

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.

Inside this issue:

Women's Reception Annual Meeting	2
An Annual Meeting to Remember	3
Scholarship Announcement	4
"A Day at the Pool"	6
Escape Room	
Donors	10
Donors Continued	11
HTC Info & Staff	12
HFMD Board & Staff	
Calendar of Events	13
HFMD 9th Annual Walk Fundraiser	16



Rare Disease Advisory Council Created in Minnesota!

On June 18th, 2019 Minnesota Governor Tim Walz signed the Chloe Barnes bill establishing a Rare Disease Advisory Council! Getting this bill passed into law has been the top legislative priority for HFMD the past two years. This is a very positive development for our bleeding disorders community and so many other rare disease patients/communities in the state. Below is the first section from Senate file 973 Chief authored by state Senator Jeremy Miller. It reads as follows: Section 1. **ADVISORY COUNCIL ON RARE DISEASES. Establishment. The University of Minnesota is requested to establish an advisory council on rare diseases to provide advice on research, diagnosis, treatment, and education related to rare diseases. For purposes of this section, "rare disease" has the meaning given in United States Code, title 21, section 360bb. The council shall be called the Chloe Barnes Advisory Council on Rare Diseases.**

Advocating for the passage of this bill has been the primary focus of our state advocacy at the state capitol in 2018 & 2019. This year, our efforts were greatly strengthened when Erica Barnes of the Rare Disease Action Network (RAN) of Minnesota, the state chapter of NORD, reached out to HFMD to join forces with us for our state Advocacy Day at the Capitol Rotunda on March 12th. We were thrilled to partner with RAN, the Sickle Cell Foundation, and advocates from other rare disease communities, many of which don't have a non-profit agency or formal advocacy organizations. Our voices were heard throughout the state capitol on March 12th, and now a continuing voice for patient/families affected by rare disease is an important part of what this advisory council will provide.

The composition of the Council will include three physicians, a researcher, affected

patients, a social worker, and a nurse clinician. These individuals will be appointed by the University of Minnesota Board of Regents. HFMD is hopeful a physician and a patient from one of our affiliated HTCs will be appointed to the Rare Disease Advisory Council.

HFMD is grateful to all of our members who made time to advocate for this bill getting passed, and to all who showed up at our Bleeding Disorders & Rare Disease Awareness Day on March 12th. We are especially thankful to Erica Barnes and her relentless efforts to line up legislative and community support for this very important bill. The bill was named in memory of young Chloe who passed away from a rare disease at age two, daughter of Erica & Philip Barnes.

We appreciate the support of RAN, NORD, and from Kim Isenberg of the Hemophilia Federation of America who all played key roles in this coalition to get the Bill passed. Thank you to state Senator Jeremy Miller, and state House Representative Alice Mann for chief authoring the bill, the unanimous support from the Minnesota state Senate, overwhelming support from the House, and to Governor Tim Walz for making this bill come to fruition.

While this is an important step on the state level, we urge HFMD members to get involved with our state advocacy day in March and related efforts in 2020, as preserving and protecting access to care for people with bleeding disorders is critical to this community, and core to what HFMD does.

By James Paist

Women's Reception at the 2019 Annual Meeting

This year's Annual meeting marked the second year of the Friday night Women's Reception. While Dad's and helpers watched the kids have a great time playing games, women with bleeding disorders and moms of kids with bleeding disorders met in the Hilton's Presidential Suite for a few hours of education, fun and prizes! The evening started off with the women enjoying hors d'oeuvres and cocktails while listening to Hemophilia Federation of America's, Andy Anderson, explain the Blood Sisterhood and Mom's in Action program and information on upcoming events. The group was particularly interested in the Glamp Out event to be held in Louisville, KY, July 26-28, 2019. The evening progressed with several rousing games of Bingo with the winners receiving a Coach handbag, cosmetic bags and wallet; an Aveda sample pack; as well as a few items from Penzey's Spice Store! After a lot of food, fun and laughs the night came to an end with everyone looking forward to meeting again next year! By Kerry Budinger



An Annual Meeting to Remember

Our 2019 community gathering was held on April 26-27. We began with a nice dinner, when the far wall slowly began to open unveiling an enormous inflatable four-station sports gallery featuring kicking a soccer ball into a net, throwing footballs and baseballs through cut-out holes, and a basketball hoop.

Kids in the room thoroughly enjoyed the multi-sport activity and took turns in line at each game. It was a hit, shot, and a kick for all, as parents stood close by to enjoy the fun.

