



# oklahoma HEMOPHILIA FOUNDATION

Winter 2019

## Unite for Bleeding Disorders



### Unite With Us!

OHF's 2019 Unite for Bleeding Disorders Walk is right around the corner.

This is the perfect opportunity to:

- ⇒ Raise awareness about bleeding disorders to your family, friends and broader connections.
- ⇒ Raise vital funds for OHF's programs and services (all funds stay here in OK).
- ⇒ Celebrate together with your bleeding disorder family.

**Sign up your team today! Go to [www.okhemophilia.org](http://www.okhemophilia.org).**

### Team Captain Dinners:

All past, present, and future team captains—we will be having two kick off dinners to help you get started on your recruitment for your teams and your fundraising efforts.

- ⇒ Learn more about walk details.
- ⇒ Exchange ideas about how to effectively fundraise and raise awareness.

See you at one of our two dinners:  
OKC—January 25<sup>th</sup>  
Tulsa—January 29<sup>th</sup>

**For details and to register go to: [www.okhemophilia.org](http://www.okhemophilia.org)**



### OHF's 2019 Unite for Bleeding Disorders Walk

Go to [www.okhemophilia.org](http://www.okhemophilia.org) to register and start your team fundraising!

**Date:** April 27<sup>th</sup>, 2019

**Location:** Oklahoma City at the South Lakes Park and Event Center

**Time:** Registration at 9 am

Unite Walk (Facebook Livestream begins at 10 am)

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# OHF CORPORATE SPONSOR OF THE YEAR

OHF awarded its first "Corporate Sponsor of the Year" award to BlueStone Natural Resources and its charitable Foundation, who together donated \$7500.

With family and friends generously giving another \$6340, the total raised by Jason's Team was \$13,840!

Nancy Nelson, the team's captain says, "I am very lucky to have such generous people in my life."

Thank you Nancy and thank you to Denise and John Redmond (BlueStone CEO) and all the other generous people who contributed to the team!



**Denise Redmond, Nancy Nelson,  
John Redmond, CEO, CB Rowan, CFO**

## MEET THE BOARD OF DIRECTORS

### ERIC WALKER—OHF BOARD TREASURER



**Eric and wife, Julie**

Eric Walker is currently serving as the Oklahoma Hemophilia Foundation Board Treasurer. He lives in South Tulsa right now but grew up in Jenks. Eric majored in accounting and economics at the University of Oklahoma and has a master's degree in Accounting.

While attending school at OU,

Eric was a member of the Phi Delta Theta fraternity, which is where he met Clint Roberson and Kelsey Pierce (current and past board members).

Eric's hobbies include golf, spending time with family, going to the lake, and flying planes (he's a private pilot). He works as a financial advisor and is a certified financial planner at Morgan Stanley. He specializes in financial planning and portfolio management. "I enjoy my current

position because it deals with the present and future, whereas my previous job as a CPA mostly dealt with events that occurred in the past."

Eric has enjoyed working with the OHF. He says, "I've learned almost everything I know about hemophilia after volunteering and joining the board. I think I was under the impression that, while serious, hemophilia is something that modern medicine has pretty much got under control. It turns out there's a lot more to it. There are mental health concerns, joint damage, quality of life issues, and the expense of medication management. I truly had no idea about any of those things. The thing I enjoy most about volunteering and giving to the OHF is the feeling that this area/issue is achieving progress. It's underfunded and kind of an 'orphan' disease, so raising awareness really does make a difference. I also like all of our programming. We aren't just an organization raising money and funneling it to some national group for research, etc. We do stuff that helps people in our local community."

## HTC CORNER— MEET A NEW MEMBER OF THE HTC TEAM

### JANNA JOURNEYCAKE MD, MSCS



Janna is a Native Oklahoman who detoured through Memphis, TN and Dallas, TX. She was born in Lawton and graduated from Bishop Kelley High School in Tulsa. After completing her undergraduate degree at Rhodes College in Memphis,

she returned to Oklahoma to graduate from OU Medicine. She completed her pediatric residency training at OU-Tulsa and then moved to Dallas to complete her pediatric hematology/oncology fellowship training as well as her

Master of Science in Clinical Science from UT Southwestern Medical School. She remained on faculty with UTSW from 2002 until 2018 when she returned to OKC at OU Medicine. She is now a Professor of Pediatrics and the Associate Division Director of the Jimmy Everest Center for Cancer and Blood Disorders.

