BIG RED FACTOR

2021—Issue 3



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It's hard to believe it's already Autumn in Nebraska!

It has been so wonderful being able to host in person meetings again this summer and fall. We have truly missed seeing your faces, interacting with you and feeling the energy and love that comes with in person programs. Thank you to everyone who has attended events, the Walk and our smaller specialty programs. We thank you for being safe, wearing masks and helping us to ensure we can continue to hold in person programming.

We will continue to hold in person events, but also found benefit in some of our virtual programs. You'll see us offering both in the coming months. Virtual programs allow us to include community members that may not be able to make it to our event site and we've had a lot of fun with some of our virtual programing. Our men's and teens group will be having some really engaging virtual events this fall.

Sarah and I have been working on our 2022 programs and calendar. We want to shake some things up and revamp some of our current programs and bring you new ones. We feel this is the perfect time to bring about something fresh and new. If you have interest in helping shape our next year, please consider joining our programs or events committees. We need you! I'm looking forward to rounding out 2021 with you all and planning an amazing 2022 full of in person programming and engagement.

Thank you for letting me serve this amazing community. Maureen Grace, Executive Director



NEBRASKA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

www.nebraskanhf.org

Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

Staff

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Maureen Grace

Program Manager Sarah Arrieta

Advisory Board of Directors

President - Peter Senior
Vice President– John Ashley
Secretary - Ann Foster
Treasurer– Bob Dick
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Joe Mickeliunas

The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

2021 Events

October 2021

October 8-10th FAB Women's Retreat

October 24th Harvest Festival

November 2021

November 6th Industry Symposium

November 20th Teen Virtual Cooking Class

December 2021

December 4th PING at the Zoo

December 20th Virtual Men's Program



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Updated Event and Program Guidelines

NHF is committed to ensure the safety of our staff, volunteers, and the community we serve.

These NHF Event Guidelines are one way for us to demonstrate that commitment.

As of October 1, 2021- In order to attend an in person NENHF event you must show proof of vaccination or a negative Covid test within 72 hours of the event. This is for any attendee 12+. Children do not need a negative covid test but still will need a mask for indoor events.

Stay Home When Appropriate

 Do not attend any program or event if you have tested positive for COVID-19, are waiting for test results, have any COVID-19 symptoms, of if you've had close contact with someone who has tested positive within the last 14 days.

Social Distancing

 Maintain social distancing with those not in your household. We are currently not encouraging handshakes or hugs.

Masks

- Masks will be required at all indoor NENHF events for the remainder of 2021.
- Masks must be worn over your nose and mouth.
- Masks are not required for kids under 2 years old, anyone who has trouble breathing or anyone who is unconscious or unable to remove a mask without assistance.
- At this time, all persons will be asked to wear a mask regardless of vaccination status.
- Masks will be made available by NENHF at all programs for adult and children.

Temperature Checks

- Temperature Checks will be taken at event check in and registration.
- Temperature must be below 100.4 according to CDC Guidelines

Hand Hygiene

- Wash hands often for 20 seconds.
- Hand Sanitizer will be made available at all programs and events.

Behavior Agreement

All attendees 16 and older will need to sign a Behavior Agreement and COVID-19
 Agreement to abide by all Guidelines at events or you will be asked to leave.



NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

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Hemophilia Golf Fundraiser

On Saturday, July 24th, 2021, Peter Senior, NENHF Board President, held a golf fundraiser at Pacific Springs Golf Course. His group was had fun in the summer sun, and was able to raise over \$1500 to benefit the bleeding disorders community and the Nebraska Chapter of NHF. It was a hot day, but that didn't stop these guys. We appreciate all the people that worked hard and played hard at this event!



