

Family Camp  
Schwenksville, PA



THE WINNING SPIRIT NEWSLETTER

FALL 2021



**EASTERN PENNSYLVANIA**  
**BLEEDING DISORDERS FOUNDATION**  
41 Counties. 1 Mission.

GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

**These serious side effects include:**

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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

  
**HEMLIBRA**<sup>®</sup>  
emicizumab-kxwh | 150 mg/mL  
injection for subcutaneous use

**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
  - swelling of arms and legs
  - yellowing of skin and eyes
  - 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
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

**What is HEMLIBRA?**

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

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I use HEMLIBRA?**

**See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**What are the possible side effects of HEMLIBRA?**

- See “What is the most important information I should know about HEMLIBRA?”

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
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For more information, go to [www.HEMLIBRA.com](http://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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**Genentech**  
A Member of the Roche Group

# NEW NAME. NEW LOCATION. SAME DEDICATION.

Dear Community Members,

On behalf of the Board of Directors and Staff, I am pleased to share an exciting change to our Foundation. Our goal always is to positively impact more lives and connect families throughout our 41-county coverage area. In 2014, we changed the Foundation name from “Delaware Valley” to “Eastern Pennsylvania” as an important step down this path. We hold educational and group programs in many of our counties and recently developed the Advocacy Ambassador program so everyone can get involved in this important effort.

To better define our Foundation’s evolving mission and those who we serve, the staff researched which bleeding disorders were supported by the Hemophilia Federation of America and the National Hemophilia Foundation. These findings were shared with our six hemophilia treatment centers to confirm that they support them as well, which they do. Therefore, our Board formally approved support for the following bleeding disorders:

- Acquired Hemophilia
- Acquired von Willebrand’s disease
- Hemophilia A (Factor VIII deficiency)
- Hemophilia B (Factor IX deficiency)
- Hemophilia C (Factor XI deficiency)
- von Willebrand’s disease (types I, II, III, aVWS, and pseudo-VWD)
- Factor I deficiency
- Factor II deficiency
- Factor V deficiency
- Factor VII deficiency
- Factor X deficiency
- Factor XII deficiency
- Factor XIII deficiency
- Idiopathic thrombocytopenic purpura (ITP)
- Acquired platelet function defects
- Congenital platelet function defects
- Congenital protein C or S deficiency
- Disseminated intravascular coagulation (DIC)
- Glanzmann disease

While conducting this research, we learned Foundations across the country were doing the same. To better reflect this positive change, many of our colleagues were replacing “Hemophilia” in their name with “Bleeding Disorders.” We agree with this movement and as a result, have changed our name to the Eastern Pennsylvania Bleeding Disorders Foundation. We thus continue to grow, touch more lives, and connect with more families. In addition, the Foundation has moved its office to Liberty Place at Kennett Square in Chester County. Please let the staff know if you are interested in visiting this new location.



Len Azzarano  
Board President  
Eastern Pennsylvania Bleeding Disorders Foundation

# MEET NEW BOARD MEMBER

## Marisa Ferger



**How long have you been involved with the Eastern PA Bleeding Disorders Foundation?**

I first learned about the Foundation when I was diagnosed with mild Hemophilia A in 2006. My then 15-month-old son was diagnosed shortly after me.

My family has participated

in some activities with the Foundation since then, and I've been to more once remote gatherings became possible.

**What inspired you to join the Board of Directors?**

After being able to get more involved with the Foundation once remote activities began, I realized how much I enjoy this community. It's been wonderful getting to know other people who have dealt with similar situations. It's also

been great working with the Foundation as an Advocacy Ambassador. I am honored to represent central Pennsylvania and other women with bleeding disorders on this Board.

**What is your current occupation?**

I am a meteorologist with the Weather Communications Group at Penn State. I teach weather communications courses to meteorology majors and produce and forecast for "Weather World", a 15-minute weather magazine show that airs on weekdays across Pennsylvania on WPSU and PCN-TV.

