



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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Dear HFMD Member/Families,

We hope you are staying safe and healthy during these challenging times. Inside this issue, you will see a combined announcement and tip sheet from our affiliated Hemophilia Treatment Centers (see page 10). The Covid 19 virus has impacted nearly every facet of our lives including the cancellation of two major HFMD events; our Rare Disease & Bleeding Disorders Awareness Day at the Minnesota state capitol on March 20th, and our Annual Meeting which had been set for April 3rd & 4th at the new MSP Intercontinental Hotel. Although these were necessary cancellations, we want our community to know we are still there for you.

In adapting to social distancing and sheltering at home, HFMD has been encouraging members to stay in communication with us, and with each other through our Facebook, Twitter, and Instagram. We will also be hosting a series of Community Education meetings via Zoom and other virtual outlets for you. Please join us on April 14th at 6:30 p.m. as we partner with the Hemophilia Federation of America to host a local Zoom conference where the topic will be your emotional well-being.

Due to the scale of this global epidemic, so many upcoming events remain uncertain and in doubt. With respect to upcoming HFMD events, including our Summer Camp in July, we will be taking direction from state and federal authorities including the CDC, and our affiliated HTCs. We will let you know as soon as we know if any other HFMD programs or events need to be canceled due to the Covid 19 virus. An announcement on the status of our 2020 Summer Camp is expected in early May. For now, we hope you will engage with us, and other member/families through our upcoming Zoom sessions, and social media. We will get through this together!

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.

LIFE HAPPENS
AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen. Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
 - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
 - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/ congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

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[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

| | | |
|-----------------|-------------|-----------------------|
| cough | headache | joint swelling/aching |
| sore throat | fever | itching |
| unusual taste | dizziness | hematoma |
| abdominal pain | hot flashes | swelling of legs |
| diarrhea | chills | runny nose/congestion |
| nausea/vomiting | sweating | rash |

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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20th Annual Hearts of Hope Gala (2/22/20)

This was a special year for our annual gala as we celebrated the 20th year of auctions, dining and dancing. We could not have chosen a better venue for this celebration than the Metropolitan Ballroom and Clubroom in Golden Valley. The newly remolded space gave a feeling of modern meets old with 1930's themed intricate wallpaper and wood details freshly painted white. Brass chandeliers hung above the main area while a stunning light installation over the stage resembles a work of art.

The new entry way gave guests plenty of space to check-in, receive their bid paddles and buy their beads to participate in a new way to win this year, a game of heads or tails. With bid paddles in hand and silver beads around their necks, guest entered the expansive reception space where they were welcomed by two bars and a table filled with charcuterie hors d'oeuvres. Off the reception space was a bright and welcoming room lined with numerous items for our silent auction. Guests were able to place their bids on items such as Timberwolves tickets, fun activities for the family and plenty of baskets filled with goodies. Included in this room was the UofM "Wine Wall." For years the wonderful staff there have collected donated bottles of wine and ran this raffle for guests to win and take home superb bottles of wine.

When the last call for the silent bid was heard, guests were ushered to their seats in the breathtaking main ballroom. There they were greeted by our Executive Director, James Paist, who introduced our Master of Ceremonies for the 8th year in a row, Dick Bremer. Next our auctioneer, Matthew Schultz, kicked things off with the heads or tails game where the guests who purchased beads stood and placed their hands on their heads or "tails" while Matthew flipped a coin. The last one left was the winner of a \$250 gift card to Continental Diamonds and a bottle of Grey Goose.

The evening took a more serious tone as we moved into the Fund-a-Need. This year was focused on our Financial Assistance Program and our Summer Camp for Kids. Once Matthew asked for the first amount to be given, bid paddles shot up around the room as our generous guests donated to our Summer Camp and Emergency Assistance Programs. The paddles were not put down because we went straight into our live auction. This year our live auction was packed with fun items to bid on including a pair of kayaks, nights out, the enormous stuffed teddy bear and our Twins package, just to name a few.

Just when we thought it was time to head to the dance floor, our Board President, Casey MacCallum stormed the stage and surprised everyone by presenting James Paist with a plaque to commemorate his 15th year dedicated to serving the bleeding disorder community. The crowd erupted in applause to show James their gratitude and in an odd turn of events, he was speechless. With the energy high and night still young, guests made their way to the dance floor to close out the evening with great songs, great friends and much laughter.

This event is not only meant for fun and entertainment, but plays a crucial part in providing the funds that HFMD needs in order to continue the programs we provide and the financial assistance to our members in need. We would like to thank all of our wonderful sponsors, volunteers and everyone who attended the gala this year. You are the reason we are able to do what we do and continue to serve our amazing community.

