

## HFMD MISSION

To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications

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## March 22nd, 2018 - Bleeding Disorders Awareness in Minnesota

We deeply appreciate the official state proclamation from Governor Mark Dayton making March 22nd our Day the past two years now. Our Day to raise awareness, share information, and to support legislation to ensure all Minnesotans get the access to the quality healthcare we need.

Our Day began at 9:00 a.m. gathered in the Capitol Rotunda with an inspirational speech from Representative Matt Dean, Chairman of the House Health & Human Services Committee, followed by Representative Nick Zerwas, and State Senator Tony Lourey. Each shared personal stories of hope, and spoke of their commitment to quality care for all. We were honored these elected officials stood with us on Bleeding Disorders Awareness Day.

With strong support from our affiliated clinics (HTCs), Dr. Mark Reding, Dr. Susan Kearney, Skye Peltier (PA), and Kerry Hansen (RN) each stepped up to the podium to stress the

importance of patients getting the care that they need. Both doctors had also previously written letters of support to the Governor requesting the official proclamation. We then heard compelling personal stories from HFMD Board members; beginning with Donald Glascock who really moved our group with his story. Then longtime member, Bob Newman, spoke about growing up with hemophilia in the 1930s and how much treatment has evolved and improved since then; while weaving in words of wisdom and light humor. Board President, Casey MacCallum, shared his very active experiences as a child and teen which included playing a number of different sports.

Our Day was also supported by the Hemophilia Federation of America (HFA) who sent Advocacy staff support from Deema Tarazi, and Vice President of Policy, Advocacy, and Government Education. Kim Isenberg shared updates from HFA, and legislative

*Continued on page 3*





Dr. Kearney



Rep. Nick Zerwas



Rep. Matt Dean



Donald Gluscock



Senator Tony Lourey



*Continued from cover*

developments from other parts of the country. To close our diverse lineup of speakers, HFMD Board member David Singer shared his personal connection to the HFMD with the loss of his longtime friend who was victim of the tragic contamination of the nation's blood supply in the late 1980's.

Our day also featured information tables led by affiliated clinic staff where supporters and the general public stopped by to learn more about bleeding disorders and our HTC's. The HFMD is grateful to everyone who stood in support of Bleeding Disorders Awareness Day 2018!

*By James Paist*

## A Personal Report from HFMD Board member Kristina Rauenhorst:

I would like to first thank Jim and Kerry and everyone involved, you made it a great day for our community.

Despite not being political, I found participating in HFMD's Day on the Hill very inspiring. It was an eye opener for me. I was thrilled to see the turn out and support at the capitol for individuals with bleeding disorders like my son. They understand and want to help our community. Currently, there are many health care bills to help maintain our current level of care and are aimed to prevent worries of the past. I felt a sense of peace that we have a voice and representation in our States government and we can make a difference. My momma bear's heart was full.

I was impressed with community members that were present and the impact that it had on the politicians that were there. It proved that we are a strong community and through our hard work we can continue to have our voice heard. It was also a good chance for us to see the politicians through a different lens. I was touched when Representative Nick Zerwas shared a very personal and moving story about his own struggles with a heart condition, allowing us to see that he understands our plight and will support bills that make a difference. He truly gets it on a personal level and will fight for individuals with bleeding disorders.

Even with all of the positive news, there are still many concerns with the future of health care that several individuals in our community have with affordability and access to care. Now is the time to act. We need to continue to increase our community's visibility with



*HFMD Members - Tom & Sadie Herrick*

the leaders in state government. It is easier to increase or maintain the care we have then to reinstate something taken away.

While HFMD does an excellent job to get our communities concerns to the table, it needs the support from members of our community to attend these events to ensure that our voice resonates through the halls of the capitol.

## 2018 Washington Days

2018 National Hemophilia Foundation (NHF) Day on the Hill was March 7-9th. This year over 500 supporters of individuals with bleeding disorders met with their states House and Senate representatives. Representing Minnesota was Justin Nelson, HTC Program Manager at Children's Minnesota. Partnered with our friends from North Dakota, meetings occurred with Minnesota Senators Klobuchar and Tina Smith's staff members.

