THE WINNING SPIRIT

41 Counties. 1 Mission.

Winter 2019

LIVE IN THE BLEED-FREE MOMENT

...with FEIBA® prophylaxis patients can have more bleed-free days as compared to on-demand treatment.

72%
REDUCTION
in median ABR with prophylaxis treatment[3]

Every joint bleed has the potential to do permanent damage[1,2]

Median ABR with prophylaxis vs. on-demand[3]*

28.7 median ABR with **on-demand** treatment[3]
629 bleeding episodes occurred during on-demand treatment[3]

VS

7.9 median ABR with **prophylaxis** treatment[3]
196 bleeding episodes occurred during prophylaxis treatment[3]

NO BLEEDS OCCURRED IN 3 OUT OF 17 PATIENTS
on FEIBA prophylaxis in a clinical study[3†]

*Based on the results from the FEIBA PROOF clinical study of 36 hemophilia A and B patients with inhibitors receiving FEIBA for prophylaxis or on-demand treatment for 12 months.[3]
†Of those patients who achieved zero bleeding events, 2 out of 3 completed the study.[4]

FEIBA is the ONLY FDA-approved treatment indicated for use in hemophilia A and B patients with inhibitors for routine prophylaxis.[3]

FEIBA [Anti-Inhibitor Coagulant Complex] Indications and Detailed Important Risk Information for Patients

What is FEIBA?

FEIBA is an Anti-Inhibitor Coagulant Complex approved for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is NOT for use in the treatment of bleeding episodes resulting from coagulation factor deficiencies without inhibitors to factor VIII or factor IX.

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- **Blood clots that block blood vessels and their effects have been reported during post-marketing surveillance following infusion of FEIBA, particularly following administration of high doses (above 200 units per kg per day) and/or in patients at risk for forming blood clots.**
- **If you experience any of these side effects, call your doctor right away.**

Who should not use FEIBA?

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product
- You have Disseminated Intravascular Coagulation (DIC), or signs of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (such as, heart attack or stroke)

What other important information should I know about FEIBA?

Events involving blood clots blocking blood vessels (such as blood clot in vein, blood clot in the lung, heart attack, and stroke) can occur with FEIBA, particularly after receiving high doses (above 200 units per kg per day) and/or in patients with risk factors for clotting.

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (such as chest pain or pressure, shortness of breath, fever, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration right away and seek immediate emergency medical treatment.

Infusion of FEIBA should not exceed a single dose of 100 units per kg body weight and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

What other important information should I know about FEIBA? (continued)

The safety and efficacy of FEIBA for breakthrough bleeding in patients receiving emicizumab has not been established. Events of thrombotic microangiopathy (TMA), a condition where blood clots and damage occur in small blood vessels, were reported in an emicizumab (Hemlibra®) clinical trial where patients received FEIBA with emicizumab as part of a treatment plan for breakthrough bleeding. If you are on emicizumab and are taking or anticipate taking FEIBA for a breakthrough bleeding episode, tell your doctor immediately because there are specific safety considerations and you must be closely monitored by your hemophilia treater or treatment center.

Allergic reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Stop using FEIBA promptly and call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, such as viruses, variant Creutzfeldt-Jakob disease (vCJD) and, theoretically, the Creutzfeldt-Jakob disease (CJD).

What are the possible side effects of FEIBA?

The most common side effects observed during the prophylaxis clinical study were low number of red blood cells, diarrhea, bleeding into a joint, positive test for hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

What other medications might interact with FEIBA?

Talk with your doctor about the possibility of formation of blood clots when taking drugs that may prevent clot breakdown such as tranexamic acid, and aminocaproic acid. There have not been adequate studies of the use of FEIBA and rFVIIa (NovoSeven®), or emicizumab together, or one after the other. Use of drugs that may prevent clot breakdown within approximately 6 to 12 hours after the administration of FEIBA is not recommended.

