



oklahoma HEMOPHILIA FOUNDATION

OHF COMMUNITY CONNECTION Fall 2018

MESSAGE FROM EXECUTIVE DIRECTOR KATHLEEN MONTGOMERY

It has been one full year since I took this position and what a year! Here are some numbers from the past 12 months:

- 60 Family members attended OHF Family Retreat at Tatanka Ranch
- 1st OHF Hill Day, 18 participants met with their legislators
- 274 Unite Walk participants at Tulsa Zoo
- 85 Youth attended Camp Independence
- 11 river raft Teen Leadership Retreat in Tahlequah attendees
- 263 attendees at OHF Annual Meeting downtown OKC
- 6 Families assisted by our Benevolence Fund
- 6 Students assisted by Jason M. Nelson Scholarship
- 60+ people attended an educational dinner (vWD, Moms, Men, Women)
- 13 working committees with over 50 volunteers
- 11 Board of Directors

All of this is only possible with your support and financial donations, funding from our Industry sponsors and other corporate sponsors and the hard work of our many volunteers.

This is an exciting time in the Bleeding Disorders community. Advances in medical technology for our care are being made at an unprecedented rate. There are more options than ever before. This has led to changes in our industry partners' funding as they are watching and anticipating changes. It is more important than ever to stay united. We need to keep educated

about our conditions and care, work together to advocate for our access to care, work together to determine program priorities and work together to find funding sources as we move forward.

It is a privilege for me to work with and for you. I invite you to reach out anytime with your thoughts and questions or just to tell me your story. In the meantime, enjoy the stories we have collected in this edition of your newsletter. Your stories are the reason we are a strong family united together.



**Kathleen and daughter
Anne Montgomery**

Unite for Bleeding Disorders



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MEET THE BOARD OF DIRECTORS

KATIE DUNCAN MEARS



Chris and Katie Mears

My name is Katie Duncan and I have Hemophilia Factor VIII deficiency. That may not sound strange now but for most of my life being a girl with hemophilia was cause for surprise, disbelief, and sometimes even ridicule. I have been the “only” female with hemophilia in Oklahoma my whole life...although now that they have redrawn the lines I have so many new blood sisters! I have less than 1 percent Factor VIII and present as a mild to moderate bleeder. I was misdiagnosed at 2 with Von Willebrand's (because I was a girl and “girls don't get hemophilia”) and then diagnosed correctly at the age of 6 in 1987. Before I was diagnosed and started receiving cryoprecipitate in the hospital they tried all kinds of things to ease my bleeds including acupuncture. Obviously that didn't work and I had a lot of pain, missed activities, and confusion for my family and me for a long time. My parents are the best to tell this story but eventually I was diagnosed by my stellar pediatrician Dr. Don Hamilton and started receiving cryo and finally feeling better. I still remember spending hours in the hospital being hooked to an IV drip. Thank God those days are long gone and now I can simply infuse myself at home in a matter of minutes. We were hooked up with

the Oklahoma Hemophilia Foundation after I was diagnosed and they have been my second family ever since. I went to Camp Independence as a child and then later came back as a counselor. I have been counseling every year (except one I skipped to go to NYC for genetic testing) for almost 18 years. It's the best week of my year and I love watching all of these great kids grow up and become awesome people. I am the Women's Junior Counselor program counselor and it is my privilege to be part of these young ladies' lives. I hope to continue for as long as they let me come back! I grew up in Tulsa and still reside here with my fiancé Chris Mears. He and my parents, Tom and Karen Duncan, are very supportive of everything I do for this community. I wouldn't change my diagnosis for the world. It has brought me so many friends and experiences that I would have otherwise never had. Thank you.

JOHN FARIA

John Faria joined the OHF Board of Directors in 2018 and he is currently the chair of the OHF Men's Committee and the Development Committee. Our new updated website is mostly his doing and his influence can be seen in many aspects of OHF as he willingly lends a hand to supporting us in many ways. Here is a bit about John from his blog justonehemophiliac.wordpress.com.

John M. Faria is a technology evangelist specializing in transportation and logistics optimization. John holds his undergraduate degree in Industrial and Organizational psychology with a minor in Literature and Criticism. In addition, John holds an MBA with concentrations in international business and management/leadership strategy. John's alma mater is the University of Massachusetts and his graduate studies were conducted at Assumption College in Worcester, Massachusetts.