Our Saturday schedule for presentations included an all-star line-up of clinical talent amongst our affiliated HTC's. Beginning with our keynote speaker Dr. Rajiv Pruthi, MDDS, and Program Manager of the Mayo Clinic Comprehensive HTC. Dr. Pruthi shared a fascinating history of hemophilia, followed by a panel which included Dr. Mark Reding and Dr. Pruthi together who spoke about the ever-changing landscape of new technology treating bleeding disorders. There was plenty of time for Q & A with the doctors.

Emergency Preparedness was the theme for our 2019 annual meeting, and Nurse Clinician Kerry Hansen shared a potent and compact presentation on being prepared in a variety of emergency situations. Child Life Programming Manager, Vicki Neis embraced this theme with the kids as part of the child care plan which included a hands on guided tour of an ambulance by a veteran EMT.

During lunch, a Blood Brotherhood session was led by Dr. Gary McClain who flew in from the east coast to share a very thoughtful presentation entitled, "Bringing Home the Bacon," with a focus on being a household provider for a family.

Afternoon breakouts featured Dr. Georgia Panopoulus on Pain Management without drugs, Kenesio Taping by Kim Baumann, PT, and von Willebrand, by Dr. Mark Reding.

We would like to thank the following sponsors of our 2019 Annual Meeting: Children's Hospitals & Clinics, Mayo Clinic, MHealth, & Takeda!

We also want to thank all of our exhibitors: Accredo, Aptevo, ARJ Infusion, Bayer Healthcare, CSL Behring, Factor One Source, Diplomat Specialty Infusion, Genentech, Grifols, HFA, InTouch Pharmacy, Novo Nordisk, Octapharma, Pfizer, Sanofi Genzyme, Spark Therapeutics, Takeda & uniQure. By James Paist



Post-Secondary Scholarships Awarded for 2019-2020 School Year

This year HFMD received a number of wonderful candidate applications for the HFMD Post-Secondary Scholarship Awards. In total four scholarship recipients were awarded \$2,500 each to assist with tuition expenses for the 2019-2020 school year at the college or vocational school they attend.

HFMD awards scholarships yearly. The amount awarded varies each year based on the number of eligible applicants that are approved. Watch our website and future issues of the Veinline for more information on applying for the 2020-2021 school year's scholarship awards.

After notifying the recipients of the scholarship awards we recently received the following letter of appreciation:

"Dear Hemophilia Foundation of Minnesota and the Dakotas,

Thank you for your tremendous generosity in granting me an academic scholarship. It feels especially special to get help from an organization I have known so well for most of my life.

I will be entering junior status at the University of Wisconsin – Madison this fall, continuing to study Atmospheric and Oceanic Sciences. I'm really excited to begin the major's core sequence of coursework.

Thanks for your help, I am able to focus more on the things that matter most, pertaining to my academics. In this way, this scholarship is an extremely valuable investment toward the future.

I will definitely make the most of it, in order to maximize the return! Thank you!

Sincerely, Xxxx Xxxx 2019 recipient"

SAVE THE DATE!



HFMD

FIRST ANNUAL SYMPOSIUM

Saturday, November 16th, 2019
10:00am - 3:00pm

Eagan Community Center
1501 Central Pkwy, Eagan, MN 55121

**A Family Friendly Event with Company
Presentations on the latest treatment and care for
bleeding disorders.**



FEATURING

**A Pizza Party
Indoor Playground
Door Prizes
Raffles
Swag Bags**



"A Day at the Pool"