By Melissa Andrisani

Educational Dinner at Bonfire (1/23/20)

A snowstorm could not keep our members from the presentation on “Cognitive Conversations” and wonderful food from Bonfire that Sanofi Genzyme treated them to on January 23rd. Sanofi’s Community Relations & Education Manager for Rare Blood Disorders, Jess Scofield Hutchison, welcomed the group and introduced the speaker for the evening Sanofi’s Gretchen McTigue.

Gretchen was an amazing speaker who took the time to get to know the whole group by name. She encouraged great conversations that inspired the attendees to ask in-depth and important questions. By the end of the evening, Gretchen resembled an educated friend more than a presenter.



During the presentation dinner was served. With all the conversation going on, it was hard to get a bite in, but when they did, attendees were delighted by salmon, prime-rib, rotisserie chicken and a quinoa power bowl. To finish the evening, petite cheesecakes in assorted flavors from chocolate to raspberry were enjoyed with none left to spare. We would like to thank Sanofi Genzyme, Jess Scofield Hutchison, Gretchen McTigue, Bonfire and the attendees for braving the storm to learn and dine with us!

By Melissa Andrisani

Common Factors Topgolf Event (1/11/20)

Twenty-five attendees gathered in a Topgolf suite ready for a day of education and fun on January 11th. CSL Behring was our gracious host and their Coagulation Products Manager, Jason Clarin, started the day with a great video of their program “Gettin’ In the Game Junior National Championship” where kids and teens with a bleeding disorder from across the United States train together in golf, swimming and baseball during a weekend that incorporates education and friendly competition.



Next, special guest and Common Factors Advocate, Perry Parker who is a PGA Professional, father and Hemophilia A patient, gave a presentation on having a bleeding disorder and being a professional athlete. To complete the presentation portion of the day, Perry gave a thorough and valuable lesson on how to hold a golf club and achieve the perfect swing.

The smell of chicken fingers and cookies grabbed the attention of the attendees and soon everyone was up on their feet and selecting a plate of wonderful treats to dine on. After the meals were finished and everyone had gained enough fuel for the game, they headed outside into the wintery cold (space heaters provided) to take part in all the fun Topgolf has to offer. We would like to thank CSL Behring, Perry Parker, Topgolf and the attendees for a day of learning and play!

By Melissa Andrisani

GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover **HEMLIBRA®**.

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:

| | |
|------------------------------|----------------------------------|
| – 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.

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

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
 This Medication Guide has been approved by the U.S. Food and Drug Administration
 Revised: 10/2018



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These are donations received from January 1st - March 31st, 2020.

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Wilson, Seth

\$50 - \$99

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Hansen, Kerry
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Hughes, Richard & Barbara
Johnson, Rick & DeeDee
Kinsella, Dana & Ashley
Olsen, Lee
Reeves, Kathi
Rued, Catrina
Schadewald, Amy
Waldeland, Trevor & Pam

Up to \$49

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Mott, Sue
Seidl, Victoria
Hayes, Scott
Mayer Area Lions Club

In memory of Sean Mathwig

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

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Mayo Comprehensive Hemophilia Center

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

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Jenny Noh, CPhT, Pharmacy Coordinator
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Hemophilia Treatment Centers' Response to COVID-19

As a united group, your HFMD affiliated Hemophilia Treatment Centers (HTCs) wanted to send this message to assure the HFMD bleeding disorders community of our presence during this challenging and unprecedented time. There is staff available at all locations to address your needs and help answer questions and direct you to resources.

Each individual HTC has put into place TEMPORARY operational changes in an effort to keep patients, families and staff safe. Please refer to your home HTC listed below for specifics on hours of operation and contact information. Changes to in-person visits have been made, please contact your HTC with specific questions.

HTC Contact information:

Center for Bleeding and Clotting Disorders, M Health Fairview

Monday-Friday 8:00-4:30: call 612-273-5005

After hours and weekends: call the hospital switchboard at 612-273-3000 and have the on-call hematologist paged.

Children's Minnesota-Center for Bleeding and Clotting Disorders

Monday-Friday 8:30 to 5:00: call 612-813-5940

After hours and weekends: call 612-813-5940 and have the on-call hematologist paged.

Mayo Comprehensive Hemophilia Center

Monday-Friday 8:00-5:00: call 507-284-8634, leave message or if urgent ask that a nurse be paged.

