



# oklahoma HEMOPHILIA FOUNDATION

## Serving those with Bleeding Disorders Spring 2022

I am so excited to announce that OHF is going live with all events on April 1! After 2 years of pandemic isolation, I can't tell you how great it will be to return to handshakes and hugs with the OHF family.

And I'm just as excited about our first live event April 1st and 2nd - Bloom. You asked for more events focused on women, and did we deliver. This women-only weekend will be filled with fun, fellowship, and education. See the OHF website for more information.

Including our usual core events - like the Annual Meeting, Camp Independence, the Walk, and Family Retreat - we will produce nearly two dozen events this year. Something for everyone. And our popular Community Connections dinners will be returning in Tulsa and Oklahoma City.

Check out our calendar of events and stay in touch through our social media, website, or email - whatever works for you. Know that we are here to educate, advocate, and support you every step of the way!

Blessings,  
**Tim Grogan**  
Executive Director

## Unite for Bleeding Disorders



### INSIDE THIS ISSUE

Upcoming Events.....	.....2-3
Red Jacket Golf Tournament.....	.....4
Washington Days.....	.....5
Day at the Hill.....	.....5
Meet the Board.....	.....6
Inside OHF.....	.....10
Stay Connected.....	.....12

**Serving those with Bleeding Disorders**

# WE ARE GOING LIVE

See you all starting April!

Information of programs to come!  
[www.okhemophilia.org](http://www.okhemophilia.org)

Please go to [okhemophilia.org](http://okhemophilia.org) and check it out! Register for events, learn about OHF's mission, and find out how you can get involved!

# UPCOMING EVENTS

**April 1-2 in OKC**

Join us LIVE! for a weekend to reunite, empower, and celebrate the strong women in our community.

Meals and your room are covered by our generous sponsors, so you can just relax, laugh, and learn from a special group of speakers discussing the topics you care about. See the OHF website for more details.

Thank you to our sponsors

octapharma



## **Ono Loco Cooking Demo April 9, 5pm — Virtual**

What would you give for the chance to cook along with and learn from a Cordon Bleu trained chef? One who also has severe Hemophilia A, lost 285 pounds, and will talk to you about how he did it? And what if the whole thing was a blast? And as if you needed a sweetener, what if OHF paid for the ingredients?

Well, you can! Don your brightest Hawaiian shirt, break out your ukulele, and cook along as we make Ono Loco Moco. But you must sign up on the OHF website by March 28th to get the recipe and shopping list.





# UPCOMING EVENTS



## Annual Meeting, June 17-18 in Tulsa

It's live at Tulsa's DoubleTree Hotel!

Save the date for one of the largest and most popular gatherings of the Oklahoma bleeding disorders community.

The event provides a variety of interesting educational sessions as well as lots of free time to catch up with friends old and new. Rooms and meals are on us. Watch OHF's website and emails for more details and registration.



## Camp July 25-29 at Camp Bond, Tishomingo

Save the date and keep your fingers and toes crossed! We are planning and praying for live camp this year, but not all the necessary participants are able to commit yet post-COVID.

Watch the OHF website, emails, and social media for further details.





# EVENT MEMORIES

## Red Jacket Challenge Golf Tournament

The 28th annual Red Jacket Challenge at Cedar Ridge Golf Club last October is in the books and was a huge success. Thank you to Dr. Joel Adkisson and the planning committee (Robert Russell, Steve Henson) for putting together such a fun and worthwhile event. Also, a special thank you to our many volunteers that helped the event run smoothly. We had a record number of teams participating last fall and raised over \$14,000. OHF is honored to be the benefactor of this widely anticipated event and will use these funds to serve and advocate for individuals with bleeding disorders in Oklahoma. The only way this event can be improved this year is if someone makes that hole in one and wins the car!





# EVENT MEMORIES

## Washington Days

Thank you to our wonderful volunteers (Miranda Williams, Liz Allen, Jim Mueller) and to NHF for some very powerful and effective Zoom meetings in March with Oklahoma's Senators and Representatives in Washington. We advocated for the needs of our community, heard some personal stories from our members that put a few tears in eyes, and brought home for the Congresspeople just how important and life-changing our issues are. We all hope to be in Washington in person next year to



## Day at the Hill

It's hard to top our great 2021 Day at the Hill event, where we reached a record 60 of our legislators and passed a copy accumulator ban bill to save you money on out-of-pocket insurance costs. But we're working hard again this year to thank the legislators who helped us, educate them about bleeding disorders, and advocate for a follow-up bill to fix a few glitches in last year's bill. Thanks to all of you who volunteer your precious time - you make a difference!

