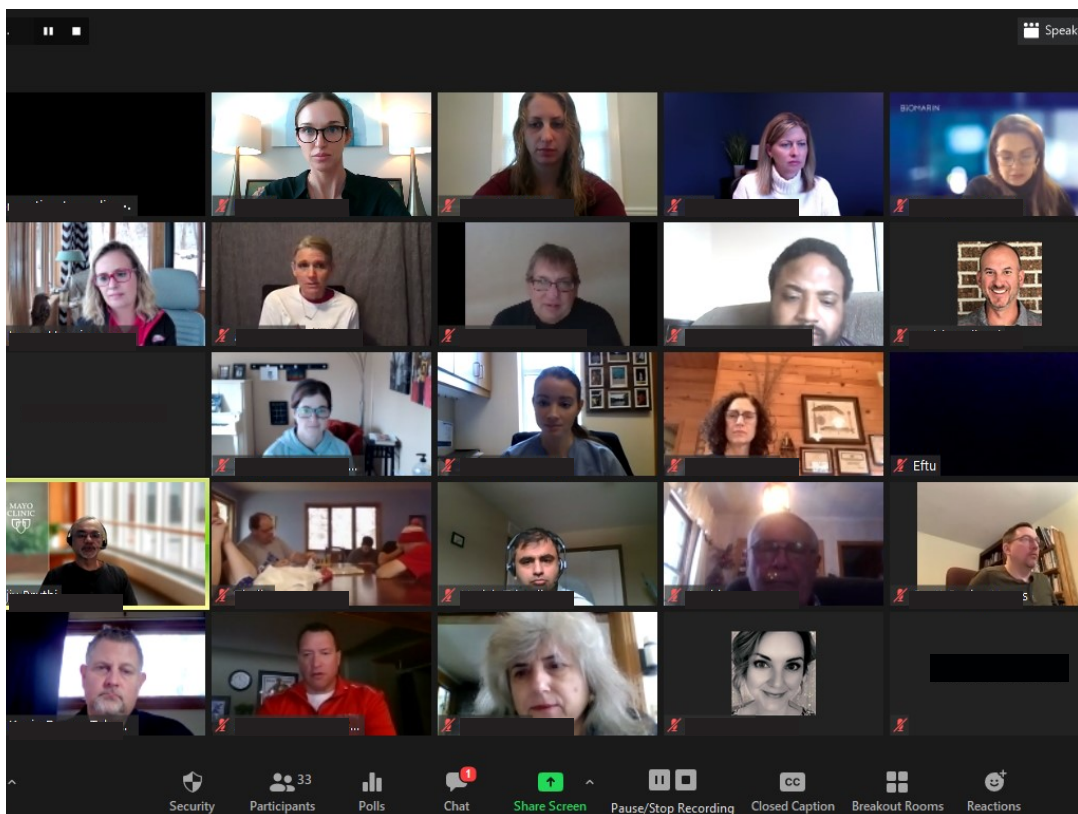


HFMD MISSION

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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Symposium 2020

The HFMD held our 2nd annual Symposium on Saturday, November 14th, and it was held virtually via Zoom with good success! This event brings our community together for information, networking, & fun.

We were excited this year to share a few videos from families sharing their personal stories. There were some heart-felt videos that really resonated with our group. This is also the one time during the year where HFMD is involved with hosting a branded event where the presentations can feature information about company medications and products. Many of our members want to know all they can about the latest medications available for treating bleeding disorders.

This year, with the event being virtual and via Zoom, we decided to keep it a 3 hour event; therefore there was just enough time to have six companies each share a 10

minute presentation with 5 minutes of exhibit time. After leading off with a welcome to all, I turned things over to HFMD Event Coordinator Melissa Andrisani, who did a wonderful job in moderating the entire event, and in managing the logistics of the videos and presentations.