John's career in the transportation and technology industries extends for over fifteen years. John's business tenure includes enterprise IT solutions, logistics engineering, project management, sales and corporate leadership. John continues to work full-time as a senior manager at Trimble Transportation Enterprise. John, Stephanie, his devoted wife of nearly ten years, and Isabella, his beautiful eight-year-old daughter, and Elijah, the rambunctious one-year-old reside in Edmond, Oklahoma.

John is also a severe hemophiliac who was exposed to both HIV and Hepatitis C through blood transfusions in the 80s. Blood transfusions were a common treatment of Hemophilia before refined, synthetic clotting factors were developed in the 90s. Miraculously, John did not contract any disease from the viruses he was exposed to from his transfusion therapy. The nature of living with hemophilia and the miraculous result of John's blood chemistry yield a unique perspective committed to positive living. John continues to be active in the hemophilia community and looks to educate others about hemophilia. John also promotes advocacy for the hemophilia community as well as individuals with disabilities or troubled backgrounds.



John Faria

OHF MEN'S GROUP - BLOOD BROTHERHOOD



OHF's Men's Group is a community of men in Oklahoma dedicated to the education and support of our member community. Each year, OHF's Men's Group works to provide resources, peer support, and communication for each other, our sons and daughters as well as our community members with a bleeding disorder. Our focus is providing resources, community support, and

education on overcoming life's challenges. We also strive to be exemplary role models to our younger community members, as they are the future of our community. *We Are The OMG.*



Micah Morgan

MY STORY

MALISHA FRANKLIN

How has my involvement in the bleeding disorder community affected my life? Where to even begin... OHF has drastically played a role in me to be who I am today. From a pretty young age I have always been involved, from camp to dinners to walks, you name it. I started camp with my three younger brothers when I was about 12 and for about 5 seconds I was nervous. For about 5 seconds I didn't know anyone, I was the outsider. And about 5 seconds later I met Katie (still looks exactly the same). And 5 seconds later, Ella. My life was forever changed. That first week at camp I was introduced to so many things outside of my comfort zone, but I was also introduced to family. I spent my time at camp having a blast. I was thrilled to pass my camper phase and onto Junior counselor phase, yet still was awed by my camp family and their support along the way. I got the opportunity to get involved more and give back to not only our community but others around us. During my time as a "JC" I learned you are bigger than you think. You can make a difference, and it's not a "hand out, it's a hand up"... also YES! Because I said I would. This program forever changed my heart. Being a part of OHF has really given me the opportunity not only to learn and grow as a person but also to help others grow. It has opened my eyes to difference and acceptance. Each year I learn something new and walk away with a new piece. I look forward to using my insight and experience to help others shine and grow and to help those outside of our community become aware. A lot of my thanks goes to OHF for giving me a place where I could find myself, and now I plan to use those strengths to help others. #ohfordie



"You can make a difference, and it's not a 'hand out, it's a hand up'."

CAMP INDEPENDENCE

by: Co-Camp Director, Lyndsey Russell

We want to thank all of our staff, cabin counselors, activities counselors, volunteers and the medical staff for pouring their hearts and talents into creating a fun, engaging and inclusive week-long summer camp each year for our bleeding disorders community.

This year we had over 75 campers join us from all over Oklahoma for Camp Independence, Avenger's Academy! Along with



Lindsey hard at work at Camp Independence

art, swimming, fishing, archery and games, the kids grow and develop relationships with others who are living with and experiencing the same things they are every day. We make time in our schedule for both fun and learning by offering infusion practice and "Learning About Hemophilia" sessions with our medical staff. Our junior counselors also learn how to be leaders through service projects and special roles at camp. The sense of self confidence and community gained at Camp Independence is truly remarkable.

If you have a kiddo who is between the ages of 7-18, or would like to volunteer at camp next year, be on the lookout for communication from our camp staff starting next March! The dates for camp are always the last week of June (24th-28th in 2019) and next year we will be celebrating Camp Independence's fortieth birthday!

KAYLEE JOHNSON'S STORY

I am 15 years old, my little brother Joshua lives with hemophilia A. We look forward to Camp Independence every year. We get to see friends and bond even more because sometimes this is the only time we see each other. Camp teaches us about all different kinds of bleeding disorders and teaches me how to help manage my little bro's hemophilia. We do lots of fun things and activities like swimming and going to LALA. Our counselors are great each year, and really work hard to make us all more independent.



CAMP INDEPENDENCE (CONT.)



Junior Counselor's Service Activity (left and below)



Clint Roberson and Peggy Brakefield, PT (above)



TEEN RETREAT: WESLEY'S FLOAT ADVENTURE

By Wesley Grizzle

My name is Wesley. I have mild Hemophilia factor 8. This summer I got to do some amazing things, but the best was with my blood family. My best friends were all there. We went to the Illinois River in Tahlequah. We had a blast! The water was calm, Cory played his guitar and joked about everything.