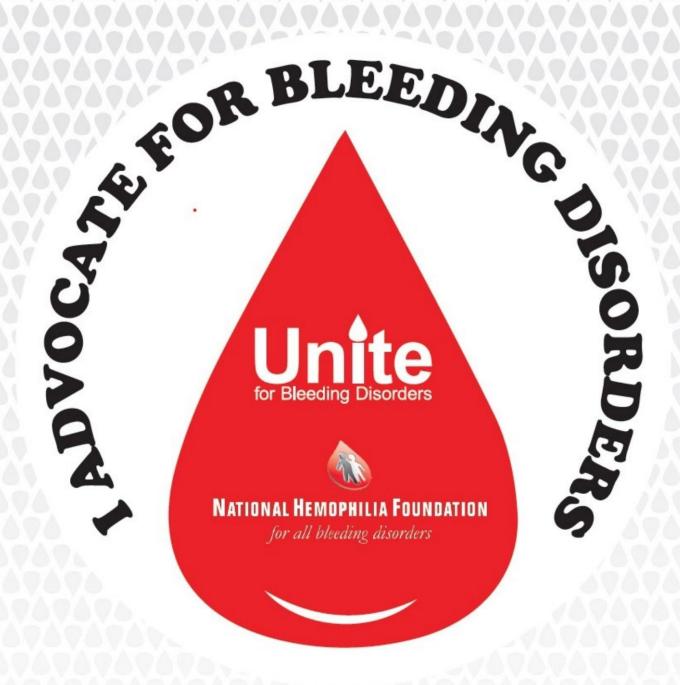
Night at the Ball Park

We had a great time spreading awareness for bleeding disorders, gathering as a community, and cheering on the Storm Chasers at Werner Park as they battled the Iowa Cubs on August 11th. The Nebraska Chapter of NHF was honored as the community partner of the night and Peter Senior threw the first pitch. Our community members shared a meal together and catch up while watching the action heat up on the ball field. The Iowa Cubs ended up winning against the Storm Chasers with a score of 47 to 37.

The night was sponsored by Paragon Healthcare and Octapharma. Thank you to all of our friends that came out to make this a fun and memorable night.



SIGN UP TO BE AN ADVOCATE Text NEBRASKAUNITE to 52886







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Nebraska Women's Retreat

The Nebraska Women's Retreat was a great opportunity for the women in our community to gather together and catch up with each other. It has been an incredibly difficult 18 months, dealing with the pandemic, being apart and losing a very important and valued community member, Kaylean Gentry.

This event was held on August 21rst at The Event Space in Lincoln, NE. The ladies enjoyed breakfast and lunch together, practiced mindfulness, made some crafts, set intentions for the future, created emergency bags, and ended the event with manicures and pedicures at Rainbow Nails and Spa. We also shared our feelings about the loss of community member, Kaylean Gentry, who is gone but not forgotten.

This event was sponsored by Takeda and Brother's and the Hemophilia Alliance Foundation.



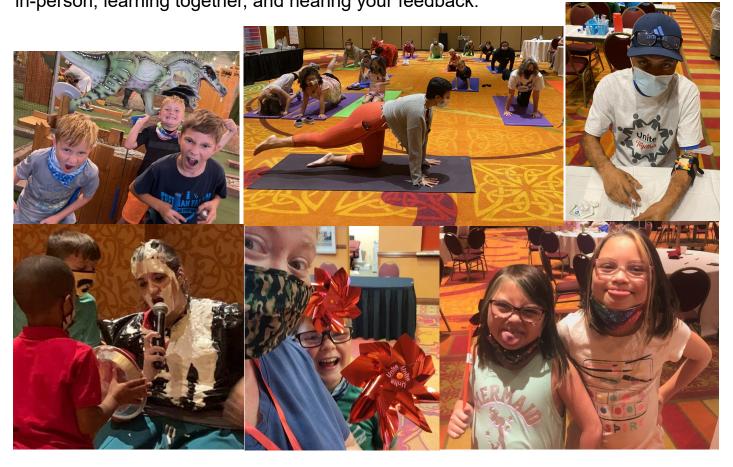




Family Education Weekend

Our Family Education Weekend took place on September 18th and 19th at the Embassy Suites LaVista. We learned about a lot of interesting and important topics this weekend. We learned that Community Voices Research (CVR) allows community members to share experiences and shape future research. We also discussed females and bleeding disorders, insurance options, PTSD and chronic conditions, communicating with your child's school, managing stress and improving wellness, and AAV gene therapy. We learned about the importance of healthy food choices during our lunch buffet. Community members brushed up on infusion skills at the infusion clinic. We got inspired at a creative writing workshop, let loose at Prehistoric Putt-Putt Golf, and focused on stretching and breathing during yoga with Madi Budin. Families also took part in a Goosechase game during the weekend, and lots of funny pictures and videos were shared. One highlight of the weekend was when we reached our fundraising goal for the Unite Walk and the top fundraiser was able to smash a pie in Executive Director, Maureen Grace's face!