During these meetings protections for the Affordable Care Act (ACA), continued funding for Hemophilia Treatment Centers (HTC) and Centers for Disease Control (CDC) were discussed. The senators' staff were very open to listening to the concerns of the bleeding disorders community.

*By Justin Nelson, Program Manager, Children's Hospitals & Clinics*



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## Group Fitness Event: Bowling at Pinz in Oakdale

Sponsored by Novo Nordisk & ARJ Infusion Services

On January 20th, the HFMD hosted a day of spares, strikes, pizza, and good information. Our event opened up with a helpful presentation on school conversations sponsored by Novo Nordisk. Dawn Hezel, NP, shared some helpful tips on establishing dialogue with teachers, school nurses, and school administration in the event of a child having a bleed while at school. Our group asked a number of thoughtful questions, and some parents shared their experiences in this area. Then it was time to limber up for bowling, pizza, and laser tag.

The unmistakable sounds of strikes, and gutter-balls rang through 10 Pin Alley, the separate space for large groups at Pinz. Members also had time to visit and catch up with each other in between turns on the shiny lanes. Shifting gears to laser tag; our group darted around the new course at Pinz with the last player standing in victory. Then we returned for seconds on bowling, pizza and Ceasar Salad. We appreciate event sponsorship from Novo Nordisk and ARJ Infusion Services.



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## A Gala to Remember

Thank you to all who joined us for the 2018 Hearts of Hope Gala at the elegant Radisson Blu Mall of America in Bloomington. We were excited to have 230 guests join us for a lovely evening of lively auctions, delicious food, and fun! We would like to offer a special thank you to our ever popular Master of Ceremonies, Dick Bremer, for making the evening especially memorable.

Thanks to the amazing work of our Gala committee and volunteers, the live and silent auctions featured a variety of unique items in 2018. The live auction featured guest favorites including Chicago Cubs baseball tickets donated by Ron and Paula Coomer, passes to Walt Disney World, a wine party for 20 from Total Wine & More, a half-inning in the FSN North Booth with Twins tickets, and a bowling party at Park Tavern in Eden Prairie. The live auction also included a pair of game-worn, autographed, size 18 sneakers from Cleveland Cavaliers Center-Forward, Kevin Love. Favorites from the silent auction included a Whitewater rafting trip, a Ryan Suter autographed Wild hockey stick, and a variety of fine dining and entertainment packages.

The HFMD raffle featured a masterfully designed and custom built liquor cabinet created and donated by talented woodworker, Richard Rauenhorst. The cabinet was stocked with high-end liquors donated by our own Gala committee. The Wine Wall raffle was a hit once again and showcased nearly 100 bottles of fine wines. Thank you to the fantastic crew at

University of Minnesota Health for coordinating this wonderful wine bottle raffle.

After an energetic auction reception, the Hearts of Hope Gala began with a touching invocation from HFMD Board President, Casey MacCallum. Dick Bremer led the program sharing his family experience with bleeding disorders and giving Gala guests a sneak peek of the 2018 Minnesota Twins baseball season. Auctioneer Andy Imholt took the stage and opened the live auction featuring many sought-after items including a couple surprises – a second FSN North Booth experience and baseballs autographed by Twins legends. Thank you to Dick Bremer for adding those incredible items! Next, the HFMD Fund-a-Need was featured with a video montage on of the Summer Camp for Kids and the Patient Financial Assistance Program. Thanks to our generous guests, the Fund-a-Need raised over \$15,000! Thank you! HFMD Executive Director, Jim Paist ended the program by thanking our generous sponsors and raffling off the coveted liquor cabinet.

Thanks to all of you, the HFMD raised over \$93,000! We are so grateful for our staff, committee, and volunteers whose hard work made the Gala a success. We would like to honor our Gala Committee members for their incredible work. We would also like to offer a special thank you to Perry Cowen for producing the wonderful Fund-a-Need video montage.

