BIG RED FACTOR

2022—Issue 2

Inside this issue:

Summer is in full swing and so our chapter events! We are gearing up for a busy summer and we can't wait to see you!

Don't forget to register for Family Education Weekend and start your walk team!

Proof of vaccination is no longer required to attend chapter events. Please stay home if you aren't feeling well or if anyone in your home tests positive.

It's hard to believe we are half way through the year with a lot of great programming still to come for all ages.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

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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.

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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.

2022 Events

Family Education Weekend– Omaha
August 5-7th

Unite for Bleeding Disorders Walk
September 24th

FAB Women's Conference
October 14-16

Harvest Festival
October 22

Industry Symposium
November 5, 2022

Holiday PING
December 10, 2022

We will be planning industry education dinners across Nebraska throughout the rest of 2022. If you want an education dinner in your area, please let us know so we can coordinate.

combined health agencies drive
MEMBER CHARITY

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.

In order to attend an in person NENHF event, it is no longer required to show proof of vaccination or provide a negative test. If you are not feeling well or someone in your household has tested positive, please stay home.

NENHF does not require vaccination to attend events but strongly encourages our community to be vaccinated.

- **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.
  - Follow the Red/Yellow/Green Stickers for personal levels of interaction.
- **Masks (UPDATED)**
  - **NENHF's Mask Guideline will be determined by the CDC level at the time of the event.**
    - **If green or yellow- masks are optional.**
    - **If red- masks are required indoors.**
  - Masks must be worn over your nose and mouth if required indoors.
  - 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..
  - Masks will be made available by NENHF at all programs for adult and children.
- **Hand Hygiene**
  - Wash hands often for 20 seconds.
  - Hand Sanitizer will be made available at all programs and events.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Advocacy Update

Chapter Advocacy Update

During the Nebraska Legislature's session that ended this year, the Chapter Advocacy Committee reviewed a number of bills in cooperation with the National Hemophilia Foundation. There were three bills we felt were beneficial to the community. We sent written testimony to the applicable committees and gave verbal testimony in favor of the other.

- LB 718 was heard by the Banking, Commerce and Insurance Committee and dealt with insurance companies not allowing copay assistance to count toward the insurer's deductible. This allows insurers to encourage the insured to utilize generic drugs, which results in lower costs to the insurance companies. The Chapter supported this bill because there are no generic drugs for controlling hemophilia and copay assistance helps all handle the high costs of the medications. The Chapter provided in person testimony in support along with other agencies who work with other high-cost diseases. The only opposition to the bill came from insurance companies. Unfortunately, the bill wasn't voted on by the committee before the end of the session and will carry over until next year.
- LB 895 provided guidance to managed care organizations in not slowing care by requiring prior authorization in emergency situations for administration of anti-hemophilia medications. This bill also was not voted on before the session ended.
- LB 1140 was reviewed by the Business and Labor Committee and allowed state employees to donate portions of their income to non-profit health and human agencies. NeHF is part of Combined Health Agency Drive (CHAD) which represents non-profit health and human agencies whose mission is to improve their members lives. CHAD participates in annual drives across the state, sometimes in conjunction with United Way campaigns. Recently, the United Way has been the only agency allowed in the state campaigns. LB 1140 also, unfortunately, was not voted on before the legislature adjourned.

This past month, NHF held its first Advanced Chapter Advocacy Training for advocacy efforts by the individual chapters. Approximately 60 people attended the two-day event and learned from the national advocacy staff and each other's best (and bad) practices. Topics included: Insurance Trends and Barriers to Care; Tips on What to Do When a Bill is Presented; Medicaid Updates and Regulatory Advocacy; Novel and Gene Therapy Updates and Public Policy Considerations; Congressional Hill Staffer Perspectives; Allied Healthcare Advocacy Organizations can assist with local advocacy. Many ideas were presented at the event and we hope we can implement many of them in the coming years.

If anyone is interested in joining the Chapter's Advocacy Committee, please contact Maureen or Dale Gibbs (mdgibbs31@gmail.com).