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 next page for Important Facts about FEIBA, including BOXED WARNING on blood clots, and discuss with your doctor.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. *Haemophilia* 2006;12(3):241-247. **2.** Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? *Haemophilia*. 2014;20(4):459-463. **3.** FEIBA Prescribing Information. **4.** Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. *Haemophilia*. 2014;20(1):65-72.

S51823 09/19

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Important Facts about FEIBA®:

FEIBA [anti-inhibitor coagulant complex]

This leaflet summarizes important information about FEIBA. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

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

FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA (above 200 units per kg per day) or in people with a high risk of blood clots. Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots.

The safety and efficacy of FEIBA for breakthrough bleeding in patients receiving emicizumab (Hemlibra®) has not been established. Events of thrombotic microangiopathy (TMA), a condition where blood clots and damage occur in small blood vessels, were reported in an emicizumab clinical trial where patients received FEIBA with emicizumab as part of a treatment regimen for breakthrough bleeding. If you take, or anticipate taking, FEIBA with emicizumab, tell your doctor, since you will need to be closely monitored by your hemophilia treating physician, preferably at the hemophilia treatment center (HTC). At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (such as chest pain or pressure, shortness of breath, fever, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration right away and seek immediate emergency medical treatment.

Allergic reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. The symptoms include rash, hives or welts, itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, and fainting. Other infusion reactions, such as chills, fever, and high blood pressure have also been reported. If signs and symptoms of severe allergic reactions occur, stop using FEIBA immediately and call your doctor or get emergency treatment right away.

Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

FEIBA may interfere with some blood tests for red blood cell antibodies, such as the Coombs test.

What is FEIBA used for?

FEIBA is used for people with hemophilia A and B with inhibitors to control and prevent bleeding episodes, around surgery, or routinely to prevent or reduce the number of bleeding episodes (prophylaxis). It is NOT used to treat bleeding conditions without inhibitors to factor VIII or factor IX.

Who should not use FEIBA?

You should not use FEIBA if you

- are allergic to any ingredients in FEIBA, including factors of the kinin generating system
- have a condition called disseminated intravascular coagulation (DIC), which is small blood clots in various organs throughout the body
- currently have blood clots or are having a heart attack.

Make sure to talk to your healthcare provider about your medical history. Tell your healthcare provider if you are pregnant or breastfeeding because FEIBA may not be right for you.

What should I tell my healthcare provider before using FEIBA?

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
- are breastfeeding. It is not known if FEIBA passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if FEIBA may harm your unborn baby.

What are the possible side effects of FEIBA?

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, bleeding into a joint, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: allergic reactions, including anaphylaxis, blood clot events, including those blocking blood flow to the brain (stroke), the lungs (pulmonary embolism), and the veins (deep vein thrombosis or DVT). Always immediately talk with your healthcare provider if you think you are experiencing a side effect. These are not all the side effects possible with FEIBA. You can ask your healthcare provider for information that is written for healthcare professionals.

What other medications might interact with FEIBA?

Talk with your doctor about the possibility of formation of blood clots when taking drugs that may prevent clot breakdown such as tranexamic acid and aminocaproic acid. There have not been adequate studies of the use of FEIBA and rFVIIa (NovoSeven® RT), or emicizumab together, or one after the other. Use of drugs that may prevent clot breakdown within approximately 6 to 12 hours after the administration of FEIBA is not recommended. For additional information on potential drug interaction with emicizumab, see the "What is the most important information I should know about FEIBA?" section.

What else should I know about FEIBA?

You should be trained on how to do infusions by your healthcare provider or HTC. Many people with hemophilia A or B with inhibitors learn to infuse their FEIBA by themselves or with the help of a family member.

Report any side effects or problems following FEIBA administration to your hemophilia treating physician right away.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use FEIBA for a condition for which it is not prescribed. Do not share FEIBA 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 about FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.feiba.com/us/forms/feiba_pi.pdf or by calling 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.