The night I arrived everyone was so inviting. Katie greeted me when I arrived. I set my blue duffel bag down and went outside. In the morning we all got ready for the long day ahead. We all had breakfast and started heading to the bus where we grabbed a life vest and a paddle and headed in for the long drive. When we arrived, Don and I grabbed a chest filled with water and Gatorade and put it in one of the rafts along with Cody and some other guys. As Don pushed us guys into the river, we started going the wrong way. We got down river about a mile or two when we stopped to play games and eat lunch. We had a relay race by untying a rope, running down and touching the other side of the river. We got back in the raft and headed further down the river where we stopped again for another activity. This time we got to do a puzzle. There was only one puzzle piece at a time and we had to cross the river to get pieces to make the full picture. The girls won the race.

It was so beautiful going down the river because there are so many green trees and small pebbles along the bank of the river. As we paddled there were fish below us. The fish were as big as the size of my forearm. We finally got back to our cabin, put our stuff up and took showers. Don and Katie prepared dinner, which was amazing! Don and Katie took great care of us. We all went down and had a bonfire and Smore's and talked. In the morning we had breakfast together and talked about what we did and then said our goodbyes. That was my amazing float trip with the OHF.

**Teen Committee Chair
Don Bowers:**
"The goal of the Teen Retreat was to help develop the OHF young adults into independent leaders within the community while still emphasizing that it is okay to ask for help from others. While rafting the river together, we bonded as a team and learned that team work and independence can go hand in hand."



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[†]Patients who have government insurance are not eligible for the loyalty and co-pay support programs.

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OHF UNITE WALK 2018

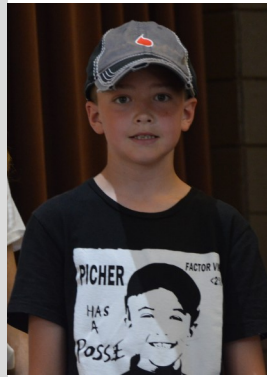
The 2018 Unite for Bleeding Disorders Walk was a huge success. We had over a 100% increase in participants from 158 people last year to 268 this year. In addition, we raised over \$25,000 more than last year making our total \$69,380. Our walk this year had a new theme which set to Unite all individuals and families with all bleeding disorders. It is our goal to bring a sense of community to all individuals with bleeding disorders and by uniting at this walk. I believe we are one step closer to achieving that goal. Oklahoma Hemophilia Foundation is here to help you and together we are able to achieve even more.

There is a strength in numbers and we proved that this year. The money we raised will go on to support all of our programs at OHF such as:

- Camp Independence
- OHF Advocacy
- Women's Group
- Men's Group
- Family Education Retreat
- Teen Retreat
- Academic Scholarships
- Assistance Fund

Thank you for helping to make this year's Unite for Bleeding Disorders Walk the best yet. We would like to also give a special thanks to our committee members. Without them we would not have been able to make this such a successful walk. Thank you to Suzan Ball, Sasha Cheatham, Kristin Voyles and Clint Roberson. We would also like to thank our sponsors for this year's walk which included Shire Pharmaceuticals, Bayer, Pfizer, Accredo, Bluestone Natural Resources, CLS Behring, Genentech, Accurate RX, Heritage Biologics, Bioverativ, Brioiva RX, NCHS, CVS, Lifeline Home Health, HPC Specialty RX, Novo Nordisk, Sanofi-Genzyme, and Diplomat Specialty Infusion Services.

Now it is time to start thinking about the 2019 Unite for Bleeding Disorders Walk. We are looking at having it in the Oklahoma City area next year in late April. Please watch for more information in the near future.



**Picher's Posse
T-shirt Design
Winner (left);
Nancy Nelson, Top
Fundraiser 2018 (below)**



VOLUNTEER NEWS



Jeanette Jones, Bob Goodley "Volunteer of the Year" Award (left), OHF Day at the Hill, March 2018 (below).



