

# 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



HFMD



HEMOPHILIA  
FOUNDATION  
OF MINNESOTA/DAKOTAS

# Veinline

SUMMER

2023

FORM A TEAM • REGISTER • DONATE



This year we are excited to have new stylish hand towels!

It's time for walkers, donors and team captains to organize your team, register and donate. **We need your help** to reach our fundraising goal so we can continue to help our bleeding disorders community. **Prizes** will be awarded to the **TOP THREE Team Captains** based on total donations raised.

Saturday, September 9<sup>th</sup>, 2023

3:00 p.m. — 6:00 p.m.

Como Park Midway Pavilion

1199 Midway Parkway | Saint Paul, MN 55103



HEMOPHILIA  
FOUNDATION  
OF MINNESOTA/DAKOTAS

Visit our website at [www.hfmd.org](http://www.hfmd.org) for more information on how to register, form a team, and donate.

## 2023 HFMD Annual Meeting By James Paist

**M**ember/Families, affiliated clinic staff, and company exhibitors all came together on a chilly weekend April 21 & 22 at the Mermaid Entertainment Center in Mounds View, Minnesota.

This venue is known for its 32-lane bowling alley, enormous arcade, axe throwing, ample convention meeting space, and an attached hotel. What a great spot for the HFMD Annual!

The Friday evening of this event is intended to be fun and casual. Our buffet dinner opened at 5:30 p.m. as our group settled in, seeing many familiar faces and some new member families who are always welcomed in with open arms. Announcements were kept short, but one that stood out is that we are one big family in this bleeding disorders community.

Bowling was our Friday night group activity, where HFMD members kept 6 lanes of rolling thunder going from 6:30 – 8:30 p.m. There were strikes, spares, splits, rolled by kids and adults alike. There were also a few gutter balls delivered by kids and adults alike.

Saturday morning opened in the Atlantis room where 19 event exhibitors draped the perimeter of this very large room. I opened the morning with some seasonal humor, which drew both laughs and jeers as we awakened to frost on our car windows on April 22<sup>nd</sup>. HFMD Board Vice President, Jean O'Connell began our education session by motivating our members to get involved in HFMD's ongoing public policy efforts to maintain the access to care we all need.

Our keynote speaker Dr. Rajiv Pruthi shared a fascinating presentation on the rapidly advancing technology in the treatment of bleeding disorders with gene therapy. His presentation was well received by our members, and we are so proud to have Dr. Pruthi on our Board of Directors.

After a break with exhibitors, our next presentation was delivered by HFMD community member Raj Trivedi. As an EMT and first responder, Raj presented on the importance of those with bleeding disorders having a medical ID bracelet or pendant on them at all times. Raj did such a nice job with his presentation by carefully weaving in some humor to a very serious subject.

After our group enjoyed a hearty lunch, this event featured an *Ask the Expert Panel* which included Dr. Rajiv Pruthi, PA Julia Colling, RN Sue Purdie, and PA Ricky Chan.

This session began with an introduction of each panelist who were each asked what motivated them to pursue a path of treating bleeding disorders. It was interesting to hear each panelist's personal story and to find out what drew them in the direction of rare disease and bleeding disorders. Our Moderator for the panel was Aubree Douglas, an HFMD volunteer who has helped at so many of our events. She handled the Q & A quite well.

A big plus with this venue is that fun activities are already built in for kids. Child Life Programming Specialist Vicki Neis and her Team of kind and thoughtful childcare givers wove in their educational programming with bowling and arcade so the childcare once again was a fun learning experience.

