



oklahoma HEMOPHILIA FOUNDATION

Summer 2021

Serving those with Bleeding Disorders

It was so great to see everyone at our recent Annual Meeting! After a year of pandemic isolation, I can't tell you how great it was to return to handshakes and hugs with the OHF family.

We had a record number of members attend - nearly 350 - and a record number of sponsors this year. I hope you all enjoyed the fine food, fellowship, and facility as much as I did. We had awards, prizes, and educational programs ranging from cannabis to VWD, so hopefully there was something for everyone.

Although we've been forced to go virtual once again with the COVID resurgence since the meeting, know that we will resume live events at the earliest possible time it is safe to do so.

In the meantime, interesting, educational. Check out our calendar, social media, website, that we are here to edit step of the way!

*Blessings,
Tim Grogan
Executive Director*



Unite for Bleeding Disorders



INSIDE THIS ISSUE

- 2021 Annual Meeting Awards.....2-3
- Annual Meeting Events.....
.....4-5
- Scholarship Recipients.....
.....6
- Incoming/Outgoing Board Members.....
.....7
- 2021 Events.....
.....10,12
- Meet the Board—Wayne Nivin.....12
- Mission Update.....14
- OHF Calendar.....
.....14
- Connect With Us.....16

Please go to **okhemophilia.org** and check it out! Register for events, learn about OHF's mission, and find out how you can get involved!

2021 ANNUAL MEETING



BOB GOODLEY VOLUNTEER OF THE YEAR AWARD

Katie Mears (left) seems to be everywhere! She volunteers her time on the Board, at Camp Independence, chairs the Teen Retreat, leads our Junior Counselors, fundraises, raises awareness and more. Katie does it all, and we're lucky to call her one of our own. Congratulations and thank you for all you do for our community.

ADVOCATE OF THE YEAR AWARD

Nate Anders (right) met with five different legislators during OHF's Hill Days. He also served as a volunteer for Camp Independence, Teen Retreat, Family Education Retreat, and Annual Meeting. Congratulations, and thank you for all you do for your community.

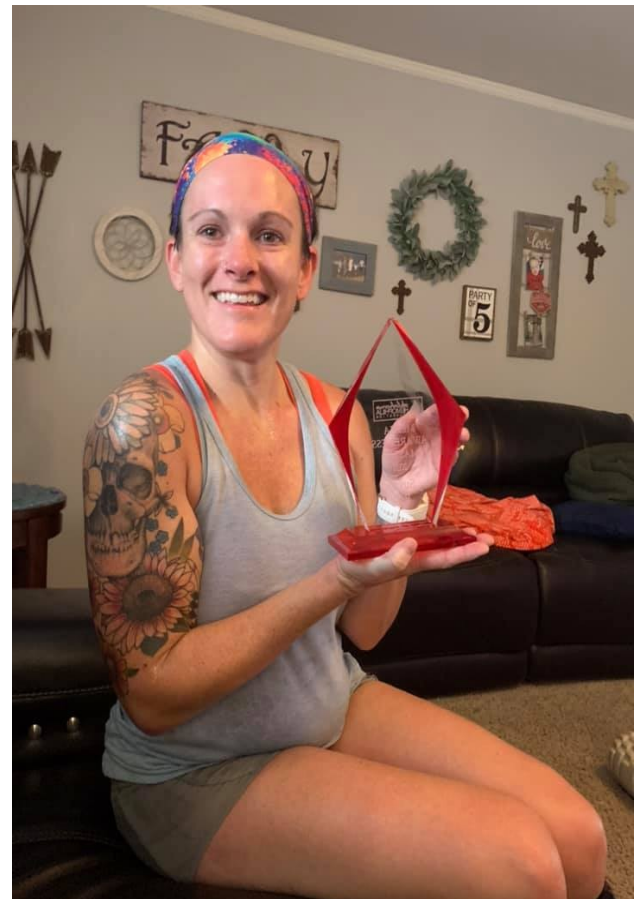


2021 ANNUAL MEETING



CHAPTER CHAMPION AWARD

Cecilia Ruberto (left) provided tremendous support during this year's advocacy efforts by keeping us informed of our spotlight bill's movement through Oklahoma's legislature. Our success this year was not possible without her. Congratulations and thank you for all you do for our community.



MEDIA AWARENESS MASTER AWARD

Susan Ball (right) posted every day about her family's journey living with hemophilia during Bleeding Disorders Awareness Month in March. It's wonderful to be open to sharing your story to help educate and encourage others. Congratulations and thank you for all you do for our community.

