



oklahoma HEMOPHILIA FOUNDATION

Fall 2019

Dear Oklahoma Hemophilia Foundation Members,

It was great to see you all at the Annual Meeting! What a great weekend! With the informative sessions, great food, time to reconnect with friends and make new ones, as well as all the foundation updates and awards, there was something for everyone.

If you haven't had a chance to fill out the annual survey, please take a minute and to let us know what you think. We review the surveys carefully as we design our programs for the year. You can find it on our website homepage. okhemophilia.org

Something new! At the business meeting on Saturday morning OHF Annual Meeting, the members voted to accept bylaw changes that include implementing a process of applying for membership in OHF to create a list of voting members.

Becoming a member is simple. Please go to okhemophilia.org and click on the "About OHF" tab. Click on "Membership Form," fill it out, and you will be included on our member's list.

We are excited for all we have been able to accomplish this year with your help and participation! Check out the Calendar of events and connect with us again soon.

Kathleen

Ways to Give

Have you signed up for AmazonSmile yet? OHF received over \$50 just from people using Smile to make Amazon orders and naming OHF as their nonprofit. Same items, same prices. Please sign up today.



Volunteers Always Needed!

All of OHF's programs and events are run by volunteers. Please let us know if you would like to be more involved! Email kmontgomery@okbleedingdisorders.org

Current committees looking for volunteers:
Annual Meeting, Women's Advocacy, Walk, vWD, Newsletter
For more pictures and event updates, like us on Facebook.



www.facebook.com/okhemophilia

Unite for Bleeding Disorders



Family Education Retreat

Nov. 8-10, 2019

\$15 per person

\$75 family cap

Price includes: lodging, food,
and long sleeve shirt.

Register by Oct. 15.



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2019 OHF ANNUAL MEETING

SENATOR DAVE RADER AND REPRESENTATIVE CAROL BUSH RECEIVED THE 2019 OHF CHAMPION OF THE YEAR AWARD



The OHF is incredibly fortunate for the honored relationships that we have with Dave Rader of the State Senate and Carol Bush, Representative House District 70, recipients of this year's OHF Champion Award presented at the Annual Meeting. This is given to individuals who make a significant difference advocating for people with bleeding disorders. Thank you for your continued support and inspiration.



BOB GOODLEY VOLUNTEER OF THE YEAR AWARD

Liz Decker was awarded the OHF 2019 "Bob Goodley Volunteer of the Year Award" for her service as the Advocacy Chair. Not only has she managed the monthly Advocacy committee meetings and goals, Liz is the mover behind the Proclamation declaring March Bleeding Disorders Month in Oklahoma and was instrumental in planning our past two Days at the Hill. She engaged us and participated in the coalition for the recent Step Therapy bill cosponsored by Senator Rader and which passed unopposed in the last session. Liz leads by example and she has modeled reaching out to her legislators with sincerity and teaches us how to do it as well. She has represented us well in Washington DC, educating our national legislators about bleeding disorders the past two years.



2019 OHF ANNUAL MEETING

CORPORATE DONOR OF THE YEAR AWARD



Denise Redmond from BlueStone Natural Resources accepts the Corporate Sponsor of the Year Award.

Thank you for your support!



OUTGOING BOARD MEMBERS

A big "Thank You" to outgoing board members Eric Walker (treasurer), Tom Ayers (President), Nathan Holloway, and John Faria (below) for their dedicated service on the OHF Board of Directors.



2019 OHF ANNUAL MEETING

THE SCIENCE OF OPTIMISM

Lunch this year included a presentation given by Shannon Paoletti and sponsored by Genentech. Shannon has worked with the University of Pennsylvania Positive Psychology Center for 18 years as a lead instructor on resilience and positive psychology topics. This work has included delivering programs to the United States Department of Education, Office of Rehabilitation Services Administration, educational institutions in the United States, United Kingdom and Australia, community mental health programs, and the United States Army.

She taught us about the science behind building an optimistic mindset. We can develop and train our minds to be more optimistic! It is a skill.

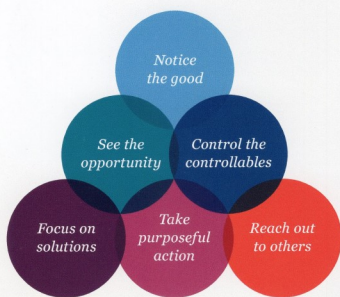
Things that an optimist does:

- Notice the Good
- See the Opportunity
- Control the Controllables
- Focus on the Solutions
- Take Purposeful Action
- Reach Out to Others

She taught us that we can all gain control of our thinking.



