



Things have been busy at the Oklahoma Hemophilia Foundation. Just take a look inside this issue to see all of the amazing events and opportunities we have had over the last several months. From Family Education Retreat last fall, to Day at the Hill this spring, and Annual Meeting in July just to name a few, we have been lucky to be able to work with and connect with so many of you.

The next several months are looking to be just as busy with the Red Jacket Challenge, Family Education Retreat, and Unite Walk all coming up very quickly.

If you are looking for ways to become more involved with OHF, please reach out. This is your Foundation and we welcome all of your thoughts and ideas. Working together we can achieve our shared goals to make OHF the best it can be!

You can stay in touch and informed of all things OHF through our social media, website, or email. Remember, we are here to help educate, advocate for, and support you in whatever way we can!

Respectfully,

Kerri Crabtree  
Interim Executive Director



OHF's Benevolence Program is designed to get emergency resources to those most in need in the bleeding disorders community. See our website for more details

## Unite for Bleeding Disorders



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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!

# Event Memories

## *Kendra Scott Fundraiser Utica Square*

Thank you to everyone who came out to support OHF at this fun fundraising event!!!



## Winter Event

A great big thank you to Tammy Jones and her family for organizing our 2022 Winter Event. Families enjoyed a great meal and learned about holiday customs from around the world. They also got creative making crafts and had a visit from Santa's elves! Be on the lookout for information on this year's event where we will enjoy an old fashioned holiday dinner along with lots of fun activities!



# Event Memories

Members of the OHF and their families met with Oklahoma legislators to educate and advocate for the needs of the bleeding disorders community. Thank you to Advocacy committee chair Liz Allen, Advocate of the Year award recipient Miranda Williams, and all those who volunteered for Advocacy Day at the Hill.



DAY AT THE HILL

# Event Memories

## *Family Education Retreat*



Last Fall, OHF families gathered together in Falls Creek for our Family Educational Retreat. throughout the three day event, families enjoyed educational sessions, outdoor activities, game nights, and most of all, coming together as a community.

A special thanks goes out to our committee chairs who brought it all together, Leisa MacDougall and Emily Johnson.

This year's Family Education Retreat will be at Tatanka Ranch in Stroud. We hope to see you all there!

A big thank you goes out to all of our amazing sponsors!!  
We couldn't do it without you!!!

Colburn Keenan Foundation, Inc.

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*Silver Sponsors:*



We would also like to extend a special THANK YOU  
to Sheryl Brittain for preparing Saturday's BBQ Lunch, Brandie Gibson for helping her  
with dessert, and Crossroads Country Market in Medford for the donation of food for the  
BBQ!

# Event Memories

## *BLOOM*

Shout out to Octapharma and HPC for once again hosting BLOOM for the ladies of OHF. The weekend focused on women's issues and gave the ladies the chance to relax, connect, and recharge. They enjoyed educational sessions, crafts, and even a pajama party! It was a fun-filled two day event that had everyone looking forward to doing it again next year!



  
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# Event Memories

## Annual Meeting

On July 28th-29th, members of the OHFfamily gathered together in OklahomaCity for the Annual Meeting. It was awonderful opportunity for everyone tospend some time catching up. Weenjoyed good food, fun activities forthe adults and the kids, and plenty ofeducational opportunities to get up todate on the latest advancements anddevelopments in the bleeding disorderscommunity.



Congratulations to Steve Henson  
OHF Volunteer of the Year



Congratulations to our Jason M. Nelson Memorial Scholarship recipients  
L-R: Easton Voyles, Sarah Annis, Alyssa Gazaway, Mallory Lanier, Trinady Smith, Reece CHeatham, Dillain Stuckey  
Not pictured: Brandy Rolling



Congratulations to Miranda Williams,  
OHF Advocate of the Year



# Annual Meeting

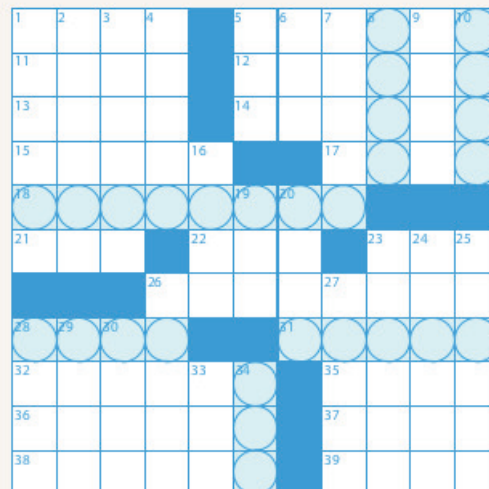


CAN YOU SOLVE

# 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 worldwide<sup>†</sup>

<sup>†</sup>Number of people with hemophilia A treated as of October 2021.

