

KHF Hemosphere

KHFiesta

KHFiesta was a “blast!” This event is Vegasville revamped, a little less formal and by all accounts a whole lot of fun. Since the newly coined theme was that of a fiesta celebration, decorations, food, and entertainment were all fiesta-style, colorful, vibrant, and lively.

This fundraiser took place in early March and awakened us from the winter doldrums in an energetic and spirited way. The Kosair Shrine Center’s ballroom proved to be the perfect venue for this event. Brightly-colored décor and table centerpieces greeted our guests. Miki Galban entertained throughout the evening with modern Latin music and Pop rhythms. Gustavo’s Mexican Grill catered the event providing tasty fajitas with sides, salsa and chips, and yummy churros for dessert. Our casino-style gaming tables stayed busy the entire evening thanks to John Silletto and his friends and family. The silent auction tables looked enticing, and all items went to the highest bidders. The grand prize was won by Roger Dabney, an off-duty security marshal for Kosair that evening. The grand prize consisted of a wagon brimming with an assortment of exquisite spirits. Based on the success of this event and the positive feedback we received, there will be a KHFiesta in 2024.

We very much thank our generous sponsors and donors for their support. They were CSL Behring, Kosair Boat Club, Kosair for Kids, Kosair Golf Club, Louisville Oral Surgery & Dental Implants, Novo Nordisk, Octapharma, Oldham County Shrine Club, Past Masters Unit Kosair Temple. We also thank all our volunteers who helped make this event possible, especially John Silletto and his gaming volunteers, our KHFiesta Planning Committee, our board members, our day of event volunteers, and our board president, Laura Webb, who kindly debuted her auctioneering skills.



Special News

Inhibitor Risk Paper Informed by Genotyping Project

Between 2013-2017, the “My Life Our Future” (MLOF) project offered eligible individuals with hemophilia free genotyping, which is historically hard to access, expensive, and not covered by insurance. Conducted through the laboratory analysis of a single blood sample, genotyping can reveal the specific genetic mutation responsible for a patient’s disease such as those located in the factor VIII and factor IX genes in the case of hemophilia A (HA) and hemophilia B respectively.

MLOF was a partnership between the hemophilia community, the National Hemophilia Foundation, American Thrombosis and Hemostasis Network (ATHN), Bloodworks Northwest, and Bioverativ/Sanofi (formerly Biogen). Individuals who participated in the program could also opt – via informed consent – to have a blood sample with their de-identified genome sequence data deposited into the MLOF Research Repository. Investigators could apply for access to the database to support their research, with acceptance contingent upon their ability to demonstrate both scientific merit and ultimate benefit to patients.

Ultimately, samples from more than 6,000 individuals were included in the repository to help advance the scientific understanding of the disorder. MLOF was a boon to researchers, particularly to those looking to better understand the genetic differences that affect bleeding severity and reactions to certain therapies. One such example is a new paper “Race, Ethnicity, F8 Variants, and Inhibitor Risk: Analysis of the ‘My Life Our Future’ Hemophilia A Database,” published in the Journal of Thrombosis and Haemostasis.

Armed with ample collection of samples generated by MLOF, the authors of the paper sought to investigate some existing hypotheses related to inhibitor risk amongst individuals with HA.

A total of 4169 subjects were included in the primary analysis, 2,443 with severe HA and 1726 with mild or moderate HA – this analysis examined several key variables including demographic, clinical, factor VIII gene (F8) sequence data. Investigators found inhibitor incidences of 30.3% in those with severe HA and 7.9% in the mild/moderate group. In the severe group, 1075 (44%) had an intron-22 inversion mutation of the F8 gene, and of those, 388 (36.1%) developed an inhibitor.

The result of a crossing over between two linked gene pairs of the same chromosome, intron 22 inversions account for nearly 50% of severe hemophilia A cases. Investigators sought to determine whether inhibitor risk

associated with these type mutations are similar to those associated with other large structural changes in the F8 gene. They ultimately found no difference in inhibitor risk amongst those severe HA participants with an intron-22 inversion vs other large structural changes in the F8 gene.

The authors also looked at another hypothesis informed by earlier research which suggested that increased inhibitor risk





could be caused by specific mutations known as non-HA causing, non-synonymous single nucleotide polymorphisms (nsSNPs). Often associated with disease, nsSNPs are caused by a change to the amino acid sequence of a genetically encoded protein. In fact, the analysis showed that nonpathogenic ns-SNPs in the F8 were not associated with inhibitor development.

The analysis also confirmed earlier studies suggesting an increased risk for FVIII inhibitor development in both Black/African American and Hispanic HA patients, relative to White non-Hispanic individuals with HA in the U.S. Investigators signaled the potential implications of this study, and future research, in helping to inform therapeutic plans that better anticipate inhibitor risk.

“It is hoped that future studies, e.g., whole-genome sequence analyses to detect genetic variations contributing to inhibitor risk, will identify specific, clinically actionable genetic correlates indicating increased susceptibility to, or protection from, hemophilic inhibitor development and possibly suggesting novel therapeutic interventions to promote immune tolerance to FVIII,” concluded the authors.

