

KHF Hemosphere

35th Play a Round for a Cure Golf Scramble

The KHF Golf Scramble has a thirty-five-year history of success. This year's event was no different, when it took place in early June at Glen Oaks Country Club in Prospect. Twenty-one teams headed out onto the well-maintained course on a pleasant day with a tolerable heat index.

The teams' golf carts were loaded with a hearty box lunch, snacks, and cold beverages and plenty of "Go Low" helpers, such as Mulligans, Hitting from the Ladies' Tee, Throw, "String Forward," and more. This completed their preparation for a fun day on the golf course. After golf, the players enjoyed a picnic-style dinner, bidding on attractive silent auction items, purchasing 50/50 and Ball Drop chances, and chatting with their teammates before the awards ceremony.

The top three teams were in 1st place "Brandon's Bombers," in 2nd place "William Black & Friends", and in 3rd place "Brian Davidson & Friends". The Longest Drive and Longest/Straightest Drive winners were Kelsey Fabel and John Joseph. Closest-to-the-pin winners were Ed Bratcher, Trevor Black, Michael Norwood, and Leo Brown. The 50/50 raffle was won by George Fischer and the Ball Drop by Cliff Routen.

Great excitement erupted when the #1 team members were presented with the KHF Champions Golf Jackets to wear during the awards dinner period and for a well-deserved photo op.



Special News

Golf cont...

continued on the next page

We thank all our sponsors, donors, contributors, and volunteers for their generous support. Our sponsors were CSL Behring, Gold Level; Novo Nordisk, Silver Level; Octapharma, Bronze Level; and LTC (R) John & Patricia Tharp, Team Plus Sponsor in memory of Gary F. Bandy.

Player foursomes were “Aaron Lopez & Friends”, “Adam McHone Team”, “William Black & Friends”, “Brandon’s Bombers,” “Brian Davidson Team”, “Bruce Jewell Team”, “Fairways & Greens,” “Glen Hitt & Friends”, “JCSO Team”, “Kosair Golf Club”, “Marwood Manufacturing”, “Milton Kamala & Friends”, “Salty Sailors,” “The Fischer-Men,” “The Pioneers,” “Tommy Kilcourse Team”, and “Worm Burners.”

We also thank our Golf Planning Committee chaired by William Black and our staff and day-of-event volunteers. They were Maddie Bowles, Glen Hitt, Sr., Matt Holland, Kim Jones, Milton Kamala, Erika Lennon, Myra Loeser, Pam Price, Travis Price, Stacey Retic, John Tharp, Pat Tharp, William Black. Proceeds from this fundraiser help fund our programs and services for Kentucky’s bleeding disorders community. The event raised \$22,000.



2024 KHF Activities Calendar

- Sept. 7** Summer Family Event/Annual Education Meeting
- Sept. 27-29** Family Camp
- Oct. 19** Kentucky Unite Walk
- Dec. 15** Year-End Family Event



Remember: KHF CARES



Kentucky Hemophilia Foundation provides financial assistance to bleeding disorder families whose household income has decreased because of loss of job, lay off, furlough, reduced hours, or due to another type of emergency and as a result unable to pay a specific household bill. Requesting families must reside in Kentucky, and the person seeking assistance must either have a bleeding disorder or be the parent of a minor child with a bleeding disorder. Assistance is contingent on the availability of funds. Call 502-456-3233 or 800-582-CURE (2873) or send an email to info@kyhemo.org to make a request.



Study Suggests Prophylaxis Can Mitigate Intracranial Hemorrhage Risk

Results of a new study published in the *Journal of Blood Medicine* (JBM), indicate that people with hemophilia A (HA) who have been on a prophylactic treatment regimen have a reduced risk for intracranial hemorrhage (ICH).

Often referred to as a “brain bleed,” ICH is a very serious event whereby blood accumulates within parts of the skull, including the brain itself. This can result in built up pressure which can block critical oxygen and nutrients from reaching brain cells and tissues. ICH events that are not treated expeditiously can result in major disability and even death. These type bleeds can occur spontaneously or triggered by something specific such as trauma. While people with hemophilia are at some risk for ICH, any given patients’ risk level will vary and depend on a variety of factors.

Authors of the JBM paper used retrospective data from the ATHNdataset to inform their research, eventually identifying 7,837 hemophilia A patients between two and 75 years of age. Included in the study were moderate and severe HA males (assigned at birth) who had hemophilia treatment center visit information from January 1, 2010, through September 30, 2020. The median follow-up period was 10.7 years.

Their investigation showed that 135 of 7837 of the subjects (1.7%) experienced an ICH. A review of the data pointed to several factors associated with a higher risk including being in the 2–12-year age range; being covered by Medicaid; having had HIV, hepatitis C, or hypertension; and never having received factor VIII replacement therapy or prophylactic treatment. The authors also conveyed that these results align with earlier studies which demonstrated that prophylaxis provides a “protective effect” against ICH.