## SOLUTIONS

ACROSS: 1. cask, 5. chiasm, 11. Aden, 12. party, 13. tore, 14. used to, 15. chisel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. M.C.s, 26. passport, 28. zero, 31. three, 32. eyetooth, 33. Crown, 36. amoro, 37. still, 38. lesson, 39. class, 40. Crayon, 41. casting, 2. address, 3. seminar, 4. friend, 5. CPU, 6. haul, 7. arena, 8. ride, 9. M.S.B., 10. dhor, 16. lira, 19. bus, 20. rest, 23. moral, 24. Creed, 25. saze, 26. poles, 27. photo, 28. zeal, 29. Elys, 30. Mar, 33. ESE, 34. tan.

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<sup>®</sup>) 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](http://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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A Member of the Roche Group


# Meet the Board

Congratulations and welcome to our newly elected Board members; elected at the Annual Meeting. We are so excited that they have joined the Board and for the work that they continue to do for the OHF community!

The Board meets the third Monday of every month. Board meetings are open to all members who would like to participate. See the OHF website for more information on the board meetings and other ways you can be involved!

*Liz Allen*

I am from Enid. I am married to Reagan and we have 2 sons, Blake and Brock. With a family history of Hemophilia B, I asked for Brock to be tested at birth. The doctor never told me that he had Hemophilia and I believed no further testing was needed. 7yrs later, I had concerns and asked that the tests be repeated, we found out that he has Hemophilia B. We were sent to the HTC, where our family was connected with OHF. We attended our first Annual Meeting that same year. It was life changing to learn we WERE NOT ALONE! We met incredible supporters, not only for our son, but for us, as caregivers. This journey has ignited my passion for advocacy. I want to share my knowledge with OHF Members to give them the confidence and courage to share their stories, get appropriate medical assistance when needed, and protect our rare Bleeding Disorders Community in legislative matters.



- 2022 OHF Advocate of the Year
- OHF Advocacy Chair 2021-Present
- Board Member, Emmanuel Baptist Church
- PEO - Past President, Vice President, and Secretary



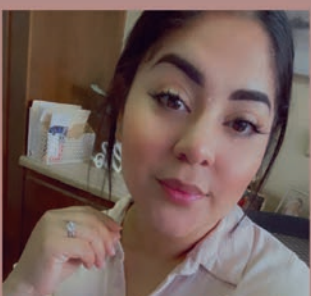
*Miranda Williams*

I live in Elk City. In 2020, my son Theodore had a severe bleed. With no diagnosed family history, it was the scariest time of my life. After he was finally diagnosed with Severe Hemophilia A and Type 1 VWD, I received my diagnosis of Mild Hemophilia A, and my husband Arron was diagnosed with low VWD. We have been active with OHF since 2020. I want to serve on the OHF Board because I believe I can teach members to advocate for themselves:

- So no mom has to be in horrible pain of hemorrhaging during childbirth
- So females don't have to suffer in silence with "bad periods"
- So Child Protective Services isn't called out of ignorance of our Bleeding Disorders

Since I became a member of OHF, I have participated in several events, including attending OHF's Day at the Hill, where I met with and educated legislators on Bleeding Disorders in the State of Oklahoma. I also created Unite Walk Team "No Stopping Theo" and successfully raised money for OHF's Walk.

## BARBARA ALEJANDRA HERNANDEZ



My name is Barbara Hernandez, I was born in Mexico, where my family resided for a short time before deciding to move to the US. Oklahoma has always been home to us, even when we tried to move to a bigger state, we were always brought back to Oklahoma. I started my family in the town of Bixby and lived there for about 10 years, before we moved to Liberty, where we enjoy living out in the country. I recently started a new career path, as a Manager in Human Resources, and am happy to say I have found my calling.

My husband Luis and I have 3 lovely children, Daniel age 14, Emilie age 13 and Mia age 3. We also have a growing chicken farm and 2 dogs.

My journey with Bleeding Disorders started before my son Daniel was born. So, when we decided to start a family, I was pretty familiar with what life, with children that have such a rare bleeding disorder, would be like.

I have grown to love this Foundation because it has taught me and my family many things and helped us to form life-long friendships, with wonderful people, that live the same lifestyle as my family. I would love the opportunity to teach my children how to be involved in this community.

Please consider electing me to the Oklahoma Board of Directors so that I can serve the new generation, new families, and existing members of OHF.

# Paige Turner

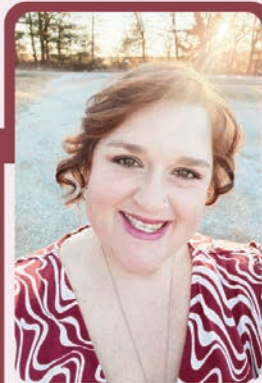
Hi! I am currently a computer lab assistant at the Pryor Public Library and an assistant volleyball coach at Pryor Schools.

I am twenty-nine years old, married to an amazing man, and we have the best two year old son, who has Severe Hemophilia A.

The core values I live by include happiness, respect, and responsibility. Those values are also what drive my passions in helping and empowering others, which are what help me in my current occupations. I get to help people with their computer needs at the library and I get to help empower young girls to seek their full potential and also be happy while doing it.

My hobbies include reading (perfect for working at a library - endless book supply!), working out, hanging out with my friends and family, and riding in the golf cart while my husband golfs.

I have been a member of the OHF for about 20 years. I would love nothing more than to help serve the community I belong to while also helping to better it!