Takeda

Eastern Pennsylvania
Hemophilia Foundation

National Hemophilia Foundation
for all bleeding and clotting disorders

Proud Member HFA

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New Board Member Spotlight – Larry McHugh

How long have you been involved with the Eastern PA Hemophilia Foundation?

Our family has been involved with the Eastern PA Hemophilia Foundation for over ten years. Both my wife and son are affected.

What inspired you to join the Board of Directors?

EPHF has had a powerful influence on our family by providing excellent educational events and opportunities to build relationships with other families dealing with similar health issues. The educational events have taught us to be advocates at health facilities where doctors may have limited experience with bleeding disorders and treatments. Without this knowledge, my wife may not have made it through a serious health issue she experienced a few years ago. Further, my son would have had a longer recovery from injuries without seeking proper attention for bone breaks and fractures.

This year, I was able to be a golf caddie for a young boy from New Hampshire at the CSL Junior National Championship in Scottsdale. At the event, he told me this was the first time he got to meet other kids who had his disease. I have heard this from many people over the years. I hope to help EPHF reach every person who has Hemophilia in our area, so they don't feel alone with their disease. Our foundation strives every day to provide the education and resources so that community members can receive proper treatment for their disease and live as close to a normal life as possible. In addition, I want to be supportive and challenge Pharma to continue to innovate and create new therapies that will continue to improve the lives of those born with a bleeding disorder.

Allyson, Madison, Jasper, Larry and Priscilla

What is your current occupation?

I am a Financial Planner through uFinancial Group, a division of Mass Mutual Financial Advisors in Exton, PA.

What do you like to do in your spare time?

When I am not working, I spend time attending my kids' different school and sporting events. I enjoy playing golf, hunting and fishing. Hiking and camping at National Parks is my idea of a great vacation; however, I always need a little beach time each year.

Advocacy Update

Annual Bleeding Disorders Advocacy Retreat

The Eastern PA Hemophilia Foundation and Western PA Chapter of the National Hemophilia Foundation held their annual Pennsylvania Bleeding Disorders Advocacy Retreat on Tuesday, November 12, 2019 at the Hilton Harrisburg. Attendees included representatives from the Eastern PA Foundation, Western PA Chapter, National Hemophilia Foundation, Hemophilia Federation of America, St. Christopher's Hospital for Children, Children's Hospital of Philadelphia, Hospital of the University of Pennsylvania, Hemophilia Center of Western PA, Lehigh Valley Hospital, Penn State Hershey Medical Center, CSL Behring and Milliron & Goodman Government Relations. There also was a special visit from Meaghan Abbott, Director of the Office of Intergovernmental Affairs, PA Department of Health. In preparation for the retreat, prior meetings were held with Dr. David Kelley, Chief Medical Officer, Department of Human Services and Alison Beam, Deputy Chief of Staff, Office of the Governor.

The Advocacy Retreat focused on national, state, industry, and HTC perspectives on issues such as the state takeover of the marketplace for insurance coverage, Medicaid preferred/non-preferred drug list, prior authorization legislation, accumulator adjusters, balance billing, and advocacy programming/lobbying strategies.

Eastern and Western PA are developing new opportunities for community involvement with our advocacy efforts so please look for the details in 2020.

Pictured with Dr. David Kelley, Chief Medical Officer, Department of Human Services

Pictured with Debbie Failor, Special Assistant to the Chief of Staff, and Alison Beam, Deputy Chief of Staff, Office of the Governor

Pictured with Meaghan Abbott, Director of Intergovernmental Affairs, Department of Health

Emotional Wellness as a Mature Adult:

Discussing the Unique Challenges of Living With Hemophilia

For more information, visit b2byourvoice.com to download *Learn from Experience: A Guide for Mature Adults.*

This content is brought to you by Pfizer.