Ways to help out at OHF:

- Join one of our committees: Blood Brothers, Women's Group, Advocacy Committee, vWD Committee, Communications Committee. We would love your input and help. Committees meet by phone once a month.
- Help out with the Unite Walk (in Late April)
- Help out with the Red Jacket Challenge Golf Tournament (Oct 8)
- Volunteer to help out in the office...anytime!
- Help out with the Family Retreat
- Use Smile.Amazon
- Invite your business to sponsor an event
- Attend an event and make a new friend

2018 RED JACKET CHALLENGE GOLF TOURNAMENT



CEDAR RIDGE
COUNTRY CLUB

RED JACKET CHALLENGE GOLF TOURNAMENT

Monday, October 8th

TEAM UP WITH

Cedar Ridge Country Club

&

Oklahoma Hemophilia Foundation

TO HELP FAMILIES
WITH BLEEDING DISORDERS



Each year for the last 25 years, Dr. Joel Adkisson and OHF have hosted an amazing golf experience at the prestigious Cedar Ridge Golf Club. In part due to Oklahoma's generous sponsors, the Red Jacket Challenge has become a key fundraising event that provides OHF funding to continue the mission of education, advocacy and service to the bleeding disorder community.

Through donning the Red Jacket at the annual Golf Classic, volunteers share the burden of overcoming bleeding disorder challenges and advocating for the bleeding disorder community. This amazing golf challenge is held each year in remembrance of John Reed and Mike Morse, who were big supporters and advocates for OHF's mission.

We hope that you will join us this year on October 8th, 2018 at Cedar Ridge Country Club in Broken Arrow. The tournament will be played as a 4-man scramble and singles will be paired with teams by the tournament committee.

Register for OHF Red Jacket Golf Tournament soon, spots are filling up quickly:
<http://www.okhemophilia.org/register/>

2018 JASON M NELSON MEMORIAL SCHOLARSHIP RECIPIENTS

OHF would like to congratulate the
2018 winners of the
Jason M Nelson Scholarship:

Nate Anders

Angie Salter

Dillian Stuckey

Keaton Robinson

Malisha Franklin

Kyle Simms

Thank you to our generous sponsors
who make this important scholarship
possible and to Katie Duncan Mears for
her efforts as chairperson.



HTC CORNER



T.J. Deaton helps a camper learn to infuse

Oklahoma Center for Bleeding and Clotting Disorders

HTC Advisory Panel Forming. The Oklahoma Center for Bleeding and Clotting Disorders is looking for a group of patients and caregivers to help guide them in the future. Similar panels are forming all across the country with the same purpose: to provide feedback to ensure that the appropriate services are offered to the bleeding disorder community.

Who: People from all over the state of Oklahoma who are affected with a bleeding disorder of any kind or their caretakers.

Please email: kmontgomery@okhemophilia.org if you are interested or if you have questions, and you will be contacted with more information.

The new & improved **RICE** is **PRICE** – **P**rotect, **R**est, **I**ce, **C**ompression and **E**levation

CONNECT WITH US

REMEMBERING: MS. DEBBIE



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
- Like us on Facebook at:
www.facebook.com/okhemophilia
- To sign up for our mailing or email list go to okhemophilia.org and click on

SIGN UP

Or email kmontgomery@okhemophilia.org



By Val Simms

On March 11, 2018, HPC Specialty Pharmacy suffered a very unexpected loss to our Oklahoma Care Team. Debbie Little was a practicing registered nurse for over 43 years and served as the HPC home infusion nurse since 2006 for many patients here in the community.

The love and amount of care Debbie had for her patients was undeniable. But it went further than that. They weren't just patients to her; they were

her family. Whether it was a question or a crisis, it didn't matter where she was or what time of day, her patients knew they could count on her. However, hemophilia wasn't just a job to Debbie; it was her passion, her life. The mother of three Severe A boys, she lived through the tears, the fears and the cheers that come along with bleeding disorders. Debbie was a vocal advocate for hemophilia awareness and cared deeply for the community. Her passing has left a void that will forever be felt and her compassion will be greatly missed.

August 31, 1954-March 11, 2018

 An advertisement for NCHS (National Children's Hospital & Medical Center). The top left features the NCHS logo with the tagline "we care. for life." The main image shows a man in a white shirt standing in a field with his arms raised in a gesture of joy or relief, with a sunset in the background. There are three small inset photos: one of two children, one of a man, and one of a man and a woman. On the right side, there is a blue box with white text listing services and contact information.

