BIG RED FACTOR

2023—Issue 2

Inside this issue:

Nebraska Chapter
National Hemophilia Foundation
www.nebraskanhf.org

Congratulations to Sarah Arrieta on her promotion to

Senior Program Manager

Sarah has been with the Nebraska Chapter for 2 years and in that time has done wonders on our programs, invested in the Teen Council and brought her expertise and sparkling personality to truly enhance the experiences of families who attend chapter programs at events. We are so grateful to have Sarah and her promotion is well deserved.

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

Executive Director
Maureen Grace

Senior Program Manager
Sarah Arrieta

Advisory Board of Directors

President - Peter Senior
Vice President– John Ashley
Secretary - Suellen Colin
Treasurer– Bob Dick
Joe Mickeliunas
Zach Fischer

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.

2023
Events

July 23rd
Infusion: Bloody Mary Mix Off

August 11-13th
Family Camp
Camp Carol Joy Holling

September 15-17th
Men's Retreat

October 7th
Unite for Bleeding Disorders Walk

October 21st
Harvest Festival

November 4th
Industry Symposium

December 9
Winter PING and
Holiday Gathering
Lincoln, NE

combined health
agencies drive
MEMBER CHARITY

BLOODIES FOR BLEEDERS!

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
PRESENTS:

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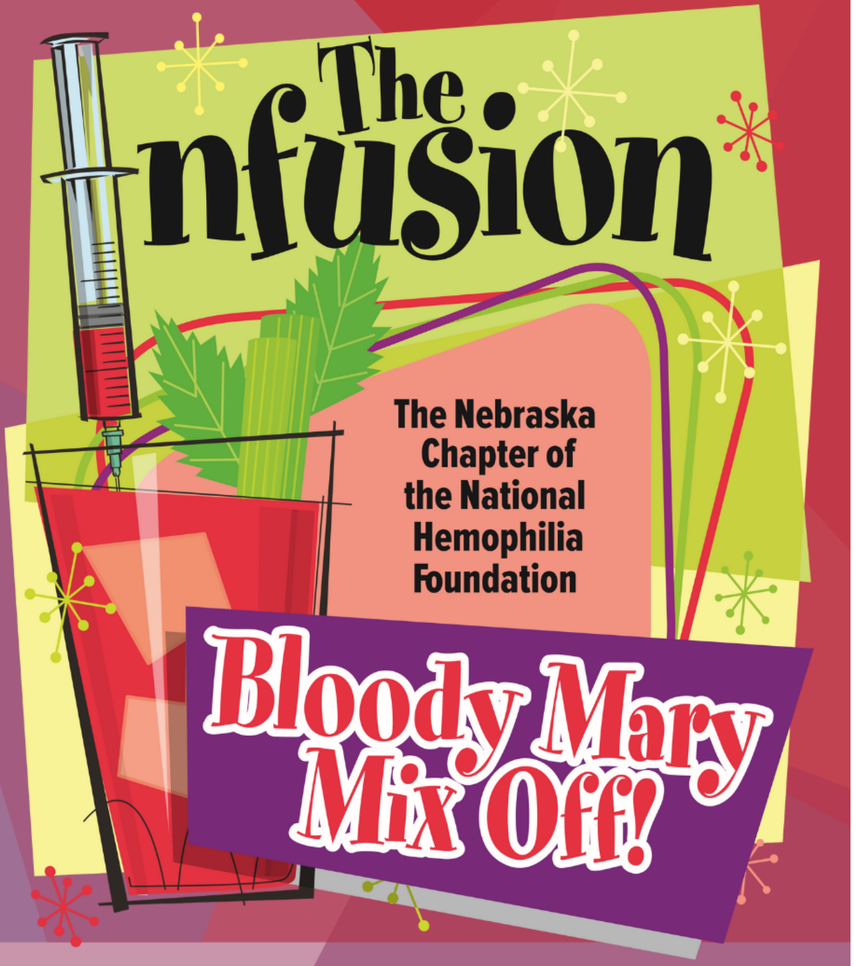


INDIVIDUAL $45
DD TICKET $30

JULY 23, 2023
10:30 AM- 1 PM
FOUNDER'S ONE NINE

TICKETS AVAILABLE ON EVENTBRITE

TICKET INCLUDES:
UNLIMITED BLOODY MARY SAMPLES
BRUNCH FROM CATERING CREATIONS
PHOTO BOOTH
RAFFLE PRIZES
VOTING FOR OMAHA'S BEST BLOODY
SUPPORTING THE BLEEDING DISORDERS COMMUNITY!