How Hemophilia Affects Mature Adults

Mature adults may look back and recognize how living with hemophilia has influenced who they are today. Persevering through the challenges of being a child diagnosed with hemophilia when less was known about the condition, and navigating the issues of being a young adult with a bleeding condition can shape one's perspective. Knowledge and wisdom are some of the benefits that accrue with age, but along with these can also come additional health concerns such as high blood pressure, diabetes, and arthritis; depression and stress; and financial planning and retirement concerns. For those who have lived with hemophilia for many decades, the task of managing these concerns of older age may seem to be less important. However, there are some key points to keep in mind when addressing the effect hemophilia can have on mental health.

The Risk of Clinical Depression

Mature adults living with hemophilia typically have experienced substantial challenges related to their disease throughout their lives. In some instances, hardships may contribute to the development of clinical depression, which is more common among people living with hemophilia than the general population. The results from one study conducted at a hemophilia treatment center showed that 37% of a sample of patients met the criteria for depression. Of that 37%, 20% had moderate to severe symptoms, and 66% reported having functional impairment due to their depressive symptoms.[1] The authors of the study concluded that the comprehensive care of adults with hemophilia should include depression screening for the potential to improve overall health outcomes.[1]

Education and support for people living with bleeding disorders and their families is one component of managing psychological wellness. Having control over life decisions and self-advocacy can also be important. For some living with hemophilia, past experiences may serve as a motivator to continue to work toward personal objectives. Others may find the journey more difficult to navigate. Self-help seminars and support groups are some of the resources that may help adults set and attain realistic goals.

> "[A reminder to] older adults that there is always somewhere to turn, even in times of immense hardship. All you need to do is ask, and you should never feel ashamed for doing so."
>
> — Judy Bagato
>
> RN, BSN, Hemophilia Specialist

Finding Support for Complex Issues

For people who acquired human immunodeficiency virus (HIV) and/or hepatitis C (HCV) from virally contaminated blood products, there may be feelings of anger and resentment. The adversity caused by a lack of family or social support during younger years or changes later in life, such as changes in one's capacity for employment or altered family dynamics, may also contribute to these feelings. Learning effective ways to cope with the stresses of living with hemophilia in older age may help an individual to be resilient to these challenges. If you are experiencing stress that is affecting your day-to-day outlook, it is important to seek help. Reach out to your treatment team to discuss your situation and learn about what help and support may be available.

Reference: 1. Iannone M, Pennick L, Tom A, et al. Prevalence of depression in adults with haemophilia. *Haemophilia.* 2012;18:868-874. doi: 10.1111/j.1365-2516.2012.02863.x.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

PP-HEM-USA-1237

September 2019

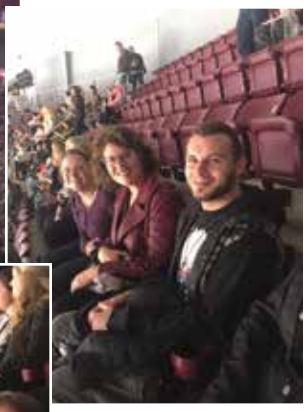
Pfizer

Teen Group

The Teen Group had a blast on Friday, November 15, 2019 at the Hershey Bears game! Teens from all over the Eastern PA coverage area met at What If…Of Hershey for dinner and a program presented by Bayer. This was a great opportunity for our teens to come together and meet each other. After the program, everyone headed over to the Giant Center to watch the Hershey Bears take on the Charlotte Checkers.

This was the final Teen Group event for 2019, and we would like thank our leaders – Nick and Andrew Snyder, Eli Nobles, Hajar Abusief and Cheyenne Gansell. We also appreciate the generous support from Genentech and Bayer.

The mission of the Teen Group is to bring teens together to learn, exchange ideas, make new friends and have fun. If you would like to share an idea for a 2020 event or become a Teen Group leader, please contact Kat Kocsi at katk@hemophiliasupport.org.



Gettin' in the Game

CSL Behring's Gettin' in the Game Junior National Championship (JNC) program was held November 8-10, 2019 at the Sheraton Wild Horse Pass in Phoenix, Arizona. Chapters throughout the United States were invited to nominate two participants for either baseball, golf, or swimming. The weekend included educational workshops, sports clinics, and sports competitions. Eastern PA nominees were Rocco Vespe for golf and Griffin Bove for baseball.