Our teen group discussed choices and risks, collaborated on future events and programming, took part in the creative writing workshop, and solved a murder mystery. Some of the kids even took a painting class. We had a great time getting together in-person, learning together, and hearing your feedback.



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Unite for Bleeding Disorders Walk

The annual Unite for Bleeding Disorders Walk took place on October 2nd at Chalco Hills Recreation Center in Omaha and we exceeded our goal and raised over \$42,500! We are so incredibly proud of you for coming together and raising funds and awareness for the Nebraska Bleeding Disorders Community.



We had a beautiful fall morning, paired with donuts, a bounce house and our chapter coming together. Thank you to all of our walkers for having such a wonderful event and raising funds to support education, advocacy and research in Nebraska.

A Huge round of applause to our Factor Club Members who raised more than \$500:

• Amelia Mickeliunas • Sam Clinkinbeard • Maureen Grace • Ann Foster • In Memory of Kaylean Gentry • Phillip Galaska • Erik Clark • Kristin Henson • Cark Clark • Justin Clinkinbeard • Sarah Arrieta • Zach Fischer • Sharon Clark • John Mickeliunas • John Ashley • Shelby Larson • Susie Zimmer • Andye Nelson • Joe Mickeliunas • Jon Tvrdik • Sue Collin • Dale Gibbs • Jenny Mickeliunas •



Harvest Festival / PING

Sunday, October 24, 2021 9 am-11 am-Roca Berry Farm

Join us for the social event of the fall with Nebraska NHF at the Pumpkin Patch! We are headed just South of Lincoln to Roca Berry Farm!!

Visit with industry sponsors, fellow hemophilia families, enjoy snacks and enjoy your day at the pumpkin patch.

We will be providing treats and tickets to Roca Berry Farm for members of our community. In order for NE NHF to provide your tickets you must meet one of the following criteria:

- Diagnosed with hemophilia, Von Willebrand Disease or another bleeding disorder
- Diagnosed as a carrier of hemophilia or another bleeding disorder
- Caregiver of a person with a bleeding disorder

We will provide tickets for the immediate family of our affected members. While we love your extended family, its imperative for us to be conscious of our budget to offer more programs and events throughout the year. They are welcome to join you for the day at the berry farm and tickets can be purchased for them online or at the gate. Thank you for your understanding.

Covid Policy: In order to attend this event, all those vaccine eligible (12+) will need to show proof



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4 Reasons to Establish Care at a Hemophilia Treatment Center

Author: Donna Behen— Hemeaware.org

Learn why HTCs can be partners in care over the course of a lifetime

If you or someone you love has been diagnosed with hemophilia, von Willebrand disease or another type of bleeding disorder, you've probably heard about hemophilia treatment centers (HTCs).

HTCs were created because people with bleeding disorders, their families and healthcare professionals literally demanded them. In 1973, the National Hemophilia Foundation (NHF) launched a two-year campaign to establish a nationwide network of centers to diagnose and treat hemophilia and other bleeding disorders. The goal was to provide an extensive range of coordinated services for patients and families within a single facility.

Today, there are <u>approximately 141 HTCs across the country</u>, which are partially funded by the Centers for Disease Control and Prevention (CDC) and other federal agencies. Although they are called hemophilia treatment centers, HTCs provide care for people with von Willebrand disease and other bleeding disorders.

Depending on where you live, you might have to travel several hours to receive care at an HTC. If that's the case, it's still a good idea to establish care at one of these centers, even if you aren't able to visit the HTC more than once or twice a year.

Here are four reasons why establishing care at an HTC is so important:

1. Comprehensive Care

Comprehensive care treats the whole person and the family, through continuous supervision of all the medical and psychosocial aspects of bleeding disorders. With comprehensive care, every facet of the person is addressed, including their physical, emotional, psychological, educational, financial and vocational needs, not just visits with a blood disorder doctor.

