Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

Summer 2024 Newsletter

From the Executive Director

by Maureen Grace

As we are half way through the year, it's been a busy year so far and we are really getting into the busy season here at the chapter. There are a lot of upcoming programs and events and we hope to see you at one of these awesome opportunities. There really is something for everyone. We also have a lot of new families joining the community, and we are so excited to have you with us.

The biggest change is that after three years, Sarah Arrieta finished her tenure at the chapter on July 15th. We are so sad to see Sarah go but very excited for her next chapter. Sarah did amazing things for the chapter in the last three years, especially with our teens and young adults. Her presence will be missed in all our programs, our outreach and everything she had her hands and energy in. We hope to see her again some day and is always welcome within the bleeding disorders community. Thank you from the bottom of my heart for all her hard work and dedication to the Nebraska Chapter and the connections she made here.

We have a lot of programs happening while we are down a staff member but we are working on the hiring process now to get another staff member in as soon as we can and are looking forward to our next adventure at the chapter as well. I appreciate your patience and grace during this transition within the chapter.

This issue:

Nebraska
Chapter

NATIONAL
BLEEDING
DISORDERS
FOUNDATION

Our Mission:

The National Bleeding Disorders Foundation—Nebraska Chapter is dedicated to finding cures for inheritable blood disorders and addressing and preventing the complications of these disorders through research, education, and advocacy enabling people and families to thrive.

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. NBDF-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.

2024 Events

New Parent Information Group
Omaha, Nebraska
July 20th

Infusion: Bloody Mary Mix-Off
Omaha, Nebraska
July 28th

Family Camp
Ashland, Nebraska
August 9—11th

Men’s Retreat
Platte River State Park
, September 6—8th

Family Education & Unite Walk
Weekend
Omaha, Nebraska

FAB Conference
Margaritaville, Missouri
October 11—13th

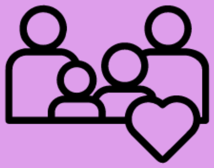
Harvest Festival
Roca, Nebraska
October 19th

New Parent Information Group
Lincoln, NE December 7th

combined health
agencies drive
MEMBER CHARITY

Save the Dates: 2024 Events

New Parent Information Group (PING)
Henry Doorly Zoo, Omaha, July 20th



Infusion: Bloody Mary Mix-Off
Omaha, July 28

Family Camp
Carol Joy Hollings Camp, Ashland, August 9 -11

Men’s Retreat
Platte River State Park , September 6- 8

Family Education Weekend/Unite Walk
Omaha, September 28 - 29

Females and Bleeding (FAB) Conference
Margaritaville, MO, October 11-13

Harvest Festival
Roca Berry Farm, Roca, October 19

New Parent Information Group (PING)
Lincoln, NE December 7

It's not goodbye, it's see you later

A Note from former Program Manager, Sarah Arrieta

I have enjoyed getting to know so many families and friends during the past three years in my position as Program Manager. This community has so many amazing people that I have truly come to love. Although I have accepted a new position at the University of Nebraska at Lincoln, it's my desire to stay in touch with as many friends as possible and to come back as a volunteer when possible. Please feel free to contact me in the future at sarah.arrieta@yahoo.com. Thank you to everyone that made me feel so welcomed and appreciated at the chapter.

2024

FAMILY CAMP

CAMP TAP-A-VEIN-A-DAY-A

AUGUST 9 - 11, 2024

CAROL JOY HOLLING CAMP
ASHLAND, NE

JOIN US FOR GAMES, WATER GAMES, TIE DYE, CRAFTS, AND LOTS OF FUN FOR THE WHOLE FAMILY!
REGISTER TODAY SO WE CAN GET YOUR SHIRT SIZE GUARANTEED!

Nebraska Chapter
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2024 Adults with Bleeding Disorders

This conference was held at the Graduate Hotel in Lincoln on April 27th. Educational topics included: Women and Girls presented by Cindy Bishop from Sanofi and Coping with Anxiety and Depression presented by Shayla Bergman from Novo Nordisk. A new mentorship program was launched intended for all ages. Other activities included a Teen Showcase where the youth displayed their talents, and Q & A sessions for all ages to share experiences and learn from each other.

Thank you to our sponsors!

BAYER

Pfizer

CSL Behring
Biotherapies for Life™

novo nordisk

HEMA Biologics™

Takeda

ARJ Infusion SERVICES
Where Caring is the Ultimate Factor.