2021 ANNUAL MEETING

A big thank you to all our youth chaperones! Our Annual Meeting is not possible without their help. Many are also counselors and assistant counselors at OHF's Camp Independence. It looks like they had a great time at Main Event!_



2021 ANNUAL MEETING



**Infusion Clinic
hosted by the
Jimmy Everest Center
for Bleeding and
Clotting Disorders**



Our Oklahoma HTC helped our youth practice their self-infusion skills.
Thank you to the Jimmy Everest Center for Bleeding and Clotting Disorders. _

2021 ANNUAL MEETING

JASON M. NELSON MEMORIAL EDUCATION SCHOLARSHIP

The Jason M. Nelson Memorial Education Scholarship was given to a great group of students this year. We could not be prouder of our students - Congratulations! And a special thank you to Nancy Nelson for continuing to honor her son's memory and the others who lost their lives by raising funds and awareness to support this scholarship..



SCHOLARSHIP RECIPIENTS

Sarah Annis	Alyssa Gazaway	Keaton Robinson
Darcy Ball	Wesley Grizzle	Brandy Rolling
Skylar Cheatham	Mallory Lanier	Trinady Smith

2021 ANNUAL MEETING

WELCOME!

We would like to welcome
Nathan Holloway
Katie Mears
Ed Paitsel
Michelle Reagor
Darla Williams
to the Board of Directors.



WE LOOK FORWARD TO WORKING TOGETHER!

Congratulations and welcome to OHF's five newly elected Board members.

Photos, introductions, and contact information for all Board members will soon be on the OHF website.

Get to know them and share your thoughts and ideas.

PLATINUM



THANK YOU FOR YOUR SERVICE AND SUPPORT!

Our Board Members are valuable members of our team and

we'd like to thank

Kerri Crabtree

Samantha Knappen

Rachael Robinson

for your years of service.

WE APPRECIATE YOU!



GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA.

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.

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
©2018 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: 10/2018



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.
©2020 Genentech USA, Inc. All rights reserved. M-US-00007357(v1.0) 09/20

Genentech
A Member of the Roche Group

2021 Events

- September 25 Unite Walk (virtual)
- October 4 Red Jacket Golf Tournament (live)
- November 12-14 Family Education Retreat (virtual)
- December 4 Winter Event (virtual)

For more details on our events, visit okhemophilia.org

UNITE WALK & FUNDRAISER



SEPTEMBER

25TH

OKHEMOPHILIA.ORG

OHF's Unite Walk for Bleeding Disorders is September 25th! While the Walk is virtual this year, you can still host safe, small group walks in your neighborhood or local park. Help raise awareness and funds for OHF. Sign up your family and friends on the OHF website.

SANOFI GENZYME 

Here for you.

Blood unites us in powerful ways. As a Community Outreach and Education (CoRe) Manager for Sanofi Genzyme, I'm here to be a source of education for you and others living with hemophilia.

Danielle Kempker
CoRe Manager for Colorado,
Kansas, Nebraska, Oklahoma

Let's connect.

816-946-1870
danielle.kempker@sanofi.com
rareblooddisorders.com
   @HemophiliaCoRes

© 2021 Genzyme Corporation. All rights reserved.
MAT-US-210070-v1.0-01/2021





Cedar Ridge Country Club in Broken Arrow

Red Jacket Challenge

GOLF TOURNAMENT
& FUNDRAISER



October 4, 2021

CALL 918.934.6133

REGISTER @ OKHEMOPHILIA.ORG



MARK YOUR CALENDARS! **October 4th** will be OHF's annual Red Jacket Challenge Golf Tournament and Fundraiser. Pay to play to raise funds and awareness for bleeding disorders. **November 12th - 14th** is OHF's Family Retreat! There will be lots of fun-filled sessions with

MEET THE BOARD—WAYNE NIVIN



Hello, I'm Wayne Nivin, the current President of Oklahoma Hemophilia Foundation. I'd love to introduce myself and my involvement with Oklahoma Hemophilia Foundation. My beautiful wife Lonny and I are grandparents of five wonderful grandchildren; one girl and four boys, one of which has Hemophilia A. With his diagnosis about 16 years ago, I became involved with OHF. This organization became a vital support system for 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.

It is my hope that we can continue to strengthen and grow OHF to continue to serve its members' needs. As board members, we appreciate your thoughts and ideas. It is through your input that we improve the Foundation and fulfill the bleeding community's needs. OHF is a loving caring family, and I am so grateful to be a small part of the organization.

We're Listening



At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

MISSION UPDATE—THE THREE PILLARS

OHF's mission is to provide **Service, Education, and Advocacy** for the Oklahoma bleeding disorders community. Here are some of the things we've been doing to fulfill that mission.

SERVICE

OHF's Benevolence Program is designed to get emergency resources to those most in need in the bleeding disorders community. So far during the COVID crisis of 1920-21, OHF has given more than \$7,500 to help members stay in their homes, keep their utilities on, and pay their medical bills. To assist members in need of food assistance during the pandemic, we awarded an additional \$5,600 of grocery gift cards to our families most in need.