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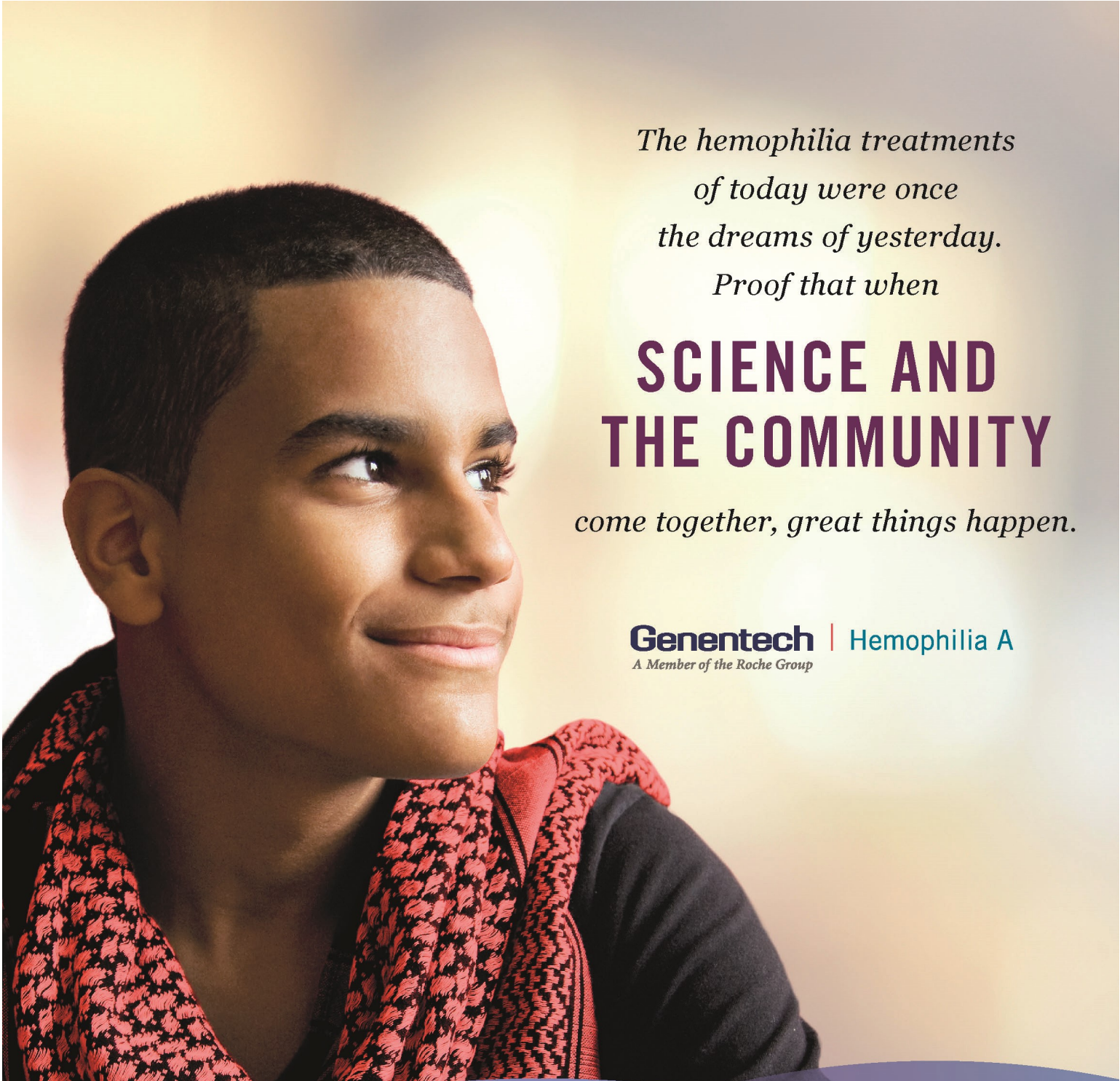
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Division Director
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Noel Minor,
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Owasso, OK 74055

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org
www.okhemophilia.org



**OKLAHOMA HEMOPHILIA
FOUNDATION**

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!



SAVE THE DATE:

Please Mark Your Calendars!

Your OHF family looks forward to seeing you soon.

Please visit our website www.okhemophilia.org for more details and to register.

- | | |
|-------------|---|
| Sept. 13 | vWD Dinner, OKC |
| Sept. 19 | Women's group event, Tulsa |
| Sept. 27/28 | Hispanic Heritage Event OKC/Tulsa (Shire, Accredo) |
| Oct. 8 | Red Jacket Challenge, Cedar Ridge Golf Club, Broken Arrow |
| Nov. 2-4 | OHF Family Educational Weekend (a.k.a. Family Camp) |
| Nov. 8/9 | Dinner-Overcoming Challenges OKC/Tulsa (Pfizer) |
| Dec. 6 | Kendra Scott Event, Tulsa |
| Dec. 15 | OHF Holiday Event, Jenks |

OHF's Mission: To be dedicated to service, education, and advocacy for Oklahomans with bleeding disorders.

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