**What do you like to do in your spare time?**

I spend most of my time driving my kids, ages 12 and 16, to and from their activities! When I'm not their personal chauffeur, I like to spend time outdoors with my family and friends - central Pennsylvania is a great place for that! I also enjoy cooking, eating, and reading.

## Medical IDs for Members

If you or a loved one has a bleeding disorder or medical condition, it's vital to wear a personalized medical ID.

The Eastern Pennsylvania Bleeding Disorders Foundation is happy to provide an engraved medical ID bracelet or necklace from American Medical ID for those who qualify.\*



\*To qualify, you must live in Pennsylvania or be treated at a Hemophilia Treatment Center found on the American Medical ID Page at [hemophiliasupport.org](http://hemophiliasupport.org).





# LONG-LASTING BLEED PROTECTION FOR THE HERO WITHIN

ONLY IDELVION DELIVERS

**0** SPONTANEOUS BLEEDS\* + UP TO **21** DAY DOSING† + **20%** STEADY-STATE TROUGH LEVELS WITH 7-DAY PROPHYLACTIC USE‡

Whether dosed every 7 or 14 days in pivotal trials

Dosing schedules that fit your lifestyle

High and sustained Factor IX levels in clinical trials

\*Zero median annualized spontaneous bleeding rate when dosed at 7 or 14 days in clinical trials.  
†Once well controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.  
‡The average dose for people receiving prophylaxis every 7 days was 37 IU/kg.  
§Hemophilia FIX Market Assessment. Third-Party Market Research.

Is it time for a switch? Learn more at [IDELVION.com](http://IDELVION.com)



## Important Safety Information

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

**Please see prescribing information for IDELVION, including patient product information.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call **1-800-FDA-1088**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

**IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein  
Initial U.S. Approval: 2016**

**BRIEF SUMMARY OF PRESCRIBING INFORMATION**

**These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.**

**What is IDELVION?**

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

**Who should not use IDELVION?**

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION, or are allergic to:

- hamster proteins
- any ingredient of IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

**What should I tell my healthcare provider before using IDELVION?**

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

**What must I know about administering IDELVION?**

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

**What are the possible side effects of IDELVION?**

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

**Based on July 2020 revision**

**Please see full prescribing information, including FDA-approved patient labeling.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.**

# ADVOCACY UPDATE

## Advocacy Ambassadors

The EPBDF Advocacy Ambassador program is in full force. We have had meetings with legislators and their respective ambassadors throughout our coverage area. We discuss issues affecting our community and the ambassadors share their personal stories. Our hope is to both educate

and develop strong relationships with our representatives and senators.

We invite you to join our advocacy team. The goal is to have ambassadors throughout our 41 counties. For more information, please contact Curt Krouse at (484) 445-4282.



EPHF thanks Senator Pat Browne, Chair of Appropriations, and his staff for meeting with us and Jaya Kunwar, RN and Carah Tenzer, LSW from the Hemophilia Treatment Center at Lehigh Valley Health Network to discuss the Hemophilia Program line item in the state budget.



Franklin County Representative Paul Schemel  
Advocacy Ambassador Megan Knepper



Luzerne County Representative Ann Flood  
Advocacy Ambassadors Priscilla and Rhett Oren



Lackawanna County Representative Bridget Kosierowski  
Advocacy Ambassador Linda Parry



Berks County  
Senator Judith Schwank  
Advocacy Ambassador  
Christopher Templin



Centre County  
Senator Jake Corman  
Advocacy Ambassador  
Marisa Fergar



Cumberland County  
Representative Sheryl Delozier  
Advocacy Ambassador  
Hajar Abusief



Huntingdon County  
Representative Rich Irvin  
Advocacy Ambassadors  
Tony & Evelyn Tezak



