NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS





SUMMER 2020

### **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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for HFMD's 10th Annual

Step Out for Bleeding Disorders

**VIRTUAL Fundraising Walk** 

In light of the Coronavirus (COVID-19), and St. Paul Parks' restrictions on large gatherings, we have made the difficult decision to convert our Annual Walk into a VIRTUAL WALK. Instead of gathering together at Harriet Island Pavilion, we are asking Walkers, Walk Teams, Sponsors and Supporters to all Zoom in at 11:00 a.m. to bring our community together and get pumped up for the virtual Walk beginning at 12 noon. See our Walk website for Zoom log in and prize eligibility. You can also walk or donate anytime. While we are saddened to not hold our Walk in-person, the health and safety of our community is our top priority.

# SUNDAY, AUGUST 16TH

Zoom Kick Off 11:00 am - 2:00 pm



For more information on how to form a VIRTUAL team, register and/or donate click

**HERE** 



#### 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.

HEMLIBRA.

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

HEMLIBRA may cause the following serious side effects when ed with activ rated 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
- stomach (abdomen) or back pain
- swelling of arms and legs
- nausea or vomiting
- yellowing of skin and eyes
- feeling sickdecreased 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
   the symptoms of the second parts of the symptoms of the sympto
- arms or legs shortness of breath
- headache
- chest pain or tightness
- numbness in your face eye pain or swelling
- fast heart rate
  - 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
- OSE HEMILIBRA exactly as prescribed by your nearlinear 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.

- 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 does an prescribed.
- rou 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 laborate a track to the four 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
- ioint 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, 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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# **HFMD Patient Financial Assistance Program**

Our program is designed for patient/families facing one-time unexpected financial crisis. The program cam help with past due rent, utility bills, automobile repairs, food, and can help with some medical bills insurance won't cover, including some dental procedures. All financial assistance requests that we receive are first reviewed, vetted and submitted by the Social Workers of our affiliated Hemophilia Treatment Centers (HTCs), who also look at other potential resources of support. Our program does have some monetary limitations. If you are experiencing a financial crisis, we encourage you to contact the Social Workers of your HTC. This program is core to our mission, and we are grateful to the sponsors who help to fund it: Children's Hospital & Clinics of MN, The Hemophilia Alliance Foundation, Mayo Clinic, M Health/Fairview, Novo Nordisk & Sanford Health.

# **HFA Webinar**

Many things have been changing due to the challenging times we are facing and one is events are transforming into webinars. The Hemophilia Federation of America (HFA) reached out to us and wanted to offer a way for our members to continue to come together and learn, but from the safety of their homes. HFMD was delighted to know that we could continue to use the valuable information that HFA provides and happily accepted their assistance.

On April 14th HFMD and HFA offered a webinar to our members titled "Maintaining Your Mental Health in Uncertain Times: Let's Talk About It" presented by Debbie de la Riva. Debbie received a master's degree in counseling psychology from the University of Houston and became a licensed professional counselor in 1989. Her work experiences have included serving as a stress management therapist in a psychiatric hospital, managing a mental health resource department and was an Executive Director of an affiliate of Mental Health America. When her son was born with severe hemophilia in 1994, the entire de la Riva family quickly became involved with the bleeding disorders community on a local and national level. Debbie is a former Executive Director of the Lone Star Chapter of the National Hemophilia Foundation, past Co-Chair of NHF Annual meeting and a recipient of the Ricky Ray Award for her advocacy efforts. Her son, Jorge, attended hemophilia camp and ultimately became a camp counselor. Her daughter, Cristina, was elected to be a member of NHF's National Youth Leadership Institute and her husband, Jorge, served as the chairman of NHF's Board of Directors. In addition to founding Mental Health Matters Too, Debbie is a certified Mental Health First Aid Instructor and provides training to hemophilia treatment centers and chapters around the country.

HFMD was honored to have such a respected member of the bleeding disorder community share her and her family's story and give an overview of the basics of mental health including facts and myths surrounding mental health, warning signs, types of mental illness and what to do if you or someone you know is experiencing a mental health crisis. We hope those that attended the webinar found Debbie's presentation as mind opening and useful as we did.

Please stay tuned for more events where we will utilize the information and expertise that HFA has to offer our members.



