

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

GREAT MEMORIES AT WOMEN'S DAY 2023



2023
ISSUE #4

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2024 EVENTS

MARCH 2 - Annual Meeting and Volunteer Breakfast, *Top of the Market*

APRIL 11-14 - HFA Symposium, *Indianapolis, Indiana*

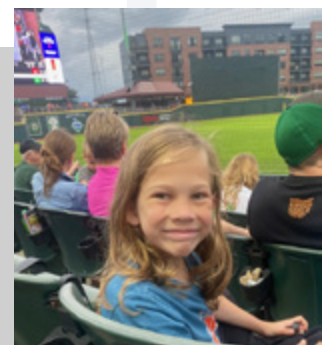
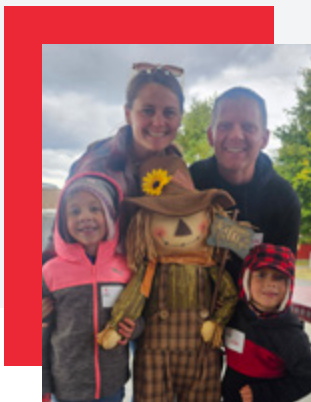
MAY 3 - Casino Night Fundraiser, *Dayton Women's Club*



JULY 12-13 - Family Fest Weekend - Scene 75 Dinner and Dayton Dragons

SEPTEMBER 12-14 - NBDF Bleeding Disorders Conference, *Atlanta, Georgia*

SEPTEMBER 14 - 5K Bleeding Awareness Walk/Run, *Rice Field*



OCTOBER 6 - Fall Outing, *Young's Dairy Farm*

NOVEMBER 9 - Women's Day Educational Program and Lunch, *The Golden Lamb*

KROGER

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Support SWOHF!**

Did you know you can support our SWOHF community just by shopping at Kroger? It's easy when you enroll in **Kroger Community Rewards!** To get started, sign up at [krogercommunityrewards.com](https://www.krogercommunityrewards.com) with your Kroger Plus Card and enter our number **#78558** as your organization. Once you've enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!

Kroger is committed to helping our communities grow and prosper. Year after year, local schools, churches and other nonprofit organizations earn millions of dollars through Kroger.



sanofi



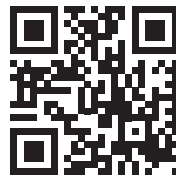
**Doing our part by sharing what we have.
Personalized Education. Empowering Resources.
Dedicated Professionals.**

 **ELOCTATE**[®]
[Antihemophilic Factor
(Recombinant), Fc Fusion Protein]



www.eloctate.com

ALTUVIIIIO[™] 
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



www.altuviiiio.com

 **ALPROLIX**[®]
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]



www.alprolix.com

HISTORY OF FAMOHIO

In March of 1992, during the HIV/AIDS (human immunodeficiency virus/acquired immunodeficiency syndrome) crises, six men came together to discuss their future and the future of their blood brothers. These men all carried the diagnosis of hemophilia and as a result of the treatment for bleeding had contracted HIV. Instead of wallowing in self-pity, they channeled their anger and feelings toward a positive goal. Believing that education was the key to ensuring the future for all people affected with bleeding disorders they got to work. In the summer of 1992, their creation, a state-wide education symposium was held called FAMOHIO. That year, FAMOHIO was the acronym for “first annual meeting of hemophiliacs in Ohio.” Going forward FAMOHIO became known as “family annual meeting of hemophiliacs in Ohio.”



Approximately, 50 people attended the first annual state-wide meeting. The city of Columbus was chosen as the location initially and continues due to the centrality of the area. Folks travel from all over the state and prior to the Covid pandemic attendees numbered in the 400 range. FAMOHIO was held virtually in 2020 and 2021. In 2022 and 2023 approximately 300 people enjoyed the weekend. The weekend starts on Friday with 3 PM registration and concludes by 11 am on Sunday.

The first attendees generally carried the diagnosis of hemophilia. As time progressed the meeting grew to include people and families living or treated in Ohio with numerous bleeding disorders. Programs are designed and selected to provide information regarding; varied diagnoses, age and developmental level, current health issues, advocacy, mental and physical challenges just to name a few.

The weekend also provides special education and programming for adults, young adults, teens, children, and daycare for toddlers and babies. One most anticipated time is when a new teenager (age 13) gets to “hang” in the infamous “Crew’s Nest,” which is the supervised hangout for those ages 13-17. Think loud music, games, unlimited soft drinks, snacks, and fun!

Education sessions are generally provided during the evening on Friday, during the day on Saturday, and sometimes on Sunday morning. Fun events

are dotted throughout the weekend and always on Saturday night. Whether a stay-in-event like a dance party with a Beatle’s tribute band to an evening out at the Clippers’ game, a good time is guaranteed.

Additionally, members of the bleeding disorder community can nominate individuals or even organizations to receive FAMOHIO awards. FAMOHIO has been giving post-secondary educational scholarships to worthy applicants for over ten years. Both the awards and scholarship information are detailed on the website. Contact FAMOHIO via the information on the website at www.famohio.org if you have any comments, questions, or would like to volunteer at any level.