Infusion: Bloody Mary Mix Off

We were officially back in person this year for our Infusion; Bloody Mary Mix Off. This year was our 7th annual event where we raised funds and awareness for the Bleeding Disorders Community while sampling some of Omaha's Best Bloody Marys and a delicious brunch. The event was held on Saturday, July 16th at Founder's One Nine. We featured six different competitors who brought their A Game on their infused bloody marys. Our competitors were Spirit World, Backlot Pizza + Kitchen, Krug Park, Saddle Creek Breakfast Club, Addy's Capitol and Catering Creations. The event was sponsored by Tito's Vodka, Bayer and CSL Behring. We raised $15,750 at Infusion!

Our 2022 Winners were:

Best Overall Bloody: Spirit World
Best Garnish: Saddle Creek Breakfast Company
Best Infusion: Krug Park
Most Creative: Saddle Creek Breakfast Club

Thank you to all who attended! We cannot wait to see you back again next year for our 2023 event.

Family Camp 2022

We were back in person for Family Camp 2022 and it was a BLAST!

Our previous venue for camp closed during the pandemic and we had to find a new home for camp and were welcomed by the team at Carol Joy Holling and it was a blast. We tie dyed, did crafts, went paddle boating, played games and rocked a ropes course.

We then headed off to Omaha's Henry Doorly Zoo for our overnight adventure. We had a sleep over in the heart of the zoo at the Harper event center where we got to explore the zoo after it closed and before it opened. We even got a private encounter with the sting rays!

Thank you to our sponsors who made this event possible and were able to bring together families of all ages to enjoy the great outdoors, worked on self infusion skills and had a great time experiencing all they can do while living with a bleeding disorder. We look forward to 2023 and a whole weekend together.

Teen Council and Programming

Big things have been happening for the teens at NENHF. We had teen programming at the Adults with Bleeding Disorders Conference, which was held on May 21st and 22nd. We were joined by speakers Marlee Whetton, Delila Arreola, and Genesis Erickson, who are members of NHF's National Youth Leadership Institute. The speakers led us in the following educational sessions: Independence and Management and Failure is an Option. We also held a Teen Council meeting and established the core group of the NENHF Teen Council. The teens learned about the benefits of the NYLI program, which is open to youth ages 19-22. It is the goal of the NENHF Teen Council to prepare youth ages 12-19 for application to the NYLI program. To honor the fact that our youth need some independence, the teens were given the opportunity to choose their own adventure by deciding to either join in a Virtual Escape Room with the adults, or to stay with Sarah, our Program Manager, to play What's in the Box. In the end, the teens and NYLI speakers joined Sarah for What's in the Box, and a lively game of Jumanji in costumes was enjoyed by all. Finally, our teens joined the adults for dinner and an escape room which everyone enjoyed.

Our Teen Council members also took on some new responsibility this year. The NENHF Teen Council was asked to lead families in a craft, and Nicolas Quiroz had the excellent idea to paint birdhouses. We were proud of our teens for taking some initiative to decide on a craft and showing leadership in guiding our families through this activity. The Teen Council will also begin a service project where they will give back to their community (look for more news about this soon). We look forward to seeing the ways this group of teens will take on leadership in the future.

We have some excellent programming and events for youth coming up in the next few months. NENHF hosted a Parent & Teen Education Dinner and Escape Room event on July 9th. Dinner was held at Biaggi's from followed by an escape room at Locked Room Omaha. Youth ages 12 – 19 will also experience some dynamic and experiential learning at our Family Education Weekend on August 6th & 7th. This programming will be brought to us by Gutmonkey, an organization that develops transformational programming for communities with chronic health conditions. We know our teens will enjoy the hands-on adventure that Gutmonkey will bring. Also be sure to keep an eye out for our Virtual Resume Workshop that will be held in October. You can register for these events at Event Calendar : Get Involved : National Hemophilia Foundation - Nebraska Chapter (nebraskanhf.org).

For more information about the NENHF Teen Council or these upcoming events, contact Sarah Arrieta at sarrieta@hemophilia.org or (402)889-0572.