Studies show that this comprehensive care model leads to improved health for people with bleeding disorders. A 2000 CDC study of 3,000 people with hemophilia showed that those who used an HTC were 40% less likely to die of a hemophilia-related complication compared with those who did not receive care at an HTC. Similarly, a separate study by CDC researchers revealed that people who used an HTC were 40% less likely to be hospitalized for bleeding complications.

2. Multidisciplinary Team of Specialists

HTCs provide specialized care from a multidisciplinary team of providers.

Members of the care team at an HTC can include:

- Hematologists: Physicians who specialize in blood disorders.
- **Pediatricians:** Physicians who specialize in caring for infants, young children and teenagers.
- **Nurses:** Medical specialists in bleeding disorders care.

Establishing Care at a Hemophilia Treatment Center

• **Social Workers:** Specialists who assist you with the issues of daily living, such as adjusting to living with a bleeding disorders, and locating resources (e.g., insurance, transportation, housing).

- **Child Life Specialists:** Specialists who focus on the developmental needs of children, and help children cope through education, preparation and play.
- **Physical Therapists:** Specialists in activity, exercise and rehabilitation.
- Occupational Therapists: Specialists in managing everyday tasks with any limitations resulting from bleeding disorders.
- Orthopedists: Physicians who specialize in disorders of the bones and joints.
- **Dentists:** Specialists in disorders of the teeth and gums. The dentists at HTCs are experts in treating children with oral bleeding problems.

The HTC team can also consult with a patient's regular primary care physician, dentist or specialist. HTCs can educate and support health care providers who perform cardiac testing, colonoscopies or other services in adults.

3. Emphasis on Education

In addition to treatment, one of the major goals of an HTC is education. For example, when a child begins prophylaxis treatment, HTCs teach parents and caregivers, and, eventually, the children, how to infuse themselves so they can treat at home. Infusing at home can save time, reduce discomfort and increase convenience during a bleed, because patients don't have to travel to an emergency room and wait.

HTCs educate others, as well. HTC staff members often visit schools so that they can help educate teachers, administrators and school nurses learn what hemophilia is, what activities are safe for children to participate in, and how to recognize an emergency.

4. Access to New and Improved Treatments

HTCs gather and share information about common health issues and medical complications that affect people with bleeding disorders, with the goal of advancing care and improving outcomes. Patients who receive care at HTCs also have access to a variety of studies and clinical trials, which gives them access to new treatments that may not yet be widely available.

However, involvement in research initiatives is completely voluntary, and is not a requirement for being treated at an HTC.

Contact your Nebraska HTC today to set up care:

Nebraska Medical Center (Adult): (402) 559-7257

Children's Hospital and Medical Center (Pediatric): 402-955-3950

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Industry Symposium



Nebraska Bleeding Disorder Industry Symposium

Saturday, November 6, 2021 Mahoney State Park



The Nebraska Chapter of NHF is excited to announce an Industry Symposium where leading hemophilia drug manufacturers are able to come tell you all about their new products, programs and answer any questions you may have. NE NHF does not usually allow Industry to do branded talks but with all of the new changes on the horizon, we wanted to give them a voice. Please come join us for a day of updates from our manufacturer partners.

Saturday, November 6 * 9:00 am- 3:00 pm

Hybrid Event- In Person and Virtual attendance are available.

Door prizes are available for both in person and virtual attendees!

Breakfast, lunch and childcare are available for in person attendees.

Takeda, Sanofi Genzyme, BioMarin, CSL Behring,

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Don't Miss This Upcoming Teen Event

Hey Teens—It's your turn again for a super fun cooking event with Chef Mike! You get to learn some great knife skills, become a wiz in the kitchen and connect with other teens in the community. Make sure you register online to receive your event kit including a chef's knife and cutting board. It's guaranteed to be a fun, interactive virtual event. We can't wait to see what you'll cook up. Don't waste time and register today!