Our members know when they attend an HFMD event, there is going to be good information, and fun. So part of that fun was a virtual pizza party where all who participated got a Domino's e-gift card. Another part of the fun was just seeing each other on Zoom, and seeing members win raffle prizes when 6 different prizes were raffled off in between presentations. We had a total of 33 Zoom feeds into the event, which included many families.

The highlight of the event was toward the end where we had a tremendous Ask the Expert Panel which featured an accomplished clinician from each of our four affiliated Hemophilia Treatment Centers. Our all-star panel featured Dr. Rajiv Pruthi from the Mayo Clinic, Dr. Brianna Murphy from Sanford Health Sioux Falls, Amy Goldstein, NP from Children's Hospitals & Clinics of Minnesota, and PT Kim Baumann from MHealth.

Members posed some very thoughtful questions to the panelists who really clicked together as a group. It was an excellent Q & A session dealing with a number of pressing topics of our time. HFMD would like to thank all of our members who attended, our HTC Panelists, and to the following presenting companies: Bayer HealthCare, Bio Marin, CSL Behring, Medexus, Sanofi Genzyme, & Takeda.

By James Paist



PLEASE JOIN US
FOR THE 2021 VIRTUAL
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6PM-8PM

SESSIONS | SATURDAY, APRIL 10th
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The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called “inhibitors,” which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.



R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

HFMD Patient Financial Assistance Up in 2020

After the pandemic hit in March, the HFMD Board took action to increase our Patient Financial Assistance budget 2020 knowing the need for help would be going up. Like all communities, many of our patient/families have been negatively impacted by the pandemic with job loss, furloughs, hours cut, and loss of income.

As a result, members facing over-due rent, mortgage, and utility payments contacted the Social Worker of their HTC for help. HFMD was able to fund dozens of requests for support in these areas and others, thanks to the following supporters: The Hemophilia Alliance Foundation, Mayo Clinic, MHealth, NHF, Bio Marin, Genentech, Takeda, sponsors and individual donors from our Gala & Walk!

All requests for assistance that HFMD reviews must be submitted by the Social Worker on behalf of the patient/family with a bleeding disorders; as our program is intended to help for one-time unexpected financial crisis. By James Paist

Covid 19 - Laptop Project

The HFMD would like to thank the Colburn Keenan Foundation for a grant in the amount of \$2,500 to support a special project through our Patient Financial Assistance Program where we were able to purchase a new laptop computer for one patient/family in need from three of our affiliated clinics.

Working closely with the Social Workers from those clinics, HFMD purchased and shipped new Lenovo laptops to two families where a child needed the laptop, and to an adult member who needed a computer. Each party was very pleased with their new computer.



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www.infucarerx.com



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BioMarin HemDifferently Virtual Event 12/3/20

By, Melissa Andrisani

On Thursday, December 3, HFMD and BioMarin hosted a virtual event on “Gene Therapy Research: Understanding the Science.” This session focused on how gene therapy research is designed to work, what different types of gene therapies are being researched and why some people are better candidates than others for gene therapy research.

Presenting on Gene Therapy was Tammueella “Tami” Chrisentery-Singleton, MD. Dr. Singleton serves as a Pediatric Hematologist, Director of MCAM’s Hemophilia Treatment Center and as Division Chief, Pediatric Hematology. She has authored numerous publications, served as a subject matter expert speaker around the world, and as the principal investigator on numerous studies pertaining to Hemophilia.

During her talk, Dr. Singleton brought together the collective knowledge of more than two dozen healthcare professionals across the U.S. and shared the science behind gene therapy. She also included poll questions for the attendees to test their knowledge and participate in the conversation.

HFMD would like to thank BioMarin, Dr. Singleton and everyone who attended this session. We hope you enjoyed your Panera!

Family Education Event October 15th

By Melissa Andrisani

Although, due to COVID-19, we were not able to meet at the Mall of America this year, Pfizer and Joe Schuch were still ready to share a helpful presentation on “Empowered: Tools for Self-Advocacy” and HFMD treated attendees to Applebee’s eGift Cards during a virtual event held on Thursday, October 15.