For more information about NYLI click on the following links:

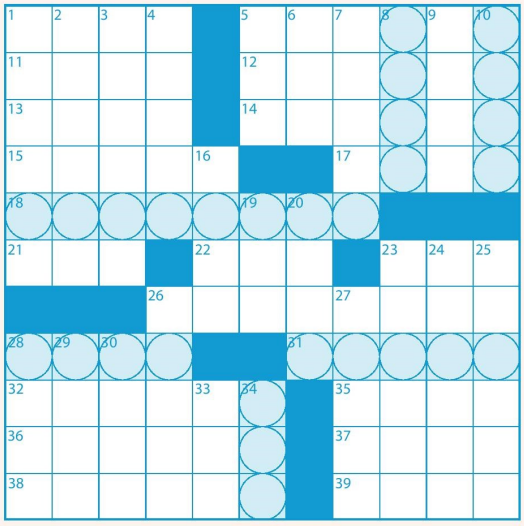
NYLI : Programs : Get Involved : National Hemophilia Foundation - Nebraska Chapter (nebraskanhf.org)

Youth Leadership (NYLI) | National Hemophilia Foundation

CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

†Number of people with hemophilia A treated as of October 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin
16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than_____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. anose, 37. tall, 38. lessen, 39. olés

Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

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
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - 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.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

