

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 Summer Camp 2019

We are happy to report that HFMD Camp at Courage North was a huge success this year! We had new record 76 campers and hope to keep the number growing in the years to come. While the kids arrived the line for Gaga Ball grew longer and longer. Before the first game was over some of them were covered from head to toe in dirt and their smiles could not be bigger. The first night of camp came with mostly laughs but some tears, however, the tears turned to giggles as the trained counselors quickly put the homesick at ease. Some of the highlights of the first night included dino themed stations, s'mores and campfire songs with the entire camp. Campers were put to the test when they were asked if they were ready to do self-injections. Some brave campers put on their game faces and were able to inject themselves for

the first time and earn a spot of the "Big Stick." This is a great accomplishment and was met by cheers, applause, and some happy tears from our volunteer staff. The following days included many activities such as a huge game of capture the flag, swimming, fishing and tubing. On the last night campers were treated to a carnival complete with snow cones, cotton candy and popcorn. Thanks so much to True Friends Camp staff, and to the wonderful clinic staff of our affiliated HTC's who provided such a safe and informative experience for the kids. We thank Children's Hospitals & Clinics of Minnesota, Mayo Clinic, University of MN Health-Fairview, and the Buuck Family Foundation for sponsoring Summer Camp 2019! By Melissa Andrisani

South Dakota Family Fun & Education Day

Saturday, July 27th was a glorious day in many ways. It was a warm sunny day for our annual event. This year it was held at the Great Plains Zoo in Sioux Falls, SD where we had plenty of room the meeting space of the Delbridge Museum of Natural History located inside of the Zoo.

In partnership with the South Dakota Center for Bleeding Disorders of Sanford Health, (a.k.a. the Castle) we opened the event with time for member families to visit the exhibit booths of 11 companies who sponsored the event. Our record attendance of 80 for this event all seemed to file in about the same time. Information was shared and thoughtful questions were asked.



The festivities continued with announcements from HFMD Event Coordinator, Melissa Andrisani followed by an HFMD presentation from James Paist, ED. Then a very clever poem about our day at the zoo created and cited by Nathan Anderson, (MSW from the clinic) and thoroughly enjoyed by all.

Then it was time for our keynote speaker Dr. George Maher who had previously agreed to speak at the zoo, but told me he didn't know much about hemophilia in animals. Dr. Maher shared an informative presentation with our group, including a bit about his background in hematology being a doctor in the military prior to his current practice at the Castle.

Then it was time for our "backyard cook-out" lunch which featured grilled hamburgers, hot-dogs, baked beans and potato salad. When it was time for our group to explore the zoo, we asked for help on the microphone from an 8 year old attendee who made the big announcement of "Its time to get your wristbands".

We had some new families and many returning families, all who came together as one bleeding disorder community from the South Dakota and surrounding area who got to enjoy seeing all of the animals in the very clean and botanical grounds of the Great Plains Zoo.

HFMD would like to extend a very special thank you to the staff of the Sanford Health Pediatric HTC at the Castle! We also thank the exhibitors and their companies who helped sponsor this grrrrreat event!

Accredo, Aptevo, ARJ Infusion, Bayer, Bio Matrix, CSL Behring, Diplomat, Genentech, Spark Therapeutics, Takeda, and Uniqure!

By James Paist





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We are grateful for having the chance to partner with you.

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Escape Room & Being Prepared – August 8th

Promised with a night full of fun and mystery, Blood Bothers & Sisters, along with their guests, arrived at Lock and Key Escapes Rooms on August 8th. Attendees were treated to a Jimmy Johns dinner with one of their huge cookies for dessert. In between bites, attendees asked Ricky Chang, Physician Assistant at M Health, great questions as he presented on Emergency Preparedness. Once the attendees were equipped with the tools on what to do in an emergency, it was time to face a real one... being trapped in a locked room! The guide gave the group a quick background story and led them in the room and locked the door behind her as she left them to their own devices.

We hope they got out! A huge thank you to everyone who attended and to HFA & Takeda for sponsoring this event!

By Melissa Andrisani





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HFMD Walk Fundraiser 2019

An unusually cold and wet fall morning did not deter members of this bleeding disorders community in a show of strength for our cause. HFMD Walk Teams and supporters came together inside the warm and dry indoor Harriet Island Pavilion Building to visit the exhibit tables, spend time with each other, and to get pumped up with HFMD and Goldy Gopher.

It was a good year to move our venue to the indoor confines of the historic Clarence W. Wigington Pavilion building. This is a very clean space with a full kitchen to help feed our group comfortably.