Lancaster County  
Senator Scott Martin  
Advocacy Ambassador  
Hillary Bauer



Lancaster County  
Representative Bryan Cutler  
Advocacy Ambassador  
Hillary Bauer



Lebanon County  
Representative Frank Ryan  
Advocacy Ambassador  
Frank Lentini



Lehigh County  
Senator Patrick Browne  
Advocacy Ambassador  
Jessica Neumann



Lehigh County  
Representative Milou Mackenzie  
Advocacy Ambassador  
Jessica Neumann



Luzerne County  
Representative Aaron Kaufar  
Advocacy Ambassador  
Joey Smiles



Monroe County  
Senator Mario Scavello  
Advocacy Ambassadors  
Nancy, Nicole & Callie Padilla



Northumberland County  
Senator John Gardner  
Advocacy Ambassador  
Jolene Scicchitano



Wayne County  
Representative Jonathan Fritz  
Advocacy Ambassador  
Martin Tully



York County  
Senator Kristin Phillips-Hill  
Advocacy Ambassadors  
Joe Butler, Ryan Nicolaisen



York County  
Representative Stan Saylor  
Advocacy Ambassadors  
Joe Butler, Ryan Nicolaisen

# BACK TO SCHOOL BOWLING

On August 7, 2021, the Eastern PA Bleeding Disorders Foundation took over Devon Lanes for a fun-filled afternoon of bowling, snacks, raffles, and educational activities!

Community members had the opportunity to reserve a lane with their family and friends and catch up with familiar faces that they haven't had the chance to see in a while. In addition to bowling, everyone was able to try their luck at winning some exciting raffle prizes, ranging from Phillies tickets to technology bundles and everything in between! Finally, after filling up on pizza and snacks, we had an informative Hemophilia Federation of America presentation

for parents and caregivers on how to best advocate for their child with a bleeding disorder in a school setting.

A special thanks to our corporate partners: Accredo, Bayer, Cottrill's, CSL Behring, CVS Specialty, Genentech, Takeda, Soleo, Penn Home Infusion, and to everyone who donated a raffle prize. Additionally, we would like to thank Julie Alexander for facilitating the HFA presentation. Our families were incredibly appreciative of your ability to share important information. We are already looking forward to next year's bowling event!



# ANNUAL GOLF CLASSIC

Eastern PA Bleeding Disorders Foundation held its annual Golf Classic on Tuesday, September 14, 2021, at RiverCrest Golf Course in Phoenixville, PA. The day featured a world-class golf course, delicious lunch, cocktail hour and dinner, contests, and prizes. It was a beautiful day full of golf, fun and camaraderie.

CSL Behring was once again the presenting sponsor of the Golf Classic, and we thank them for their generous and continued support. Special thanks also to Accredo, CVS Specialty, Soleo Health, Cottrill's, Penn Home Infusion Therapy, Novo Nordisk, Giant, Milliron & Goodman, Visual Communications, Proteck Consulting, and Louis P. Canuso Inc.



Bleed Have to cancel  
Late for school  
When will this bleed end?  
Another bleed  
Time Visit to ER  
Frustration Bleed



For the treatment of bleeding episodes in people\* with hemophilia A or B with inhibitors

## I'M READY TO MOVE ON

**Get rapid, predictable, and reliable bleed control with SEVENFACT 225<sup>†</sup>**



**Rapid effect: 3 hour**

At 3 hours, 84% of mild/moderate bleeding episodes were controlled with a single dose



**Predictable<sup>‡</sup> response: 84%**

At 9 hours, 84% of mild/moderate bleeding episodes treated achieved bleed control after a single dose



**Reliable control: 99.5%**

At 24 hours, 99.5% of mild/moderate bleeding episodes were resolved



**Convenient home use: 98%**

98% of bleeding episodes were treated at home

<sup>†</sup> 225 mcg/kg initial dosing regimen in the clinical trial.

<sup>‡</sup> As seen in the clinical trial.