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: 12/2021

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

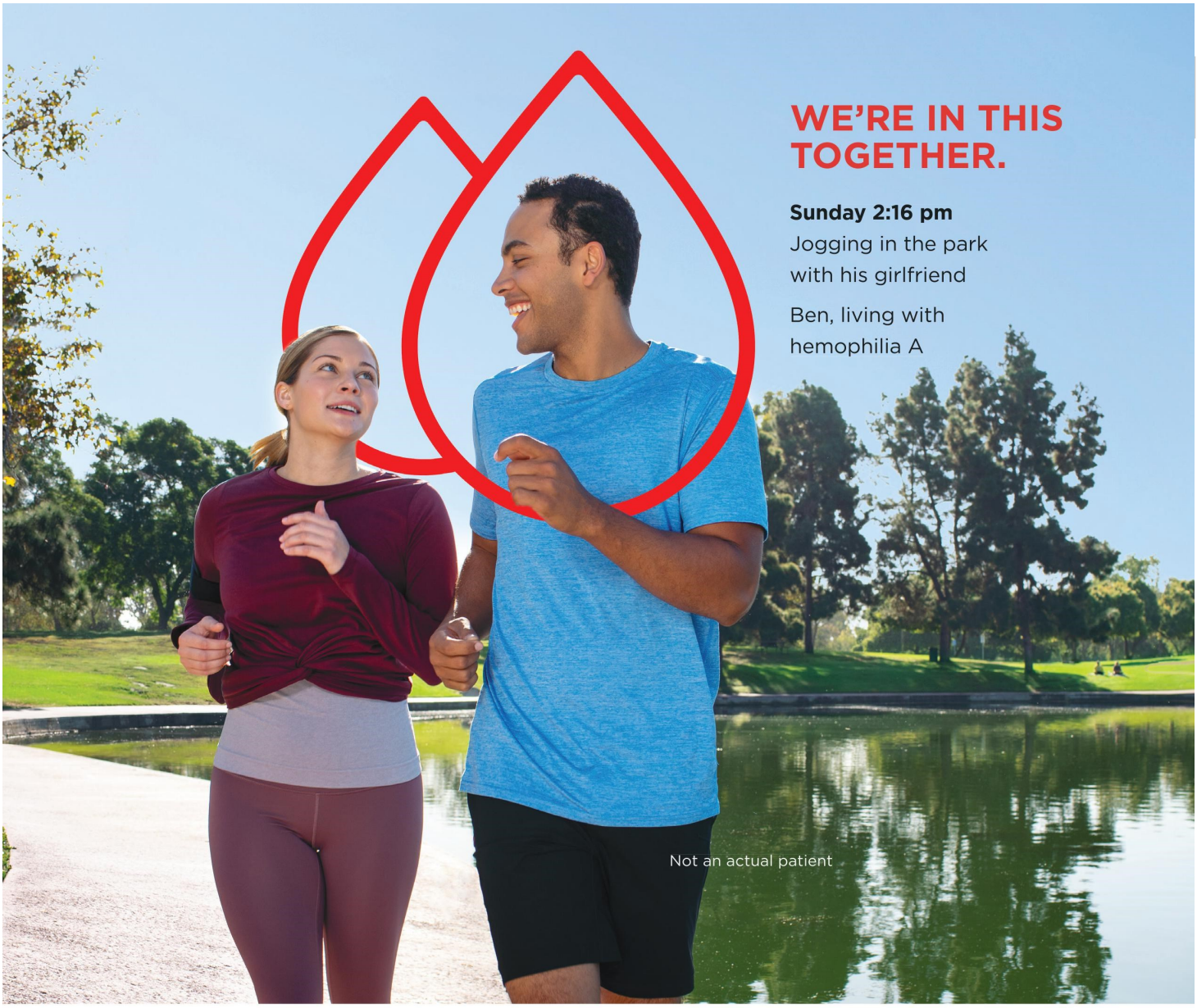
Genentech
A Member of the Roche Group

Unite
for Bleeding Disorders

Saturday, September 24th, 2022
Chalco Hills Recreation Center

Register at:
www.uniteforbleedingdisorders.org

Pancake Man | Face painting | Bounce Houses
Community and Connection



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.

bleedingdisorders.com

Takeda

Embracing the Unique

By Laurie Kelley

When children are diagnosed with hemophilia, they are each given an essential diagnostic label: for example, hemophilia A or hemophilia B, severe, moderate, or mild. These labels originate from a lab analysis of the child's blood. The diagnosis determines what type of factor replacement therapy each child will get. Labels like these can help draw a picture of who your child is and what he or she needs. But when it comes to dosing and prophylaxis regimen, sport choices and bleeding patterns, and even pain management, your child with hemophilia is unique. Diagnostic labels don't adequately explain a person's individuality and needs.

We asked parents from Facebook about their children with hemophilia: Has anyone ever used the labels of hemophilia to categorize your child, which resulted in limiting treatment options, or limiting what people think your child can do? What is it about your child that is not "typical" for someone with hemophilia? The responses poured in. While a child's uniqueness may be revealed in a preference for certain sports or a physiological reaction to a particular product, most of the parental responses we received were about each child's unique half-life, and about subsequent bleeding patterns.

Half-life was barely mentioned when my son was born. In the late 1980s and early 1990s, we dosed his factor using a chart based on his weight; it was very mathematical. We took one-half of his weight in kilograms times the factor level we desired, and this equaled the number of units of factor VIII we needed to infuse. Over time, as parents, we developed intuition about how much or how little factor our son needed based on his response to factor and his bleeding patterns, and we could adjust his dosage ourselves.

Up until about the last 10 years, hemophilia treatment centers (HTCs) often prescribed factor dosages based on weight, and determined a prophylaxis regimen based on a strict protocol from clinical studies. We now know that every child needs to have a pharmacokinetic (PK) or recovery study done to determine his or her individual, unique half-life response to a specific factor VIII product. Determining the unique half-life can help hone the amount of factor a child should receive, or indicate the best prophy regimen. A short half-life may mean more frequent infusions, higher doses, or the use of extended half-life products.

If anyone knows about the uniqueness of factor half-lives in children with hemophilia, it's June Reese, who has four sons with hemophilia. She says, "One son has always had a short half-life and has really struggled with bleeds. His teachers often compare him to his brothers, one of whom never bleeds." And this was a problem for the Reese family: in categorizing two brothers with textbook half-lives as "normal" for hemophilia, teachers dismissed the third brother's frequent bleeds—they thought he was being careless, or worse, that he was imagining the bleeds.

Embracing the Unique Continued

Crystal Eskine has two sons with severe hemophilia A, ages 9 and 10. "I expected two similar stories," she laughs. Despite having the same diagnosis as his brother, Crystal's 10-year-old bleeds spontaneously, "if you look at him too hard." Her younger son "never needs factor," and "he isn't even on prophy he bleeds so little!" When Crystal's doctor wanted her to adhere to a traditional dosage and infusion schedule with her older son, her gut instinct told her it wasn't good enough. She knew her children's unique responses to factor. "I started giving my older son double doses. I took notes, showed our doctor, but he still he thinks I'm worrying too much, while I still don't think the dosing regimen is good enough." Crystal continues, "I've asked for a PK test, with blood samples taken over a much longer time period, but he has said no."

And then there is Jen Miller's five-year-old with severe hemophilia A. Jen calls him a "typical boy" who enjoys video games, swimming, T-ball, and playing with his friends. His factor half-life is very short, which is not typical, but this doesn't seem to impact his bleeding patterns.