# MEET THE BOARD

“I am a grandfather of 5; one of whom has Hemophilia A. This organization became a vital support to my family. It is so helpful when you are surrounded by individuals who have walked in your shoes and can relate to your problems and situations.”

~Wayne Nivin OHF Board President



A huge thank you to Wayne Nivin, our outgoing President of the Board of Directors. Wayne led our organization through these last few challenging years of the pandemic with courage, commitment, and compassion. We're a stronger and closer family because of his loving leadership - Thank you for your service, Wayne  
And a huge welcome to Jennie Shoemaker, elected by the Board as its new President.

## Jennie Shoemaker

Hello, I am Jennie Shoemaker, the current President of the Oklahoma Hemophilia Foundation. I have 2 boys, Mason 9 and Aiden, 7. Both boys have Hemophilia, one with a history of inhibitors.

I am currently serving as the Advocacy Chair. Most of my time is spent at the baseball field watching Aiden taking Mason to golf, or volunteering at the school. When my boys were diagnosed, we quickly became involved with OHF and the community has taught us that even with Hemophilia the boys can live very active and normal lives.







## Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at [HemDifferently.com](https://HemDifferently.com)

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

**BiOMARIN**

©2020 BioMarin Pharmaceutical Inc. All Rights Reserved. MMRCGTH0226 0420



## Do you have hemophilia A? Support the hemophilia community by taking part in a research study.

The aim of this study is to understand how common it is for people with hemophilia A to have existing antibodies against adeno-associated virus (AAV), which are frequently used in clinical trials for gene therapy.

By participating, you can help researchers understand how the body may develop these antibodies and what it could mean for the development of innovative therapies for people with hemophilia A.

Scan the code  
to learn more



Hear what the experts in hemophilia  
are saying about the SAAVY study



**Dawn Rotellini**  
Chief Operating  
Officer, NHF



**Kim Schafer,**  
MSN, NP-C  
Nurse Practitioner,  
Hemostasis and  
Thrombosis Center,  
UC Davis Health

B: 8.75"

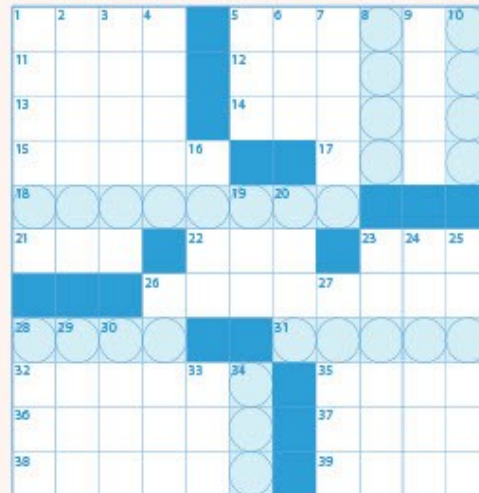
T: 8.5"

S: 7"

**CAN YOU SOLVE**

**FOR A DIFFERENT  
HEMOPHILIA A  
TREATMENT?**

**Test your HEMLIBRA knowledge**

**ACROSS**

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost

18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors\*

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

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

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

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

**DOWN**

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy

19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW

34. More than \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

**SOLUTIONS**

30. Rm., 33. ESE, 34. inn  
25. really, 26. polo, 27. photo, 28. real, 29. Eym,  
19. km, 19. bus, 20. met, 23. moral, 24. Czech,  
5. CPU, 6. mm, 7. arena, 8. mile, 9. M51, 10. book,  
Down: 1. coding, 2. advice, 3. arena, 4. brand,  
20. Czech, 25. movie, 27. net, 30. lesson, 33. one  
20. Caspian, 28. zero, 31. town, 32. yacht,  
18. HEMLIBRA, 21. yrs, 22. nm, 23. MCA,  
13. km, 14. used to, 15. chet, 17. met,  
Answer: 1. cash, 5. dollars, 11. Adam, 12. parish,

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**.