The HFMD would like to thank all of our speakers and volunteers for making this another fun and informative HFMD Annual Meeting. We would also like to extend a special thanks to our event exhibitors:

























FOR THE THRILL SEEKER WITH HEMOPHILIA B

# ACHIEVE NEW HEIGHTS

with long lasting bleed protection



## ONLY IDELVION LETS YOU

**RECLAIM  
SPONTANEOUS  
WITH 0 SPONTANEOUS  
BLEEDS<sup>†</sup>**



**FIT DOSING TO  
YOUR LIFESTYLE  
WITH 7- AND 14-DAY  
DOSING OPTIONS<sup>‡</sup>  
FDA APPROVED**



**TAKE FIX LEVELS  
TO ANOTHER LEVEL  
WITH 20% STEADY-STATE  
TROUGH LEVELS ON 7-DAY  
PROPHYLACTIC USE**

<sup>†</sup> Hemophilia FIX Market Assessment, Third-Party Market Research

<sup>‡</sup> The average ASBR for people who started and stayed on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the average ASBR was 0.7 ASBR-annualized spontaneous bleed rate

<sup>§</sup> Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of  $\leq 40$  IU/kg), people 12 years and older can be transitioned to 14-day dosing

### IMPORTANT SAFETY INFORMATION

IDELVION<sup>®</sup>, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications

you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

**Please see additional Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

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## A Core Conversation

**O**n June 15, 2023, the HFMD partnered with Sanofi and hosted a Core Conversation Dinner at Crave Restaurant located at the Rosedale Center in the private Minnesota Room.

Jess Hutchison spoke about Factor Fluency and how Higher Factor Activity Levels Matter. We learned why factor activity levels matter and how the levels are measured, because the more you know about your factor activity levels, the better you can manage your hemophilia.

Do you know what Pharmacokinetics is? (pharmacology + kinetics)

For people with hemophilia, understanding your unique PK parameters can be a useful tool when working with your HTC doctor to optimize your hemophilia management and treatment.

We want to thank everyone who joined us and a special thank you to Jess for an enjoyable and educational evening.

*by Tammy Ward*



## Welcome New Board Members!

### *Congratulations to*

**Danielle Flores** of ARJ Infusion Services (SP Rep) and  
**Chris Becchetti** of Hema Biologics (Pharma Company Rep)  
 in being elected to the HFMD Board by our Industry Relations Committee.

We look forward to officially welcoming Chris & Danielle on to the HFMD Board on July 25<sup>th</sup> during our next Board Meeting.



# Talking About Hemophilia at School

*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.

Parents and caregivers are the first adults responsible for their child with hemophilia. As children get older, however, they may attend daycare or school, participate in sports, and have playdates, where they are cared for by others. Families need to make decisions about who should be aware of the hemophilia diagnosis and how much information to disclose.

## Making the Decision to Disclose

Telling people about hemophilia is a personal decision. One step in educating others is having a good understanding of the condition yourself. Parents and caregivers may want to take advantage of educational opportunities that are offered from the hemophilia treatment center (HTC), patient advocacy groups, and factor manufacturers. Helping staff learn about hemophilia may lead to an improved experience at school.<sup>1</sup>

Tweens and teens living with hemophilia may want to let friends in their class know about their condition. Parents can suggest age-appropriate language kids can use, or even set up a time and place for their child to talk with friends.

## Who Does the Talking?

For younger children, parents or caregivers may want to direct the conversation, especially with other adults. As kids get older, they will probably want more say in making decisions about disclosing to friends, people at school, and acquaintances. Parents may want to talk to their kids about the benefits of having close friends know about hemophilia. As kids become tweens, teenagers, and young adults, they could need encouragement to take a larger role in educating others about hemophilia.<sup>2</sup>

## What Others Should Know

Disclosing at school should be important because of the possibility of needing care during the day. Giving teachers, coaches, administrators, and the school social worker and nurse access to information about hemophilia as well as specifics about the current care plan will be helpful.

Some families may choose to use this as a teaching moment as well, to discuss the emotional needs of the student while at school and raise awareness about hemophilia among staff.<sup>3</sup>

There are legal protections in place for children with disabilities who attend school.<sup>4</sup> Parents can consider putting a 504 plan in place. Personnel at the HTC may be helpful in providing sample 504 wording or suggestions. At least yearly, or more often when needed, parents should meet with school staff to discuss the plan. Some of the specifics can include:

- Accommodations needed (like modifications to physical education classes)
- How to manage an injury or a hemophilia emergency
- Medications or treatments needed during school hours
- Managing schoolwork during medical absences
- Supplies needed at school (either for every day or in the case of an urgent situation)
- Visits to the school nurse

## Starting the Conversation

A formalized plan, such as the 504, can provide a framework in talking with school staff. Putting it together helps parents get organized about what their child might need while at school. Meeting with all the stakeholders at school helps in working out the plan and in answering one another's questions. A follow-up meeting is a good option if anyone needs another touchpoint to discuss what is or what isn't working.