When a shorter half-life does impact bleeding patterns, and parents instinctively know something isn't right, they need to alert their HTC staff, sometimes to prove that their child does not fit a category or label. In these cases, parents should request a PK study. Crystal laments, "My boys' hematologist makes me feel like I'm doing something wrong, but refuses to do a PK study." June adds, "For years, our medical staff acted as though we were to blame when he'd have bleeds—even though he was infusing regularly."

Kate Stotz, who has a 22-month-old with severe hemophilia A, felt she had to fight against the standard prophy infusion schedule of three times a week. "This was not working for our son," she explains. "He was having frequent bleeds on Sunday, the day he was unprotected. Trough levels indicated that in order to maintain a minimal 1% trough, we could not exceed 48 hours between infusions." Though Kate wanted to infuse every other day to keep him protected, her son's hematologist didn't want to break from the traditional schedule the HTC normally prescribed. "It took a lot of advocating on our part and ultimately finding a new doctor at a different HTC."

Sarah Hueston successfully advocated for a new prophy regimen for her 16-year-old son with severe hemophilia A, who plays two varsity sports. When they determined he had a short half-life, the HTC team, Sarah, and her son developed his treatment plan together. He now infuses standard factor daily. "It's what works for us," says Sarah, "and his doctors are so proud of him, as are we, his family! Never did we think he'd be doing the things he's doing even 10 years ago!"

By logging her son's bleeds, Stacey Mollinet was able to convince her HTC team to change the treatment schedule. When her son with severe hemophilia A was a young teenager, he didn't bleed like a typical severe and was not very active by nature. "I had to push the HTC," she recalls, "so he could treat only twice a week, instead of a standard prophy schedule." Around age 14, he started to bleed more like a typical severe. So Stacey worked with the HTC to adjust her son's dosing schedule, and ended up dosing every other day until he switched to extended half-life factor two years ago.

"There's not a one-size solution for everyone," Stacey has learned. "Keeping good infusion and bleed logs so you know what schedule works best to prevent bleeding is important."

Crystal laughs, "I could probably write a book about all the ways my boys 'differ' from the typical definition of hemophilia."

And in a community where boys "typically" have hemophilia while women are carriers, women are now advocating to redefine what it means to have hemophilia. Labels have their place, but when we define hemophilia and determine treatment plans, we sometimes need to look outside the box at hemophilia—and trust the parents and patients when they describe their own uniqueness and needs.

Thank you to our Industry Sponsors who support our programming, advocacy and outreach efforts throughout Nebraska for all bleeding disorders.

Rural Outreach and VWD

Blue Cross and Blue Shield of Nebraska (BCBSNE) has awarded the Combined Health Agencies Drive (CHAD) and its statewide umbrella of 23 health care agencies the company's Health of Nebraska Sponsorship, which is dedicated to supporting programs and services for Nebraskans affected by a medical diagnosis.

For more than 80 years, BCBSNE has offered security and stability to its members faced with medical expenses. Through its Health of Nebraska initiative, BCBSNE seeks to support programs that address social determinants of health and health equity, BCBSNE's sponsorship will directly benefit the missions of the various CHAD organizations, helping them to continue to offer meaningful, vital programming for communities across the state.

"Our goal with community funding is to cultivate lasting relationships and give back to our communities in ways that directly advocate for the health of Nebraskans," said Kathy Nellor, health transformation leader at BCBSNE. "Nebraskans count on support from all CHAD member agencies, and it is a privilege to help them help others for the second year in a row."

In 2020, CHAD's 23 member agencies collectively assisted more than 37,133 Nebraskans with professional care or resources, ensured access to specialized or long-term support for over 9,625 patients and invested approximately $518 million in medical research alongside their national affiliates. Since the onset of the COVID-19 pandemic, CHAD and its member agencies have continued to find impactful, innovative alternatives to get and stay connected to the people they help across the state.