Because emicizumab became available at the tail end of the study period, data relevant to its use and findings relevant to its use, along with opportunities for comprehensive analysis, were limited. “As of 2018, the standard of care for congenital hemophilia A has evolved to include emicizumab, a humanized antibody that mimics activated FVIII to allow continuation of the coagulation cascade. This study’s period includes data from before and after emicizumab approval in 2018. The ICH rate significantly decreased across the study period, but data from the periods before and after emicizumab approval cannot be conclusively analyzed because of the limited sample size after emicizumab approval and the inability to account for all possible confounders,” explained the investigators.

However, the authors urge continued investigation into ICH risk factors, especially as the availability and use of newer novel therapies continue to rise.

“This study, using data from the ATHNdataset, identified the following risk factors for ICH in PWHA: being aged between 2 and 12 years, having ever received Medicaid coverage, having had certain comorbidities (HIV and HTN), never having received factor treatment, and never having received prophylactic treatment. These risk factors will need to be continually reevaluated as the treatment landscape for hemophilia evolves to include increased use of non-factor products and gene therapy.

The study, “Risk of Intracranial Hemorrhage in Persons with Hemophilia A in the United States: Real-World Retrospective Cohort Study Using the ATHNdataset,” was published April 25th in the *Journal of Blood Medicine*. Read the full paper to learn more.

Source: docsirenews, May 21, 2024

Event News

KHFiesta Fundraiser

KHFiesta surpassed our expectations once again in 2024. This fiesta-style fundraiser embodies unbridled fun for a very worthy cause. The food, the music, the decorations, and the atmosphere meld into a colorful, fabulous event that is uplifting



and enjoyed all who attend. Jennifer Dunegan handcrafted beautiful paper flower centerpieces. Gustavo's provided authentic Mexican Cuisine, and the talented Miki Galban del Val entertained with contemporary Latin tunes and popular pop music. John Silletto and friends captured our guests' attention with their casino-style gaming, which featured blackjack, Poker, and Roulette, while the Grand Prize drawing and 50/50 raffle added another exciting gaming option. The Grand Prize, a wheelbarrow stuffed with a multitude of bourbons and other spirits, was won by Brandy Fox of Mount Washington. Much attention was also paid to a sought-after array of silent auction items as well.



We thank all our sponsors and donors for their support. They were CSL Behring,

Novo Nordisk, Octapharma, Takeda, Kosair for Kids, Kosair Boat Club, Oldham County Shrine Club, Glen & Deborah Hitt, Dr. Joseph H. Cieslak, and Republic Bank. We also thank all our volunteers, especially John Silletto and his gaming volunteers, musician Miki Galban del Val, auctioneer Bob Frye, magician Ken Abbott, our KHFiesta Planning Committee, our Board members, and our day-of-event volunteers. The event raised \$24,000 for KHF's programs and services.



Spring Scholarships

KHF extends congratulations to its Spring 2024 scholarship recipients! Marissa Johns was awarded the \$500 Betty Meadors Mattingly Memorial Scholarship. Marissa is the daughter of Chris and Shannon Johns of Shepherdsville. She is on a pre-med tract at the University of Louisville majoring in Neuroscience. She expects to graduate in May 2026

and has her sights set on attending Medical School. Marissa is a member of the National Bleeding Disorders Foundation's National Youth Leadership Institute.

John Riley Graham was awarded the \$500 Theodore (Ted) L. Forcht Memorial Scholarship. John Riley is the son of John and Leah Graham of Winchester. John Riley completed his studies this May at Centre College with a major in Finance and Economics. At the end of the 2024 spring semester, John graduated with a Bachelor of Science degree. Since that time, John has accepted a position at Amazon's Corporate Office in Tempe, Arizona. We wish Marissa and John much success in their current and future endeavors.