Virtual Cooking Class

November 20th, 2021 at 3pm

Ages 12 - 18



Register by ll/8/2021 at www.nebraskanhf.org to receive your knife and cuttingboard



www.nebraskanhf.org



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Men's Program

Join us for mental health education & happy hour

Virtual Men's Education & Mixology Glass



DECEMBER 11, 2021 7 PM - 9 PM REGISTER BY 12/8/2021 AT WWW.NEBRAS KANHF.ORGTO RESERVE YOUR MIXOLOGY KIT



Hemdifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at HemDifferently.com

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN

FINANCIAL AID

HOW NENHF CAN HELP IN 2021 and beyond!

The Financial Assistance program is part of NENHF's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. Families can request up to \$500 per year of support.

Example eligible expenses include, but are not limited to, the following:

Expenses incurred in the care, treatment, or prevention of a bleeding disorder

Transportation services to medical appointments and HTCs

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Medical supplies not covered by insurance

Basic living expense emergencies (rent, mortgage, utilities, food, etc.)

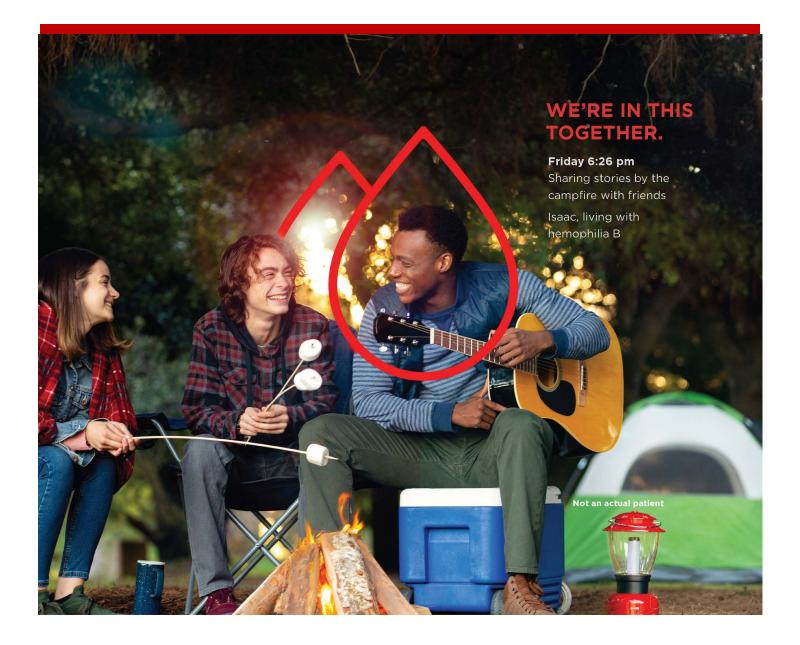
Unexpected home or car repairs

Medic Alert Bracelets

Dental expenses

Health insurance premiums

Find more information and apply at: https://www.nebraskanhf.org/support-resources/financial-assistance-program.html



Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.





Keep track of your bleeds, infusions, and activity.



with enhanced activity tracking

The little app is getting bigger.

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









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

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Hemophilia can be difficult. Tracking it shouldn't be.

HemMobile[™] was designed to help you keep track of your bleeds, infusions, and factor supply.*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level as well as your dosing regimen.

Download the app, pair your device, and start tracking





For iPhone® and Android™



For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday from 8:00 AM to 8:00 PM Eastern Time.

*HemMobile™ is not intended for curing, treating, seeking treatment for managing or diagnosing a specific disease disorder, or any specific identifiable health condition. iPhone is a trademark of Apple Inc., registered in the US and other countries. App Store is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.

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JIVI[®] ADYNOVATE[®]

PK (Pharmacokinetics) Study Data



Talk to your doctor about the study.



Scan the QR code to learn more about PK at UnderstandingPK.com



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**.



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
- stomach (abdomen) or back pain
- swelling of arms and legs
 yellowing of skin and eyes
- 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 HEMUBRA:

 swelling in arms or legs

 pain or redness in your

 pain or ledness in your

 page of logs.
- arms or legs shortness of breath

- headachenumbness in your face
- chest pain or tightness
 fast heart rate
- eye pain or swellingtrouble 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
- 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 (subcutaneous injection) by you or a caregiver. ection under vour skin

- 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

- 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?" $\label{eq:likelihood}$

The most common side effects of HEMLIBRA include:

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and

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U.S. License No. 1048
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018



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