## Summary of Selected Safety Information

### What is the most important information I should know about SEVENFACT?

The most serious possible side effect of SEVENFACT is abnormal clotting involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

#### **You should know the signs of abnormal clotting and seek medical help immediately if they occur.**

Signs of clotting in places other than your site of bleeding can include new onset of swelling and pain in limbs, new onset of chest pain, shortness of breath, loss of sensation or motor power, or altered consciousness or speech.

### \*What is SEVENFACT?

SEVENFACT is an injectable medicine used for the treatment and control of bleeding episodes occurring in adults and adolescents 12 years of age and older with Hemophilia A or B with inhibitors.

Injecting medicines requires special training; do not attempt to self-infuse unless you have been taught how by your healthcare provider.

### Who should not use SEVENFACT (coagulation factor VIIa)?

You should not use SEVENFACT if you are allergic to rabbits, or if you have known allergies to SEVENFACT or any of its components. Seek immediate medical help if you experience hives, itching, rash, difficulty breathing with cough or wheezing, swelling around the mouth and throat, tightness of the chest, dizziness or fainting, or low blood pressure after taking SEVENFACT.

Tell your healthcare provider prior to using SEVENFACT if you have begun treatment of a bleeding episode with another bypassing agent.

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

Tell your healthcare provider if you are pregnant, are nursing, or plan to become pregnant; if you have had prior blood clots, heart disease or heart failure, abnormal heart rhythms, prior pulmonary clots, or heart surgery; or if you have or have had any other medical conditions.

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

The most common adverse reactions for SEVENFACT are headache, dizziness, infusion-site discomfort, infusion-site hematoma, and infusion-related reaction and fever.

Seek immediate medical help if you have signs of a blood clot or an allergic reaction.

**To report SUSPECTED ADVERSE REACTIONS or product complaints, contact HEMA Biologics at 1-855-718-4362. You may also report SUSPECTED ADVERSE REACTIONS to the FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch).**

**Please see Patient Product Information on the next page.**



## PATIENT PRODUCT INFORMATION

### SEVENFACT® (SEV-en-fact) coagulation factor VIIa (recombinant)-jncw

#### For Intravenous Injection After Reconstitution Only

#### PLEASE READ PATIENT PRODUCT INFORMATION AND THE INSTRUCTIONS FOR USE THAT COME WITH SEVENFACT BEFORE YOU START TAKING THIS MEDICINE AND EACH TIME YOU GET A REFILL. THERE MAY BE NEW INFORMATION.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition and treatment. If you have questions about SEVENFACT after reading this information, ask your healthcare provider.

#### WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT SEVENFACT?

The most serious possible side effect of SEVENFACT is abnormal blood clotting involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

You should know the signs of abnormal clotting (thrombosis) described below and seek medical help immediately if they occur.

New onset of swelling and pain in the limbs or abdomen, new onset of chest pain, shortness of breath, loss of sensation or motor power, and altered consciousness or speech can all be signs of clot formation in places other than your site of bleeding. Seek immediate medical attention if you experience one or more of these symptoms.

SEVENFACT should be used as prescribed and directed by your healthcare provider.

#### WHAT IS SEVENFACT?

SEVENFACT is a recombinant human Factor VIIa protein for injection. SEVENFACT can allow adolescents and adults with Hemophilia A or B with inhibitors to create clotting at the site of bleeding without needing Coagulation Factor VIII or IX replacement.

SEVENFACT, coagulation factor VIIa (recombinant)-jncw, is indicated for the treatment and control of bleeding episodes occurring in adults and adolescents 12 years of age and older with Hemophilia A or B with inhibitors.

Injecting medications requires special training. Do not attempt to self-infuse unless you have been taught how by your health care provider or hemophilia treatment center. Once trained, you will need additional infusion materials along with your SEVENFACT so that you can successfully treat your bleeding episodes at home. Be sure to collect all necessary infusion materials before starting the reconstitution process.