# **Debbie de la Riva**, CEO at Mental Health Matters Too





# Ask the Provider Webinar

As the COVID-19 pandemic swept the globe, HFMD wanted to think of ways that we could still bring our community together in a safe and effective way. With Zoom being the "new normal" platform to hold group



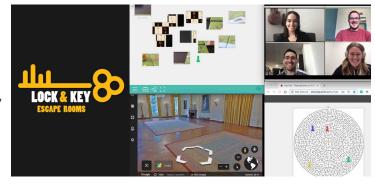
gatherings, it was a no brainer to host a webinar for our members. The big question was, what can we offer during this time that would benefit the attendees most? After a few committee calls, it was clear that there were so many questions and so many unknowns that we would hold a forum to ask Health Care professional your pending questions regardless of the topic.

On Thursday, May 5th, at 6:00 p.m. HFMD hosted our first Zoom Webinar, "Ask the Provider." Featured on the provider panel were: Dr. Susan Kearney (Children's), Dr. Mark Reding (M Health), Kim Baumann (PT, M Health), Dawn Rusk (RN, Mayo) and Amy Schadewald (Social Worker, M Health). It was an hour of valuable information as the attendees asked their pending questions to the panel. The experienced panel never skipped a beat and offered concise and knowledgeable responses that left the group feeling better informed and well equipped for the upcoming challenges that they may face.

It was not all information and no play, at the end of the webinar, each attendee was entered in a drawing to win a Dairy Queen Gift Card. We want to congratulate Kim Makela on winning the \$25 Dairy Queen Gift Card, we hope you have had the chance to enjoy a treat! We would like to thank the provider panel and all the attendees for making our first webinar a success! If you would like to view a recording of the webinar, please visit https://www.youtube.com/watch?v=g4gkuPlauOg

# Lock & Key Virtual Escape Room

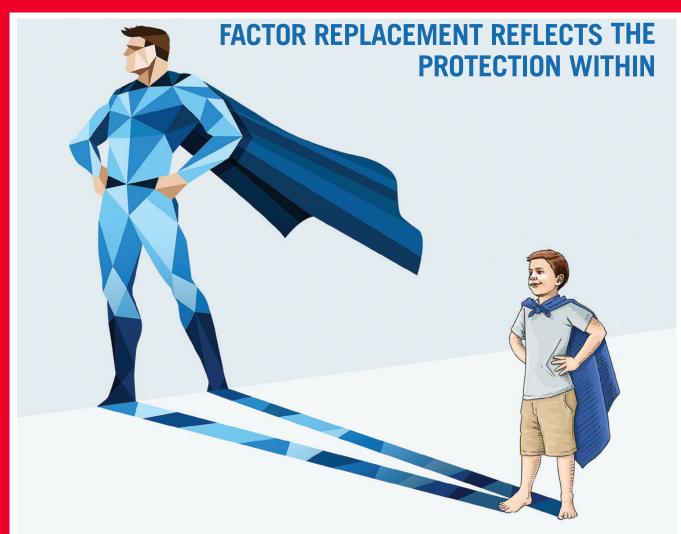
The amazing Lock & Key Escape Rooms Minneapolis graciously hosted HFMD last summer for a fun-filled in-person event last summer, so when we heard they were offering virtual escape rooms, we knew this was something we did not want to miss! On June 25th, 2020 we offered our members a fun night of participating in a virtual escape room hosted by our friends at Lock & Key.



The game our players needed to solve was "Uncle Milton's Inheritance." In this one hour long game, the participants were spilt into two groups where they were asked to come together with a sense of team-work, play, and cooperation. Once in their groups, they were told their mission: You and a group of friends are attending the online reading of the last will and testament of your late uncle Lester Milton, legendary game inventor, and eccentric millionaire. As you began the game, a lawyer informs you that the reading of will begins in one hour; any addendum's to the will must be submitted before then. She then sends you to a cryptic website. The final conclusion to the division of his estate will be as odd as the man himself.

During this game there was fun, laughs, and much deliberating. In the end, everyone escaped and can now say they are victors of a virtual escape room! Immediately after the game ended, participants were gifted a \$25 GrubHub gift card that was sent directly to their inbox so they could enjoy a dinner to accompany their victory. We would like to thank everyone who participated and Lock & Key Escape Rooms Minneapolis. Keep your eyes peeled for more fun events in HFMD's future plans!

By: Melissa Andrisani



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

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

# 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, Milkovic D, Elezovic I, Zabczyk M, Hutenby 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.

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# Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com** 

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

**BIOMARIN** 

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The HFMD gratefully acknowledges our donors who have given so generously. These are donations received from January 1st - June 30th, 2020.