Rebrand Update

NHF is celebrating their 75th anniversary this year. This signifies a long history of supporting the bleeding disorders community. However, it's been known for a while that our name is no longer inclusive of all the inheritable bleeding and blood disorders NHF and the chapters serve. As a result, after a lot of community and chapter input, NHF will be announcing their new organizational name at this year's Bleeding Disorders Conference in August. The Nebraska Chapter is part of NHF and so our name will be changing as well. This will not change our mission or the serves we are providing to our community. Keep your eyes out for more information next month regarding the new name, the new logo and what it means for the future of the organization. We are excited to be more inclusive in our name and hope you will be thrilled with the new name and look as well.

Getting in the Game 2023

October 6 – October 8
Henderson, Nevada
https://www.csljnc.com/

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and currently the only national sports competition designed specifically for the bleeding disorders community.

Participants will have the opportunity to learn about the importance of physical fitness in managing a bleeding disorder, build relationships with fellow members of the bleeding disorders, and participate in baseball, basketball, golf, or swimming activities to learn the fundamentals and enhance their skills in that sport.

- This program is for kids and teens aged 7-18. One parent or guardian will accompany the participant.
- CSL Behring covers all travel costs and meals during the event.
- There are only 2 spots available. Please contact Maureen at mgrace@hemophilia.org or text at 402-499-8025 to be considered. Preference will be given to new attendees.

Teen Program Update

Our teens have been busy this year with programs at multiple events across the state and working on a service project. The Teen Council is gaining traction and we are thrilled to have more teens involved each year. We asked the teens in our Teen Council to pick a career that they would like to learn more about, and they chose nursing. As a result, the Teen Council created a service project to benefit Children's Hospital. We continue to accept donations for our care packages for HTC staff and children at Children's Hospital. We are working with the social worker, Kylie Meyer, at Children's Hospital to make this possible. We plan to deliver our first care packages soon. To donate to our Teen Council fundraiser, please visit: https://www.uniteyourway.org/event/nenhf. All proceeds will go to the Teen Council service project.

The Teen Council has also finished their videos for our Ask-A-Nurse program. We will plan a Teen Council Viewing Party so that everyone can watch each other's videos and see the responses from nurses at the HTC. We're excited to see what the teens will do as we finish up the service project for this year and shift to our next project. Keep your eye out for more exciting and education teen events and programs.

Please contact Sarah Arrieta at sarrieta@hemophilia.org if you have fundraising ideas for the Teen Council.

Upcoming Events

JOIN US FOR NENHF'S

2023 FAMILY CAMP BIGFOOT ADVENTURE

AUGUST 11 - 13, 2023
AT CAROL JOY HOLLAND
27146 RANCH ROAD, ASHLAND, NE 68003

REGISTER ONLINE AT
WWW.NEBRASKANHF.ORG
CONTACT SARAH ARRIETA WITH QUESTIONS
AT SARRIETA@HEMOPHILIA.ORG OR
(402)887-0572

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

NENHF Teen Council is holding a fundraiser for our annual service project. All proceeds will go to benefit the Omaha Children's Hospital.