Our group gathered around our festive balloon arch starting line altogether to “Step Out for Bleeding Disorders” for our 9th annual Walk. This lovely venue provided options in Walk length with one time around just about one mile, so our Walkers to do one lap, two, or more laps depending on how hungry they were with mountains of Boca Chica tacos and fixings ready to be served by the HTC staff Team from the University of Minnesota – MHealth. It is no easy task to serve tacos, rice and beans to a group of 200, but the MHealth volunteers kept the food line running like clock-work.

As our group settled in to enjoy these delicious tacos, the top three fundraising Walk Teams were announced. Congratulations to Team Naumann who finished first raising nearly \$2,000, and to 2nd place Team Charlie, & 3rd place Team Carson. Thank you to all of our 2019 Walk Teams!

It took 26 dedicated volunteers to help pull this event off successfully as we needed each



and every one of you. Thank you so much to all of our Walk volunteers! Thank you to each of our generous sponsors and exhibitors (listed below) for supporting this very important event!

Our Walk is just one of two event fundraisers we hold each year. HFMD looks forward to returning to Harriet Island next year with even more Walk Teams with our patient/families affected by bleeding disorders! So please mark your calendars for Sunday, August 16th, 2020 to Step Out for Bleeding Disorders!
By James Paist

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Playing it Safe at Valleyfair – August 17



This event was one of HFMD's fastest to fill and we think we might know why...RIDES! We were thrilled to offer our members an afternoon of education, great food and fun at Valleyfair Amusement Park in Skakopee, MN on August 17th. The group met at the park gate and you could feel the excitement from the younger members as they starred at the rides and made notes of what they wanted to jump on first. Before they could be cut loose in the park, we led them over to the picnic area where they dined on a full backyard cookout that included burgers, hotdogs, mac n' cheese and fruit while Sue Purdie, RN, BSN at Children's, gave a fun and engaging presentation on NHF's "Playing it Safe." With so many young athletes in the audience, it was a great discussion that got everyone talking. When the discussions wrapped up and some of the kids could no longer wait, the families headed off into the park for the evening. Thank you to everyone who attended and to Octapharma for sponsoring this event!
By Melissa Andrisani



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Return To the Jonathan Padelford

The HFMD partnered with Aptevo to host an education dinner cruise excursion on the historic Jonathan Padelford docked at Harriet Island in St. Paul. On a hot, sunny evening in July a group of HFMD community members and staff boarded the boat and settled in for a presentation that featured Myles Ganley and Corbett Reinhold's discussion on "Facing the Pain of Hemophilia: Dealing with Chronic Pain and Medication Abuse". The group listened intently and peppered the speakers with many questions. Each family was provided helpful handouts loaded with information on pain control and when to contact your doctor when experiencing pain.

The lemonade flowed freely as the speakers gave their presentations. The group enjoyed broasted chicken and pulled pork with potato salad and all the fixin's, and delicious sweets for dessert. After everyone was done eating and the presentation was completed most everyone ventured out on the decks to enjoy the cool breeze off the river. The greenery of the river banks was dotted with a dozen or more orange kayak's making their way upriver as the sun dipped lower in the sky. The picture of this perfect summer evening was enhanced by the backdrop of the beautiful St. Paul skyline. The HFMD would like to thank Mark Hunter and Aptevo for sponsoring this exciting education dinner down the mighty Mississippi River. By Kerry Budinger



The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1st - September 30th, 2019.

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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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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


HEMLIBRA®
emicizumab-kxwh | 150 mg/mL
Injection for subcutaneous use

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	– stomach (abdomen) or back pain
– weakness	– nausea or vomiting
– swelling of arms and legs	– feeling sick
– yellowing of skin and eyes	– 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	– cough up blood
– pain or redness in your arms or legs	– feel faint
– shortness of breath	– headache
– chest pain or tightness	– numbness in your face
– fast heart rate	– 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.

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.

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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: 10/2018



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Children's Minnesota

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Sioux Falls, SD 57117
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**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

Current Calendar of Events

October 26, 2019	Women's & Teens High Tea & Floral Design Saint Paul Hotel, St. Paul, MN
November 16, 2019	HFMD Symposium Eagan Community Center, Eagan, MN
January 11, 2020	CSL Behring Education Event Top Golf, Brooklyn Center, MN
January 31-Feb 2, 2020	Winter Teen Retreat Camp Courage South, Annandale, MN
February 22, 2020	Hearts of Hope Gala Metropolitan Ballroom, Golden Valley, MN
April 3-4, 2020	HFMD Annual Members Meeting The Intercontinental Minneapolis-St. Paul Airport
August 16, 2020	HFMD Walk Fundraiser – Step Out for Bleeding Disorders Harriet Island Pavilion, Indoor & Outdoor

Visit our web site at www.hfmd.org for more exciting news, events, and updates!

Veinline

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

HFMD

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