"We would like to thank the Eastern Pennsylvania Hemophilia Foundation for sending us and CSL Behring for hosting the Getting in the Game Junior National Championship. It is an amazing weekend where the kids are made to feel special and appreciated. It was great meeting so many families from all over the country that share bleeding disorder experiences." – Denise Bove (Griffin's Mom)

"Spending time with Perry Parker and the other athletes with bleeding disorders really inspired me to pursue the sport I love – golf!" – Rocco Vespe

Family Camp

Eastern PA Family Camp was held on the weekend of September 20-22, 2019 at Camp Kweebec in beautiful Schwenksville, Montgomery County. The Foundation was thrilled to host 180 community members from all over its coverage area, including 10 families that were new to camp this year! The weekend began with dinner and sports activities followed by the Friday night Kids' Zone, featuring a variety of games, treats and giveaways provided by our corporate partners. Campers were able to enjoy a relaxing massage or watch the new Aladdin movie, projected on a 21-foot inflatable outdoor movie screen. The movie was complimented by popcorn and bottled water courtesy of Accredo.

On Saturday after breakfast, families participated in many different activities including yoga, fishing, paddle boarding, tennis, street hockey, mini golf, nature walk, and a game of kickball. Kids also enjoyed a basketball clinic, which focused on fundamentals and was presented by our friends at CSL Behring. Camp Kweebec staff hosted various arts and crafts projects throughout the day. Hemophilia Federation of America speaker Stacey Powell led a Mom's Group session called "In the Driver's Seat to Your Health" and an interactive game for families called "It's All in the Family." There also was a session on Gene Therapy presented by Tessa Field of Spark Therapeutics.

In the evening, families enjoyed a thrilling dinosaur show called Jungle John's Jurassic Journey. The show was followed by a Dance Party with a professional DJ, glow sticks, and refreshments. Children of all ages danced and sang. The weekend concluded with Sunday brunch.

Family Camp is free for families. A special thank you to Genentech, Takeda, CSL Behring, Accredo, Cottrill's, CVS Specialty, BioMatrix, and the HTC at the Children's Hospital of Philadelphia for their sponsorship! We also want to recognize Sharon Littig, RN from the HTC at Thomas Jefferson University Hospital. She volunteers her time each year to provide medical assistance for Family Camp.

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
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

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

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

Genentech
A Member of the Roche Group

Trick or Trot Family Walk

On Sunday, October 13, 2019, over 400 walkers from throughout Pennsylvania and southern New Jersey gathered at the Philadelphia Zoo to take part in the annual Trick or Trot Family Walk hosted by the Eastern PA Hemophilia Foundation. The course took walkers throughout the zoo and past the animal exhibits. With registration, walkers could enjoy the Family Entertainment Area, which included many fun activities such as moon bounces, face-painting, and a DJ playing music to pump up the crowd.

Refreshments were provided by Skinny Pop Popcorn, Asher's Chocolates, Wawa and Lenka Bar. Families also received a wristband that entitled them to all-day admission. There also were 17 sponsor tents handing out Halloween treats along with special guest appearances from the Sixers Stixers, Sixers Dancers, and the Sixers Dunk Squad.

In addition to awarding team prizes and costume contest winners, the Eastern PA Hemophilia Foundation presented a research grant for $10,000 to Dr. Ruben Rhoades from the HTC at Thomas Jefferson University Hospital.

The Eastern PA Hemophilia Foundation would like to thank all the teams, volunteers and sponsors for making this event such a success. We look forward to seeing you next year!

Adventures in Learning

Adventures in Learning was held on Saturday, October 26, 2019 at Spooky Nook Sports and The Warehouse Hotel in Manheim. The program began at 12 noon with a buffet lunch and comments from the host Colleen Farrell, RN BSN for the Hemophilia Treatment Center at the Penn State Hershey Medical Center. Families also received an update on advocacy and upcoming events from the Eastern PA Hemophilia Foundation.