## Emily (Johnson) Keller

I am from Ardmore, OK, where I work as an LPN for Mercy Ardmore. In 2011 I adopted my four children, Kaylee, Josh, Lillian, and Layla and have been blessed with 1 grandchild, Bentley. I recently married Rodney Keller.

In 2011 we were told about Camp Independence, by the HTC, where Josh was being treated for Severe Hemophilia A. The kids started attending camp in 2011 and I became heavily involved with OHF in 2014.

As a well known OHF Community Member, whom attends many events and functions, I believe I will be able to bring members' voices and opinions to the OHF Board, while offering a fresh perspective.

- One of OHF's 2022 Volunteer of the Year

-OHF Family Education Retreat Committee Co-Chair 2014 - Present

-Unite Walk "Johnsons Tribe" Team Captain

# 2023 Board of Directors

**Nathan Holloway**

**Liz Allen**

**Nakita Parnacher**

**Paige Turner**

**Nate Anders**

**Barbara Hernandez**

**Emily Johnson**

**Katie Mears**

**Michelle Rolling**

**Darla Williams**

**Miranda Williams**

**Easton Voyles**

**President**

**Vice President**

**Treasurer**

**Secretary**

**Board Member**

**Board Member**

**Board Member**

**Board Member**

**Board Member**

**Board Member**

**Board Member**

**Board Member**

*Thank  
you!*

# Get Involved

**If you are looking for a way to get more involved with the OHF, please consider joining one of our many committees!**

**Advocacy:** Recruit members to reach out to legislators at the State and Federal level to educate and fight for the needs of those affected by bleeding disorders. Committee organizes “Day at the Hill” activities and participates in “Washington Days” to promote advocacy for the Bleeding Disorders Community. If you have passion for educating and advocating for others, this is the committee for you!

**Women’s Group/Blood Sisterhood:** Promote networking and community for women with bleeding disorders and women who are connected to the bleeding disorders community. Committee organizes “Bloom” retreat and other events that focus on the ladies of the community.

**Teen Retreat:** This is an opportunity to create programming to engage our teen population. If you enjoy creating new events, this is the opportunity for you.

**Men’s Group/Blood Brotherhood:** Promote networking and community for men with bleeding disorders and those who are connected to the bleeding disorders community. Participates in HFA’s Blood Brotherhood which is a program designed to enrich the lives of those with bleeding disorders through education, activity, and fellowship. This is an opportunity to create programming to engage our gentlemen.

**Camp Independence:** This committee shapes and executes one of the Community’s largest and most beloved events. Plan and execute a week long sleep-away camp for youth from 7 to 17. This is a great way to get plugged in and many different sub-committees and needs exist—there is truly something for everyone.

**Annual Meeting:** The Committee is responsible for planning and executing OHF’s largest Community event. This event has many moving parts and can utilize talents in a variety of areas—event planning, logistics, graphic design, youth programming, etc. This outreach to the Community provides an opportunity to network with industry representatives as well as fellow Community members to further the mission of OHF.

**Unite Walk:** This committee plans one of the largest fundraising events for our Community. This is a great way to get plugged in and many different sub-committees and needs exist—there is truly something for everyone.

**Red Jacket Challenge:** The committee is currently preparing for the 30th Annual Red Jacket Challenge—a golf tournament which has been held at Cedar Ridge Country Club in the Tulsa area for the last several years.

**Family Education Retreat:** This committee plans a fun-filled, educational weekend for families to get together and reconnect with their fellow bleeding disorders community members. This is a great way to connect with other families and share common experiences.

**Winter Event:** Committee plans, organizes, and executes a holiday party for the community. This is a great opportunity to put your holiday party planning skills to the test!

**Jason M. Nelson Memorial Scholarship:** The Jason M. Nelson Memorial Scholarship was established in 1989 in memory of OHF community member Jason Nelson. The scholarship has supported many individuals and families as they further their education. The committee reviews applications to ensure the applicants meet the criteria for award, selects the recipients, and announces the awardees at the Annual Meeting.



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



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](http://www.okhemophilia.org). Click on "Sign Up" to receive event emails and information.

# Upcoming Events

- |                |  |
|----------------|--|
| October 5      | Community Dinner - Saltgrass Steakhouse, OKC<br>6:30PM – sponsored by Novo Nordisk & CVS Specialty |
| October 9      | Red Jacket Challenge Golf Tournament – Cedar Ridge Country Club, Tulsa                             |
| October 12     | Community Dinner – IFly, OKC 5:30pm – sponsored by Paragon, Medexus, & Hema Biologics              |
| October 16     | Board Meeting, 7pm   |
| November 10-12 | Family Education Retreat – Tatanka Ranch, Stroud, OK   |
| November 12    | Unite for Bleeding Disorders Walk – Tatanka Ranch, Stroud, OK                                      |
| November 20    | Board Meeting, 7PM   |
| December 9     | Winter Event – Sapulpa Senior Citizen Community Center, Sapulpa, OK                                |
| December 14    | Kendra Scott Fundraising Event – Tulsa   |



*Connect with us.*



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