SEVENFACT comes in a sterile dry powdered dosage form that must be reconstituted with sterile Water for Injection.

It is not known if SEVENFACT is safe and effective in children under 12 years of age.

#### WHO SHOULD NOT USE SEVENFACT?

You should not use SEVENFACT if you:

- Are allergic to rabbits.
- Have known allergies to SEVENFACT or any of its components.

Tell your doctor prior to infusing SEVENFACT if you have begun treatment of a bleeding episode with another bypassing agent such as activated prothrombin complex concentrate (FEIBA®).

#### WHAT SHOULD I TELL MY HEALTHCARE PROVIDER BEFORE I USE SEVENFACT?

Tell your healthcare provider if you:

- Are pregnant, planning to become pregnant or nursing, as SEVENFACT has not been studied in patients with Hemophilia A or B with inhibitors who are pregnant or nursing.
- Had prior blood clots, heart disease, heart failure, abnormal heart rhythms, prior pulmonary clots or heart surgery.
- Have or have had any other medical conditions.

You and your doctor can then decide whether SEVENFACT is the right treatment for you, as well as the proper timing and doses you will need for SEVENFACT to control your bleeding episodes at home.

#### HOW SHOULD I USE SEVENFACT?

Treatment with SEVENFACT should be started by a healthcare provider who is experienced in the care of patients with Hemophilia A or B with inhibitors.

SEVENFACT is given as an injection into your vein.

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

Treating at first sign of a bleed is important for bleed management. Your healthcare provider will tell you how much

SEVENFACT to use based on your weight and when to administer SEVENFACT.

#### To administer SEVENFACT:

- Collect all materials needed for your prescribed dose
- Follow the **Instructions For Use** guide to reconstitute the prescribed number of SEVENFACT vials
- Infuse following your healthcare provider's instructions, using infusion materials from your pharmacy

#### CONTACT YOUR HEALTHCARE PROVIDER IF YOU:

- Miss a dose, or
- Administer more than your prescribed dose, or
- Think your bleed is not controlled within the expected time frame discussed with your healthcare provider.

#### WHAT SHOULD I AVOID WHILE USING SEVENFACT?

- Avoid activity that can create more bleeding once you have completed your SEVENFACT infusion
- Avoid mixing SEVENFACT with other medications
- Avoid infusing SEVENFACT and other factor-containing therapies [such as activated prothrombin complex concentrate (aPCC) or other recombinant Factor VIIa products] at the same time. This increases your risk of having a disabling blood clot.

#### WHAT ARE THE POSSIBLE SIDE EFFECTS OF SEVENFACT?

The most common adverse reactions reported in clinical trials for SEVENFACT were headache, dizziness, infusion-site discomfort, infusion-site hematoma, infusion-related reaction and fever.

A serious allergic reaction to SEVENFACT may occur. If you experience the severe symptoms of an allergic reaction after infusing SEVENFACT, seek immediate medical attention. Severe symptoms occur when your immune system reacts very strongly to foreign proteins or drugs.

- Hives, itching, rash, difficulty breathing with cough or wheezing, swelling around the mouth and throat, tightness of the chest, dizziness or fainting, and low blood pressure are all symptoms of a severe allergic reaction (anaphylaxis). Call 911 should you experience one or more of these symptoms.

**These are not all the possible side effects of SEVENFACT. For more information, ask your healthcare provider or pharmacist.**

**Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.**

#### HOW SHOULD I STORE SEVENFACT?

- SEVENFACT should be stored in its product packaging to protect from light.
- Prior to reconstitution, the SEVENFACT kit should be stored at room temperature but can be stored between 36°F to 86°F (2°C to 30°C).
- After reconstitution, SEVENFACT should be stored at room temperature but can be stored between 36°F to 86°F (2°C to 30°C), for up to 4 hours.
- SEVENFACT should not be frozen.

#### GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF SEVENFACT

This leaflet summarizes the most important information about SEVENFACT.

Do not use SEVENFACT for a condition for which it was not prescribed. Do not give SEVENFACT to other people even if they have the same symptoms you have. It may harm them.

You can ask your pharmacist or healthcare provider for information about SEVENFACT that is written for health professionals.

For more information, go to [www.SEVENFACT.com](http://www.SEVENFACT.com) or call 855.718.HEMA (4362).

#### WHAT ARE THE INGREDIENTS IN SEVENFACT?

**Active ingredient:** coagulation factor VIIa (recombinant)-jncw

**INACTIVE INGREDIENTS:** ARGININE HYDROCHLORIDE, GLYCINE, ISOLEUCINE, LYSINE HYDROCHLORIDE, POLYSORBATE 80, TRISODIUM CITRATE DIHYDRATE, HYDROCHLORIC ACID, NITROGEN AND WATER FOR INJECTION.

#### FOR INFORMATION CONTACT:

HEMA Biologics, LLC  
4441 Springdale Road  
Louisville, Kentucky 40241-1086

Manufactured by:  
Laboratoire Francais du Fractionnement et des Biotechnologies S.A. (LFB S.A.)  
Les Ulis, 91940  
France

Distributed by:  
HEMA Biologics  
Louisville, KY 40241  
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"SEVENFACT" is a trademark of LFB S.A.

PATENT Information: <https://hemabiodup.wppengine.com/patents/>

Approved 04/2020

**HEMA**  
Biologics®

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# 2021-22 Scholarship recipients

EPBDF is thrilled to award college scholarships to each of the talented students below.



**Hajar Abusief**  
Sophomore  
New York University



**Kristian Azzarano**  
Freshman  
Rochester Institute of  
Technology



**Nickolas Azzarano**  
Junior  
Rochester Institute of  
Technology



**Gabriel Martinez DeLeon**  
Freshman  
Thaddeus Stevens College  
of Technology



**Elliot Copeland**  
Junior  
Penn State University



**Kataryna Iannuzzi**  
Sophomore  
Rowan College at  
Burlington County



**Michael Iannuzzi**  
Sophomore  
Rowan College at  
Burlington County



**Rylee Knepper**  
Sophomore  
Lancaster Bible College



**Justine Lampe**  
Freshman  
Indiana University



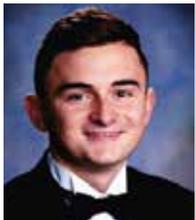
**Nadine Lampe**  
Junior  
University of Southern  
California



**Elisa Macera**  
Junior  
University of Delaware



**Tori Robbins**  
Senior  
Stockton University



**Dylan Rooney**  
Junior  
The Catholic University  
of America



**Tejas Sharma**  
Sophomore  
Villanova University



**Jacqueline Torres**  
Junior  
Community College of  
Philadelphia



**Ryan Zhao**  
Junior  
University of California  
Berkeley

## Senior Spotlight

**TORI ROBBINS**

Stockton University



**What is your major at Stockton University?**

I am majoring in Political Science concentrating in International Affairs with minors in Public Health and Environmental Studies

**What is your goal upon graduation?**

After graduation, I would like to continue my education in sustainable food systems, nutrition, and communications, particularly videography and photography. I hope to make a positive difference in the areas of environment, public health, sustainability, and human rights through advocacy and awareness. This semester I will be exploring many of my interests as a virtual intern with the Government

Affairs Department for the Environmental Working Group based in Washington D.C., an organization that advocates and educates on environmental, sustainable, and public health issues.

**What has been your favorite experience in college so far?**

During the summer of my freshman year through my sophomore year I had the opportunity to be a Transition Activity Leader of New Students. In this role, I worked with some incredible people to help new students through orientation and transition to college.