After hours and weekends: call Mayo operator at 507-284-2511 to reach Adult and Pediatric Hematology on call.

Sanford Children's Specialty Clinic (Sioux Falls):

Monday-Friday 8:00-4:30: call 605-312-1000

After hours and on weekends: call 605-312-1000 to reach after hours call center and be paged to physician.

Factor production, supply and distribution has currently not been affected in ANY way.

The NHF website has links from each of the pharmaceutical companies about individual products.

We want to stress the importance of taking care of your mental health

The outbreak of the coronavirus disease 2019 (COVID-19) may be stressful for people. It can be overwhelming and cause strong emotions with everyone reacting differently.

Stress during an infectious disease outbreak can include:

- Fear and worry about your own health and the health of your loved ones
- Changes in sleep or eating patterns
- Difficulty sleeping or concentrating
- Worsening of chronic health problems
- Increased use of alcohol, tobacco, or other drugs

Things you can do to support yourself:

- Take breaks from watching, reading, or listening to news stories, including social media. Hearing about the pandemic repeatedly can be upsetting.
- Take care of your body. Take deep breaths, stretch, or meditate. Try to eat healthy, well-balanced meals, exercise regularly, get plenty of sleep, and avoid alcohol and drugs.
- Make time to unwind. Try to do some other activities you enjoy.
- Connect with others. Talk with people you trust about your concerns and how you are feeling.
- Call your primary care provider or your HTC social worker if stress gets in the way of daily activity for several days in a row.

The following links provide information on reducing stress in yourself and others:

- [Sharing the facts](https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/share-facts.html) about COVID-19 and understanding the actual risk to yourself and people you care about can make an outbreak less stressful.
<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/share-facts.html>
 - When you share accurate information about COVID-19 you can help make people feel less stressed and allow you to connect with them.
- Learn more about [taking care of your emotional health](https://emergency.cdc.gov/coping/selfcare.asp).
<https://emergency.cdc.gov/coping/selfcare.asp>
- Reference more detailed information from the CDC on managing stress and anxiety.
<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html>

Here are some additional resources regarding COVID-19:

National Hemophilia Foundation (NHF)
Hemophilia Federation of America (HFA)
Minnesota Department of Health (MDH)
Centers for Disease Control (CDC)
World Health Organization (WHO)
United Way



Explore **HEAD-TO-HEAD** Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi**[®] and **Eloctate**[®].

Visit [PKStudies.com](https://www.pkstudies.com) to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

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antihemophilic factor
(recombinant) PEGylated-auid
LET'S GO

Current Calendar of Events

| | |
|-------------------------|--|
| July 12 – July 17, 2020 | HFMD Summer Camp Camp Courage N, Lake George, MN |
| July 25, 2020 | South Dakota Family Education Day GreatLIFE Suburban Lanes Family Fun Center, Sioux Falls, SD |
| August 16, 2020 | 10th Annual Step Out for Bleeding Disorders Walk Fundraiser Harriet Island Pavilion, St. Paul, MN |
| November 14, 2020 | HFMD Industry Symposium Eagan Community Center, Eagan, MN |

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

* Events subject to cancellation based on government regulations regarding COVID-19.
Please watch our website

Keep track of your bleeds, infusions, and activity.

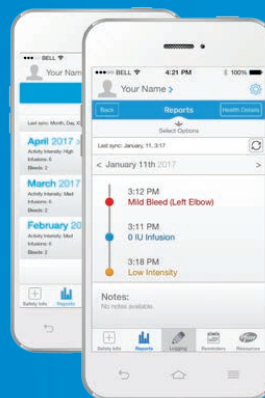
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with *enhanced* activity tracking

The little app is getting bigger.

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



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



Download the app,
pair your device,
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For iPhone® and Android™

**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.
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is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.



This year, more than 450 participants of the bleeding disorders community gathered on Capitol Hill in Washington D.C. for National Hemophilia Foundation's annual Washington Days advocacy event February 26th-28th. Minnesota's group consisted of some fresh, new faces and some experienced advocates. Our day started with coffee and a meet and greet with Senator Amy Klobuchar's staff and an inspiring video message from the Senator herself. Five more meetings followed, speaking to legislative assistants from the offices of Senator Amy Klobuchar, Senator Tina Smith, Representative Tom Emmer, and Representative Ilhan Omar.