Two Events
One Weekend

Family Education Weekend

Saturday, September 27th

Omaha Regency Marriott

- Adult and Teen Programming
- Child Care Program
- HTC Update
- Family Fun
- Connect with your Bleeding Disorders Community!

Family $50 | Individual $25

First time Family- Free

Register by August 25 to guarantee hotel

Unite for Bleeding Disorders

Sunday, September 28th

Chalco Hills Recreation Center

- Create your Walk Team
- Fundraise with your friends and family for the Chapter
- Enjoy a great walk morning with games, face painting, breakfast and more!

www.uniteforbleedingdisorders.org

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World Hemophilia Day
April 17, 2024

World Hemophilia Day was an engaging event that brought the community together to create and grow connections. Sponsored by Sanofi, the event commenced with an informative dinner at The Old Mattress Factory Bar and Grill in Omaha and culminated with a gathering at the Bob Kerrey Pedestrian Bridge, illuminated in red as a tribute to the day.

Thank you to Sanofi for sponsoring this event!

sanofi

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

Board Update

Board & Committee Recruitment

The Nebraska Chapter of NBDF 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@bleeding.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.

FAB: Females and Bleeding Conference

NENBDF 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 11-13, 2024 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
https://gatewayhemophilia.org/events/regional-midwest-womens-retreat/

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

2024
Harvest
Festival

OCTOBER 19TH, 9 - 11 AM
JOIN US FOR ALL THE FUN AT
ROCA BERRY FARM
16531 S 38TH ST, ROCA, NE 68430

2024 Women's Retreat

This event took place on May 11th at the Hilton Garden in Aksarben in Omaha. We enjoyed educational sessions provided by Takeda and Sanofi, and had a great time at the nail salon. It was a day of crafts, education, and connection

Thank you to our sponsors

sanofi

novo nordisk

Takeda

2024 TEEN RETREAT

The Teen Retreat was held at The Younes Conference Center North in Kearney, Nebraska on June 15th & 16th. Educational topics were provided by the National Bleeding Disorder Foundation and graduates from the National Youth Leadership Institute (NYLI). Teens enjoyed planning for future mentorship projects and the Teen Council service project for 2024 which will focus on athletics. A great time was had swimming, going on water slides, and making friends.

Thank you to our sponsors!

Genentech

CSL Behring
Biotherapies for Life™

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2024 MEN’S RETREAT
SEPT. 6TH - 8TH, 2024

JOIN US FOR AN OUTDOOR EVENT FOR THE GUYS

HIKING, CAMPFIRE STORIES, ADVENTURE CHALLENGES, AND MORE!

This event is for men ages 18 and up in the Bleeding Disorders Community. Join Brian Rodgers and Kevin Harris from Trails for Healthy Living for a fun weekend for the guys.
Platte River State Park

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

Coverage Denied: The Growing Problem of Formulary Restrictions

When health insurers stop covering medications, patients and families have to scramble for solutions. (Featuring Nebraska's Romans Family)

By Lisa Fields– Hemaware 2024

For many years, Rodney Dalrymple, of Booneville, Mississippi, has managed his severe hemophilia A with a factor product that he infuses daily. In November 2023, he was shocked to hear that his health insurance company's pharmacy benefit manager (PBM) wouldn't cover his medication anymore. The only product that it would pay for, Dalrymple learned, is one that he doesn't feel comfortable taking.

Dalrymple's hematologist appealed to the PBM on his behalf and even had a peer-to-peer meeting to discuss the benefits of Dalrymple staying on his current medication, but the requests were denied. Dalrymple told the PBM that he'd be willing to switch to another factor VIII drug, but he hasn't been offered an alternative. As his factor supply dwindles, Dalrymple is uncertain about his prospects and growing anxious about his treatments.

"I've been skipping days to try to stretch and manage my factor, but I'm running out," he says. "My ankles have been bothering me, and I'm worried that I could start having more bleeds. Or in the situation of an accident, I wouldn't have any factor on hand. It puts me in a really bad situation. I don't know what I'm going to do."

Dalrymple's situation isn't isolated. In recent years, a growing number of PBMs — third-party companies that function as intermediaries between insurance providers and pharmaceutical manufacturers — have removed many medications from their lists of prescription drugs that they will cover, known as formularies. These formulary restrictions can limit patients' access to specific brands of medications — or in this case, particular brand-name clotting factors that people need to help them manage their bleeding disorders.