MINDSET OF AN OPTIMIST



Genentech
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2019 OHF ANNUAL MEETING

JASON M NELSON SCHOLARSHIP WINNERS

Keaton Robinson
Sarah Annis
Skylar Cheatham
Mallory Lanier
Angie Salter
Dillain Stuckey
Not shown:
Courtney Kosemund
Malisha Franklin
Nathan Anders

Congratulations!
We wish you a successful year!



2019 OHF ANNUAL MEETING

Platinum Sponsor:

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KEDRION BIOPHARMA **PARAGON** HEMOPHILIA **HFA** Hemophilia Federation of America™ **NATIONAL HEMOPHILIA FOUNDATION**

Thank you to the Jimmy Everest Center for Bleeding and Clotting Disorders and At Home Specialty Pharmacy

SPOTLIGHT—SARAH ANNIS

I was introduced to the OHF community in 2009, when my older brother was diagnosed with ITP (Idiopathic Thrombocytopenia Purpura) at the young age of 12, and I was 8 at the time. Since I was so young, it was difficult to adapt to the changes. I didn't understand why I couldn't rough house with my brother anymore.

My parents and I also had to learn multiple first aid precautions for his safety. In the early years of his diagnosis, my parents tried to equally give time and attention to both my brother and me, but at 8 years old it didn't feel that way. For example, when my brother had appointments every week in Oklahoma City, I always had to stay with my grandparents, and I didn't understand why. However, the first time I attended Camp Independence I started to understand bleeding disorders in depth and how it affected our lives. Through camp, I've experienced life changing events.

One thing I will never forget is LAH LAH (Learning About Hemophilia) I learned how to help my brother and others who are affected by bleeding disorders. Camp Independence also introduced me to life-long friends. I don't know what my life would be like if I was not involved

in OHF, however, I am beyond thankful for the experiences and lessons I've learned through this community.

In February 2019, I had the privilege of attending a YETI (Youth Effectively Transitioning to Independence) conference in Gresham, Oregon. This was my first time flying, so I was excited from the get-go. Katie Mears and I were chosen as the adult and teen representatives for OHF, respectively. I met other teens and adults from all over the country who are either affected, siblings of the affected, or carriers of bleeding disorders. A majority of the attendees were affected by Hemophilia. This trip truly was a blessing in disguise because I was never fully aware of the struggles of Hemophiliacs. I feel now I have a little more insight.



OHF VOLUNTEER SPOTLIGHT—NATE ANDERS

Hello! I grew up in southeast Oklahoma City, and currently live in Stillwater, Oklahoma. I am a full-time student at Oklahoma State University majoring in Aerospace Administration and Operations with a Professional Pilot focus. Soon I will start training to be a flight instructor and plan to fly for a regional airline following college graduation.

I was diagnosed with a Von Willebrand deficiency when I was a high school junior, and the following summer decided to go to camp as a Junior Counselor. I had an



incredible time at camp, and it was a great way to jump into this community. Since then I have had the privilege of volunteering on both the OHF Teen Committee and the Camp Independence Camp Committee. It has been an absolute blast working with other members of OHF to serve the youth in our community.

When I'm not doing schoolwork I like to keep myself busy with our university flying club and flight team. Growing up I always loved aviation and flying, and I have had my pilot's license for three years now. On the weekends I like to go fly somewhere fun or visit family back home. I would encourage everyone to volunteer in some way with OHF! This is a special community that comes together to support one another, and it truly would not be possible without all the individuals who work in our committees that make it happen. Though I only had one year at camp as a camper, I learned so much from it. I want the kids who go to camp today to have the same experience that I had, and it has been an incredible experience to help put together Camp Independence and the teen retreat.