The FAMOHIO founders believed that an annual meeting of people/families with bleeding disorders provided opportunities for shared information and increased knowledge through education and camaraderie. The current FAMOHIO board shares the founders’ beliefs. The positive rippling effects of FAMOHIO are difficult to quantify. However, attendees largely agree that the FAMOHIO experience provides increased knowledge and a better understanding of how to live with a bleeding disorder.

Please consider adding this extraordinary event to your calendar for 2024. Further details will be added to the website in early 2024.

LOOKING FOR THE DATE FOR FAMOHIO'S 2024 EDUCATIONAL CONFERENCE?

**AUGUST
2024**

9, 10 & 11



**HOPE SEE YOU
THERE!**

EMAIL
FAMOHIOINFO@GMAIL.COM
WWW.FAMOHIO.ORG

My Factor Fam is the first email program of its kind, dedicated to meeting the unique needs of people using or thinking about using factor to manage a bleeding disorder.



Members have access to:



Meaningful Videos



Helpful Resources



Useful Tips



Real Stories

Join now to access up-to-date disease and factor-related information at [MyFactorFam.com](https://www.MyFactorFam.com)

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Unless otherwise indicated, images are not actual patients, caregivers, or healthcare providers.

FALL OUTING 2023





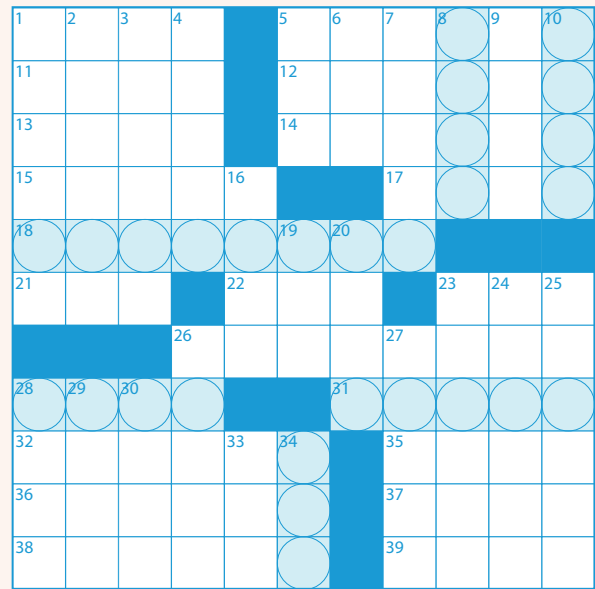
2023 SWOHF FALL OUTING SPONSORS



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 cities
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. M.C.s; 26. passport; 28. zero; 31. three; 32. eyelid; 35. Oloz; 36. anozse; 37. tall; 38. lessen; 39. oles
Down: 1. catny; 2. adover; 3. summs; 4. kneel; 5. CPU; 6. has; 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. Eye; 30. Reis; 33. ESE; 34. ten

Discover more at [HEMLIBRA.com/answers](https://www.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**.



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

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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: 03/2023



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OBDC STATEHOUSE DAY 2024

A MESSAGE FROM

RANDI CLITES
OBDC STATE POLICY DIRECTOR

RANDI@NOHF.ORG

The Ohio Bleeding Disorders Council Statehouse Day will be held on Tuesday, April 9, 2024.

We will officially recognize March of 2024 as the first Bleeding Disorders Awareness month in Ohio. So, it will be an exciting time for our families to gather at the Statehouse to spread awareness and share with our lawmaker's issues impacting our bleeding disorders community.

During the event, families will share their story and advocate for issues impacting our community with their elected officials in small group meetings and over a luncheon. While it is our goal that each family meet with their State Representative and Senator, because of scheduling issues this isn't always guaranteed. This year we are focusing on increasing access to the Complex Medical Health (formerly Children with Medical Handicaps) treatment program up to age 26, banning the use of copay accumulators on health insurance plan designs, and addressing issues of delays in treatment and care because of the prior authorization process.

I hope you will join us for this very inspiring and impactful day of action. If you cannot make the day in Columbus, please reach out to me to schedule a meeting in your area with your elected official.



Ohio Bleeding Disorders Council

Save the Date!



Ohio Bleeding Disorder Council
Ohio Statehouse Day
Tuesday, April 9, 2024

Dinner and training will be provided on Monday, April 8th

Statehouse Day is open to everyone!

This year we are extending a special invitation to those who

- Depend on co-pay assistance
- Experience delays in treatment because of Prior Authorization denials
- Young adults 18-26 for the CMH increase

To RSVP please email:
obdcsvp@gmail.com

Please visit for registration information.

www.ohiobdc.org



MEDICAL IDs

In collaboration with Dayton Children's HTC, SWOHF has recently switched to a new provider for our Medical ID's. We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.



[Phone not included]

CONTACT US



DO WE HAVE YOUR EMAIL?
DON'T MISS OUT ON
PROGRAM UPDATES.



11 WEST MONUMENT, SUITE 605
DAYTON, OH 45402



937-298-8000

WE WANT TO HEAR FROM YOU!

MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

EXECUTIVE DIRECTOR

Joy Linder, joy@swohf.org

DISCLAIMER

The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Southwestern Ohio Hemophilia Foundation

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