"It can be very disturbing to our practice, and to our relationship with the patient," says Maissaa Janbain, M.D., director of the Louisiana Center for Bleeding and Clotting Disorders and an associate professor of hematology and oncology at Tulane University School of Medicine. "This is a problem that is going to come up more and more, now that there are so many products that are completely different."

A Cost-Cutting Measure

When insurance companies' PBMs adjust their formularies, it's often to remove very expensive medications and replace them with cheaper generic alternatives. Because the majority of biopharmaceutical products used to treat or manage bleeding disorders are quite costly and have no generic versions, some have been restricted from formularies.

"We understand the importance of managing costs and keeping the bottom line down, but that can't come at the expense of a patient's health, well-being, or their life," says Nathan Schaefer, senior vice president of public policy and access for the National Bleeding Disorders Foundation (NBDF). "They're limiting access to the medication that a physician and the patient have determined is most appropriate."

In 2023, CVS Caremark, one of the country's largest PBMs, removed all standard half-life products for people with hemophilia B from its 2024 formulary. Before that, BlueCross BlueShield of Tennessee removed at least 17 treatments for bleeding disorders from its 2023 formulary.

Formulary restrictions have been increasing for more than a decade, according to research published in March 2024 in the journal *Health Affairs*. In 2011, Medicare Part D plans excluded 20.4% of medications from their formularies. In 2020, the number of Medicare formulary exclusions rose to 30.4%. The study found significantly more restrictions for brand-name medications, which are pricier than generic drugs, but generics were also restricted.

PBMs don't often share details about the internal processes that lead to decisions on formulary restrictions. "They tell you, 'We run it by our experts.' Who are your experts?" Janbain says.

"As individualized therapeutic approaches are encouraged, these decisions need to be left to the clinician who knows the patient well and not be imposed as a formulary by the company," she says.

After CVS Caremark removed standard half-life products from its formulary, Schaefer asked the company to explain its decision, but he didn't get specifics.

"They indicated that they have an expert panel that advises what gets onto the formularies and what does not," he says. "I asked them if they could share with me who those panelists are, and they declined to provide that information but indicated that there is hematology expertise represented on their panel."

Potential Long-Term Repercussions

Hematologists and bleeding disorders advocacy groups worry that formulary restrictions could negatively affect patients' health. When someone responds well to a medication, they typically remain on it long term. But formulary restrictions may require people to switch drugs unless they can pay out of pocket, which isn't typically feasible.

"If a patient is stable on a particular factor medication, we usually recommend staying with that factor medication for as long as possible," says Kaitlin Rigsby, R.N., a specialty nurse at the Arkansas Center for Bleeding Disorders at Arkansas Children's Hospital in Little Rock. "When you switch factor medications, you can run the risk of developing an inhibitor."

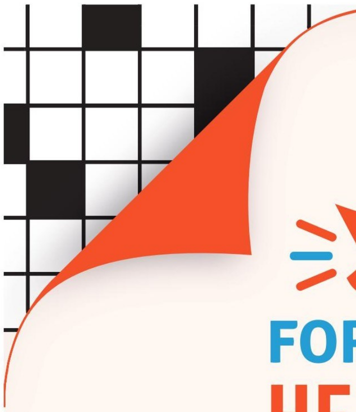
While awaiting a PBM's approval for a nonformulary drug, patients may be nonadherent, causing gaps in their care. Others may not respond well to factor listed on a formulary. Both scenarios can be problematic.

Schaefer says that while formulary restrictions may appear to save money in the short term, they can end up leading to much higher costs.

"A person could very well end up in the emergency room," he says. "If they've got permanent joint damage, they could have very expensive interventions that they require for years after the actual episode. We have to consider the patient's health and well-being for the rest of their life."

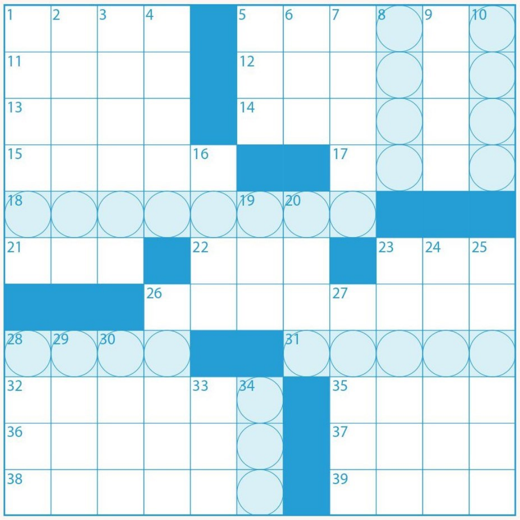
Continue reading this article online at:

https://hemaware.org/increase-of-formulary-restrictions-is-problem



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 (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use 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†

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

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

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
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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: 03/2023

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

Genentech
A Member of the Roche Group

ALTUVIIIO®
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

SWITCH IT UP like Brian did!