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LET'S GO

CAMP INDEPENDENCE

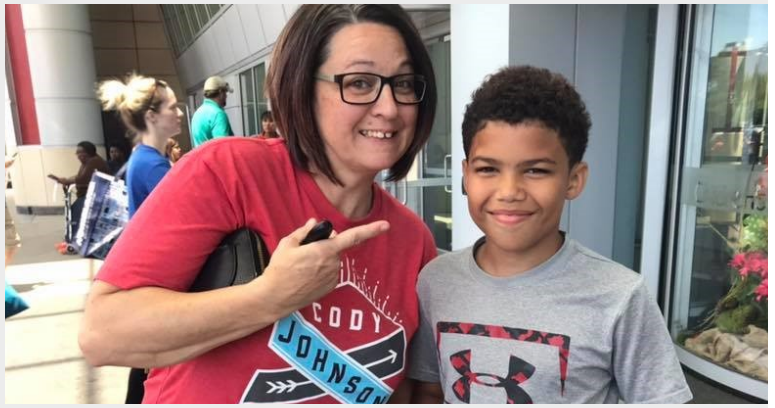
By Henry Clark-Smith

I have gone to camp for four years, since I was eight. I like to go to camp because I want to learn more about Hemophilia, and I want to be a JC and an AC some day. At camp, my favorite things are: the zipline into the water, seeing my friends, meeting new people, and learning! The ukuleles were fun! This year we had a pirate theme. We built boats out of cardboard and tape and whoever floated the longest won. I was picked to be in one of the boats. When we pushed the boat in the water, I sat in it and then it started to tip over. My team came in second place.

The blob is really fun, but they took off the slide this year. Everyone in my cabin voted to go to the blob, so we went three times. For people who don't know, the blob is an inflatable trampoline with a rolling log and launch pad that is out on the pond.

I want to be a JC because I want to see what the camp does when I get older. The JC's get to help out in the community. I look up to them because they help people. This year they went to a place and helped clean it up.

In Lah Lah I learned that there are lots of different types of bleeding disorders, not just Hemophilia. There is also von Willebrand disease. I learned how to infuse myself and this is important so I can do it myself if something happens.

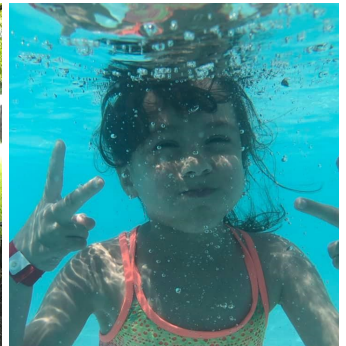


My counselor was Nick. He is really fun and he hung out with us. He was a really cool counselor to have.

If someone asked me if they should go to camp, I'd say "Go!" It helps a lot with self-infusions and you get to meet new people!

THANK YOU

so much



**Donors
Fundraisers
Volunteers**

Event Sponsors:



HTC CORNER—

HEALTHY JOINTS-MUSCULOSKELETAL ULTRASOUND CAN HELP

Hemophilia has been recognized since biblical times. It is an X-linked recessive process and is the most common severe inherited bleeding disorder. Patients with mild to moderate disease generally bleed with minor trauma or invasive procedures while patients with severe hemophilia can present with spontaneous bleeding into joints, soft tissue or muscles.

The hallmark of hemophilia is repeated hemarthrosis (bleeding into joint spaces), leading to progressive arthropathy (a disease of a joint) that may even require joint replacement surgery in the third or fourth decade of life. Joint bleeding, leading to arthropathy, is the leading cause of morbidity in patients with Hemophilia. The goal of therapy in hemophilia is to stop bleeding and subsequent joint damage with prophylactic administration of coagulation factors and aggressive on-demand treatment of bleeds. Detection and early treatment is important.

The current standard of care for assessment of joint health is to use patient history and physical examination. Radiological evaluation can be accomplished by X-ray or MRI, both of which have limitations. X-ray, while widely available and economic, is not sensitive to early joint changes and is associated with exposure to radiation.

MRI is the gold standard for radiological joint evaluation. While it is sensitive and specific, it has limited availability, high cost, long scan periods, and often requires sedation in young children.

Furthermore, MRI is not sensitive in detecting low concentrations of blood in the joint and in discriminating between bloody and non-bloody fluid, whereas ultrasound is able to detect those differences. Objective evaluation of joint status utilizing **point of care (POC) musculoskeletal ultrasound (MSKUS)** has the potential to be an outstanding diagnostic tool to optimize therapy. It is particularly appealing since it is economic, easily accessible, does not require sedation for young children, does not involve radiation and is sensitive to soft tissue changes and hemarthrosis.

Evaluation of an acute painful event with MSKUS can diagnose the presence or absence of a joint or muscle bleed versus an arthritic flare up of the joint. Moreover, sequential evaluation of joint status with ultrasound has the potential to provide longitudinal data to optimize treatment strategy and further reduce the likelihood of long-term joint damage.



**JOIN US JOIN US JOIN US
FOR A JOINTS FOR GOOD EVENT!**

**ON SEPTEMBER 14TH
PUT YOUR JOINTS TO USE AS WE CLEAN UP
THE TULSA GARDEN CENTER FROM 10AM – 12PM.**

The National Hemophilia Foundation and Sanofi Genzyme have teamed up to encourage the community to develop lifelong habits that promote safe, joint-building physical activities – not just in June, but all year long.

