, Jean O'Connell then shared some motivational comments about her personal history with HFMD and in how our members can truly make a difference by becoming advocates for the Bleeding Disorders community.

HFMD events like our Walk are not only informative and social, there's also much fun to be had. A special thanks to the St. Paul Saints baseball team and their charming mascot Mudonna for

entertaining our group. A new balloon artist, Mr. Twisty, lived up to his name making some creative balloon animals and helmets for all the kids. Team Carson brought a carnival style popcorn machine for all to enjoy delicious, buttered popcorn throughout the day.



Before the Walk began, a recent recipient of our Emergency Financial Assistance program shared their story in how they were facing a past due utility bill which included an immediate shut off notice if not paid by the next day. HFMD paid this hefty utility bill by phone to prevent a loss of electricity for this wonderful family who happened to be in an unexpected financial crisis. This program of ours is big reason why people donate to the HFMD.

Then it was time for everyone to gather together at the starting line with help from Mudonna. The count-down began and at 4:00 p.m. sharp our group began to Step Out for Bleeding Disorders on a 2.4 mile walk to and around the picturesque shores of Lake Como. A short burst of rain came down just as the Walk started. This did not deter our group.



This year instead of having Walk event T-shirts each walker received a colorful hand towel decorated with sponsor logos. As our group made their way back to the pavilion, the M Health

Continued on page 7

Walk Article Continued from page 6

Team of volunteers prepared the distribution of Subway sandwiches for all.



Next it was time to announce the top three fundraising teams and to award prizes to each of those amazing Team Captains. 3rd Place was Team Charlie's Guardians, 2nd Place was Team Taylor, and 1st Place was Team Carson, who not only received a \$300 gift certificate, but was also given a remarkable replicate statue/trophy of the adorable HFMD Walk logo.

This hard rubber statue was created by HFMD member Mike Heath of Heath Creations. This truly unique victory trophy drew great attention and fascination from our group.

Altogether the gross funds raised were nearly \$40,000. Our 13th annual Walk fundraiser was another big success thanks to a collective effort of this community coming together to raise awareness and donations to keep the HFMD going strong.

~ By Jim Paist



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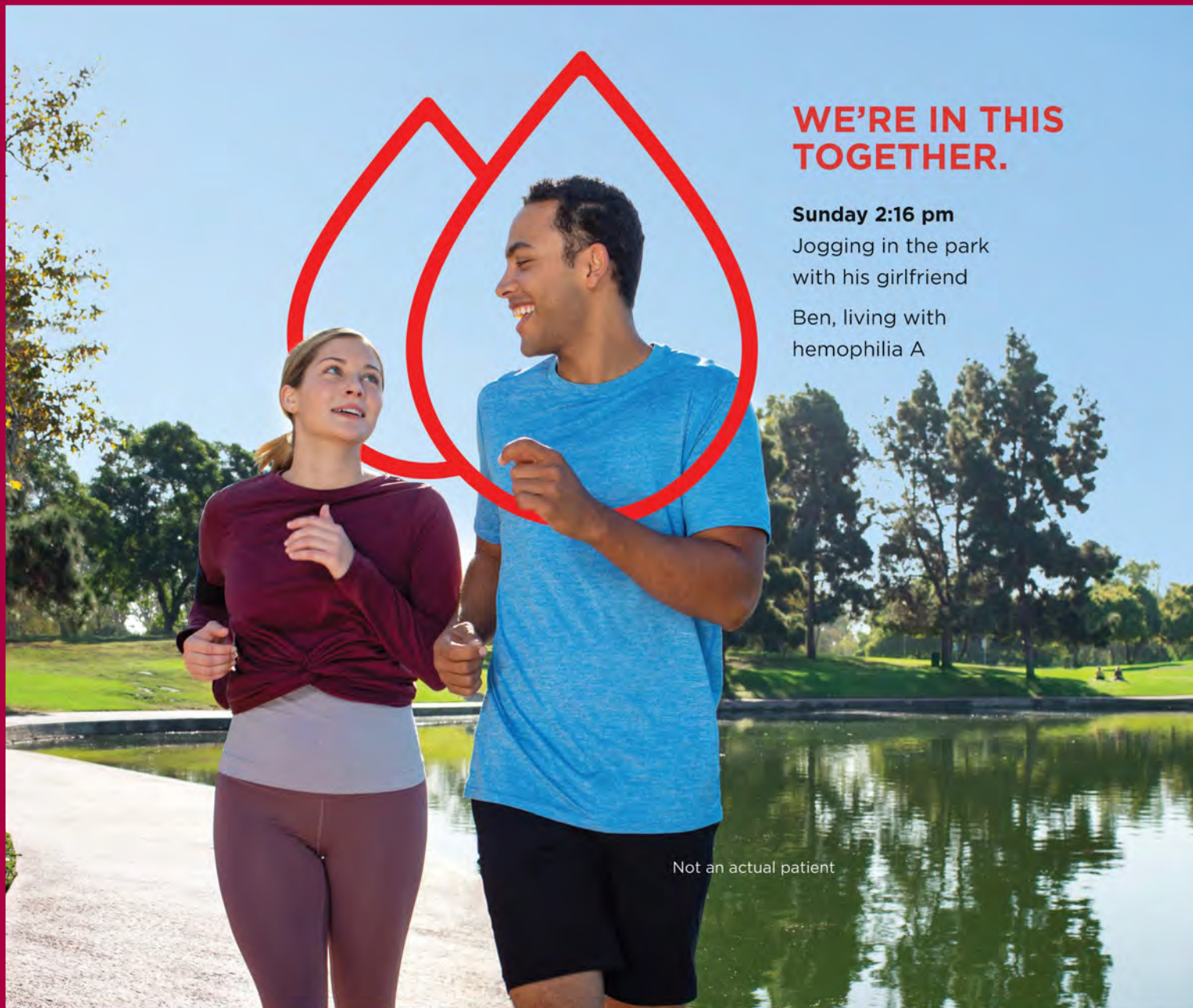
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Sunday 2:16 pm