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In memory of Sean Mathwig

Mott, Sue

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## 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, HTC Medical Director and Physician

Marvin Holmes-Leopold, MBA, MPH, HTC Programs and Operations Manager Allison Albright, HTC Program Coordinator Elizabeth Boegeman, LGSW, HTC Social Worker Latrice Daniel, CPhT, HTC Pharmacy Technician Chase Elgard, RN, Nurse Stephanie Fritch Lilla, MD, Physician Kate Garland, MD, Physician

Amy Goldstein, APRN, CNP, DNP, Nurse Practitioner University of Minnesota Health - Fairview

Nicole Hart, RN, MS, Nurse

Ashley Kinsella, Clinical Research Coordinator

Rachel LaQuere, RDN, LD, Dietitian

Jennifer Lissick, PharmD, HTC Clinical Pharmacist Jessica Ovans, PT, DPT, Physical Therapist

Skye Peltier, PA-C, MPH, Physician Assistant

Sue Purdie, RN, BSN, Nurse

Rachel Saunders, MS, CGC, Genetic Counselor Michael Sprehe, MD, MPH, Physician

Meghan Winans, HTC Administrative Assistant

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

Aneel Ashrani, MD, MS Darrin Christopherson, M.B.A., 340 Program Manager Renata Ducharme, Secretary Amy Eckerman, RN Sandy Heisler, L.P.N., Research Coordinator C. Christopher Hook, MD Dawn Inman, RN Ashley Losing, Pharm.D., R.Ph. Ariela Marshall, MD

William Nichols, MD 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 Kasey Gauthier, RN, CPHON George Maher, DO KayeLyn Wagner, MD Dan Steventon, PT Wendy Jensen, CCLS Nathan Anderson, MA, LSW Kay Schroeder, RD

**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 Vice President, Operations Kim Baumann, PT, MPT, Physical Therapist Tim Boonstra, RPh, Pharmacist in Charge/Manager Sarah Bray, Genetic Counselor Mya Cajas, Intake Coordinator/Financial Specialist Kenneth Caldwell, Certified Medical Assistant Ricky Chan, PA-C, Physician Assistant Susan Curoe, RN, MS, Nurse Clinician Jill Gilbertson, Intake Coordinator Vicky Hannemann, RN, BSN, Nurse Clinician Kerry Hansen, RN, BS, Nurse Clinician Maggie Herrity, RN, Nurse Clinician Marie Leirmo, RN, BSN, Research Coordinator

Amy Marquez, BS, CPhT, Operations Manager Marshall Mazepa, MD, Physician Jenny Noh, CPhT, Pharmacy Coordinator

Skye Peltier, PA-C, Physician Assistant

Amber Ramirez-Acosta, Intake Coordinator/CMA Amy Schadewald, MSW, LICSW,

ACM, Social Worker

Makada Williams, CPhT, Pharmacy Technician

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> Kris Manns **Board Member**

Ignacio Ramos Board Member

#### Staff

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Kerry Budinger Administrative Assistant

> Melissa Andrisani **Event Coordinator**



# **Legislative News**

Co-pay Assistance Under Attack – Again

A troublesome ruling was issued in May by the federal Department of Health & Human Services in Washington DC. This ruling would allow insurers to resume a highly questionable practice affectionately known as the Accumulator Adjuster Program which is more easily understood as health insurance companies and PBMs not counting third party co-pay assistance coupons to patients toward the patient's annual out-of-pocket co-pay.

This hurtful action grew out of an administrative ruling in Minnesota in June of 2016 when our state Departments of Health & Human Services & Department of Commerce together issued a directive allowing this practice to occur. The original intention of this action was to encourage consumers to use generic drug equivalents, but as it applies to our community; there are no generic equivalents. Not long after this state directive, HFMD began receiving calls from members who were shocked when the co-pay assistance manufacturer's coupon they received was not counted toward their out of pocket cost.

HFMD contacted the Minnesota Department of Commerce to challenge the legality of this action, and was extremely disappointed in the Department's evaluation that this was indeed legal. We then opened dialogue with the MN Council of Health Insurers and commended the companies who have chosen not to utilize the Accumulator Adjuster Program, and to urge those who are to stop. Ultimately they are hurting our members and patients with other rare diseases in their ongoing battle to persuade drug manufacturers to lower their prices. Unfortunately this practice spread to use on a national scale. NHF & HFA stepped in along with other rare disease advocacy groups and convinced HHS in 2019 to reword the policy language so patients could resume using manufacturer coupons toward their out of pocket co-pay. One year later, they reversed their decision.