For kids, opportunities such as camps or activities designed for children affected by hemophilia provide an excellent opportunity to improve social skills.<sup>2</sup> Children might also benefit from role-playing scenarios with trusted adults in order to practice telling their friends about hemophilia. Starting small, with the basics of hemophilia, and then offering links to reading material is one way to encourage friends to become more educated.

**References:** 1. Cassis FR, Buzzi A, Forsyth A, et al. Haemophilia Experiences, Results and Opportunities (HERO) Study: influence of haemophilia on interpersonal relationships as reported by adults with haemophilia and parents of children with haemophilia. *Haemophilia*. 2014;20(4):e287-e295. doi:10.1111/hae.12454 2. Limperg PF, Haverman L, Beijlvelt M, et al. Psychosocial care for children with haemophilia and their parents in the Netherlands. *Haemophilia*. 2017;23(3):362-369. doi:10.1111/hae.13186 3. Cassis FR, Querol F, Forsyth A, Iorio A; HERO International Advisory Board. Psychosocial aspects of haemophilia: a systematic review of methodologies and findings. *Haemophilia*. 2012;18(3):e101-e114. doi:10.1111/j.1365-2516.2011.02683.x 4. Your rights under Section 504 of the Rehabilitation Act. U.S. Department of Health and Human Services. Published June 2000. Updated June 2006. Accessed July 13, 2021. <https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.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](http://www.pfizerpal.com) to connect with your Patient Affairs Liaison.



CAMP NOT-A-CLOT!



**July 16 - July 21, 2023**

**at YMCA Camp Ihduhapi**

**3425 Ihduhapi Road Loretto, MN 55357**

[Register Here](#) Use code HEMOPHILIA

For children with bleeding disorders, ages 8 -17



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Talk to your doctor about the study.



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## HFMD ANNOUNCES 2023-2024 SCHOLARSHIP RECIPIENTS

*Mendota Heights, Minnesota, July 7, 2023* - 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!***

To the following scholarship award recipients:

**Chase Moran**

*University of Wisconsin-La Crosse*

**Sky Mitchell**

*Winona State University*

**Nathan Miller**

*University of St. Thomas*

**Colin Orth**

*Chippewa Valley Technical College*

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 2024-2025 academic school year can be found on the Hemophilia Foundation of Minnesota and Dakotas' website at [www.hfmd.org](https://www.hfmd.org).

The HFMD is committed to seeing that our community gets the access to care and life-saving medication needed to stay healthy. We all know that hemophilia and chronic bleeding disorders are some of the most expensive conditions to treat.

Lawmakers on state and federal levels are continually looking for ways to keep health care costs down, so naturally they often gravitate toward looking at ways to lower the rising costs of treating hemophilia and other rare diseases.

**The position of HFMD is the following:** We cannot control the cost but are dedicated to seeing that our member/patients have access to the medication their hematologist prescribes.

The HFMD was deeply involved in a coalition of rare disease groups led by the Rare Disease Action Network to introduce and get a state bill passed (known as the Chloe Barnes bill) in 2019 to establish the state of Minnesota's Rare Disease Advisory Council. The Council is led by Executive Director Erica Barnes. While this was an impactful legislative accomplishment, the next major step was secure funding to keep this Advisory Board operating.

Below is a report prepared by JWB who HFMD contracted with in 2023.

### 2023 LEGISLATIVE SESSION REPORT

The 2023 legislative session began on January 3, 2023, with many newly elected DFL Senate and House members holding a majority in both houses for the first time in over a decade. With Governor Walz at the helm, the session and administration were known as a "DFL trifecta". Political observers on both sides of the aisle agreed that it was an extremely productive session for passing legislation including a budget, something they were unable to do in 2022. Other highlights of the session were passage of a bonding bill, a cannabis legalization bill including social justice reform, industry-specific reforms in warehouses and meat-packing plants, tax equalization and reform legislation, family and medical paid leave as well as a separate sick and safe leave bill, among others.