*By Brianna Hager, HFMD Event Coordinator*



**Be sure to save February 9th for the 2019  
Hearts of Hope Gala at the Metropolitan  
Club & Ballroom in Golden Valley!**

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*Andy Imholt & Dick Bremer*

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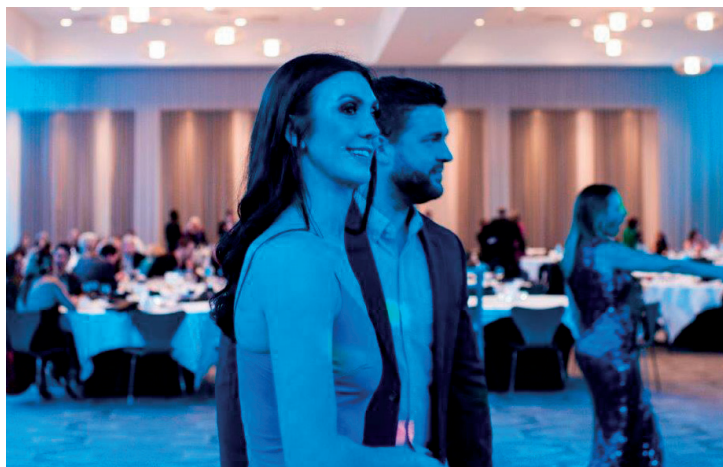
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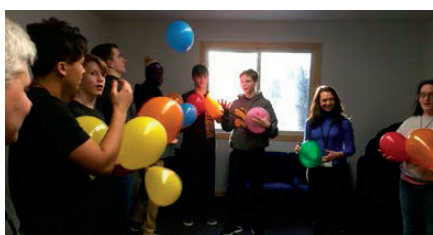
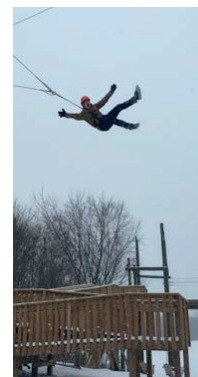



## Bleeding Disorders Winter Teen Retreat!

The Bleeding Disorders Winter Teen Retreat is an opportunity to build community amongst teen participants ages 13-18 in the Midwest. It acts as a bridge between the summer program and the school year, including both former campers as well as folks who have not participated in camp before.


Participants were encouraged to take an active role in defining the direction of the weekend and managing their bleeding disorder.

From sledding to archery tag, s'mores to working together at the ropes course, community was built and memories were cemented for years to come!





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These are donations received from January 1, 2018 through March 31, 2018.

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1600 West 22nd Street  
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## 2018 HFMD Scholarship Applications

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More information and forms for this scholarship and information on additional scholarships is available online at [www.hfmd.org](http://www.hfmd.org) or by calling the HFMD office at 651-406-8655 or 1-800-994-4363.

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## 2018 Calendar of Events

- |                           |                                                                                             |
|---------------------------|---------------------------------------------------------------------------------------------|
| April 20-21, 2018.....    | HFMD Annual Member Meeting<br>Marriott Airport, Bloomington, MN                             |
| May 17, 2018 .....        | Shire Hello Talk: Journey of Factor: A Deeper Dive<br>Rojo Mexican Grill, Edina, MN         |
| July 8-13, 2018 .....     | HFMD Summer Camp<br>True Friends—Courage North, Lake George, MN                             |
| July 28, 2018 .....       | South Dakota Family Day (SD Patients only)<br>Wild Water West Waterpark, Sioux Falls, SD    |
| August 5, 2018 .....      | HFMD Annual Walk Fundraiser<br>Como Park Picnic Pavillion, St. Paul, MN                     |
| October 11-13, 2018 ..... | 70th Annual NHF Bleeding Disorders Conference<br>Orlando World Center Marriott, Orlando, FL |

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**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.**



#### 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.**

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.



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

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**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

**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  
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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.

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