During Joe’s presentation he targeted on recognizing and discussing the unique challenges of hemophilia while providing practical tips and resources to attendees to help them become self-advocates in many areas of their life.

We would like to thank Pfizer, Joe Shuch and everyone who attended this virtual event. We look forward to hopefully hosting it again at Mall of America!

Inspiring Golf Shots Clinic with the Wingmen Foundation (Sept. 12 – Oct. 11)

by Melissa Andrisani

HFMD was presented with a wonderful opportunity by the Wingmen Foundation to host their Inspiring Shots Golf Clinic here in Minnesota at Columbia Driving Range & Learning Center. The Wingmen Foundation was founded in 2012, by two hemophiliacs, Chad Brown and Donald Regan II. Both Mr. Brown and Mr. Regan have volunteered their time over the years for Florida's hemophilia foundations and The American Cancer Society. Together, they formed The Wingmen Foundation to further assist and support the much needed void in these and other communities for education and advocacy in physical fitness. At the time of its founding, services did not exist for the inclusion of physical therapy and related necessary treatments of physical disabilities in the bleeding disorder, cancer, and chronic conditions communities.

Their Inspiring Shots Clinic is a free clinic for people with bleeding disorders and caregivers that are 18 years of age or older. This was an opportunity for a first time or advanced golfers with the clinic offering to teach how to learn to golf or improve your game.

Over this four week course attendees were given:

- a general overview of golf fundamentals
- fundamentals of swing with discussion of etiquette on course
- discipline of golf practice
- mental keys to success on course and life
- short game lessons
- putting and sand shot lessons

For the last session of the clinic attendees were treated to one-on-one mini sessions with Pro Golfer and Hemophilia A patient, Perry Parker. Perry has played three United States Opens, made the cut in 1997 at Congressional C.C. in Washington D.C, and has also played the following tours: Asian, Australasia, Canadian, Nike, Japanese, PGA tour, and many mini-tours in the United States. He currently resides in Laguna Niguel, California with his wife, Lori and their twins, Scott and Diana. He continues to play professional golf, work as a teaching pro, motivational speaker, and tournament consultant.

We hope everyone who attended enjoyed this amazing opportunity and we would like to thank the Wingmen Foundation for including us in this special clinic!

The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1st - December 31st, 2020.

Organizational Contributors:

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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.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

**HEMLIBRA**
emicizumab-kxwh 150
injection for subcutaneous use mg/mL

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,
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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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**HEMOPHILIA
FOUNDATION**
OF MINNESOTA/DAKOTAS

Current Calendar of Events

January 14, 2021	HFMD & BDAND HFA Hemophilia Jeopardy Zoom Event @ Zoom 6 pm - 7pm
January 30, 2021	Virtual Family Event by The Coalition for Hemophilia B For Hemophilia B Patients Only @ Virtual 2 pm - 7pm
March 1, 2021	2021 Washington Days @ Virtual 12 am - 11:45 pm
April 9, 2021.....	2021 Annual Members Meeting @ Virtual Zoom Event All Day
May 1, 2021	2021 Hearts of Hope Virtual Gala @ Virtual 7 pm

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

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NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

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HEMOPHILIA
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WE NEED YOUR HELP! The 21st Annual Hearts of Hope Gala is right around the corner on May 1, 2021 and we are in need of sponsors and high value donated items. This year the gala is completely virtual and our fundraising efforts will be greatly impacted by our online auction and sponsorship. Due to the affects that COVID-19



has had on businesses, getting companies to give has been a difficult process. However, you can help! Do you know a business owner who would be willing to give to our amazing cause? Do you frequent a business that you think may want to help? If so, please reach out! To make it easier for you, we have drafted a donation request letter found [HERE](#) and a sponsorship request letter found [HERE](#). With your help, we can make the Gala a great success!