If you have been affected by this, please contact the HFMD at info@hfmd.org. We want to share personal stories to tell HHS how this short-sighted ruling negatively impacts patient families with rare diseases.

By James Paist

# The Veinline Newsletter is Going Paperless in 2021!

The HFMD Veinline Newsletter will be going paperless in 2021! The Veinline is one of the ways we keep our community informed of our programs and events. However, each year as our community grows we are printing and mailing more and more copies. In an attempt to reduce our printing and postage costs, as well as reduce our paper and ink usage we're asking community members to provide an email address where we can send the quarterly Veinline electronically. You can also access a copy of the most recent issue of our newsletter, as well as past issues, on our website at hfmd.org/news.

So, don't delay! **Starting with our January 2021 issue, we will no longer be printing and mailing hardcopy newsletters.** To continue to be informed and updated on our programs and events, please provide us your email address by sending it to info@hfmd.org.

# Minnesota 2020 Legislature Recap

- Prior Authorization
  - May 27th- Governor Walz signs bill into law that brings a number of reforms to prior authorization (Please see HFMD website under News/Advocacy for more detail).
- Access to care
  - Blue Ribbon Commission By October 1, 2020, the BRC is charged with "developing an action plan to improve program efficiencies, produce savings, and promote better outcomes in health and human services"
- Copay issues
  - https://www.dhs.state.mn.us/main/idcplg?IdcService=GET\_DYNAMIC\_
     CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS16 146878
  - Updated Jan 30, 2020: Minnesota healthcare policy allows providers to bill recipients of care for certain circumstances, but does not allow providers to accept or request payments from recipients, family, or anyone on behalf of the recipient for: Base rate changes made by MHCP (other than copays and spend downs), missed appointments, provider contract reductions, services covered by MHCP, unless an MHCP copay or cap applies
- Misc. policy change
  - Extension of some COVID-19 waivers through June 2021
  - Includes an expanded definition of "telemedicine" so certain providers can provide care over the phone
  - Allows for a providers first visit with a patient to be over the phone
  - Allowing Children's Health Insurance Program (CHIP), Medical Assistance or MinnesotaCare enrollees to have more than three telemedicine visits in a week; and
  - Requiring managed care plans to follow these policies. This includes the expansion of providers who are permitted to provide services through telephone and video visits to include the following providers and their tribal provider equivalents:

This recap information was gathered and prepared by Brian Duval, HFMD Volunteer



# **Current Calendar of Events**

July 12 – July 17, 2020 Kids Virtual Summer Program

This program consists of 1 hour sessions for different age groups

each day of the week.

July 25, 2020 South Dakota Family Education Day

GreatLIFE Suburban Lanes Family Fun Center, Sioux Falls, SD

August 16, 2020 "Step Out for Bleeding Disorders" Virtual Walk Fundraiser

Zoom Call Kickoff - details to follow

November 14, 2020 HFMD Industry Symposium

Eagan Community Center, Eagan, MN

February 20, 2021 Hearts of Hope Gala

Graduate Hotel, Minneapolis, MN

April 9-10, 2021 Annual Members Meeting

Intercontinental Hotel Airport

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

Keep track of your bleeds, infusions, and activity.

# HemMobile

with enhanced activity tracking

### The little app is getting bigger.

Talk to your doctor about HemMobile™—and which activities may be right for you.









- Share single consolidated reports with your treatment team
- Set reminders for resupply, appointments, etc
- Sync with fitness apps and wearable devices







# Hemophilia can be difficult. Tracking it shouldn't be.

HemMobile™ was designed to help you keep track of your bleeds, infusions, and factor supply.\*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level as well as your dosing regimen.



For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday from 8:00 AM to 8:00 PM Eastern Time.

\*HemMobile™ is not intended for curing, treating, seeking treatment for managing or diagnosing a specific disease disorder, or any specific identifiable health condition. iPhone is a trademark of Apple Inc., registered in the US and other countries. App Store is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.

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# **Renew Your HFMD Membership Today**

Dear Community Members,

On behalf of the Hemophilia Foundation of Minnesota/Dakotas (HFMD), I hope that you and your family continue to be well and are enjoying some of the freedom that summer weather makes possible.

