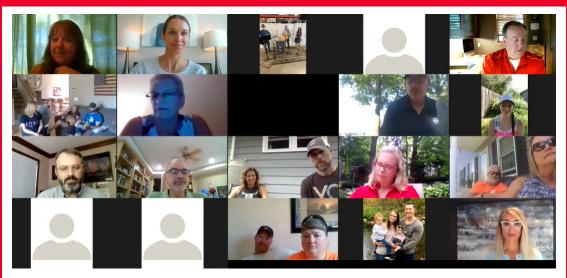
NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS





FALL 2020



#### HFMD MISSION We dedicate ourselves to

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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Gala Date changed to May 1st 2021

#### **HFMD Walk 2020**

Due to the social distancing restrictions from the city of St. Paul, we converted our Walk from in person at the Harriet Island Pavilion to a virtual Walk where this bleeding disorders community came together via Zoom to raise donations with a two-mile Walk at each family and participants choosing.

So, at 11:00 a.m. on Sunday August 6th our community came together to support the HFMD; community member Walk Teams, HTC clinic staff, volunteers and sponsors. HFMD Event Coordinator Melissa Andriansani not only ran master control of our Zoom session, she did



a wonderful job in opening and hosting the event as the Moderator. I went on the front end to share some words of encouragement with our Walkers and Walk Teams, and took a moment to also thank all of our generous donors and sponsors.

Then Doctor Rajiv Pruthi, Medical Director of the Mayo Clinic HTC took to the virtual stage to share important information and words of wisdom in how to stay safe during this pandemic. Then, it was the namesake of Team Carson, who put together a super-creative video about 15 year old Carson and his family and their involvement with the HFMD over the years. Way to go Carson and thank you for doing that!

Like all HFMD events, we strive to make sure everyone has fun. And thanks to HTC Social Worker from Sanford Health Sioux Falls and his two very talented band-mates played a few sets of classic acoustical songs that some of Walkers and Teams danced along too. Short Notice stole the show and really helped to make this a fun event for all who streamed in.

Also hailing from Sanford Childrens- Sioux Falls, SD, Dr. Brianna Murphy shared a very thoughtful and uplifting presentation on playing sports safely, incorporating some of the ratings of sports from NHF's Play It Safe guide for playing sports while having a bleeding disorder. Also sharing their family story for this event was defending, and now still defending 1st place fundraiser Team, Team Naumann.

It was inspiring to hear their story and to see Team Naumann enjoying the outdoors getting ready for their walk on a lovely summer day.

Seven different sponsors each shared information with the group during their time-slot, and time was taken for a raffle drawing for a pair of Airpod headphones before PT Kim Baumann got out group limber and stretch out with a condensed PT session. HFMD Board President, Casey MacCallum and his two daughters got our group pumped up to go out and do their two mile Walk in various parts of Minnesota and South Dakota.

When we reconvened, the top 3 fundraising Teams were announced/ 1st place Team Naumann, 2nd Place Team Carson, and 3rd place Team Charlie. HFMD is so grateful to all of the Teams, supporters, sponsors and donors who together helped to raise over \$44,000 for the HFMD and our 10th annual Walk fundraiser. As part of our thanks to all Walk supporters and participant, each were given a DQ gift card. As we wrapped things up, Short Notice helped close this fun virtual event with two more songs that everyone enjoyed.

By James Paist







# Exploring the science behind gene therapy research

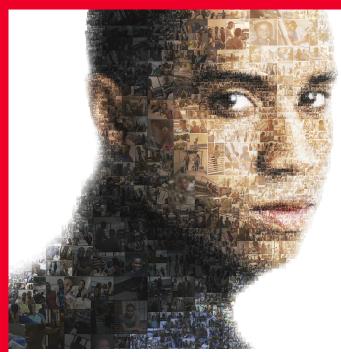
Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, 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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**ADYNOVATE** [Antihemophilic Factor (Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.\*

AdynovateRealLife.com

#### HEMOPHILIA A IS A PIECE OF YOU.

#### NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week. 1,2

> \*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

No actual patients depicted.

#### ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds2

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)<sup>2</sup>

- Children Under 12 Years: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment?
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median<sup>†</sup> overall ABR<sup>†</sup> of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

Adolescents and Adults 12 Years and Older: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups<sup>2</sup>

- 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
- 0 bleeds in 40% (40 out of 101 per-protocol§ patients) during 6 months on twice-weekly

\*Median is defined as the middle number in a list of numbers arranged in numerical order.

\*ABR=amnualized bleed rate, the number of bleeds that occur over a year.

\*Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

#### **ADYNOVATE Important Information** What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### **DETAILED IMPORTANT RISK INFORMATION** Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- · Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be

#### What should I tell my HCP before using ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not

#### What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center

#### What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE?

• The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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 ADYNOVATE on the following page and discuss with your HCP.

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

References: 1. Valentino L.A. Considerations in individualizing prophylaxis in patients with haemophilia A. Haemophilia. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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#### Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. 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 ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADYNOVATE so that your treatment will work best for you.

#### What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

#### Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

#### How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 ADYNOVATE by themselves or with the help of a family member.

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

#### How should I use ADYNOVATE? (cont'd)

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

#### What should I tell my healthcare provider before I use ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

#### What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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.

The common side effects of ADYNOVATE are headache and nausea. 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 ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

#### What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE 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 ADYNOVATE. The FDA-approved product
labeling can be found at www.ADYNOVATE.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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## HFMD & Colburn-Keenan Foundation "Family Camping Package"

by Melissa Andrisani

Due to the risk of the Coronavirus (COVID-19), we unfortunately had to cancel our Bleeding Disorders Camp this year. We were extremely saddened to have to make this decision, but as always, our members' health is our main priority.

HFMD's staff knew that something needed to be done to keep the excitement of Camp going strong and that is where the Colburn-Keenan Foundation came in. The Colburn-Keenan Foundation is a charitable organization dedicated to improving the health and well-being of individuals and families living with chronic illnesses, with priority placed on those living with bleeding disorders. They graciously give out grants to worthy causes and our Event Coordinator, Melissa, took this opportunity to write a grant request of why our Campers deserve to have a camping experience that they missed due to COVID-19. She proposed sending a "Family Camping Package" that consists of educational materials, a s'more maker, s'more ingredients, campfire popcorn and a camp board game for the whole family. The Colburn-Keenan Foundation agreed that our Campers deserved this package and granted us with the funds to support our request.

We are extremely grateful and excited that The Colburn-Keenan Foundation was so generous and we hope that we hope that this package brought an experience that keeps the spirit of Camp going strong.







#### **Virtual Summer Program**

By Allison Albright/ HTC Program Coordinator Children's Minnesota

The Virtual Summer Program Week was a great success! Thank you to all of the wonderful campers that participated in the fun week. Although we could not meet in our traditional camp setting, it was so nice to have everyone together for a little taste of camp at home.

We kicked off the program with games and a scavenger hunt on Monday. Campers had to retrieve an item and bring it back to the screen first in order to win. Tuesday was followed with an educational session brought to us by Dr. Sue Kearney from Children's. Campers learned about the components of blood and made their own blood model using corn syrup and candy! We had the talent show on Wednesday where our campers showed off their incredible talents. There was wall-climbing, basketball-shooting, golf-swinging, and so much more! On Thursday, we said goodbye and reminisced on the week we had. Campers and staff alike are already looking forward to the next time we are able to get together.

Thank you to all parents and families for their involvement in making this virtual program week possible.

## Takeda Hello Talk Zoom Session (September 24)

by Melissa Andrisani

Thank you to Takeda's Layne Henningsgaard, Territory Business Manager; April Shaw, BSN, RN; and Rebecca Coney, DNP, APRN, FNP-C, Senior Clinical Specialist, for taking the time and using their expertise to present on Lesson Plans: Navigating School With a Bleeding Disorder and Building Skills to Address Bullying. With the ongoing pandemic and the school year for most students being in-person while also including online classes and communication, we felt these were extremely important and timely subjects to provide insight into for our families.

April and Rebecca dove deep into these subjects and gave great information on how students, parents, family members, and school staff can work together to provide a positive learning environment for students

with a bleeding disorder—from preschool through college. As well as why it is important to know when you or someone you care about is the target of bullying or cyberbullying. Through engaging role play and practice, they explained how to respond to a bully and how to find help.