The pace of the session was swift, often with multiple hearings in both bodies happening simultaneously. A handful of conference committee reports which can only be voted up or down on the Senate and House floors were sent back to conference committee to work out inadvertent mistakes. After much speculation of early adjournment, the 2023 Legislature finished its work on May 22.

To follow are the major bills that the Hemophilia Foundation supported and followed.

### RARE DISEASE FUNDING

In last year's legislative session, the Rare Disease Advisory Council (RDAC) was moved from the University of Minnesota to an independent state agency. Some preliminary funding or seed money was available when the transfer was authorized. This year, RDAC requested \$647,000 for fiscal year 2024 and \$586,000 for fiscal year 2025 (HF 988). In the omnibus health and human services bill, SF 2995, which passed on the last day of the legislative session, the total amount authorized by the state was \$314,000 for FY23 and \$326,000 thereafter. This amount does not include the amount RDAC requested for increasing program capacity. On a positive note, the sunset was removed, so the base budget does not expire in four years as did the original funding.

### ACCESS TO SPECIALISTS

Patients with rare diseases will have immediate access to licensed healthcare providers regardless of whether they are in-network. In other words, no health plan company may restrict an enrollee's choice regarding where they receive services. This change will assist in the diagnosis, monitoring, and treatment of a rare disease or condition when criteria are met. No greater cost-sharing requirements (financial burden) nor benefit or services limitations for the diagnosis and treatment of a rare disease or condition must be placed on the enrollee as compared with requirements for in-network medical treatment. This provision will become effective January 1, 2024. Advocates of this bill, including the Hemophilia Foundation, were successful working with SEGIP (the State Employee Group Insurance Plan) to create a more realistic fiscal note on the potential costs of this change in legislation.

*Prepared by JWB Associates*



HEMOPHILIA  
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## 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)**





# FACTOR **UP** with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

**ALTUVIIIIO™**  
Antihemophilic Factor (Recombinant),  
Fc-VWF-XTEN Fusion Protein-ehrl



## HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).<sup>\*†</sup>

**48**

## HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,<sup>†</sup> ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

**0.7**

## BLEEDS PER YEAR<sup>‡</sup>

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.<sup>‡</sup>

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

<sup>\*</sup>Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

<sup>†</sup>159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

<sup>‡</sup>Data based on treated bleeds.

## CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



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### INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehrl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