During this period of continued precautions due to COVID-19, HFMD has strived to continue offering programming that meets social distancing requirements and keeps our community members informed and engaged with HFMD and each other. These include:

- 1. We continue to provide emergency financial assistance to community members experiencing financial hardship.
- 2. We held a webinar featuring a number of medical staff members from our affiliated Hemophilia Treatment Centers to answer community members' questions about continued care and the impact of COVID-19 on those with bleeding disorders.
- 3. We are working with Children's Healthcare to offer online programming for kids from all clinics to continue engaging with medical staff and each other as they would at camp.
- 4. We hosted a virtual Escape Room activity that drew community members together to have fun and challenge each other in a fun game.
- 5. We are continuing to research and develop future programming that will keep you, our community members, engaged and informed.

Since 1965, the HFMD has been a resource for the bleeding disorders community. We dedicate ourselves to advancing the quality of life for people living with hemophilia and other chronic bleeding disorders by providing a broad range of programs and services. These programs and services are funded, in part, by Annual Membership Dues from individuals and families. Because most of our membership applications are generated at our Annual Members Meeting; which was canceled due to social distancing requirements, our Membership numbers have suffered and are down substantially.

Our foundation is a small local 501(c)(3) charity with a 55 year track record of being the only resource serving the bleeding disorder community in Minnesota and South Dakota, and we are now in danger of closing our doors and ceasing to support our members. A membership donation to us has an immediate and substantial impact on the continuance of our foundation programming and support of community members that need help.

You are most welcome to contact me at the HFMD office if you ever have questions or comments about the organization.

James Paist, Executive Director jamesp@hfmd.org

# NATIONAL CONFERENCES GO VIRTUAL: Free for Everyone!

#### A Note from NHF:

Every year NHF's Bleeding Disorders Conference brings together thousands of families and passionate professionals for in-person education and networking. This year, in order to keep our community safe and help prevent the spread of COVID-19 we have made the decision to host the 2020 Bleeding Disorders Conference virtually.

The Bleeding Disorders Conference will be held from August 1 to August 8, 2020.

As we work through the details, we will keep you informed as the new format of the conference develops.

Our virtual educational conference will be full of interesting sessions and fun networking activities for all members of the bleeding disorders community. Everyone will be able to find something to pique their interest or strengthen their professional skills. Affected individuals and families will find sessions on nearly every aspect of living with a bleeding disorder, from the basics of hemophilia and VWD to the latest in gene therapy treatment. Our providers will find information on the latest treatments and techniques, and chapter staff will be able to learn more about best practices and ways to strengthen their local organizations.

One of our greatest strengths is our ability to adapt and reinvent ourselves when needed. Our team is working tirelessly to bring the 2020 Bleeding Disorders Conference to you, in the safety of your own home.

For more information and to register for the event visit NHFs event site at:

https://events.hemophilia.org/ehome/bleedingdisordersconference/welcome/.

#### A Note from HFA:

The global health pandemic caused by Covid-19 has forced mankind to rethink how we approach almost every facet of life. While we know that gathering in person in Baltimore would provide us all with a much needed sense of support and community, the reality is that we too must adapt. Now, more than ever before, the need to come together and support each other is paramount.

We're working hard to plan a virtual Symposium of epic proportions that will honor our longstanding tradition of providing quality educational programming, access to resources, and opportunities for the bleeding disorders community to connect with and support one another.

#### What you'll find at HFA's Virtual Symposium:

- The same great sessions, available online, both live and recorded with trusted bleeding disorders experts
- A networking lounge and ways to connect with your friends
- An interactive Exhibit Hall with opportunities to chat with industry partners
- A welcome session with Keynote Speaker Lindsay Vos
- Our annual awards ceremony with a special announcement about Symposium 2021
- Watch and listen to sessions on your own time throughout the week

HFA's Annual Symposium will be held August 24 to August 29, 2020.

For more information and to register for the event visit HFAs event site at: https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/.

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NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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### 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

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# Please join the

# HEMOPHILIA FOUNDATION

OF MINNESOTA/DAKOTA

for our

SECOND ANNUAL

## **INDUSTRY SYMPOSIUM**

This is a family friendly event with **childcare provided**.

During the Symposium companies will be giving presentations on the latest treatment and care for bleeding disorders.

# Saturday, November 14th 2020

9:00 am (sharp) - 4:00 pm

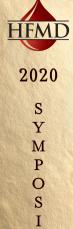
# City of Eagan Community Center

1501 Central Pkwy, Eagan, MN 55121

### THE SYMPOSIUM FEATURES:

A Pizza Party
Indoor Playground
Raffles
Swag Bags

WIN PRIZES!



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