I was feeling extremely nervous, but fortunately the NHF has been organizing these yearly Washington Days events, and they took great care in providing us with the information that we needed. The NHF ran some great introductory sessions for us on the afternoon that we arrived, along with keeping us well fed and hydrated. The next day, our group had the privilege of having a great resource from NHF along with us for the day. Kate, who is originally from Minnesota, fit in wonderfully with our group, which consisted of myself, Kris Rauenhurst, HFMD Board Vice President, Casey MacCallum, HFMD Board President, and Allison and Meghan from Children's. NHF not only provided the talking points for the day but were instrumental in setting up all the meetings for us.

There was 2 main talking points that we shared with both the Senate side and the House side. NHF and the bleeding community was asking all Members of Congress to support policies that ensure access to comprehensive insurance and health care services that people with bleeding disorders need to live healthy,

productive lives. Access Act Support federal hemophilia programs at CDC, HRSA and NIH that support the bleeding disorders community. HRSA Maternal and Child Health Bureau Hemophilia Program, which provides funding to hemophilia treatment centers and allows Participation in the 340B Program, which supports comprehensive care CDC Division of Blood Disorders, which supports critical surveillance and prevention activities NIH National Heart Lung and Blood Institute, which funds high-priority research on bleeding disorders and their complications. The second ask was support policies to improve access to skilled nursing facilities for Medicare beneficiaries with bleeding disorders House: Co-sponsor H.R. 5952, the Hemophilia SNF Access Act and in the Senate: Co-sponsor S. 3233, the Hemophilia SNF.

Despite not being political, I found participating in Washington Days very inspiring. It was another eye opener for me on a different level. I have participated in our local HFMD Day on the Hill at the Minnesota Capitol but never had the chance to tell my story and how support for these programs impact my family. I was hesitant at first, thinking I don't have much to contribute but by the end of the day things had shifted. I was noticing that the individuals we met with wanted to hear my stories and see the pictures of us infusing our son. I truly think the stories of how having access to care impacts our family was well received. I recounted a time when we didn't have that access to our factor and the ER visit that was a result. I believe that is what was needed to make our voices heard. 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 may not know their names, but I felt a sense of peace that we have a voice and we can be heard to enable us to 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. Even with some 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. While HFMD does an excellent job to get our communities concerns to the table, it needs the support from members of our community to stand up to ensure that our voice resonates through the halls of not only the National Capitol but our State Capitol.

By Kris Rauenhorst

2020 HFMD Scholarship Applications

The Hemophilia Foundation is accepting scholarship applications for post-secondary education from now until June 1st.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota or South Dakota, or being a patient of one of the Hemophilia Treatment Centers in these states, and be a participant in HFMD programs and services, and (3) be accepted into a post-secondary educational program.

More information and forms for this scholarship and information on additional scholarships is available online at <https://www.hfmd.org/resources/scholarships/> or by calling the HFMD office at 651-406-8655 or 1-800-994-4363.

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NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
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HFMD Symposium Report November 2019

The HFMD held our first Industry Symposium on Saturday, November 16th at the Eagan Community Center. Historically we do not host or participate in branded company programs. So with a variety of new treatments available from manufacturers, HFMD decided to hold a one day forum where companies could present the information about their new treatments for bleeding disorders. There were options to present and exhibit, or just exhibit.

Like all HFMD events, we wanted to make it a fun time for all in addition to the presentations. Children 12 and under got to experience “the Blast” Indoor playground under the direction of Child Life Programming expert Vicki Neis. Vicki and her Team who created a fun and educational experience for the kids, and HFMD Event Coordinator, Melissa Andrisani held a series of thought provoking games with our teens at this event.

Before each presentation, drawings for prizes were held to add some intrigue and excitement to the event. Everyone got a nice break over the lunch hour where we hosted a pizza party for all with pizza by Green Mill which was thoroughly enjoyed by all.

As a part of our “get to know em” campaign, several HFMD Board members spoke on stage to share their personal story in how they got involved and became a member of our Board. It was quite compelling to hear the stories of Board members who are all so passionate and dedicated to our cause. Our Board speakers included Casey MacCallum, Kris Rauenhorst, Kris Manns, Carson Oullette, and Donald Glascock.

It was a good balance to hear Board member stories in between the seven presentations we had; each twenty minutes or less. This included presentations from Bayer, CSL Bering, Genentech, Novo Nordisk, Sanofi Genzyme, Takeda, and the Hemophilia Alliance. Companies who exhibited only were Diplomat, Factor One Source, and Pfizer. The HFMD would like to thank all of our member families who attended, Board members, presenters, and exhibitors for helping to make this a fun and successful event. Please mark your calendars for November 14th, 2020 as we return to Eagan for our 2nd annual Symposium.

By James Paist