**REGISTER AT
WWW.OKHEMOPHILIA.ORG/JOINTS-FOR-GOOD**

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HEM-5-4788 08/19



*The Jimmy Everest Center
for Bleeding and
Clotting Disorders staff*

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GO AHEAD.



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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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. **HEMLIBRA** may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; **FEIBA®**), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

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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: 10/2018



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TEEN RETREAT

By Kody Farguson

This year was my second year at the Teen Retreat. I wanted to go because it was so much fun last year. We went to a shotgun range and did skeet shooting; we made smores and we did karaoke the whole time we were there. We went on a fun walk the first night— It was a time when we were quiet, and we could just enjoy being together. It rained most of the time we were there, but it was still really fun and we were able to have a lot of fun inside. Cory played the guitar and we hung out and played all different kinds of games. I did not play the epic game of dominoes.

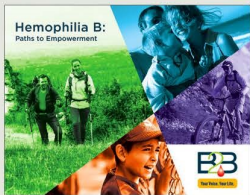
The Teen Retreat helps you grow as a person and it helps you make closer friendships with other friends with hemophilia. We had a lot of different team building activities and it taught me how to work more as a team. On the ropes course, we had to find different ways to do something. There was not a set way to do it so we had to think and be creative. The food was also really good. I got enough sleep but no one else did. I snore really bad.

I feel like everybody should go, even if you aren't sure it will help you, I guarantee it will.



B2B: Your voice. Your life.

Interested in stories and personal experiences *from* the hemophilia B community *for* the hemophilia B community? Turn to B2B.



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More topics include . . .

- Educating your child's school about hemophilia B
- HEMO 101 for caregivers
- Managing relationships with hemophilia B
- Life for girls and women with hemophilia B

VISIT WWW.HEMOPHILIAVILLAGE.COM
to explore all B2B materials

CONNECT WITH US

Media Minute

Keep up with all OHF news and events.

Follow the OHF:



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www.OKHemophilia.org



ADVOCACY AMBASSADOR PROGRAM

How Can You Help? Be an Advocacy Ambassador!

- Learn more about the community's issues
- Create awareness campaigns
- Mentor less experienced volunteer advocates
- Build relationships with legislators

What Does an Advocacy Ambassador Do?

- Attend monthly advocacy meetings with your state bleeding disorders coalition
- Attend the annual advocacy stakeholder summit in the fall
- Build and strengthen relationships with legislators
- Mentor new Advocates

How Advocacy Help?

- Generates awareness of the disease/disorder
- Helps protect patients with access to care
- Teaches community members the importance of self-advocacy and story telling
- Builds and strengthens "community"
- Voice of the patient when the patient can't speak for themselves

Join the Team! Email Liz (OHF Advocacy Chair for more information or to get started: elizabettadecker@gmail.com



The Mission of OHF is to serve, educate, and **ADVOCATE!**



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Education, Advocacy, Awareness

National Hemophilia Foundation
Oklahoma Hemophilia Foundation
8283 North Owasso Expy, Suite H
Owasso, OK 74055

kmontgomery@okbleedingdisorders.org
www.okhemophilia.org



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 serve over 300 people with bleeding disorders in Oklahoma and surrounding states.

We welcome you to join us! Click on "Sign Up" or go to www.okhemophilia.org to receive information.



SAVE THE DATE:

- Aug. 17** "M-Powered Moms" Bayer-Tulsa
- Aug. 29** "Hemophilia/vWD overview & Nuwiq" Octapharma-Tulsa
- Sept. 5** "Game On" Bayer/Factor One Source-OKC
- Sept. 12** "Back to School" Novo Nordisk/CVS-OKC
- Sept. 14** Joints for Good Service Event: 10 am -noon, Tulsa Garden Center sponsored by Sanofi Genzyme
- Sept. 19-20** "Hispanic Heritage" Takeda/Accredo-Tulsa/OKC
- Sept. 26** "Hemlibra" Genentech-Muskogee
- Oct. 7** Red Jacket Challenge Golf Tournament, Cedar Ridge Country Club, Tulsa
- Oct. 8** Community Dinner sponsored by Takeda and HPC, Tulsa
- Oct. 10** Community Dinner sponsored by CSL Behring and Factor One Source, Oklahoma City
- Oct 24** "Hemlibra" Genentech, Mustang OK
- Nov. 8-10** Family Educational Retreat, Post Oak Lodge, register by Oct. 15
- Nov. 14** M-Powered Moms, Bayer
- Dec. 14** OHF Winter Event, 11 am-1 pm, Guthrie Depot

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