Citation
Ahmed AE, Pratt KP. Race, ethnicity, F8 variants, and inhibitor risk: analysis of the “My Life Our Future” hemophilia A database. *J Thromb Haemost.* 2023 Apr;21(4):800-813. doi: 10.1016/j.jtha.2022.12.017. Epub 2022 Dec 26. Erratum in: *J Thromb Haemost.* 2023 Apr 25;: PMID: 36696179.

Visit the Journal of Thrombosis and Haemostasis to view the abstract.

NOTE: Corrigendum to ‘Race, ethnicity, F8 variants and inhibitor risk: Analysis of the “My Life Our Future” Hemophilia A database’ [Journal of Thrombosis and Haemostasis Volume 21, Issue 4, April 2023, Pages 800-813]



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Event News

KHF Family Day at the Louisville Zoo



The 2023 KHF Family Day at the Louisville Zoo is as popular as ever. This was our 24th annual gathering of bleeding disorders families who travelled from across the state to the Louisville Zoo to participate in this family-oriented event. It was a warm, sunny day in May, perfect for bringing the entire family to enjoy touring the zoo and all its attractions and animal exhibits, stop for our picnic lunch at the Oasis Tent, participate in carnival games with prizes for the kids, and a drawing of door prizes for the adults. Everyone seemed to greatly enjoy these activities, and it was such a joy to chat and interact with all the families at the event.

Many thanks to our exhibitors who provided information to our guests regarding their products and services. They were Bayer HealthCare, CSL Behring, CVS Health, Novo Nordisk, Paragon Hemophilia Solutions, Pfizer, Sanofi, and Takeda. Many thanks also to our volunteers and board members who helped stage and facilitate our children's activities. They were Nick Mazat, Ivy Webb and "L," Pam Price, Travis Price, Jennifer Dunegan, Patrick Dunegan, and Milton Kamala.

KHF Family Camp

KHF's 3rd Annual Family Camp featured a Polynesian theme this year, which was evident in the Tiki totem poles created by each family as well as by the decorations, music, and food at the final night event. Of course, participating families also engaged in true and tried camp activities, including canoeing, archery, and roasting s'mores at the camp fire. The kids also enjoyed games of basketball and Gaga Ball. The expressive photography program was fun as well. It was designed to capture animals, plants, leaves, trees, flowers, and water scenes in the great outdoors, but was cut short because of the interference of rainy skies. A visit by the Second Chances Wildlife Center from Mt. Washington with some of their rescued, small animals left everyone appreciative of their good works. Our hemophilia nurse's educational presentation and discussion regarding mouth- and nosebleeds was very informative, prompted questions, and generated an interactive discussion among parents.



The Tiki totem poles our families created were fabulous. Each family explained how their Tiki totem pole reflects the idiosyncrasies of their family. The final event transported us, so to speak, to the Hawaiian islands. We served pulled pork on Hawaiian buns with authentic Hawaiian barbeque sauce from Honolulu, macaroni salad, and sliced pineapples. Everyone received a lei and the ladies in addition a plumeria hair clip. The outdoor pavilion where this activity took place was decorated with tiki mask banners, plumeria tablecloths, and pineapple centerpieces.

Hawaiian music and the Tiki bar created by Travis Price who served a mango fruit punch completed the Polynesian setting. For dessert we had, of course, pineapple upside down cake. Fun and enjoyment was had by adults and kids alike, and we received great feedback from the families who attended. Many thanks to the members of our camp committee who planned and facilitated this wonderful weekend family program. Many thanks also to our sponsor Takeda.



KHF Play a Round for a Cure Golf Scramble

KHF's 34th Play a Round for a Cure Golf Scramble went off without a hitch at Glen Oaks Country Club in Prospect under blue and sunny skies after a light drizzle early on. Twenty foursomes enjoyed a great day of golf on the well-maintained and enjoyable golf course. Adding to the players' enjoyment were the various contests we offered and "go low" aids, including the sought-after mulligans, hitting from the ladies' tee, "String Forward," and Team Throw. A box lunch, snacks on the course, complimentary beverages, silent auction, 50/50 raffle, Ball Drop, and picnic-style awards dinner after golf rounded out the day. The top three teams were in 1st place Aaron Lopez & Friends, in 2nd place Brian Davidson & Friends, and in 3rd place Novo Nordisk. The Longest Drive and Straightest Drive winner was Reid Thacker. Closest-to-the-pin winners were Jacob Lusk, Darrell Layman, Howard Goldberg, and Pat McElhone. The 50/50 raffle was won by LTC (R) John Tharp and the Ball Drop by Chris Kukla. Both generously donated their winnings back to KHF.