The first program was entitled "Having Emergency Plans" presented by Darlene Shelton President/Founder of Danny's Dose Alliance. Topics that were covered included EMS treatment plan, ER treatment plan, as well as safety plans for school, travel, sports and other areas of everyday life. Breakout sessions followed for different age groups. Angela Forsythe, PT, DPT led a session for 1st through 6th graders. In this guided activity, children discovered what happens inside a joint with a bleed by learning through anatomic body art. Kids got a glimpse of what is happening inside the body and why it is so important to follow treatment advice. Veronica Conde from the Hemophilia Federation of America held a session on "Staying Safe as a Teen" where different scenarios were discussed related to a teen's life and how to best stay safe. This included meeting people through social media and video games. The session for adults was led by Charles Gilbert, ACSW, a member of the Hershey Hemophilia Center Treatment staff since 1985. The discussion was entitled "Nurturing Couple Relationships and Parenting Children with Health Issues."

Following the sessions, families could go into the play area and participate in Bubbleball, Backyard Games, and the Ninja Warrior course.

A special thank you Bayer, CSL Behring, Genentech, Takeda, Accredo, Cottrill's, CVS Specialty, BioMatrix, Grifols, Novo Nordisk, Octapharma, BioTekreMEDys, Sanofi Genzyme and Diplomat for their support.

Golf Classic

Eastern PA Hemophilia Foundation held its annual Golf Classic on Tuesday, September 10, 2019 at RiverCrest Golf Club in Phoenixville, PA. The day featured a world-class golf course, delicious lunch and dinner, a silent auction, and fun contests. This included a 50/50 golf ball drop from a drone onto a green. One lucky winner took home over $700. Participants also could have professional golfer Perry Parker hit the longest drive for their foursome. In addition, Perry analyzed golfers' practice swings on the driving range during lunch.

CSL Behring was once again the presenting sponsor of the Eastern PA Golf Classic, and we thank them for their generous and continued support. Special thanks also to Novo Nordisk, Penn Home Infusion, Visual Communications, Accredo, Cottrill's, CVS Specialty, BioMatrix, Milliron Goodman, Warrington Collision, ProTek Consulting, Len and Karin Azzarano, Arlene and Steve Cohen, and Sandy and Bernie Krouse.

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Important Safety Information

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AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and 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 FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

