



oklahoma HEMOPHILIA FOUNDATION

Wrapping Up 2023

2023 is coming to a close and it has been an exciting year for us at OHF. We were able to gather together for so many wonderful events and fun activities.

We kicked off the fall with our Red Jacket Challenge Golf Tournament. Our golfers and volunteers enjoyed a perfect Oklahoma day at Cedar Ridge Country Club. We appreciate everyone who came out to support and raise funds for OHF!

Several community dinners were held by a variety of our very generous sponsors. Community members also got to enjoy some fun activities at IFly and Main Event.

As usual, our Family Education Retreat was one of the most well attended events of the year! 29 families were on hand to enjoy a wonderful weekend of fun, education, and fellowship.

Following the Family Education Retreat, we gathered for the Unite for Bleeding Disorders Walk. Once again the weather was beautiful and participants enjoyed music and carnival games before heading out to walk the lovely trail around the lake at Tantanka Ranch.

Wrapping up the year, we celebrated the holidays at our Winter Event in Sapulpa and our annual Kendra Gives Back fundraising event at Kendra Scott in Tulsa.

Families came together at our Winter Event to enjoy a scrumptious holiday meal, decorate cookies, and just enjoy getting to spend some time together catching up with friends.

2023 was packed full of so many wonderful times together, we can't wait to see what 2024 will bring!



The Oklahoma Hemophilia Foundation's Benevolence Program is designed to provide emergency resources for those most in need in the bleeding disorders community. Please visit www.okhemophilia.org for more details on how OHF can help!

Inside this issue:

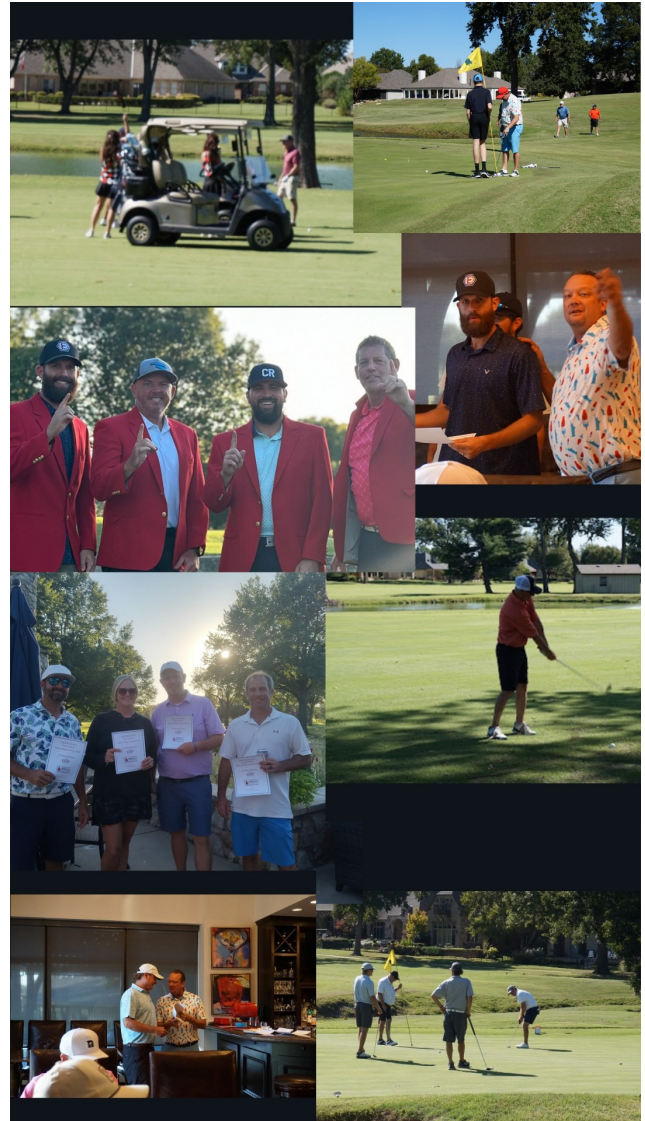
RJC Golf Tournament	2-3
Community Dinners	4-5
Family Education Retreat	7-9
Unite Walk	10
Winter Event	13-15
Upcoming Events	16

Save the date!!



Day At The Hill 2024
February 25-26

**Red Jacket Challenge
Golf Tournament
Cedar Ridge Country Club
Tulsa, OK**



Thank you to our sponsors



Community Dinners



OKC
Community
Dinner
10-05-23



Serving those with Bleeding Disorders

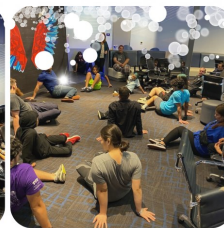


*Tulsa Community
Dinner*

sanofi



Serving those with Bleeding Disorders



HEMA
Biologics
MEDEXUS
PHARMA

I-Fly OKC



COMMUNITY EVENT

10.12.2023



PARAGON
HEALTHCARE



Serving those with Bleeding Disorders



Tulsa Community Family Fun Night



Community Dinners



Tulsa Community Dinner 11-16-2023


antihemophilic factor
(recombinant) PEGylated-auct

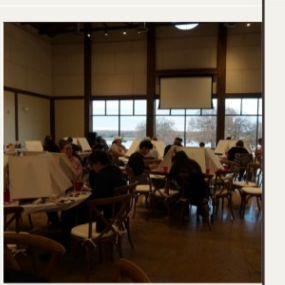


Jivi[®], now with up to **7 YEARS OF DATA.**

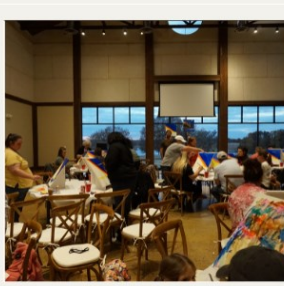
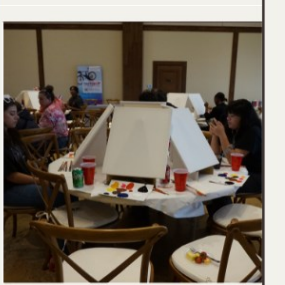
Talk to your doctor about the study.