### IMPORTANT SAFETY INFORMATION

#### What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

#### Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

#### What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

#### What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

**sanofi**

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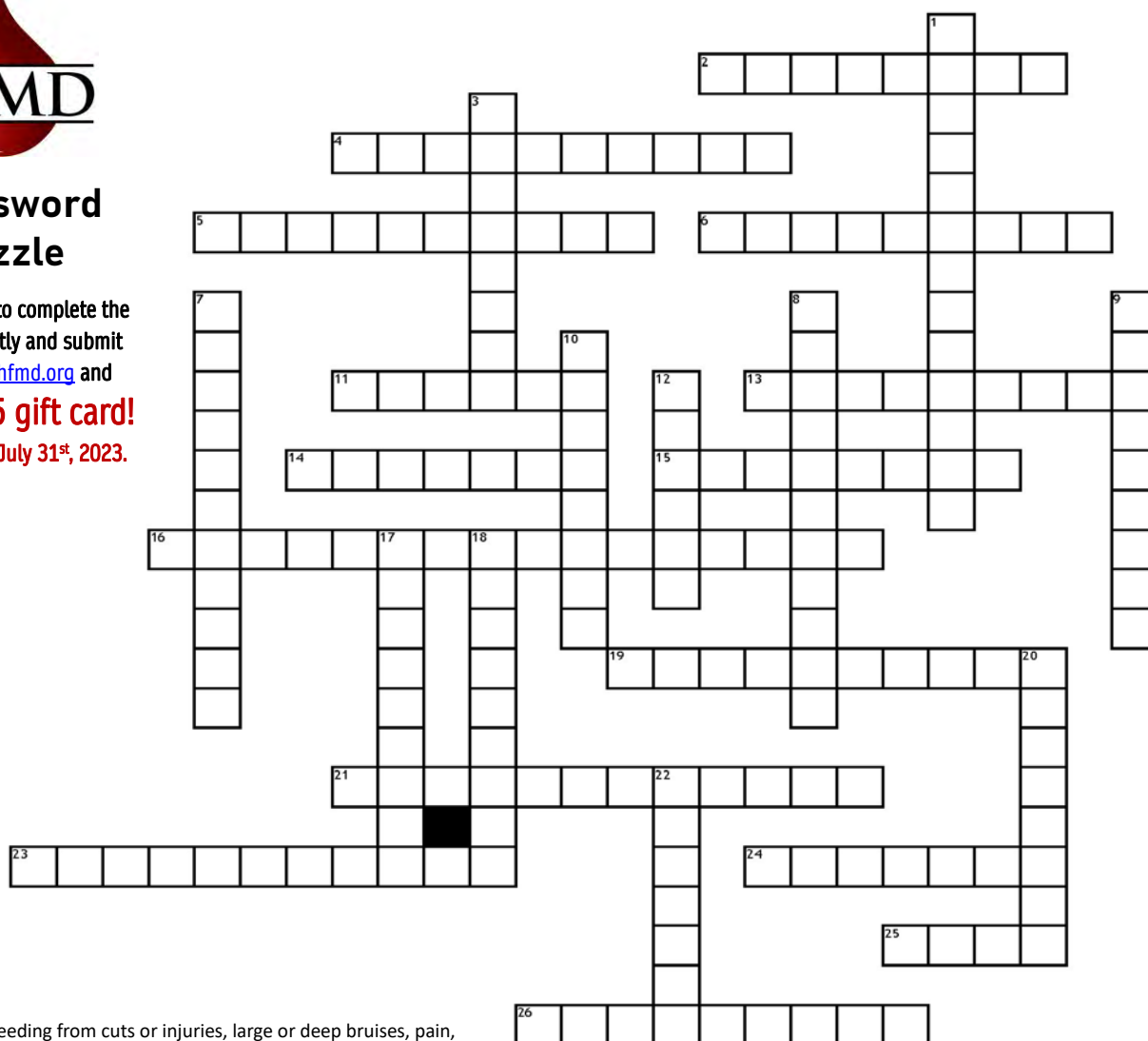


## Crossword Puzzle

Be the **FIRST** to complete the puzzle correctly and submit it to: [info@hfmd.org](mailto:info@hfmd.org) and

**WIN a \$25 gift card!**

Contest ends July 31<sup>st</sup>, 2023.



### ACROSS:

2. Excessive bleeding from cuts or injuries, large or deep bruises, pain, swelling or tightness in your joints are all \_\_\_\_\_ of Hemophilia.
4. What is the name of the HTC in Rochester, MN?
5. Who is the HFMD's Executive Director?
6. Glanzmann thrombasthenia is caused by the lack of a protein that is normally on the surface of \_\_\_\_\_.
11. The Sanford Health HTC children's clinic in Sioux Falls, looks like a \_\_\_\_\_.
13. Hemophilia is usually \_\_\_\_\_, meaning a person is born with the disorder.
14. Factor is a \_\_\_\_\_ that helps blood clot.
15. Blood contains many proteins called \_\_\_\_\_ factors that can help to stop bleeding.
16. Hemophilia is a rare \_\_\_\_\_.
19. A human genetic disease that impairs the body's ability to make blood clots.
21. Because the hemophilia gene was passed from Queen Victoria to the ruling families of Russia, Spain, and Germany, Hemophilia is called a \_\_\_\_\_.
23. What Minnesota HTC clinic is also known as "The Kid Experts"?
24. A female who inherits one affected X chromosome becomes a \_\_\_\_\_ of hemophilia and can pass the affected gene on to her children.
25. Acronym for Hemophilia Foundation of Minnesota and Dakotas?
26. Clotting factors are proteins in the blood that work with cells known as \_\_\_\_\_ to form clots.