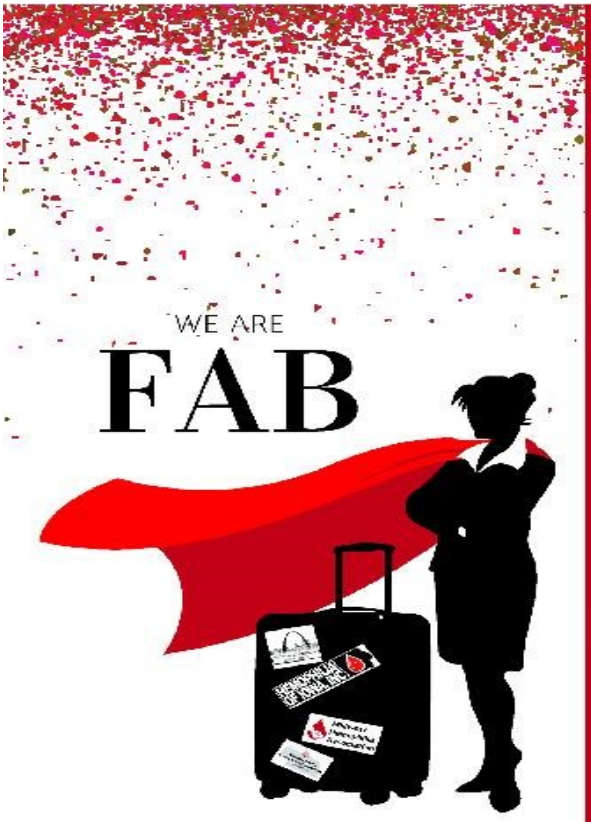
CHAD is a local organization raising funds with and for Nebraska's health agencies across Nebraska since 1972.

"As we approach our 50th year serving Nebraska, CHAD is so pleased to have an outstanding community leader like BCBSNE to work with on what matters to the constituents of our health agencies across the state. March of Dimes, American Lung Association, JDRF and so many more are going to have the funding to support Nebraskans with new or expanded programming," said Michelle Grossman, president and chief executive officer of CHAD. "We sincerely thank BCBSNE for investing in the health and well-being of all Nebraskans."

Nebraska NHF received a grant through CHAD and BCBS focused on rural outreach and VWD Guideline distribution to providers. We are working to host educational outreach dinners across the State of Nebraska while hosting community connection dinners. If you are interested in having a program in your area, please let us know. We are excited to get more bleeding disorders awareness and VWD treatment and diagnostic guidelines out to all Nebraskans. We would like thank CHAD and BCBS for their support in these endeavors.

combined health agencies drive
MEMBER CHARITY

BlueCross BlueShield Nebraska



FINANCIAL AID

HOW NENHF CAN HELP IN 2022 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
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

Keep track of your bleeds, infusions, and activity.