She is nationally recognized for her research and clinical expertise in pediatric bleeding disorders and thrombosis and has received federal and foundation funding for her work in the prevention and treatment of catheter-related thrombosis. She is currently on the Board of Directors for the Hemostasis and Thrombosis Research Society and Chair-Elect for the American Thrombosis and Hemostasis Network. Although her research focus has been in hemostasis and thrombosis and she is an advocate for all blood disorders and childhood cancer, her clinical areas of focus is benign hematology in all aspects.

## NHF CONFERENCE

### LEISA MACDOUGAL

My name is Leisa MacDougall and I live in Enid, OK. I was so grateful and excited when I was offered the opportunity to attend the National Hemophilia Foundation's 70<sup>th</sup> Annual Bleeding Disorders Conference. My son, Jayden, was diagnosed with Hemophilia B and von Willebrand disease three years ago when he was five. Since then, I have been diagnosed as a carrier of Hemophilia B and my mother, Sheryl, who attended the conference with me, has been diagnosed as a symptomatic carrier of Hemophilia B. I wanted to attend the conference because I want to learn as much as possible about the Bleeding Disorders that affect my son and I enjoy networking with other moms that are going through some of the same things that I am going through as a caregiver. One of the tracks that we attended was exclusively about von Willebrand Disease. In that hour and a half session I learned more about my son's disease than I have in the past three years. The community was open to share and answer questions and experiences. We met lifelong friends and received a wealth of

information. I am so grateful to Kathleen and the Oklahoma Hemophilia Foundation for allowing us the unforgettable experience of attending the conference.



***Sheryl Brittain and Leisa MacDougall***

# OHF FAMILY EDUCATION RETREAT— NOVEMBER 2-4, 2018



***OHF's Family Educational Retreat is an event that began four years ago when OHF saw the need for the families to have a recreational and educational event together.***

***The retreat takes place in the fall, currently at Tatanka Ranch in northeast Oklahoma, a simple rural setting where the families can stay in one place and enjoy the outdoors.***

***The OHF Family Educational Weekend is a chance for families to connect and learn.***

***"Our family recognized the need to connect with our bleeding community. We needed to have the opportunity to talk to other families and to help find support with others. These connections encourage us that it will get better with time."***

***—Retreat Attendee***

OHF's Family Educational Retreat 2018 was an amazing weekend full of learning, relaxing, connecting and great food! Activities included: kayaking, horseback riding, hiking, foosball, pumpkin crafts, HPC helped us with ongoing infusion workshops, HFA led us in a family craft, tower climbing, football on the grass and a lot of eating and talking.

Thank you to our fabulous committee: Jeanette Jones, Paula Hooper, Leisa MacDougall, Emily Johnson, and JR Brawner.

Thank you also to our sponsors: Colburn-Keenan Foundation, Genentech, Shire, Pfizer, Bayer, HPC, CVS Specialty, NCHS, Bioverativ, Accurate Rx, Briova Rx, BioEthics Advantage, NHF, HFA.



# 2018 RED JACKET CHALLENGE GOLF TOURNAMENT



The 25<sup>th</sup> annual Red Jacket Challenge at Cedar Ridge Golf Club is in the books and was a huge success. Thank you so much to Dr. Joel Adkisson and the planning committee (Tim Cheatham, 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 this year and raised over \$13,000. OHF is honored to be the benefactor of this widely anticipated event and will use these funds to better serve and advocate for individuals with bleeding disorders in Oklahoma.

Our only dream for the future is that someone will make that hole in one and win the car!



**CSL Behring**  
Biotherapies for Life™

## 7 SUPERPOWERS OF BLEEDING DISORDERS MOMS & DADS

**Having a child with a bleeding disorder can unleash a host of superhuman qualities:**

**Bionic inner strength** so you can be your child's fiercest advocate.

**Supernatural precision** at accessing tiny veins to infuse your child's factor.

**Awe-inspiring nerves of steel** to stay calm and collected when you're infusing your child.

**Herculean multitasking skills** to juggle everything on your to-do list—from making appointments for the hemophilia treatment center to filing insurance claims to meeting with teachers and school nurses.