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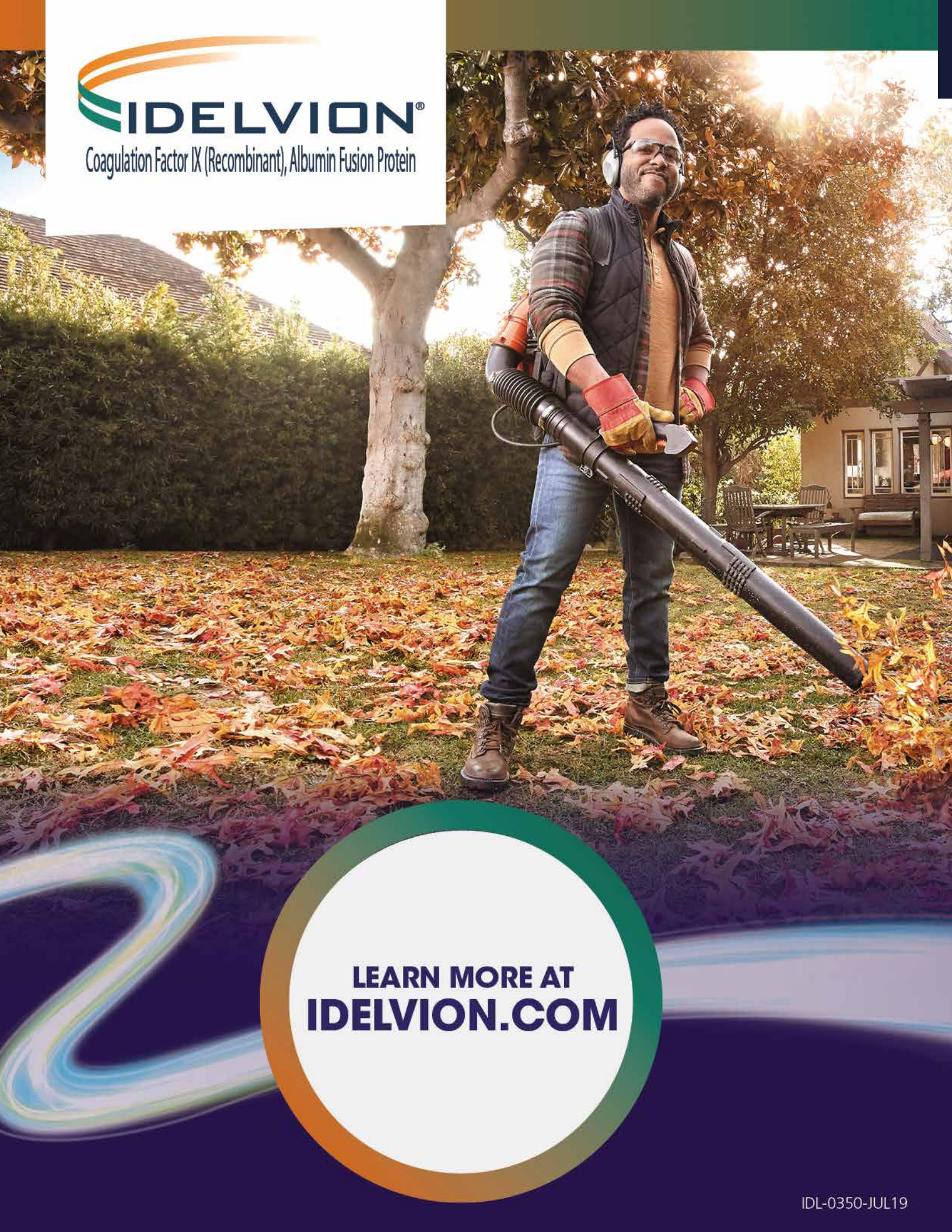
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Holiday Party

The Eastern PA Hemophilia Foundation held its annual Holiday Party on Saturday, December 7, 2019 at Canstatter Volksfest Verein in Northeast Philadelphia. Over 170 members of our community were in attendance. The party started with a buffet lunch and ice cream for dessert.

Jungle John Entertainment presented an exciting Winter Wonderland Show featuring Frostbite the Snowman. BioMatrix provided a cookie decorating station, Cottrill's hosted a stocking decoration station, Soleo Health had tons of great giveaways, and Accredo provided games such as an oversized Connect 4 game and air hockey. Festive hats and headbands were also provided.

Each child received a small stocking containing a gift card and candy, as well as the opportunity to have a photo taken with our special guest, Santa Claus! The Annual Holiday Party was a wonderful way to finish out the year and celebrate the holidays.

Men's & Women's Groups

The Men's Group had its final outing of the year on Wednesday, December 4, 2019 at Troegs Independent Brewing in Hershey, PA. Guys traveled from as far away as York, Scranton, Lock Haven and Jenkintown to enjoy great food, drinks and camaraderie. There were lively and engaging discussions about advocacy, programming and education. Special thanks to Bayer for sponsoring the program. For more information about the Men's Group, please contact Curt Krouse at 484-445-4282 or curtk@hemophiliasupport.org.

The Women's Group met on Friday, December 6, 2019 at Bonefish Grill in King of Prussia, PA. There were 17 women from various parts of our coverage area in attendance. The evening included a delicious four-course dinner, a mason jar holiday craft project hosted by Tina McMullen, and wonderful conversation. For more information about the Women's Group, please contact Lindsay Frei at 484-445-4282 or lindsayf@hemophiliasupport.org.

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