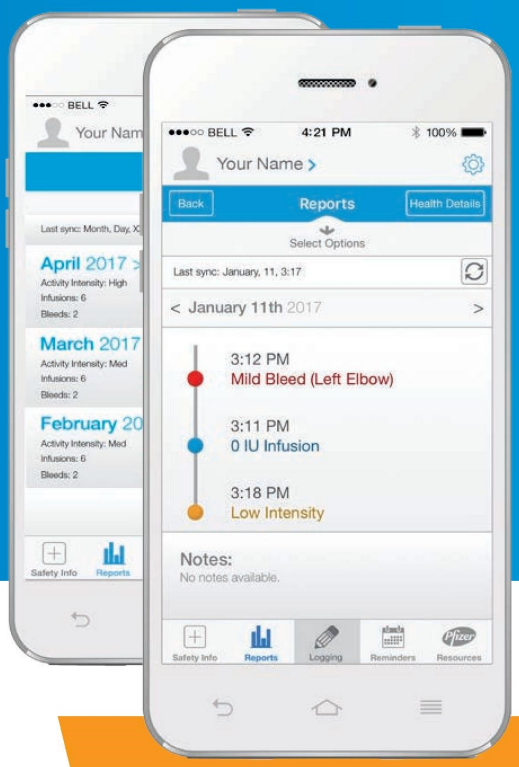
HemMobile™

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



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

Download on the App Store | ANDROID APP ON Google play

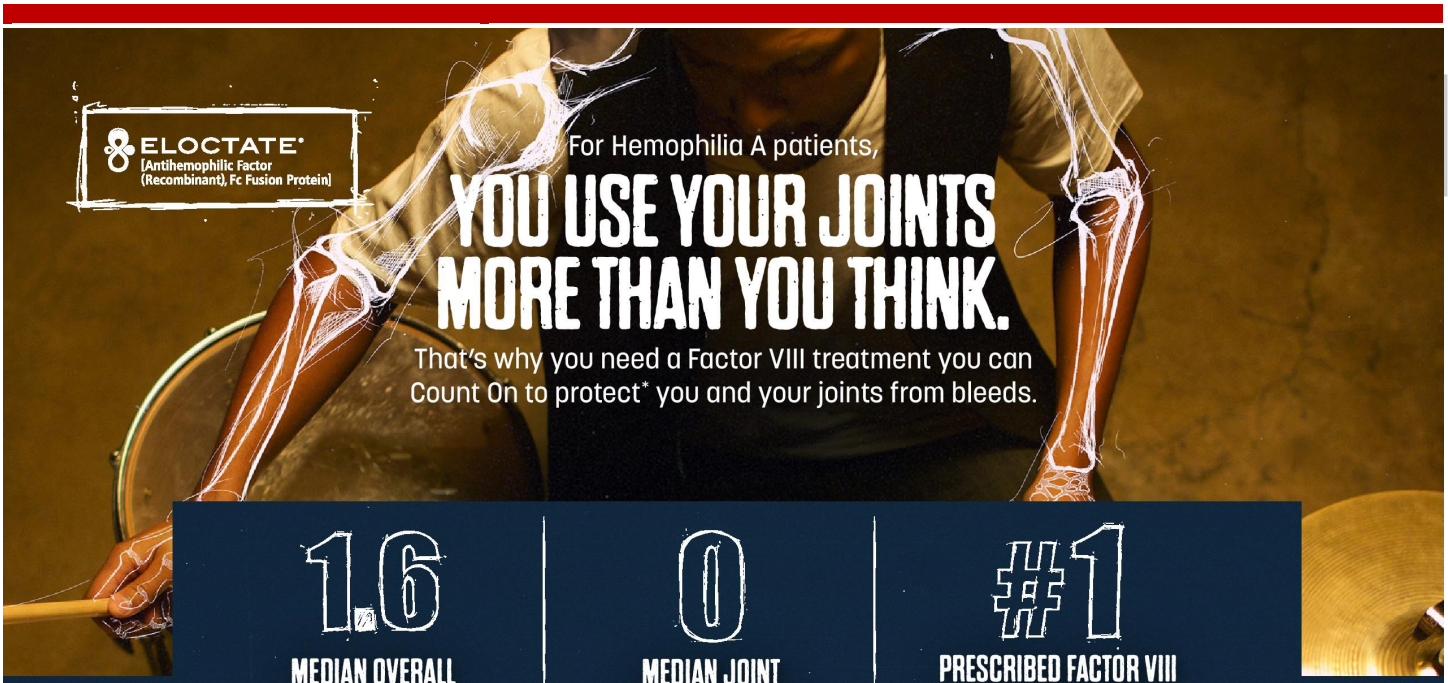
For iPhone® and Android™

Pfizer Hemophilia Connect

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.



1.6
MEDIAN OVERALL BLEEDS PER YEAR†

0
MEDIAN JOINT BLEEDS PER YEAR†

#1
PRESCRIBED FACTOR VIII FOR PROPHYLAXIS IN US‡

*ELOCTATE has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

†In the A-LONG study, 164 previously treated adults and adolescent males with severe Hemophilia A ages 12-65 received Eloctate either every 3 to 5 days, once weekly, or on demand.

‡#1 prescribed based on HTC reported data as of September 2020.

A CONNECTION YOU CAN COUNT ON

Learn more about how to protect you and your joints from bleeds by connecting with your local CoRe.

Danielle Kempker
danielle.kempker@sanofi.com
(816) 946-1870

Connect with your CoRe

INDICATION

ELOCTATE® [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ELOCTATE when you have surgery.

IMPORTANT SAFETY INFORMATION

- Do not use ELOCTATE if you have had an allergic reaction to it in the past.
- Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.
- Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.
- Your body can also make antibodies called "inhibitors" against ELOCTATE, which may stop ELOCTATE from working properly.
- Additional common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.
- If you have risk factors for developing abnormal blood clots in your body, such as an indwelling venous catheter, treatment with Factor VIII may increase this risk.
- These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, or if bleeding is not controlled after using ELOCTATE.

Please see full Prescribing Information.

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