**Enhanced surveillance skills** to immediately identify a potentially dangerous activity and quickly intervene before an accident happens.

**Extrasensory perception** at recognizing when something isn't right and your child may be at risk for a serious bleed.

**Amazing resilience** to cope with the day-to-day stresses of raising a child with a bleeding disorder and stay positive and hopeful for your child's future.

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**Photo credit: Beth Stallings**

# OHF WINTER EVENT 2018



OHF Families gathered for a wonderful holiday time together on December 15th. We filled the Jenks Community Center with conversation, cookie decorating, ornament making, crafts, Santa, great food and companionship. Thank you to our committee chairperson, Jennie Shoemaker and committee member, Jennifer Mackey, for all their efforts to make this event a success. Thank you to our sponsors:



# OHF VOLUNTEER SPOTLIGHT—BAILEY RIGBY



*This year OHF has been fortunate to have had an amazing volunteer helping behind the scenes. Bailey Rigby has helped in some way with almost all of our events: addressing and stuffing envelopes, updating our database, mailing postcards, and helping to keep up our website including compiling our list of patient assistance programs. Thanks so much Bailey!*

My name is Bailey Rigby! I live in Collinsville, Oklahoma, and I'm currently a senior at Collinsville High School. I love anything to do with art! I love photography, piano, painting, sketching, baking, and anything in nature! I am in the photography program at Tulsa Tech and I plan on taking what I'm doing there to college. I am going to attend Utah State University and I will be majoring in Art & Design under the photography division. I love to do studio work, but outdoor photography is my favorite part about what I do! I also use editing software like Photoshop for post-processing, which is so much fun! Along with all of these things, I love to volunteer at the Oklahoma Hemophilia Foundation! I work a lot on the website, where I add new events, edit the calendar, and so much more! I've learned so much from volunteering here, especially about website design, that will be a big help to me in college! I have had such a great experience working with the amazing people at this foundation!

## NOW AVAILABLE

The Jivi logo features a stylized bird icon in shades of green and blue, followed by the word "Jivi" in a bold, blue, sans-serif font. Below the logo, the text "antihemophilic factor (recombinant) PEGylated-aucI" is written in a black, sans-serif font. The background of the advertisement is light blue and features a flock of many small, stylized birds in various shades of green and blue, flying in different directions.

**Jivi**<sup>®</sup>  
antihemophilic factor  
(recombinant) PEGylated-aucI

To learn more, visit [www.jivi.com](http://www.jivi.com).

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# ADVOCATING FOR BLEEDING DISORDERS



OHF is dedicated to advocating for the Bleeding Disorders community.

Many of you may know our advocacy chairperson, Liz Decker. Liz works hard to keep our advocacy goals on track and is a wonderful example of advocacy in action. She has reached out

to her representative, Rep. Carol Bush, and has developed a great relationship with her. We appreciate Carol Bush and her husband attending our Annual Meeting this year and she has also committed to help us make March "Bleeding Disorders Awareness Month" in Oklahoma. She is a wonderful resource and person and now she is a champion for us because Liz reached out to her and told her a bit about living with a bleeding disorder.

Many people wonder how they can make a difference and help with advocacy efforts. It starts just the same way Liz did.

Let's ask Liz:

*My district elected a new member of Congress in the mid-term election and I'd like to start building a relationship with them. How can I connect with my legislator as they prepare to take office?*

Liz: There are several ways to connect with your new legislator.

- You can see if they are on Facebook or Twitter and send them a Congratulations message.
- You can go low tech and send them a note of Congratulations.
- If you want to email or make an appointment with them in their district office, go to [www.usa.gov/elected-officials](http://www.usa.gov/elected-officials). You can access their information along with their website address.
- Find out when they are going to be speaking in your area. Every opportunity for connection with your legislator matters.

However you connect, tell them a little bit about yourself and mention you or your child have a bleeding disorder and how you would appreciate their support on important patient protections.