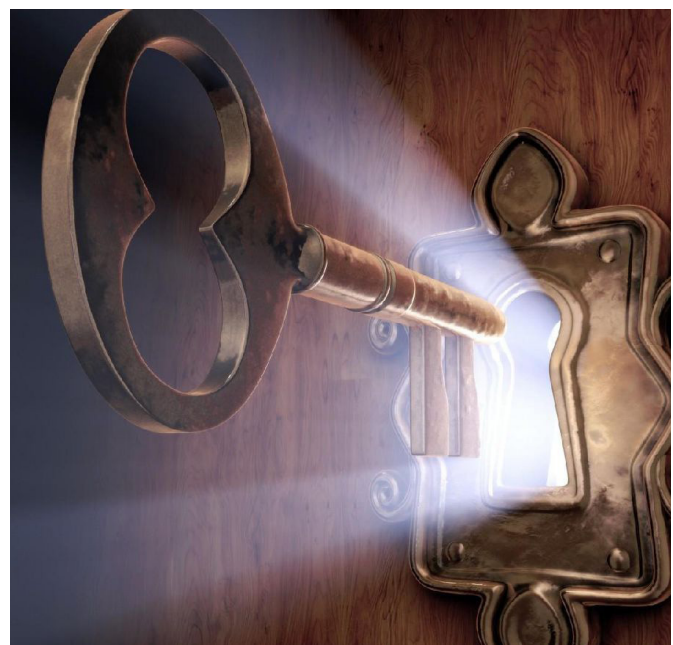


A little dreary weather could not keep our amazing families from enjoying a fun day the Apple Valley Aquatic Center on June 15th for a "Day at the Pool"! The kids kept warm with beach towels as they and their families intently listened as Julia Mason, R.N. from CVS gave an informative presentation on "School Conversations." Once all the questions had been skillfully answered, the families were given Jimmy Johns to fuel up so they could enjoy the rest of the day in the water. We would like to thank everyone that attended and CVS for making this event a success! By Melissa Andrisani

Escape Room

HFMD Invites Members of the Blood Brotherhood & Sisterhood and Their Guest Who is Over 12 Years of Age to a Night of Dinner and Fun at the **Lock & Key Escape Rooms**, 4020 Minnehaha Ave, Minneapolis. **Thursday, August 8, 6PM – 8PM.**

Join us for informative updates, great food and an escape room experience where you will spend about an hour immersed in a captivating story, solving puzzles and riddles with your Blood Brothers and Sisters. Expect to have fun, share some laughs, and get your pulse pumping with adrenaline as the time ticks away! To register go to www.hfmd.org/events





InTouch
PHARMACY
Hemophilia Specialists

Serving the Hemophilia Community

Family Owned & Operated

We're family & you'll feel like it, too.

Just Hemophilia

You're 100% focused on hemophilia. Shouldn't your pharmacy be as well?

More Than Just A Box of Factor & Ice

We deliver support and smiles with every shipment.

Call today to start the conversation

877-854-5099

www.intouchpharmacy.com



We're Listening

At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

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

—Your Pfizer Hemophilia Team

PRHEM-USA-1120-02
All rights reserved.

© 2018 Pfizer Inc.
Printed in USA/November 2018





FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

For people with hemophilia, Factor treatment temporarily replaces what's missing.^{1,2} With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.²⁻⁶

Brought to you by Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.⁷

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. 2. Canadian Hemophilia Society. Factor replacement therapy. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/>. Accessed May 18, 2018. 3. Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. 4. Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. 5. Antovic A, Mikovic D, Elezovic I, Zabczyk M, Huttenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. 6. Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*, 5th ed. New York, NY: WH Freeman; 2002. <https://www.ncbi.nlm.nih.gov/books/NBK22589/>. Accessed May 18, 2018. 7. Shire. Shire's 70+ year commitment to the hemophilia community. <https://www.shire.com/en/newsroom/2018/january/7sossj>. Accessed June 6, 2018.

Copyright © 2019 Takeda Pharmaceutical Company Limited. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. S46132 03/19





FEEL EMPOWERED
to step up to the challenge
with **Jivi®**

Are you ready to see what Jivi offers?
Visit www.explorejivi.com to learn more.

Ask your doctor if Jivi may be right for you.

© 2019 Bayer. All rights reserved. Bayer, the Bayer Cross and Jivi are registered trademarks of Bayer.

Printed in USA 02/19 PP-JIV-US-0467-1

Jivi®
antihemophilic factor
(recombinant) PEGylated-aucI

LET'S GO

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

Organizational Contributors:

\$40,000 and Up

Mayo Foundation

\$20,000 - \$39,999

M Health

\$14,000-19,999

Children's Hospitals &
Clinics of MN

\$9,000 - \$13,999

Bayer Healthcare
CSL Behring
Express Scripts
Genentech
Novo Nordisk
Octapharma
Takeda

\$3,000 - \$8,999

Aptevio
CVS Caremark Specialty
Hemophilia Alliance
Pfizer
Sanford Health Sioux Falls

\$1,000 - \$2,999

Accredo
ARJ Infusion

Community Health Charities
Diplomat Specialty Services
Facebooks Network for Good
Factor One Source
Grifols
Hemophilia Fed. of America
InTouch Pharmacy
Spark Therapeutics
uniQure

\$500 - \$999

3M Foundation
ARJ Infusion
NCHS Holdings

Up to \$499

AmazonSmile
Thrivent Financial
YourCause
PayPal Giving Fund
Richard Schmitt Accounting
Thomson Reuters
United Healthcare

Individual Contributors:

\$1,000 and Up

Bremer, Dick & Heidi
Collins, Chris & Mardell
Etterman, Pete & Andrea
Rauenhorst, Richard & Liz