In addition, with the support of our generous sponsors HPC and Octapharma, we mailed back-to-school boxes to every child in our community filled with much needed school supplies - as well as a fun treat or two. And finally, we provided gas cards from Love's and QuickTrip to our HTC to give to members who needed help with travel expenses to receive medical treatment.

EDUCATION

The pandemic has forced OHF to move to virtual programming for the safety of its members. But that doesn't mean we had to cut any programming. In fact, over the past year we've not only produced all our normal educational events, but we also added our Thursday night Community Connections webinars.

ADVOCACY

2021 was a banner year for our advocacy efforts as we played a key role in getting a copay accumulator ban passed in the Oklahoma legislature. This bill requires your insurance company to count all your copay assistance from manufacturers and others towards your deductible and out of pocket amounts, potentially saving you thousands of dollars. To do this, we contacted a record number of state representatives and senators this year, through both email and Zoom. Dozens of you took part, which made all the difference - *Thank you.*

OHF CALENDAR

September

Saturday 25th @ 10am: Unite Walk and Fundraiser (virtual)

Monday 20th @ 7pm: Board Meeting (virtual)

Thursday 30th @ 6pm: Community Connection (virtual)

Monday 4th @ 10am: Red Jacket Challenge Golf Tournament, in Tulsa

Coping With Hemophilia as a Family: Suggestions for Managing the Family Dynamic



For more information, visit
b2byourvoice.com to download
Hemophilia B: A Family Perspective.

This content is brought to you by Pfizer.

Hemophilia Affects the Whole Family

Despite improvements in the medical management of bleeding disorders, raising a child living with hemophilia still affects the lives of everyone in the family. It's important to address the needs of caregivers and family members as well as acknowledge how a diagnosis of hemophilia alters family dynamics.¹

Hemophilia is a complex disorder that requires treatment for a lifetime. If hemophilia is new to the family, feelings of uncertainty about coping with day-to-day management can occur. In particular, infusing factor may initially be upsetting to the child and stressful for the caregiver who is experiencing challenges with the process.¹

“One thing we learned was that growing up is a learning process for all children, whether they have hemophilia or not.”

— Jill L.

Mother of 2 sons with hemophilia B

Discipline and Limits

It's important for parents and other caregivers to support one another in the daily care of the child, including talking about emotions and overcoming hemophilia-related challenges together.² Some of these challenges can include providing discipline and setting limits. Parents and caregivers are often advised to address these issues in the same way they would for children who are not diagnosed with a bleeding disorder.

Some suggestions from the National Hemophilia Foundation that may help in caring for a child with hemophilia include³:

- Praise your child when he or she reports a bleed to a caregiver
- Reinforce that having a bleeding disorder that requires treatment is not a punishment
- Openly discuss the potential effects of behavior and activities
- Never punish your child for having a bleed

One major concern that parents or caregivers may face is knowing when a child is having a bleed. In some cases, bleeds can be tricky to identify, as a child may exhibit one or more of the following signs or symptoms of a muscle bleed⁴:

- Holding a part of the body in an awkward position or reluctance to use that part of the body
- Complaining of pain or a tingly sensation in the injured area
- The injured area feels warm, swollen, and/or firm to the touch

It's important to recognize that caring for a child with hemophilia may create changes to which the family must become accustomed. Lifestyle modifications are a part of living with hemophilia, and sometimes these changes extend to the entire family. However, these adjustments represent opportunities for positive change through learning and self-awareness.⁵

References: 1. Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia*. 2007;13(5):570-579. 2. Wiedebusch S, Pollmann H, Siegmund B, Muthny FA. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia*. 2008;14(5):1014-1022. 3. National Hemophilia Foundation. Steps for Living website. Discipline. www.stepsforliving.hemophilia.org/first-step/family-life/discipline. Accessed July 12, 2019. 4. Rivard G-E, Blanchette V, Hilliard P, Mulder K, Zourikian N. Management of bleeds. In: *All About Hemophilia: A Guide for Families*. Montréal, Québec: Canadian Hemophilia Society; 2010: 4-1-4-32. 5. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).



Education, Advocacy, Awareness

Executive Director: Tim Grogan
TGrogan@OKBleedingDisorders.org

Info@OKBleedingDisorders.org

NEW Phone Number:
918-605-2579

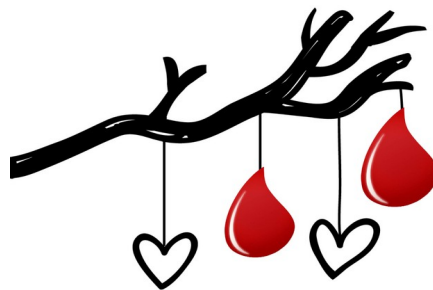
NEW Address:
Oklahoma Hemophilia Foundation
9524 E. 81st. St. Ste. B1510
Tulsa, OK 74133



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. Click
on "Sign Up" to receive event
emails and information.



Connect with us.



@OklahomaHemophiliaFoundation

OKHEMOPHILIA.ORG