Brian is a promotional speaker compensated by Sanofi.

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIO, and point you toward helpful support and resources.

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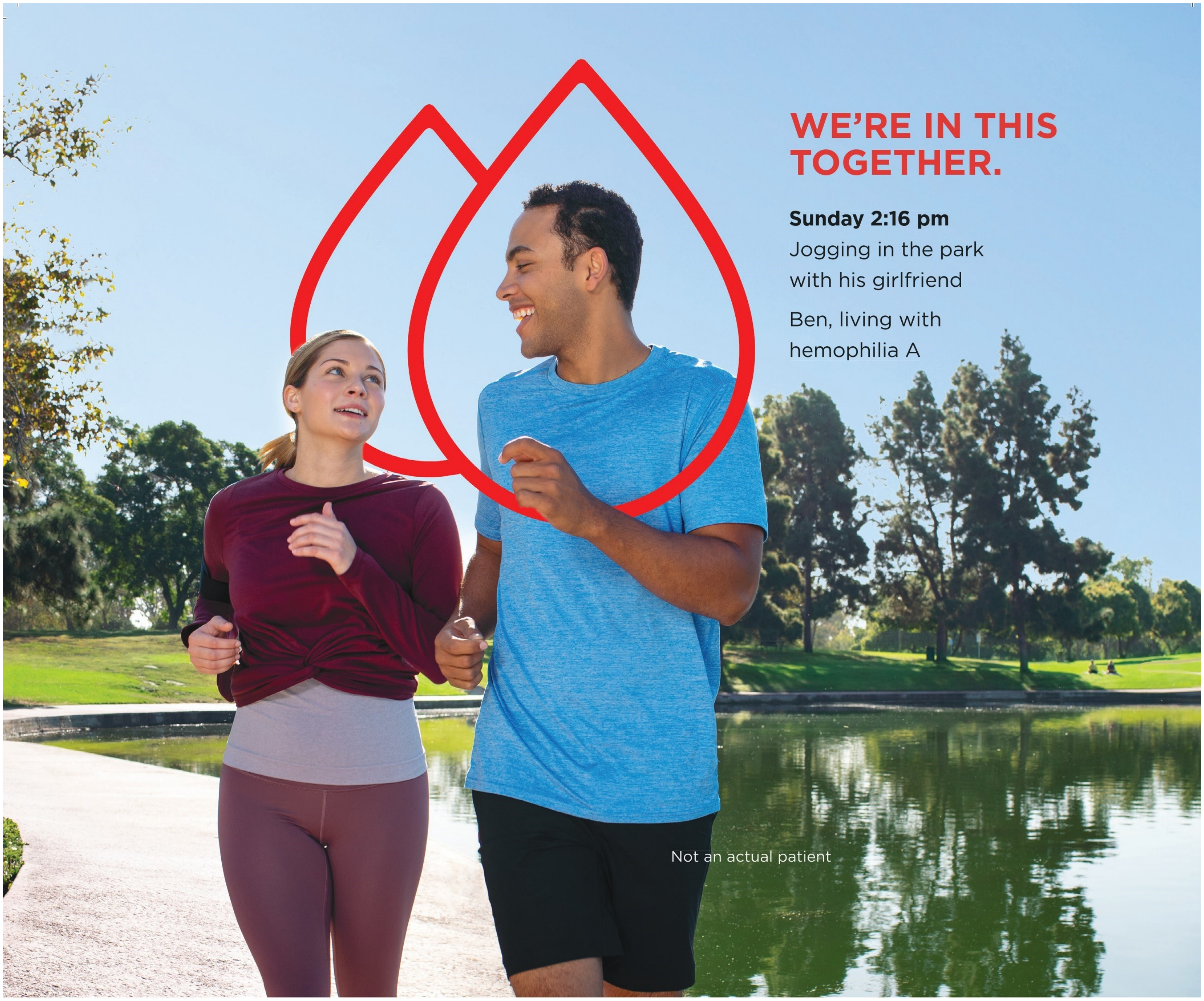
WE'RE IN THIS TOGETHER.
Sunday 2:16 pm
Jogging in the park with his girlfriend
Ben, living with hemophilia A
Not an actual patient