Proceeds from this fundraiser help fund our programs and services for Kentucky's bleeding disorders community. Therefore, we appreciate all sponsors, donors, and contributors for their support. Our sponsors were Takeda, Platinum Level; Bayer HealthCare, CSL Behring, and Kosair for Kids, Gold Level; Novo Nordisk, Octapharma, Bronze Level; Team Plus Sponsor in memory of Gary F. Bandy, LTC (R) John & Patricia Tharp; Business Tee Sponsors, HEMA Biologics and Republic Bank & Trust Company; Player Foursomes: Aaron Lopez Team, "Brandon's Bombers," Brian Davidson Team, DJ Axel Team, JCSO Team, Kosair for Kids Golf Club, "Lousy Golfers," Marwood Live Edge Slabs & Lumber, Mike Wheeler Team, Milton Kamala Team, William Black Team, "Salty Sailors," Tommy Kilcourse Team, and "T-Rocks." Much appreciation also for our Golf Planning Committee chaired by William Black and our day of event volunteers, who were William Black, Tamara Bryant, Greg Carter, Ashley Chapman, Morgan Cook, Deborah Hitt, Glen Hitt, Sr., Aisha Irvin, Kim Jones, Milton Kamala, Myra Loeser, Jessica Lovercamp, Nick Mazat, Travis Price, Stacey Retic, LTC (R) Tharp, and Patricia Tharp.



2023 KHF Activities Calendar

- 23-27 July** Camp Discovery • Cedar Ridge Camp, Louisville, KY • for children and teens, ages 7-17 with bleeding disorders and unaffected siblings
- 16 Sept.** Summer Family Event • Hyatt Regency Louisville, Louisville, KY
- 21 Oct.** Kentucky Unite Walk • E. P. "Tom" Sawyer State Park, Louisville, KY
- Nov-Dec.** Poinsettia Sale Fundraiser
- Dec.** Year-End Community Event

More News

Spring-Summer Donations

April 2023 – June 2023

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

Donor, \$1,500

Sanofi

Donor, \$500+

Neil Gabehart

for KHFiesta

Glen & Deborah Hitt

for KHFiesta

Kosair Golf Club

for KHFiesta

Lindsay Martin

for KHFiesta

Past Masters Unit Kosair Temple

for KHFiesta

Donor, 250+

Dianne Hardman

for 2023 Walk

Cory & Whitney Meadows

for KHFiesta

Patrick Miller

for KHFiesta

Donors, \$100+

Dr. Chris Babcock

for KHFiesta

William & Karen Black

for KHFiesta

Karina Brown

for KHFiesta

Greg Fiscus

Andrew Hartmans

for KHFiesta

Melissa Hitt

for KHFiesta

Milton & Ursela Kamala

for KHFiesta

Kroger Community Rewards

Chris Kukla

Ball Drop winnings at Golf Scramble
donated back to KHF

Marwood Live Edge Slabs & Lumber

for KHF Golf Scramble

Stacey Retic

for KHFiesta

Clark & Sally Rhea

for KHFiesta

Danny & Sharon Schroeder

for KHFiesta

Britani Silletto

for KHFiesta

Sara Silletto

for KHFiesta



LTC(R) John & Patricia Tharp

50/50 winnings at Golf Scramble donated
back to KHF

Donors, \$50 - \$90

Shawn Beasley

for KHFiesta

Melissa L. Bowen

for KHFiesta

Ken Huffman

for KHFiesta

Travis Price

for KHFiesta

Donors, up to \$49

Amazon Smiles

Pamela & Kelly Anderson

for Easter Lilies

Dolores T. Davis

for Easter Lilies

Jenifer Schultz

for Easter Lilies

Sadalia Sturgill

for Easter Lilies

Jim Huff



More News



Kentucky Hemophilia Foundation Membership

July 1, 2022 – June 30, 2023

We thank all members of the Kentucky Hemophilia
Foundation who are supporting the current program year!

Individual/Family Memberships, \$20

Megan Davidson
William J. Hamilton
Barry Hatfield
James Huff
Evelyn Barr Kramer
Mary K. Norman
Grayson Riddle
Nita Wayne-Zehnder

Supporting Memberships, \$35

Judy Hayes
in memory of Jason Hayes
Travis Price
Sarah Richardson

Patron Membership, \$50

Danny & Maritza Adams
Holly Hadley
Jim & Shannon Hoskins
Vivian Marcum
Charles & Cheri Music

Sustaining Memberships, \$100

Cathy & Jewel Daugherty
John & Leah Graham
Arthur Hackman
Glen & Deborah Hitt
Dr. David & Leslie Houvenagle
Keith Peterson
Laura & Glenn Webb

Benefactor Memberships, \$250

Barbara W. Grayson

Champion/Corporate Membership, \$500-\$1,000

Marion Forcht &
Terry Forcht
LTC (R) John Tharp & Patricia Tharp



In Memory

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

March 2023 – June 2023

Jeanne Hurt
Lisa & Heath Alexander
Cole Anderson
Vivian & Jim Secrest, Jr.
Pat & Nancy Willis

Jon Price
Fireside Ministries Corporation
Lesa Hibbs
Roy & Marie Hicks

Doug & Rachel Humphrey
David & Laurie Jurgens
Stacy Troutman Logsdon
Anthony & Vicky Passafiume
Betty Price
Keith & Dawna Price
John & Ann Renfrow
Cherie Ann Stiles
Dennis & Karen Whitaker





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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