\$500 - \$999

Bickmore, Sue
Boonstra, Tim & Diana
Carl Dietz Charitable Fund
In Memory of Mason Schulte
Haffield, Sue
Kearney, Susan & Rothaar, Rob
Langworthy, James
Manns, Joel & Kris
Muller, Cory
O'Brien, Patti & Tim
Paist, James
Purdie, Sue
Reeves, Aaron & Paige

\$200 - \$499

Andersen, Jon & Beth
Bremer, Nathan
Budinger, Kerry
Glascocock, Donald
Hutchison, Jessica
Kruse, Larry
Oliver, Kirk & Julie
Rauenhorst, David & Kris
Schlosser, Jon
Schuch, Joe & Cynthia
Trammell, Orenthia
Wegner, David & Judith

\$100 - \$199

Andrisani, Demitrios & Melissa
Bracho, Ruben
Curoe, Phil & Sue

Doll, Rick and Carol
 Drake, Traci
 Erdenberger, Kane & Kari
 Fournier, Charlotte
 Gilmer, Greg
 Gleason, Troy & Stacy
 Hedlund, Todd & Paula
 Kallberg, Dan & Sarah
 Lawrence, Andrew
 Lyon-Dugin, Bruce & Fran
 MacCallum, Greg & Helene
 Malm, Lucas & Lydia
 Mazeppa, Marshall
 Melhado, Deb
 Morales, Melisa
 Rappa, Steven
 Reeves, Ron & Kathleen
 Roberts, Sharon
 Ruona, Phoebe
 Schmeichel, Linda
 Stocker, Chris & Katie
 Swenson, Nancy
 Tinklenberg, Dan
 Wiener, Mark
 Zimmer, Stephen & Dena
 Warden, Louise
 Webber, Benjamin & Elizabeth

\$50 - \$99

Boyer, Geoff & Emily
 Brace, Eric & Natalie
 Brown, Nissan
 Cavallaro, Drew & Heather
 Chianta, Rose

Cowen, Stacie
 Garcia, Yalmer & Ana
 Gronberg, Jodi
 Guild, Maira
 Heath, Michael
 Huerta, Benigno & Dora
 Hunter, Mark
 Johnson, Rick & DeeDee
 Jordan, David & Briana
 Martinez, Justine
 Neubert, Mike & Heidi
 Paulson, Levi
 Ramos, Nacho
 Schadewald, Amy
 Slavic, Shari
 Spangler, Nayan
 Waldeland, Trevor & Pam
 Wilson, Seth

Up to \$49

Abel, Tanya
 Daniels, Richard & Angie
 Barnes, Erica
 Bray, Jon & Sarah
 De leon, Martin & Leonor
 Hayes, Scott
 Herrity, Maggie
 Kalenborn, Jason
 Koester, Tim & Barb
 Looney, Craig
 McMahon, Amy
 Ouellette, Carson

Donations in Memory of David Kaisershot

Anderson, Julia
 Behrens, Angela
 Beltowski, Andrew
 Fleischhacker, Martin
 Goldfus, Donald
 IEEE, Global Spec, Executive
 Team, Eileen Lach
 Lach, Eileen
 Lach, Patricia
 Livingston, Rand
 MN Forest Inventory Group
 Nelsen, Ann
 Nida, Ronald
 Radanke, Jodi
 Wagner, Mary
 Warehime, Marilyn
 Wendt, Lois
 Williams, Christine
 Wilson-Jarrard, Maureen

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

Allison Albright, Program Manager
Elizabeth Boegeman, LGSW
Latrice Daniel, CPHT, Pharmacy Tech
Stephanie Davis, Administrative Assistant
Stephanie Fritch Lilla, MD
Kate Garland, MD
Nicole Hart, RN, MS
Maggie Herrity, Nurse Clinician
Marvin Holmes-Leopold, MBA, MPH, HTC Operations Manager
Susan Kearney, MD Medical Director
Rachel LaQuere, RDN, LD, Dietitian
Nicole Leonard, RN, BS
Jennifer Lissick, PharmD, Pharmacist
Linda Litecky, RN
Kristin Moquist, APRN CNP
Steve Nelson, MD
Jessica Ovans, PT, DPT
Skye Peltier, PA-C, MPH
Sue Purdie, RN, BSN
Michael Sprehe, MD, MPH
Amy Toberman, APRN CNP

Mayo Comprehensive Hemophilia Center Mayo Clinic
Mayo 10-55E
200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726