### DOWN

1. People with von Willebrand disease have low levels of \_\_\_\_\_ factor.
3. What is the name of HFMD's sponsored summer camp at YMCA's Camp Ihduhapi?
7. According to WFH guidelines, \_\_\_\_\_ are the most common type of bleed, and can cause lasting damage and increase the risk of recurrent bleeds.
8. People living with hemophilia B may benefit from a one-time infusion that offers consistent bleed protection lasting years instead of weeks is known as \_\_\_\_\_.
9. In case of an emergency, you should always wear a \_\_\_\_\_ to alert emergency responders to your bleeding disorder.
10. The HFMD's quarterly newsletter is called the \_\_\_\_\_.
12. The most common type of hemophilia is hemophilia A, which is associated with a low level of \_\_\_\_\_ 8.
17. What is the term used when concentrates of a clotting factor are slowly dripped or injected into a vein to help replace the clotting factor that is missing?
18. \_\_\_\_\_ thrombasthenia is a congenital bleeding disorder caused by a deficiency of the platelet integrin alpha IIb beta3.
20. Some people develop hemophilia with no family history of the disorder. This is called \_\_\_\_\_ hemophilia.
22. The HFMD holds a fundraising walk every year called the \_\_\_\_\_ for Bleeding Disorders Walk Fundraiser.



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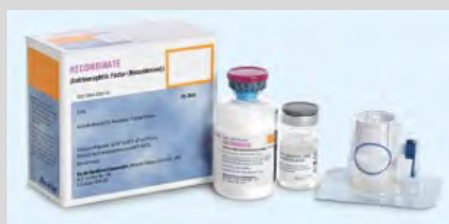


Please consider donating expired or soon to expire factor to HFMD for the twinning program between Children's Minnesota and the Hemophilia Society of Ethiopia.

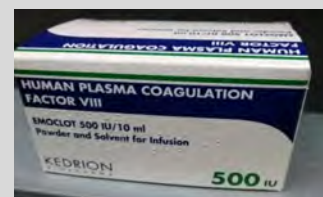
The World Federation of Hemophilia Twinning Program creates short-term collaborative partnerships between medical professionals and patient and youth leaders in emerging and established countries for a period of two to four years. Hemophilia treatment centres, patient organizations and youth groups can participate in this program, helping improve treatment and care for people living with an inherited bleeding disorder in developing countries.

Donations will be hand carried to Ethiopia by members of the care team.

Please submit donations by August 25<sup>th</sup> to: HFMD Office  
750 S. Plaza Drive, Suite 207  
Mendota Heights, MN 55120



Thank you,  
Sue Purdie, RN  
Children's MN





# Upcoming Calendar of Events

July 16-21, 2023	<b>Camp Not-a-Clot</b> (Summer Youth Camp) YMCA Camp Ihduhapi, Loretto MN
July 29, 2023	<b>South Dakota Family Education Day</b> Sioux Falls Canaries Baseball, Sioux Falls, SD
September 9, 2023	<b>HFMD Annual Step Out for Bleeding Disorders Walk</b> Como Park, St. Paul, MN
October 4, 2023	<b>HELLO Talk at the Lexington Restaurant</b> St. Paul, MN
November 18, 2023	<b>HFMD 5th Annual Symposium</b> Eagan Community Center, Eagan, MN
February 10, 2024	<b>24th Annual Hearts of Hope Gala</b> Metropolitan Ballroom & Clubroom Golden Valley, MN

Visit our website at [www.hfmd.org/events](http://www.hfmd.org/events) for more information and to register!

## 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](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 - June 30, 2023

## **Business & Organization**

### **Contributors:**

#### **\$47,000 and Up**

Mayo Foundation for Medical  
Education & Research

#### **\$9,000 - \$47,000**

Bayer Healthcare  
CSL Behring  
CVS Health  
Genentech Foundation  
M Health Fairview

#### **\$3,000 - \$8,999**

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