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





Just for Fun: Word Search

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

ACQUIRED

BLEEDING DISORDER

CAMP NOT A CLOT

CARRIER

CHILDRENS MN

CLOTTING

FACTOR VIII

GENE THERAPY

GLANZMANN

HEMOPHILIA

HFMD

HTC CENTER

INFUSIONS

INHERITED

JOINT BLEEDS

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The National Hemophilia Foundation Has a New Name



In 1948, the foundation got its start as simply “The Hemophilia Foundation” – then in 1956, the foundation formally incorporated into what is known today as – the National Hemophilia Foundation. Even then, it was important to capture the organization’s expanding footprint across the U.S. Now, in 2023, the time for change has come again.

Because of our longstanding name, the National Hemophilia Foundation is best known for helping people with hemophilia and also for serving the individuals and professionals who care for that community.

However, in the foundation’s many decades, we have also long served those facing other blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Over the past 75 years, our powerful combination of research, education, and advocacy has improved the lives of people and families with a range of conditions – yet our name and image has not reflected that.

Now, as the **National Bleeding Disorders Foundation (NBDF)**, we can be more inclusive of *everyone* we serve. Although hemophilia remains a major focus, our name ensures that all people with VWD and rare and ultra-rare deficiencies know that they can find a home within NBDF.

Although we’re adopting a new name and a new look, our work will not change in the short term. We remain dedicated to supporting our network of over 50 chapters across the country and channeling funds into blood and bleeding disorders research. And we will continue to educate and support families with these disorders as we work tirelessly to protect access to health care on the state and local level.

Over the long term, our new name will challenge us to explore how we can harness our resources and networks to help people facing other blood and bleeding disorders – because after all, bleeding disorders *are* blood disorders. In the same way that the National Hemophilia Foundation evolved to help people facing blood and bleeding disorders beside hemophilia, we can evolve once again to assist more families in need. Many rare blood and bleeding disorders don’t have a national support and advocacy network like ours — and together, we have a historic opportunity to change that.

As the National Bleeding Disorders Foundation, we will use our longtime legacy to inspire a future where even more people have access to the treatments and support they need to thrive. We will remain true to our core vision while raising awareness, expanding reach, and continuing to build upon 75 years of history, hope, and progress.

~ Courtesy of NBDF



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HFMD Education Dinner at McCoy's

It was a fun evening at McCoy's Public House, on August 24th, at the Education Dinner, sponsored by Novo Nordisk and Optum Rx.

The education topic was "Food and Fitness Basics". The session led by Kathy Tiggs, discussing ways we can make healthier choices for ourselves, and the group discussed how we can make small changes for a healthier lifestyle in our own lives. It was great to see the camaraderie and hear the laughter from our group.



I don't know where the Thai Curry Bowl rates on the healthier choices scale, but it certainly was delicious!

~ by Tammy Ward




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2024 Expected Camp Dates

Please mark your calendars for these **expected** dates for Camp Events.

We are currently in the process of securing the dates for these two events so these dates could be subject to change. Announcements will be made accordingly.

ANNUAL WINTER TEEN RETREAT

WHEN: February 18-19, 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!



SUMMER CAMP NOT A CLOT

WHEN: JULY 14-19, 2024

WHERE: YMCA Camp Ihduhapi, Loretto, MN

FOR CHILDREN AND TEENS AGES 8-17 WITH A CHRONIC 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 YMCA Camp Not a Clot will go live in November.



HFMD UPCOMING CALENDAR OF EVENTS

OCT
4
Wed

HELLO Talk Dinner at The Lexington Restaurant

October 4th, 6:00 pm – 8:00 pm

OCT
9
Mon

HFA Blood Brotherhood Monthly Chat

(for adult men with bleeding disorders)

October 9th, 8:00 pm – 9:30 pm (ET)

OCT
14
Sat

Group Fitness Event at Bowlocity Entertainment - Rochester

October 14th, 11:00 am – 2:00 pm

NOV
18
Sat

HFMD Industry Symposium at Eagan Community Center

November 18th, 10:00 am – 3:30 pm

FEB
10
Sat

Hearts of Hope Gala Fundraiser at the Metropolitan Ballroom

February 10th, 2024 6:00 pm – 11:00 pm. *(Registration opening soon.)*

APR
19-20
Fri-Sat

Annual Members' Meeting at Mermaid Entertainment Center

April 19th-April 20th, 2024 5:30 pm – April 20th, 3:00 pm

Registration opening soon.

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 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!



**The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1 - September 30, 2023**

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Minnesota State Fair

Minnesota Twins
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Kaye, Aaron

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