B: 11.25"  
T: 11"  
S: 9.75"



**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](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 12/2021



HEMLIBRA® 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.  
©2022 Genentech USA, Inc. All rights reserved. M-US-00011996(v2.0) 03/22

**Genentech**  
A Member of the Roche Group



# INSIDE OHF

***Meet two key players in our community. Stina Pineyro, who comes to us from the Florida bleeding disorders chapter, is our new communications person. And Liz Allen, with a background working for legislatures, has generously agreed to serve as our new Advocacy Committee Co-Chair.***

***Welcome and congratulations!***

## **Stina Pineyro**

Hi there, I'm Stina. I am the new Social Media and Marketing Coordinator for OHF! I was raised in Florida and just relocated to OKC in August.

I have been a part of the hemophilia foundation back home since I was around 13 years old, when my family found out my nephew has vWB. I have worked at various Serious Fun Camps around the US. My passion is encouraging growth and connection in all the work I do.

In my spare time you can find me rock climbing, spending time outside, cuddling my dog, baking with my partner, and bookmarking tiny homes on AirBnB for future adventures.

Thank you all for welcoming me into this wonderful community at OHF. I am so excited to begin meeting all



## **Liz Allen**

I am Liz Allen, married to Reagan. We live in Enid with our 2 sons, Blake and Brock. Brock (13) has Hemophilia B and we just started prophylactic treatment. Our family has learned so much through OHF. I look forward to advocating and sharing knowledge with state and national legislators as advocacy co-chair.







# Dedication and Personal Support

**Your Pfizer Patient Affairs Liaison** is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



## Jeffery McFall

TN, AR, OK, LA, MS

[jeffery.t.mcfall@pfizer.com](mailto:jeffery.t.mcfall@pfizer.com)

O: 615-961-0746

*"I have over 32 years of health care experience coupled with a true passion for community advocacy."*

### My work is guided by:

#### Compassion

Listening to your needs and addressing questions and concerns that you may have

#### Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

#### Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

HemMobile is a registered trademark of Pfizer Inc.  
HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.



# STAY CONNECTED

## UPCOMING EVENTS

APRIL 1ST & 2ND	Bloom 2022: Women's Retreat
APRIL 14TH	Community Dinner
APRIL 19TH	Community Dinner
MAY 5TH	Cinco de Mayo Celebration
MAY 12TH	World Hemophilia Day Dinner
JUNE 17TH-18TH	Annual Meeting/Advocacy Summit
JUNE 30TH	Community Dinner
JULY 25TH-29TH	Camp Independence

SEE OHF'S WEBSITE FOR DETAILS AND A FULL-YEAR CALENDAR

## Follow us on Social Media



OklahomaHemophiliaFoundation



@oklahomahemophiliafoundation





**ELOCTATE**

[Antihemophilic Factor  
(Recombinant), Fc Fusion Protein]

**JOIN THE CONVERSATION.  
LEARN ABOUT ELOCTATE.**



Sanofi Genzyme Community Relations and Education Managers (CoRes) have years of experience working with patients on ELOCTATE and can provide you with helpful resources and support.



**MEET YOUR CoRe, Danielle Kempker**

Serving Colorado, Kansas, Nebraska, Oklahoma

"I enjoy connecting with patients and their families in the community to help support them along their journey. It's what I do."

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



**Scan with your phone to  
contact your local CoRe.**

**SANOFI GENZYME** 

© 2020 Genzyme Corporation. All rights reserved. ELOCTATE is a registered trademark of Bioverativ Therapeutics Inc., a Sanofi company.

MAT-US-2022365-V1.0-11/2020



Education, Advocacy, Awareness

**Executive Director:** Tim Grogan  
[TGrogan@OKBleedingDisorders.org](mailto:TGrogan@OKBleedingDisorders.org)

[Info@OKBleedingDisorders.org](mailto:Info@OKBleedingDisorders.org)

**\*NEW\*** Phone Number:  
918-605-2579

**\*NEW\*** Address:  
Oklahoma Hemophilia Foundation  
9524 E. 81st. St. Ste. B1510  
Tulsa, OK 74133



Education, Advocacy, Awareness

serve nearly 1,000 people  
with bleeding disorders in  
Oklahoma and surrounding  
states.

We welcome you to join us!  
[www.okhemophilia.org](http://www.okhemophilia.org). Click  
on "Sign Up" to receive event  
emails and information.



*Connect with us.*



**@OklahomaHemophiliaFoundation**

**OKHEMOPHILIA.ORG**