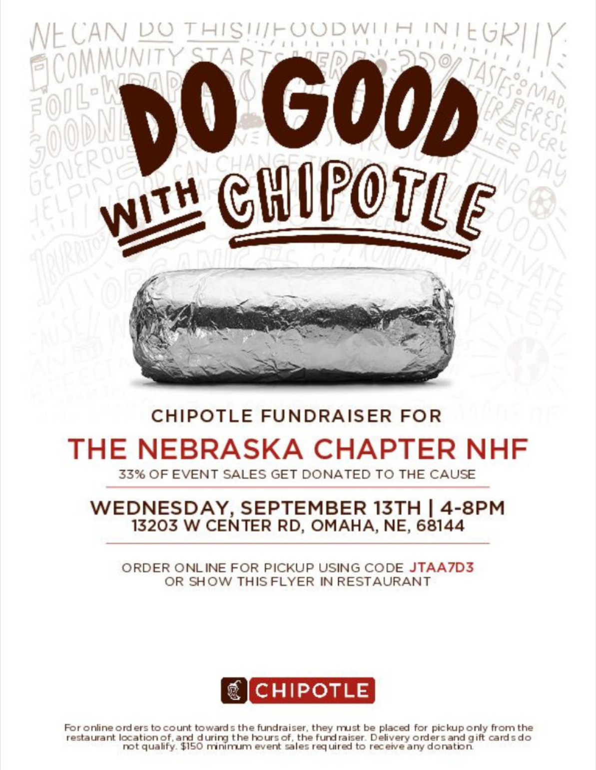
To guarantee your purchases counts:

*Show the cashier a digital or printed flyer shown here prior to paying or

*Order online and pickup Chipotle for your fundraiser by using the **Promo Code JTAA7D3** on the Chipotle app or website. Please note that fundraiser online ordering is only valid through pickup during your fundraiser's scheduled date, time, and assigned restaurant. Ordering delivery for fundraisers is not permitted at this time.

Contact Sarah Arrieta with questions or concerns at sarrieta@hemophilia.org or 402-889-0572

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION



DO GOOD WITH CHIPOTLE

CHIPOTLE FUNDRAISER FOR
THE NEBRASKA CHAPTER NHF
33% OF EVENT SALES GET DONATED TO THE CAUSE

WEDNESDAY, SEPTEMBER 13TH | 4-8PM
13203 W CENTER RD, OMAHA, NE, 68144

ORDER ONLINE FOR PICKUP USING CODE JTAA7D3
OR SHOW THIS FLYER IN RESTAURANT

CHIPOTLE

For online orders to count towards the fundraiser, they must be placed for pickup only from the restaurant location of, and during the hours of, the fundraiser. Delivery orders and gift cards do not qualify. $150 minimum event sales required to receive any donation.

Unite

for Bleeding Disorders

Saturday, October 7, 2023
9:00 am-12:00 pm
Chalco Hills Recreation Center

We cannot wait to see you and your family as we raise funds and awareness for the Nebraska Bleeding Disorders community at our 2023 Unite for Bleeding Disorders Walk

Register and start fundraising or make donations at www.uniteforbleedingdisorders.org

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Adults with Bleeding Disorders Conference

The Adults with Bleeding Disorders Conference took place on April 22nd & 23rd at the Younes Conference Center North in Kearney, Nebraska. There was programming for both adults and teens this year, and families also enjoyed the fabulous waterslides at the venue. We discussed community values together and began creating our Behavior Guidelines for events which is a living document that we will continue to build and create. Elliot G. with CSL Behring discussed how to maintain an active lifestyle. We were also joined by Mosi Williams and Katherine Cabrera from The National Hemophilia Foundation. They discussed aging and pain with the adults, and independence and mental health with the teens. The teens also brainstormed ideas for upcoming events and enjoyed playing games and getting to know more about each other. An educational dinner was held at the Coppermill Steakhouse and Lounge brought to us by Mya Anderson from Bayer. We had a great time coming together as a community in lovely Western Nebraska.

NEW- Men's Retreat

Join us for an unforgettable men's only adventure in the great outdoors! Trails to Healthy Living will be facilitating our first ever men's retreat being sponsored by BioMarin. Come enjoy two nights with just the guys.

Registration Details Coming Soon

Date | September 15-17 | Platte River State Park

Board Update

Board & Committee Recruitment

The Nebraska Chapter of NHF is looking to expand our Advisory Board of Directors. We are currently recruiting both affected and unaffected board members. We specifically are looking for members with diverse backgrounds including those who reside in rural areas, Spanish speaking or bilingual, individuals comfortable in the rare disease space, those with financial or accounting backgrounds, community connections or a knack for fundraising. This list is not exhaustive. If you know someone who would be a good fit for our Board and Chapter, please reach out to Maureen at mgrace@hemophilia.org.