Scan this QR code to learn
more about the data at
[JiviExtensionStudy.com](https://www.jiviestensionstudy.com)



Oklahoma Hemophilia
Foundation's
2023
Family
Education
Retreat





THANK YOU TO OUR SPONSORS

PLATINUM



sanofi



GOLD

CSL Behring



Genentech
A Member of the Roche Group

SILVER

CK Colburn Keenan
Foundation, Inc.



welpha⁺

BRONZE



We would like to extend a special THANK YOU to Sheryl Brittain for preparing Saturday's BBQ Lunch as well as Brandie Gibson for helping her get everything ready.



2023 OHF Unite Walk



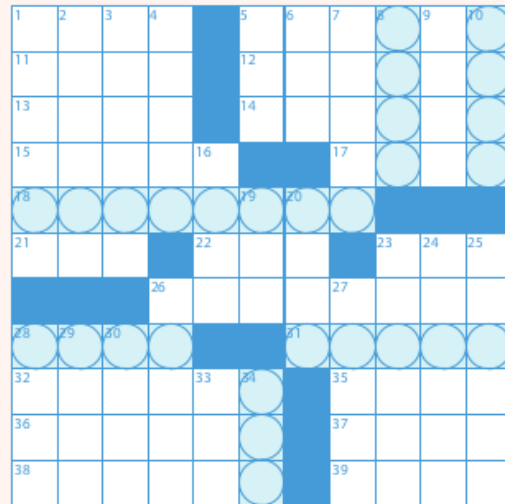
HEMOPHILIA ALLIANCE FOUNDATION



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 (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 worldwide¹

¹Number of people with hemophilia A treated as of October 2021.

SOLUTIONS

30. Euro, 33. East, 34. ten
25. sock, 26. polo, 27. photo, 28. jail, 29. Eyre,
16. lire, 19. bus, 20. mall, 23. mortal, 24. Cordero,
5. CPU, 6. hair, 7. arena, 8. side, 9. MSTR, 10. shot,
Down: 1. catchy, 2. adverb, 3. seminar, 4. kneel,
35. Crow, 36. armoire, 37. sill, 38. lesson, 39. oaks
26. passport, 28. euro, 31. three, 32. kayak,
18. HEMLIBRA, 21. yes, 22. num, 23. MCI,
13. tote, 14. used to, 15. crew, 17. nest,
Across: 1. cork, 5. chiasm, 11. Aiden, 12. patch,

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**.



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
©2021 Genentech, Inc. All rights reserved.

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® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.
©2023 Genentech USA, Inc. All rights reserved. M-US-00011998(v3.0) 08/23

Genentech
A Member of the Roche Group

Winter Event 2023



This year's Winter Event was held in Sapulpa at the Sapulpa Community Center. We had a tradition holiday meal catered by Wimpy's Sandwich Shoppe. Families enjoyed decorating cookies with kits supplied by Okie's Cookies. We all enjoyed some much needed fellowship and time spent catching up with friends. Many of those in attendance wrapped up the event by enjoying the Sapulpa Christmas Chute on historic Route 66.

A huge thank you goes out to our Winter Event committee chair Tammy Jones and her family for all of their hard work in planning and executing this event to make it such a big success!



Winter Event 2023

Thank you to our Sponsors
Platinum

B:OMARIN[®]

CSL Behring

sanofi



HEMA
Biologics[®]

Gold



CVS
specialty[™]

PARAGON
HEALTHCARE



Silver

accredo[®]
Specialty Pharmacy

Optum



Kendra Scott Gives Back To OHF





Education, Advocacy, Awareness

Interim Executive Director:

Kerri Crabtree

director@okbleedingdisorders.org

info@okbleedingdisorders.org

Phone Number: (918) 605-2579

Address: 9524 E. 81st St Ste. B1510

Tulsa, OK 74133

WE'RE ON THE WEB!

OKHEMOPHILIA.ORG

Upcoming Events

January 22	Board Meeting
February 15	Community Dinner sponsored by Paragon & Octapharma — OKC
February 19	Board Meeting
February 25-26	Advocacy Day at the Hill — OKC
March 6-8	NDBF Washington Days
March 18	Board Meeting



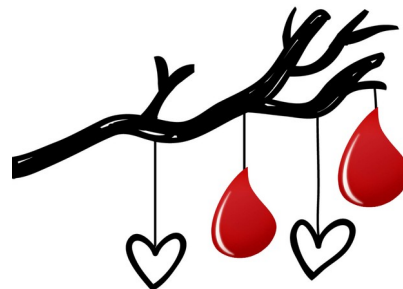
Education, Advocacy, Awareness

OHF originally began with a group of concerned families. It became a non-profit in 1997 and today it has grown to nearly 1,000 people with bleeding disorders in Oklahoma and the surrounding states.

We welcome you to join us!

www.okhemophilia.org

Click on "Sign Up" to receive



Connect with us.



@OklahomaHemophiliaFoundation

OKHEMOPHILIA.ORG