Thank you to everyone who attended this Zoom session!







# Jivi® Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

▶ Dive in at JiviExtensionStudy.com

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#### **South Dakota Family Education Day**

By James Paist

On Saturday July 25th, our South Dakota community came together for a day of fun, food, and important information. This event was held on Saturday morning at the Suburban Lanes Family Fun Center in Sioux Falls, SD.

HFMD brought face-masks for everyone in our group to wear, and I worked with the bowling alley staff to space out our seating and exhibit table to maintain good social distancing. Volunteer and Sanford Health Children's, Social Worker Nathan Anderson, and HFMD Board President Casey MacCallum were big help in setting up the venue. They also helped to greet our South Dakota area members as families began to show up.

After opening the event with HFMD updates, it was a pleasure to introduce Nathan Anderson who lightened the mood with his quick wit. He then introduced Dr. Brianna Murphy who shared an informative and interactive presentation relating to children playing sports and having a bleeding disorder. Our group posed a number of good questions about what is safe and what is not. Dr. Murphy's presentation was so good, we asked her to return for an encore performance at our upcoming virtual Walk. Dr. Murphy was followed by Casey MaCallum who shared his personal experience playing sports as a teenager and having hemophilia.

While everyone wore their face-masks almost the entire time, we did briefly remove them to enjoy a delicious lunch from Cluckin Good Chicken. Before hitting the lanes our group had time to visit with our exhibitors and exhibit tables. HFMD would like to thank ARJ Infusion Services, Bayer HealthCare, Bio Marin, CSL Behring, CVS Specialty, Genentech, & Novo Nordisk.





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

#### **Organizational Contributors:**

#### \$40,000 and Up

Mayo Foundation

#### \$20,000 - 39,999

Hemophilia Alliance Foundation Mayo Foundation University of Minnesota Health

#### \$9,000 - \$19,999

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Makepeace, Ray

Naumann, Dylan & Abby

Metz, June

Naumann, Raven
Nichols, William
O'Brien, Patti & Tim
O'Connell, Jean
Olsen, Sue
Olson, Judy
Osborne, Tim
Padilla, Ryan
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#### What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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

#### 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
  - weakness
- yellowing of skin and eyes
- swelling of arms and legs
- 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:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath

  - chest pain or tightness fast heart rate
- feel faint - headache
  - numbness in your face
  - eve pain or swelling
  - trouble seeing

- cough up blood

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

#### 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

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. neral 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



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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

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
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Sandy Heisler, L.P.N., Research Coordinator
C. Christopher Hook, MD
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Ariela Marshall, MD
William Nichols, MD
Melinda Otto, LSW

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
Brianna Murphy, MD
KayeLyn Wagner, MD
Dan Steventon, PT
Wendy Jensen, CCLS
Nathan Anderson, MA, LSW
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University of Minnesota Health - Fairview 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 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

#### Hemophilia Foundation Of Minnesota/Dakotas 2020 Board of Directors

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> Susan Kearney, MD Board Member

Kris Manns Board Member

Ignacio Ramos Board Member

#### & Staff

James Paist
Executive Director

Melissa Andrisani Event Coordinator



#### **Current Calendar of Events**

October 15, 2020 ..... Empowered: Tools for Self-Advocacy

Zoom Session sponsored by Pfizer

6 pm - 7pm

October 22, 2020 ...... Nurturing Couple Relationships

Zoom Session sponsored by HFA

6 pm - 7pm

November 5, 2020 ...... Get Connected: Virtual ITP Education & Networking

Zoom Session sponsored by Children's MN

6 pm - 8 pm

November 14, 2020 ...... 2nd Annual HFMD Symposium – Virtual

Zoom Session 9 am - 12 pm

April 9-10, 2021 ..... Annual Members Meeting

Intercontinental Hotel Airport

May 1, 2021 ..... Hearts of Hope Gala

Graduate Hotel, Minneapolis, MN

Visit our web site at https://www.hfmd.org/events/ for more information and to register!



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

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NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS



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### 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