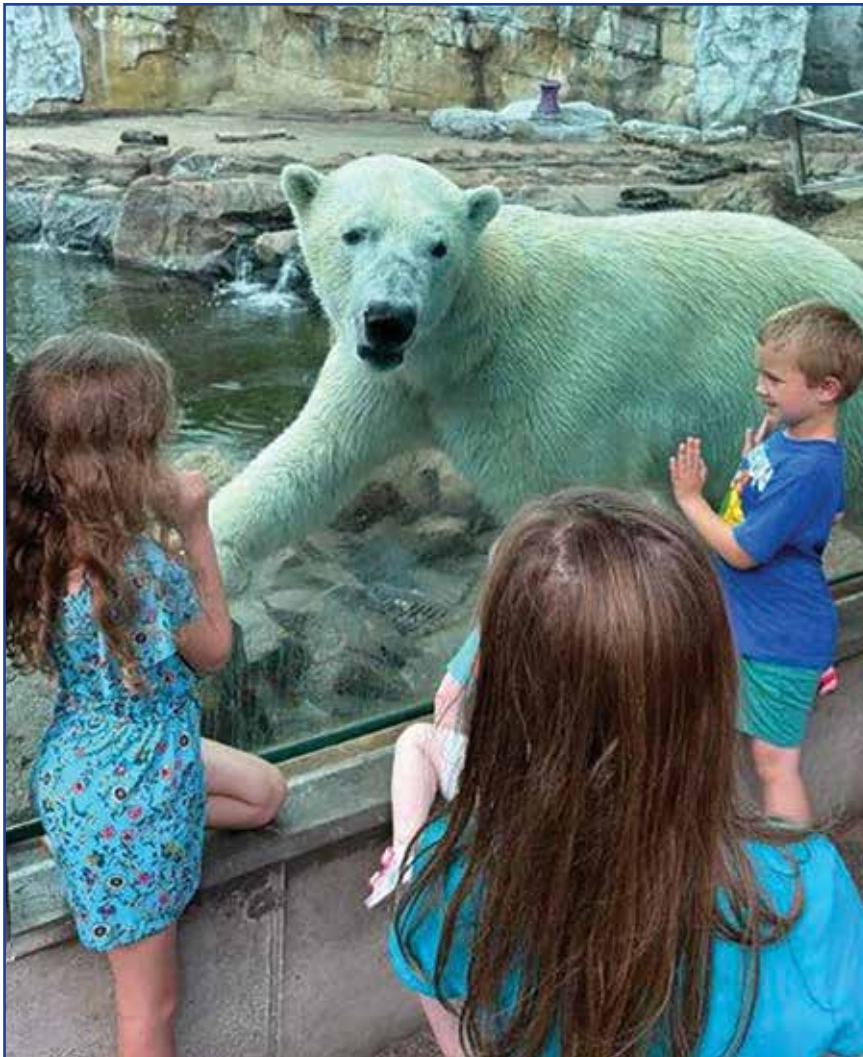




Family Day at the Louisville Zoo

The 2024 Family Day at the Louisville Zoo was a resounding success. This was our 25th annual gathering of bleeding disorders families from across Kentucky. Under sunny skies at Louisville's magnificent zoo, this family-oriented event offered something for everyone to enjoy. After our guests toured the animal exhibits, they relaxed at the Oasis Tent for a delicious picnic lunch, while their little ones had fun playing our carnival games and relished winning great prizes. A drawing for door prizes equally delighted the adults. This event provides respite and relaxation for our bleeding disorders families and an opportunity to visit with current friends and make new friends.

We thank our exhibitors who provided valuable treatment information by discussing their products and services. They were Accredo, Bayer HealthCare, CSL Behring, CVS Health, Genentech, HEMA Biologics, Novo Nordisk, Octapharma, Paragon Hemophilia Solutions, Pfizer, Sanofi, and Soleo Health. Many thanks also to our volunteers and staff, who helped us facilitate this wonderful event. They were Maddie Bowles, Patrick and Jennifer Dunegan, Brandy Fox, Sam Johnson, Milton Kamala, Erika Lennon, Pam Price, and Owen Vanmeter.



More News

Spring/Summer 2024

March 2024 – June 2024 Donations and Contributions

We thank the following individuals and companies for their generous support!

Donor, \$1,900+

CSL Behring

Donor, \$1,000

Kosair for Kids
for KHFiesta”

Donors, \$500-\$600+

Dr. Joseph H. Cieslak
for KHFiesta
Glen & Deborah Hitt
for KHFiesta
Kosair Boat Club
for KHFiesta
Republic Bank & Trust Company
for KHFiesta
Soleo Health

Donors, \$250-\$400

Kroger Community Rewards
Oldham County Shrine Club
for KHFiesta

Donors, \$200+

Greg Fiscus
Kathleen Gossett
for KHFiesta

Donors, \$100-\$150

William Black
for KHFiesta
Karina Brown
for KHFiesta
Ed & Sharon Gould
for KHFiesta

Milton & Ursela Kamala
for KHFiesta

Ken & Brenda Reiss
for KHFiesta

Stacey Retic
for KHFiesta

Danny & Sharon Schroeder
for KHFiesta

Anton & Cassandra Titus
for KHFiesta

Melissa & Patrick Wilkerson
for KHFiesta

Constellation Corporate Match
for 2024 Walk

Dianne Hardman
for 2024 Walk

Donors, up to \$99

Andrew Hartmans
for KHFiesta
Immanuel United Church of Christ
for Easter Lily & Spring Flowers Fundraiser
Lebanon Junction First Baptist Church
for Easter Lily & Spring Flowers Fundraiser
PayPal Giving Fund
Rania Salem
for KHFiesta
Dr. Donald Stokes
for Easter Lily & Spring Flowers Fundraiser
Nancy Ward



In Memory

*Gone from our sight but never
our memories; gone from our
touch but never our hearts...
May their memory be a blessing!*

Spring 2024

Ronald DeVary
Chuck & Sharon Harrison





WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 bleedingdisorders.com | 

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Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

1. **Get an annual comprehensive checkup at a hemophilia treatment center.**
2. **Get vaccinated – Hepatitis A and B are preventable.**
3. **Treat bleeds early and adequately.**
4. **Exercise to protect your joints.**
5. **Get tested regularly for blood-borne infections.**

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.



Like us on Facebook and keep up-to-date on all KHF activities and events.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.



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