## ANNOUNCING OHF'S 3RD ANNUAL HILL DAY



### 116 Congress:

#### Crystal Ball Predictions

Topics Congress Could Explore:

 **Pre-Existing Conditions Protections**

 **Surprise Billing**

 **Opioid Issues**

 **Drug Pricing**

Learn more with 



Please register at:  
<http://www.okhemophilia.org/ohf-day-at-the-hill-2019/>  
and go to the advocacy tab.

The March 12<sup>th</sup>/13<sup>th</sup>, 2019 event will include:

- \* Dinner on March 12<sup>th</sup>, 6:30 p.m. Includes an education program designed to prepare participants for the meeting with their legislators.
- \* Overnight stay at a downtown OKC hotel.
- \* Breakfast and morning training and review of talking points.
- \* Legislator visits at the Capitol from 10 am-1pm. Participants will use talking points and their own story to make visits to their legislators.
- \* Lunch at 1 pm, report back on visits and debriefing.

Credit: Hemophilia Federation of America; reprinted with permission

# CONNECT WITH US

# NEW AT OHF



Are you new to the community or looking to connect with old friends? Check out OHF!

- Check out our website to find out about and register for upcoming events:  
[www.okhemophilia.org](http://www.okhemophilia.org)
- Like us on Facebook at:  
[www.facebook.com/okhemophilia](http://www.facebook.com/okhemophilia)
- Follow us on Instagram  
@oklahomahemophiliafoundation
- To sign up for our mailing or email list go to [okhemophilia.org](http://okhemophilia.org) and click on

**SIGN UP**

Or email [kmontgomery@okhemophilia.org](mailto:kmontgomery@okhemophilia.org)

## "Factors For Success"

A webinar series for young adults

Join your OHF friends live online for 3 sessions:

February  
May  
August

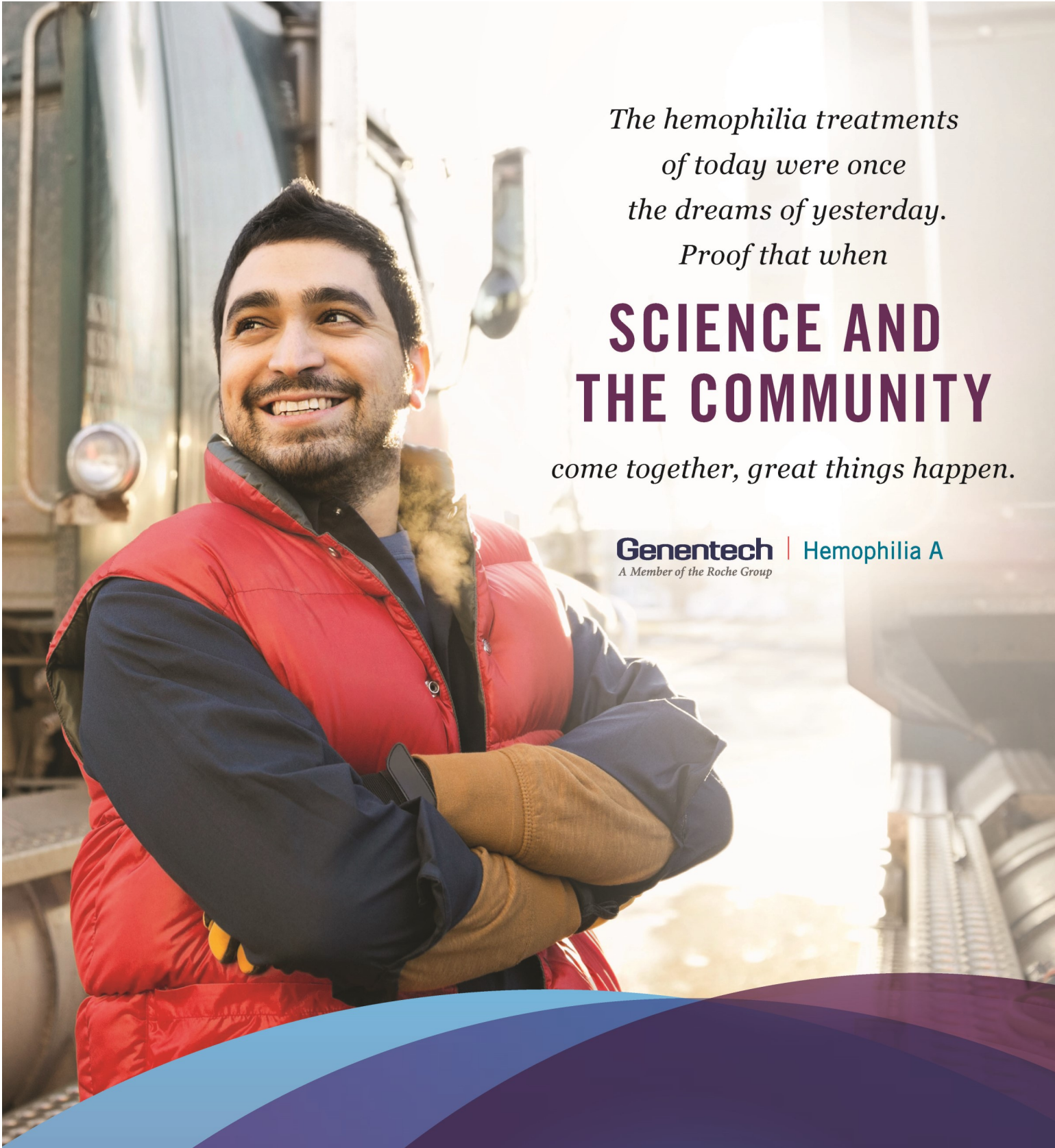
Each webinar is 45 minutes long with professional panelists giving insights on topics you need to know:

- Funding College through scholarships
- Life planning for success
- Finances to go

Go to [www.okhemophilia.org](http://www.okhemophilia.org), Resources, and click on "Factors For Success" webinars for more information and to register.



The advertisement for NCHS (National Children's Home and Child Abuse Center) features a man in a white shirt standing in a field with his arms raised in a gesture of triumph or relief. The background is a sunset over a field. In the top right corner, the NCHS logo is displayed with the tagline 'we care. for life.'. Below the logo, the text 'Care you can count on.' is written in large, bold letters. To the right of the man, there are three small inset photos: a man and a woman, a man, and two children. Below these photos, the text 'Individualized Patient Services' is followed by a list of services: 'Therapy Management', 'Education &amp; Counseling', 'Personalized Reimbursement Services'. At the bottom right, contact information is provided for Mimi Law (Division Director, 877-646-4529), Noel Minor (Nurse Coordinator, 877-598-7706), and Angela Brown (Customer Services Supervisor, 877-598-2702). A yellow banner at the bottom of the ad reads 'NEW! Dedicated Patient Hotline CALL NOW! 877.616.6247'. The website 'nchwecare.com' is listed at the bottom right.



*The hemophilia treatments  
of today were once  
the dreams of yesterday.  
Proof that when*

# **SCIENCE AND THE COMMUNITY**

*come together, great things happen.*

**Genentech** | Hemophilia A  
A Member of the Roche Group

[GenentechHemophilia.com](http://GenentechHemophilia.com)

*Let's put science to work*



Education, Advocacy, Awareness

National Hemophilia Foundation  
Oklahoma Hemophilia Foundation  
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Owasso, OK 74055

KMontgomery@okhemophilia.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" to receive information.



## SAVE THE DATE:

Your OHF family looks forward to seeing you soon!

**January 17<sup>th</sup>**

Advocates Unite Dinner at Charleston's OKC

**January 25<sup>th</sup> OKC**

Unite Walk Team Captain Kickoff Dinner

**January 29<sup>th</sup> Tulsa**

Unite Walk Team Captain Kickoff Dinner

**March 12<sup>th</sup>-13<sup>th</sup>**

Day at the Hill in OKC

Dinner training on March 12 and meetings on March

13 at Embassy Suites OKC Downtown

**April 27<sup>th</sup>**

Unite for Bleeding Disorders Walk

South Lakes Event Center, Moore, OK

**May 18<sup>th</sup>**

Teen Retreat

**June 24<sup>th</sup>-28<sup>th</sup>**

Camp Independence

**July 26<sup>th</sup>-27<sup>th</sup>**

OHF Annual Meeting,

Marriott Tulsa Hotel Southern Hills

**October 7<sup>th</sup>**

Red Jacket Challenge Golf Tournament

Held at Cedar Ridge Country Club, Tulsa, OK

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