Ivy Akogyeram, PharmD, Pharmacist
Aneel Ashrani, MD, MS
Renata Ducharme, Secretary
Amy Eckerman, RN
Sandy Heisler, Research Coordinator
C. Christopher Hook, MD
Dawn Inman, RN
Ariela Marshall, MD
William Nichols, MD
Deepti Warad, MBBS
Melinda Otto, LSW
Rajiv Pruthi, MBBS, Medical Director
Vilmarie Rodriguez, MD, Pediatric Hematologist
Dawn Rusk, RN
Deepti Warad, MBBS

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

Daniel Callaway, MD
George Maher, DO
Sam Milanovich, MD
KayeLyn Wagner, MD
Dan Steventon, PT
Wendy Jensen, CCLS
Nathan Anderson, MA, LSW
Kay Schroeder, RD

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

Mark Reding, MD - Medical Director
Helen McIntyre, MBA, FACHE - Executive Director
Marshall Mazepa, MD
Ricky Chan, PA-C
Skye Peltier, PA-C
Susan Curoe, RN, MS
Vicky Hannemann, RN, BSN
Kerry Hansen, RN, BS
Kim Baumann, MPT
Sarah Bray, Genetic Counselor
Shannon Nelson, Data Registrar
Amy Schadewald, MSW, LICSW, ACM
Jill Gilbertson, Intake Coordinator
Tim Boonstra, RPh, Pharmacist
Amy Marquez, CPhT, Pharmacy Coordinator
Jenny Noh, CPhT, Pharmacy Coordinator
Kate Winter, Supervisor of Quality & Research

Hemophilia Foundation Of Minnesota/Dakotas 2019 Board of Directors

Casey MacCallum, President
Minneapolis, MN

Kristina Rauenhorst, Vice President
Circle Pines, MN

Kris Manns, Treasurer
Hudson, WI

Donald Glascock
Rochester, MN

Susan Kearney, MD
Maple Grove, MN

Angie Klersy-Daniels
Big Lake, MN

Carson Ouellette
Fargo, ND

Ignacio Ramos
Chaska, MN

Staff

James Paist
Executive Director

Kerry Budinger
Administrative Assistant

Melissa Andrisani
Event Coordinator



**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

Current Calendar of Events

July 7-12, 2019	HFMD Summer Camp Camp Courage, Lake George, MN
July 18, 2019	Padelford Riverboat Cruise (Event is full) Harriet Island, St. Paul, MN
July 27, 2019	South Dakota Family Education Day Great Plains Zoo, Sioux Falls, SD
September 29, 2019	Step Out for Bleeding Disorders Fundraising Walk Harriet Island Pavilion, St. Paul, MN
October 26, 2019	Women's & Teens Education Event St. Paul Hotel, St. Paul, MN
November 16th, 2019	HFMD 1st Annual Symposium & Pizza Party Eagan Community Center, Eagan MN
Feb 22, 2020	HFMD Hearts of Hope Gala Metropolitan Club & Ballroom, Golden Valley MN
April 3-4, 2020	HFMD Annual Member Meeting Intercontinental Hotel, MSP Airport

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

GO SEEK. GO EXPLORE.
GO AHEAD.



Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

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**.



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:

<ul style="list-style-type: none"> – confusion – weakness – swelling of arms and legs – yellowing of skin and eyes 	<ul style="list-style-type: none"> – 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:

<ul style="list-style-type: none"> – swelling in arms or legs – pain or redness in your arms or legs – shortness of breath – chest pain or tightness – fast heart rate 	<ul style="list-style-type: none"> – 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.

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
 ©2018 Genentech, Inc. All rights reserved.

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



© 2018 Genentech USA, Inc. All rights reserved. EMI/061818/0106a
 HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
 The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
 The Genentech logo is a registered trademark of Genentech, Inc.
 All other trademarks are the property of their respective owners.

Genentech
 A Member of the Roche Group

Veinline

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

HFMD

750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363

info@hfmd.org

www.hfmd.org

 facebook.com/theHFMD

 twitter.com/hfmd

Standard
U.S. Postage
PAID
Twin Cities, MN
Permit # 7732

Join Us For HFMD's 9th Annual Walk Fundraiser "Step Out for Bleeding Disorders"



Sunday, September 29, 2019

Check-In/Activities 11AM

Walk 12PM - 2PM



NEW LOCATION!

Harriet Island Pavilion
St. Paul, MN



REGISTER, CREATE/JOIN A TEAM TODAY AT

<https://www.firstgiving.com/event/hfmd/2019hfmdwalk>



HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS