



HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

Veinline

Spring

2022

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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HFMD Annual Meeting 2022 *(by Jim Paist)*

It was so exciting to have our community back together in person and face to face on April 8th & 9th at the Intercontinental Hotel at the MSP Airport. Friday night opened with a delicious taco buffet. Families got to reconnect and meet new families who attended their first HFMD event.

Our Board President Kris Rauenhorst hosted a bundle of fun and games with a series of six competitions with an always exciting and action packed Minute to Win It! The intensity and drive to win from our family teams was thrilling not only for contestants, but for those watching as well.

Members of all ages showed some incredible focus and skill in stacking candy peeps to a memorable plastic Easter egg toss where 8 year old Malik Jr. shot a record 14 eggs into a basket to win 1st place and one of six gift cards.

Saturday morning opened with breakfast and time to visit our exhibitors. After an HFMD welcome, Skye Peltier, PA, and Dex Tuttle, M.ED from Children's MN shared an interactive and theatrical presentation on helmet safety.

(Continued on page 3)



With graphic pictures and molds illustrating the human brain, they showed how impact and trauma can adversely affect somebody if they are not wearing a helmet when doing activities where there is a risk to head injury.

This was a unique and very well received keynote presentation with a universal topic that applies to everyone, and especially those living with bleeding disorders. After the presentation, each child was **fitted was a brand new helmet from Children's. Thank you to Skye, Dex & Children's.**

Our child-life programming was led once again by Victoria Neis of Children's Hospitals & Clinics of Minnesota. Vicki and her Team do a terrific job in making it a fun and educational experience for the kids. This year, we also had the pleasure of having child program from Optum, led by PT Angela Forsyth. Thank you to Vicki, Angela, and Optum!

HFMD members love seeing each other in person, and truly enjoy sharing their personal stories with others who can identify with them. So, Roundtable Discussions were next on the agenda where we moved tables together to make 3 large Roundtables with the following topics at each; 1) playing sports with a bleeding disorder, 2) mental health, and 3) pain management. Members shared and learned from each other, as these engaging group discussions are always well received at HFMD events.

After lunch, our group separated into two breakout sessions: Advocacy & Youth Transitioning into adulthood led by Mayo Clinic.

Our Advocacy session featured HFA Public Policy Director, Miriam Goldstein who shared **important updates and developments on the federal level. Then from HFMD, Jean O'Connell and I** went into to depth on HF 3611 & SF 2136 - state bills to end the Accumulator Adjustor; a highly questionable practice by some health plans where they dismiss 3rd party assistance toward patient/family out-of-pocket costs.

HFMD has been working hard at the Minnesota state capitol with support from a collation of other Patient Advocacy groups to get these bills passed into law in 2022. We then had the pleasure to introduce our former and now current lobbyist, Jennifer Breitingner who shared her experience and wisdom with our members, and what they can do to help get these bills passed. Jennifer stressed how impactful letters, phone calls, and emails to your elected officials can be in determining the outcome of a bill.

The Transitioning into Adulthood session featured Dawn Rusk, RN, and Melinda Otto LSW from our Mayo Clinic HTC in Rochester, MN. They put so much thought and preparation into this program which can be so beneficial not only to the teens and youth, but also to the parents and siblings. We are very grateful to Dawn, Melinda, and Mayo Clinic for sharing this very important program at the HFMD Annual Meeting!

(Continued on page 4)

The final program of our event was the much anticipated Ask the Expert Panel, moderated by the multi-talented Skye Peltier. At HFMD, we like to boast about our affiliated clinics and the dedication these providers have in caring for our community. Our panel featured Dr. Mark Reding; Amy Goldstein NP; Melinda Otto, LSW; Dawn Rusk RN; Dana Smith, Pharmacist & Kim Baumann PT.

The HFMD Annual Meeting is a time where our whole community comes together; patient/families, HTC staff, and our sponsor/exhibitors. We would like to thank the following companies and clinics for exhibiting at our 2022 Annual Member Meeting:



Annual Meeting 2022

Thank You Sponsors and Exhibitors

Accredo
 ARJ Infusion
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 CSL Behring
 CVS Specialty Pharmacy
 Genentech
 HEMA Biologics
 M Health Fairview
 Mayo Clinic
 Novo Nordisk
 Optum
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 Takeda





WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the
campfire with friends

Isaac, living with
hemophilia B

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 | 

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HFMD Member Action Needed – Call and/or Email Your Minnesota State Representatives Today!

Ask them to support House File 3611 & Senate File 2136 to stop the **“Accumulator Adjustor”** by some Minnesota health plans.

Click here: [Minnesota Legislature \(mn.gov\)](http://mn.gov)

Rare diseases are very expensive to treat. There are HFMD families and individuals who rely on 3rd party assistance to help offset their high out-of-pocket costs; which for many hit the maximum of \$8,700 for an individual, and \$17,400 for a family each and every year.

Now, some health insurance companies have taken aggressive steps to deny families from using out-of-pocket assistance intended to help them, including assistance from the medication manufacturer. Some HFMD members have been stunned to find out they still owe money that has already been collected but NOT applied to their maximum out-of-pocket cost calculation. This clause in some insurance policies is known as the Accumulator Adjustor.

It is wrong., it is misguided., it is harmful to families., and it should be banned in Minnesota!

By Jim Paist

Contact the HFMD today to get involved and to stand up for families!

info@hfmd.org, or call 651-406-8655

HEARTS OF HOPE GALA 2022

The 22nd Annual HFMD Hearts of Hope Gala was back, live and in-person, on Saturday, February 26, 2022. The Gala was held at the Graduate Hotel on the U of M campus in Minneapolis.

We would like to thank all of the Gala sponsors for their generous support. Also, a big thank you to everyone that attended the event. It was fun and heart-warming to see so many of you turn out for this fun evening!

The evening's program included a video with some touching stories of young people and families who have been helped by HFMD programs. There were also some stories shared of personal journeys with bleeding disorders.

Thanks to the generosity of many local businesses and individuals, we were able to hold an exciting live auction, featuring John Berner, from Kurt Johnson Auctions, as auctioneer. There was also a silent auction. Both auctions offered a wide variety of interesting and creative items to bid on – everything from Minnesota-made foods and gift items, to professional sporting event tickets, family activities, restaurant gift cards, adult beverages and more!



(Continued on next page)

M Health Fairview hosted a gift card raffle this year, which was filled with great gift card prizes and a grand prize drawing at the end.

The ballroom at the Graduate Hotel was decorated beautifully for the Gala, and the dinner was delicious. Guests enjoyed music by DJ Sarge from Level 11 Events. As always, dancing was encouraged but not required.

The Gala is an important event for the HFMD and those we serve. There was a feeling of festivity, generosity and community spirit throughout the entire occasion that night. We were so very grateful for the opportunity to host the event.

-By Peggy Nasby

[Thank You 2022 HFMD Gala Sponsors!](#)

Bayer Healthcare • M Health Fairview • Takeda

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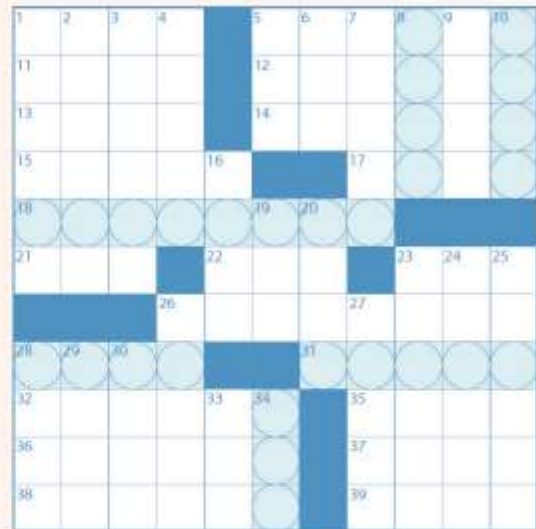
Children's MN • Genentech • HEMA Biologics

Maguire Agency • Novo Nordisk

Deano's Collision



CAN YOU SOLVE **FOR A DIFFERENT** **HEMOPHILIA A** **TREATMENT?** Test your **HEMLIBRA** knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

*Number of people with hemophilia A treated as of October 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than _____ thousand patients have been treated with HEMLIBRA worldwide¹

SOLUTIONS

Across: 1. cast, 5. dreams, 11. Aspen, 12. patch, 13. tone, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCM, 26. passport, 28. zero, 31. three, 32. eyewit, 35. Clinic, 36. answer, 37. eat, 38. answer, 39. class
Down: 1. costly, 2. about, 3. answer, 4. bleed, 5. CPU, 6. box, 7. arena, 8. sock, 9. MCM, 10. shot, 11. sea, 12. bus, 13. rent, 14. mortal, 15. Credo, 16. lira, 17. photo, 18. zero, 19. zero, 20. Eyr, 21. Rye, 22. ESE, 23. 600

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

See "What are the possible side effects of HEMLIBRA?" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule.
- **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "What is the most important information I should know about HEMLIBRA?"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration.
Revised: 12/2021



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BLEEDING DISORDER CAMP



We are excited to announce registration is now open for Summer Camp! Check out the great information below on how to register for camp.

The Hemophilia Foundation of Minnesota/Dakotas is Collaborating with YMCA Camp Iduhapi this summer to host a six day traditional camp experience for campers who have hemophilia and other chronic bleeding disorders. The mission of camp is to foster community among bleeding disorder patients and promote transition to independence. Campers will enjoy all of the fun of an outdoor summer camp while in a medically-safe environment.

Who Can Attend: Any child, age 8-17, who has hemophilia or another chronic bleeding disorder.

Dates: Sunday, June 19 – Friday, June 24.

Cost: The cost of camp (\$715/camper) is covered by the Hemophilia Foundation of Minnesota and the Dakotas. During registration you will be prompted to enter a coupon code in order to reflect this coverage at check-out. The coupon code is –HEMOPHILIA.

Staff: Our highly trained, skilled, and energetic Camp Iduhapi staff provide a week full of fun traditional camp activities. They are supported during the week by medical professional volunteers who provide bleeding disorder education and medical support.

Accommodations: Campers spend their session with two counselors and a group of other campers in a cabin group. Campers are assigned to their cabin based on age and gender. All food is provided (including options for allergies and other dietary requirements). Hemophilia Camp is peanut- and shellfish-free.

Transportation: Drop off (Sunday) and pick up (Friday) is at YMCA Camp Iduhapi in Loretto (30 minutes west of the Twin Cities). Transportation is not provided.

Registration: Registration must be completed by June 1, 2022. To register for camp, follow this [link](#). Scroll to the bottom of the page for registration. A paper form of the registration is also available by calling 612-813-5940.

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

Current Calendar of Events

June 19-24, 2022.....	Kids Summer Camp YMCA Camp Ihduhapi, Loretto, MN REGISTER HERE
July 30, 2022.....	SD Education Day Great Plains Zoo, Sioux Falls
August 21, 2022.....	Step Out for Bleeding Disorders Walk Harriet Island REGISTER HERE
November 11-13, 2022.....	Mayo Clinic Family Event Embassy Suites, Bloomington, MN & Science Museum of MN

Visit our website at <https://www.hfmd.org/events/>
for more information and to register!



SCHOLARSHIP APPLICATIONS NOW AVAILABLE FOR THE 2022-23 SCHOOL YEAR

HFMD is now accepting applications for the upcoming school year. To be eligible for a scholarship, applicants must meet the following requirements:

- ◆ Must be a person with an inherited bleeding disorder.
- ◆ Must be a resident of Minnesota or South Dakota, and/or a patient of one of HFMD's affiliated Hemophilia Treatment Centers in these states.
- ◆ Must use the HFMD Scholarship to pursue a course of post-secondary education.
- ◆ Completed scholarship application, letters of recommendation, and transcripts must be received by HFMD no later than June 1, 2022 to be considered for the following academic year.
- ◆ It is the applicant's responsibility to assure all forms are received at HFMD by June 1, 2022.

[Click HERE for the application form.](#)

The HFMD gratefully acknowledges our donors who have given so generously.

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\$40,000 and Up
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Gollinger, Deirdre
Lees, Mason
Manns, Kris & Joel
Mazepa, Allie
Nelson, Justin
Schulte, John & Karen

\$100-\$199
Barham, Mark
Baumann, Kim & Brad
Gleason, Troy
Hedlund, Todd
Holmes, Mike

Ianello-Zimmer, Dena
LaBarre, Robert
Lunde, Melissa
Makepeace, Jeff & Annie
Marema, Kristin
Nagel, Bill & Michelle
Osip, Joni
Phillips, Anika
Schmitt, Richard
Schulte, Cole
Tokar, Paul & Mary
Wessel, Michael
Wiener, Mark
Wilson, Amy

\$50-\$99
Benner, Jordan
Chan, Ricky
Colling, Julia
Geer, Rosemary
Hemann, Josh
Kilroy, Michelle Marie
Kivel, Anne, Nick & Casey
Kunkel, Cody
Murray, Milena & Chris
Naughton, Tyler & Maggie Herrity
Williams, Jovon & Kevin

Up to \$49
Ace, Julie
Bearss, Bryan
Germain, Matt & Tresa & Family
Goodale, Doug
Hickman, Janice
Kuper, Lindsey
Nixon, Rebecca
O'Donnell, Renee
Pechter, Stacy
Strauss, Becca

Hemophilia Treatment Centers (Tri-State Area)

Children's Minnesota—Center for Bleeding and Clotting Disorders
2530 Chicago Ave S, Suite 175
Minneapolis, MN 55404
612-813-5940

Susan Kearney, MD, Medical Director
Elizabeth Boegeman, LGSW, HTC Social Worker
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Mayo Comprehensive Hemophilia Center
Mayo Clinic
Mayo Building 10-55E
200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726

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Melinda Otto, LSW
Tiffany Plowman, L.P.N., Research Coordinator
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Sanford Health, Sioux Falls, SD Region
South Dakota Center for Bleeding Disorders
1600 West 22nd Street
P.O. Box 5039
Sioux Falls, SD 57117
605-312-1000 or 800-850-0064

Brianna Murphy, DO
Ashlee Blumhoff, CNP
Amanda Gerber, RN
Catherine Nelson, MD
Dan Steventon, PT
Amanda Van Holland, LSW
KayLyn Wagner, MD

M Health Fairview Center for Bleeding and Clotting Disorders
2512 South 7th St, Ste 105
Minneapolis, MN 55454
612-273-5005

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Emina Dzafic, Program Registrar
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Maggie Herrity, RN, Nurse Clinician
Jenny Lesnar, CPhT, Pharmacy Technician
Amy Marquez, BS, CPhT, Operations Manager
Marshall Mazepa, MD, Physician
Skye Peltier, PA-C, Physician Assistant
Erica Staub, RN, Nurse Clinician
Dana Smith, Pharmacist
Amy Wilson, MSW, LICSW, ACM, Social Worker

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