Additionally, there's always room on committees for non board members at all. If you want to get involved and help with Advocacy, Programs and Education, Fundraising and Events or more. We will be hosting monthly virtual committee meetings for the following programs and events:

⇒ Family Education Weekend
⇒ Family Camp
⇒ Infusion: Bloody Mary Mix Off
⇒ Unite for Bleeding Disorders Walk

Please join us for these virtual meetings to help us make these programs and events even more dynamic. Keep an eye out on your email and social media for the dates for these meetings. If you would like a reminder– please reach out to Sarah at sarrieta@hemophilia.org

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

Women's Retreat

The Spring Women's Retreat was held on May 13th, 2023, at the Hilton Garden Inn in Omaha, Nebraska. Ladies came together at this event to set goals and get creative by making vision boards. We discussed the different types of goals, and how to plan and take steps to get closer to those goals. Martina Willis-McCullough with Octapharma discussed the impact of VWD and Hemophilia on women. Lisa Cardarelli from Takeda discussed resilience and how that plays a part in almost everything we do, especially when faced with a bleeding disorder. We also enjoyed yoga brought to us by Rosa Ruiz Kennedy and Brother's Healthcare which allowed us time to center ourselves, focus on the moment at hand and connect with our inner selves and find a few moments of peace in the chaos. Then, the women all enjoyed their choice of manicures and pedicures at Aksarben Nails. The ladies of the NENHF community know how to have a good time. Thank you to our sponsors, Takeda, Octapharma, InfucareRX, Bayer, Novo Nordisk, and Brother's Healthcare.

FAB (Females and Bleeding) Conference

NENHF will co-host a Women's Retreat with Midwest Hemophilia Association, Gateway Hemophilia Association, and Hemophilia of Iowa, for women 18 and older with a bleeding disorder, carriers, spouses of a person with a bleeding disorder, and parents of a person with a bleeding disorder . Parents must live in the same household. Attendees must be a member and live in one of the 4 chapter's service areas.

The retreat will be held October 13-15, 2023 at Margaritaville Lake Resort, 494 Tan Tar A Dr., Osage Beach, MO 65065. The focus of the conference will be education, personal growth, and networking. Sessions will focus on bleeding disorders, treatment options and relaxation!

There is a non-refundable $20 registration fee, which includes your room, meals during the conference, and conference materials. **The deadline for registration and payment is September 9!**

Register at www.nebraskanf.org

Family Education Weekend

Family Education Weekend was filled with fun, family, and community on June 24th & 25th at the Lincoln Marriott Cornhusker Hotel in Lincoln, Nebraska. The community came together to create the Behavior Guidelines for Events, discuss teen programs and fundraising, and share their experiences with Hemophilia with each other. Community members were had an active role in planning the event by serving on the Program & Events Committee, and community members led breakout sessions this year. Educational sessions were brought to us from Heritage Biologics, Novo Nordisk, Sanofi, Takeda, Octapharma, Spark, and Genentech. We discussed health insurance and bullying with our teens, and later the teens went rock wall climbing. Teen Council members, Elizabeth and Nicolas Quiroz engaged in some Q & A about the work they've put into the program. Community members infused themselves and others at the Infusion Clinic. Families also enjoyed a murder mystery game and a trip to the Lincoln Children's Zoo. There's never a dull moment at Family Education Weekend.

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antihemophilic factor
(recombinant) PEGylated-aucl