Additionally, I love being a part of the Model United Nations team. Since my first semester, I have represented Iran, Russia, and China on the Environmental Assembly and General Assembly at a pre-pandemic conference in New York City and two online conferences since the pandemic. It is inspiring to work with other dedicated students from around the world and build international comradery.

# FAMILY CAMP

The Foundation was excited to host Family Camp from September 17-19, 2001, at beautiful Camp Kweebec in Schwenksville, Montgomery County. The weekend began with dinner and sports activities followed by a Friday Night Kids' Zone, featuring face painting and balloon arts presented by Party Business, as well as a variety of games, treats and giveaways provided by our corporate partners. Friday evening also included a delicious dinner, relaxing massages for the parents, and a movie on a giant 21-foot inflatable outdoor screen.

On Saturday, there were a plenty of activities, including fishing, canoeing, tennis, street hockey, mini golf, a nature walk, kickball, and various arts and crafts projects hosted by Camp Kweebec staff. Kids also enjoyed a basketball clinic, which focused on fundamentals and was presented by Coach Steve Polinsky. Women and Teens enjoyed a Women's Group craft activity sponsored by our friends at Cottrill's Specialty Pharmacy. In the evening, there was an incredible magic show featuring Leon Etienne – America's Rock Illusionist. Leon has been seen on Penn and Teller, America's Got Talent, and Late Night with Jimmy Fallon! To end the night, there was a dance party with a new professional DJ, glow sticks, and refreshments. The weekend concluded with Sunday morning brunch.

Family Camp is free for families. We would like to give special thank you to Accredo, Cottrill's, CSL Behring, CVS Specialty, Soleo Health, Takeda, Novo Nordisk, and the HTC at the Children's Hospital of Philadelphia for their support!





# EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.\*

Not actual patients.

 **More than 20 years\* of experience**—the first recombinant treatment for individuals with hemophilia B

 **Dosing options to meet your needs**—for once-weekly prophylaxis and on-demand use

 Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix

 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<sup>®</sup>**  
Coagulation Factor IX (Recombinant)  
Room Temperature Storage

\*BeneFix was approved February 11, 1997.

R<sub>x</sub>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](http://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.

## BLEEDING DISORDERS



Hemophilia • Willebrand (vWD)

### Patient care and service is our top priority

- We will supply you with your choice of products and all needed ancillaries.
- We will provide assistance with maintaining infusion treatment logs and communicating these with your health care provider.
- We are committed to maintaining consistent communication between you, your primary care provider, your Hemophilia Treatment Center and any other designated or responsible family members.
- We offer expert assistance from our reimbursement specialists who carefully review any patient cost sharing obligations making sure you receive the benefits you are entitled to.

**Tony Tezak** 717-480-8008

**Evelyn Tezak** 717-557-6004

Representing  
**COTTRILL'S Specialty Pharmacy**



cotrillspharmacy.com

Helping you maintain a happy healthy, lifestyle

## Trust the Experience

**At CVS Specialty™**, we've been helping families like yours for over 30 years. Our caring patient support helps ensure safety, convenient access and satisfaction.

**CVSSpecialty.com**

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...for the human factor®

### INFORMATION IS EMPOWERING

At Accredo, we believe the more you know about your condition and available options, the better. We provide educational materials and a team of dedicated professionals. We're here to help you make informed decisions about your care. A personal touch from people who know bleeding disorders.

Jim Seagrave-Daly | (484) 225-3788  
JASegrave-Daly@express-scripts.com

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HEM-00078b-122314 amc5305



**SOLEO HEALTH**  
Innovators in Specialty Pharmacy

### Your Choice for Personalized Service and Care

Our Bleeding Disorder Therapy Management Program is led by dedicated specialized care teams with extensive experience in Hemophilia A, B, Factor X Deficiency, Von Willebrand, and other factor deficiencies.

Our goal is to provide services and education which encourages your independence and enhances your care experience.



\*2018 J.D. Power® data



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[www.soleohealth.com](http://www.soleohealth.com)





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