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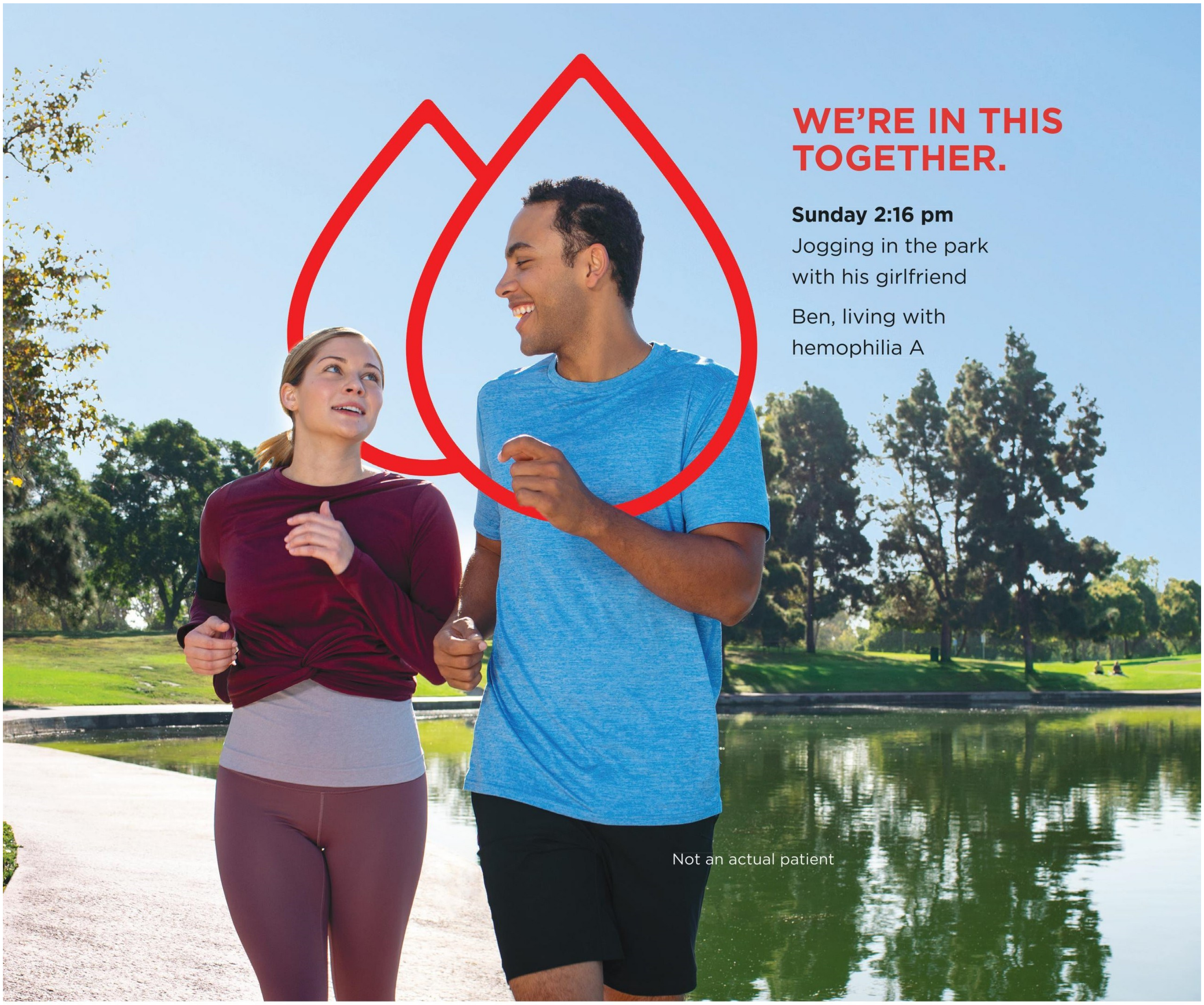
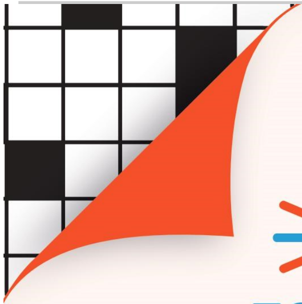
Talk to your doctor about the study.

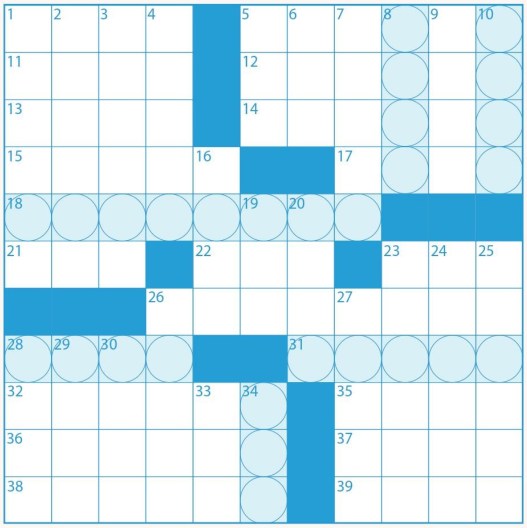
Scan this QR code to learn more about the data at JiviExtensionStudy.com


WE'RE IN THIS TOGETHER.
Sunday 2:16 pm
Jogging in the park with his girlfriend
Ben, living with hemophilia A
Not an actual patient



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
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. ariose, 37. tall, 38. lessen, 39. oles
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

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

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 150 mg/mL
injection for subcutaneous use

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

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

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

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

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

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

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
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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: 12/2021

What Women with Bleeding Disorders Need to Know About Joint Problems

Author: Kathryn Anne Stewart

Kolbie Clarke, 17, has mild hemophilia A and low von Willebrand factor, and when she started having joint issues playing soccer five years ago, she wasn't surprised. Her father and uncle have severe hemophilia, and Kolbie saw them deal with repeated knee and ankle bleeds.

Until recently, the medical community wouldn't have expected joint issues like Kolbie's. Now, that is changing.

A leading researcher in this area is Robert Sidonio Jr., MD, director of hemostasis and thrombosis clinical operations at the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta. Sidonio attended patient advocacy group meetings where carriers shared stories of joint bleeding. "It really hadn't been known that the carriers would be at any significant risk for joint bleeds," he says.

Since then, his research has uncovered evidence that indicates prior joint bleeding in hemophilia carriers, particularly those with levels less than 60%.

For women with bleeding disorders, seeking care from a hemophilia treatment center (HTC) is the first step to progress.

Data collected by HTCs populates the registries of groups such as the Centers for Disease Control and Prevention and the American Thrombosis and Hemostasis Network. "If you don't become an active part of those datasets, then it's really hard for us to do any research," Sidonio notes.

He urges all carriers, even those without a confirmed bleeding disorder diagnosis, to consider being evaluated at an HTC. It's possible that many carriers have mild hemophilia based on their clotting factor levels.

How to Recognize Joint Issues

Joint bleeds are most likely in the knees and ankles in males and females with hemophilia, Sidonio says, and sometimes in the elbows. "It typically starts off as a tingling, pins-and-needles sensation," he explains. "Then it progresses to warmth."

The joint may also look different, as swelling obscures typical contours of bones. Often the range of motion will decrease, and there will be pain.

To help tell the difference between a strain or sprain and a joint bleed, Sidonio encourages people to take pictures and talk about joint issues with their physicians, who may suggest an X-ray or a point-of-care musculoskeletal ultrasound. These tests can reveal a lot, especially if done within 12 to 24 hours of the injury, he says.

Joint Problems Continued...

What You Can Do

Sidonio recommends you document joint issues with a bleeding diary to record details such as the date, the duration and what makes it feel better. You can keep track on paper, download a bleeding app or use your phone's notes feature, as Kolbie Clarke does.

If you have lingering joint injuries, your HTC can help. Most have a dedicated physical therapist, and some have an orthopedic surgeon who visits throughout the year. You can also request that your joint range of motion be followed.

Information like this helps the medical community further its knowledge of women and joint issues. Sidonio says, "That's what really makes a difference."

Women with bleeding disorders are also encouraged to join the National Hemophilia Foundation's registry, Community Voices in Research (CVR). CVR connects the experiences of people with bleeding disorders to researchers investigating improving treatments and care.

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HIGHER FACTOR LEVELS FOR LONGER
Above 40% for most of the week (near-normal to normal range).[*][†]

48 HOUR HALF-LIFE IN ADULTS
In a Phase 3 study,[†] ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7 BLEEDS PER YEAR[‡]
Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[†]

In people taking ALTUVIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

[*] Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†] 159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡] Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIO, living with hemophilia, and treatment options from your local CoRe.

Jess Hutchison
jess.hutchison@sanofi.com
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INDICATION

ALTUVIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIO?

You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department 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 ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full Prescribing Information.

sanofi

NEBRASKA CHAPTER NEEDS ASSESSMENT

- NEW SURVEY DEVELOPED BY SARAH, MARIA, & MAUREEN
- CHANCE FOR THE COMMUNITY TO SHARE THEIR OPINIONS & PREFERENCES
- HELP US BETTER UNDERSTAND YOUR NEEDS
- IMPROVE PROGRAMS & SERVICES

We need your feedback!

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Your voice matters and
will help shape the future of NENHF