

KHF Hemosphere

2022 KHF Year-End Event

KHF's popular year-end celebration once again surpassed all expectations. Many bleeding disorders families gathered at the Clifton Center for a Sunday afternoon filled with food, fun, and friendship. Many thanks to our guests who brought items to enter into the silent auction, which always generates competitive bids for these sought-after items.

To everyone's delight, we were able to bring back the ever-popular bake contest, which was won by April Zimmerman with her Peach Dump cake entry. Second place was secured by Tira Miller with her Buckeye Brownies, and Laura Webb placed third with her Snickerdoodle Bundt Cake.

The children had fun making adorable holiday crafts under the watchful eye of Connie Thacker until the long-awaited arrival of Santa Claus and Mrs. Claus who carried gifts for all the children. A surprise visit by the Grinch only heightened the excitement in the room. Guests also had an opportunity to interact and chat not only among each other but also with our exhibitors and enjoy a drawing for door prizes. We thank Novo Nordisk, Genentech, Heritage Biologics, CSL Behring, and Octapharma for their generous support of this important community event, and we also thank our volunteers, who helped make this event possible. They were Laura Webb, Connie Thacker and helpers, Myra Loeser, Cathy Cain, Pam Price, Patrick and Jennifer Dunegan, Jaclyn Maria's dad, Nick Mazat, and Milton Kamala.



Special News

Guilt in Mothers of Children with Hemophilia Focus of New Study

Researchers from the Children's Healthcare of Atlanta and Emory University recently published the results of a small study investigating the subject of guilt in mothers of children with hemophilia (CWH).

Anonymous electronic surveys were distributed to 291 mothers of CWH from May to October 2021, which measured feelings of guilt along with potential contributing factors, subsequent coping strategies, and perception of their child's life satisfaction.

In all, 87 mothers completed the survey. The mean of respondents were 41.6 years and their CWH were a mean age of 13.3 years. While mothers indicated perceptions of their child's life satisfaction that didn't vary appreciably from the general population, 40% did indicate increased guilt. The most commonly cited reasons associated with this guilt were passing on the X chromosome associated with their condition and putting their child through painful infusions. The most common coping strategies were accessing social support, self-education, and connecting with other mothers of CWH in the inherited bleeding disorders community.

The authors emphasized the need for healthcare providers to "tactfully" provide anticipatory guidance and counseling for these mothers. They also suggested some positive takeaways.

"Community immersion was beneficial, as other mothers in the community served as a source of social and educational support. Most mothers did not report guilt, illustrating the adaptability and resilience of the haemophilia community," concluded the authors.

The study, "The Emotional Experience of Mothers of Children with Haemophilia: Maternal Guilt, Effective Coping Strategies and Resilience within the Haemophilia Community," was published online in the journal *Haemophilia*.

Source: *Hematology Advisor*, February 21, 2023



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Saturday 1:22 pm
Swinging in the
backyard with mom
Evan, living with
hemophilia A

Not an actual patient

WE'RE IN THIS TOGETHER.

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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Event News

Washington Days

The National Hemophilia Foundation's annual advocacy effort took place in person in early March in Washington, DC. Washington Days is a gathering of bleeding disorder advocates from all across the nation. KHF was represented by board vice president, Eric Marcum, who is a committed and effective peer advocate. Of primary importance for legislative action this year was H.R.830, the HELP Copays Act or Help Ensure Lower Patient Copays Act, which was introduced by Rep. Earl L. "Buddy" Carter from Georgia in 2023. This bill requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the plan requirements and prevent the use of copay accumulator adjuster programs and maximizers by insurance companies. On the state level, fourteen states, including Kentucky, have already banned these restrictive accumulator adjuster and maximizer practices, which are unfair and present an inordinate hardship for the insured. The same needs to occur on the federal level so that the ban will apply to all types of plans.



2023 Spring Semester Scholarships



Spring post-secondary education scholarship awards went to Marissa Johns of Shepherdsville and John Graham of Winchester. Marissa received the \$500 Betty Meadors Mattingly Memorial Scholarship and John Graham received the \$500 Terry D. Turner Memorial Scholarship. Marissa is a first-year student at the University of Louisville and has selected Neuroscience as her major. Her goal is to attend the University of Louisville School of Medicine. John is a junior at Centre College in Danville. His major is Finance and Economics. He will graduate

in May 2024 with a Bachelor's degree. His career goal is to practice law. We congratulate both recipients and wish them continued success with their studies.



The next scholarship application deadline is July 15, 2023, for the fall semester. For an application form and guidelines, please contact KHF at 502-456-3233 or info@kyhemo.org.

Poinsettias Fundraiser

With help of our dedicated volunteers, we sold 1,142 poinsettias during the 2022 Christmas holiday season. We would like to express our gratitude to the many churches, businesses, and individuals who ordered from us and to our volunteers who facilitated these orders. They include Sharon McMahan, Owensboro; Sadalia Sturgill, Lebanon Junction; Mason Stout, Somerset; Eric Marcum, board vice president, Louisville; Deborah Hitt, Shelbyville; Myra Loeser and Nita Wayne-Zehnder, Louisville; and Travis Price, board member, who assisted our customers with their flower pick-ups. We also thank Republic Bank for accepting our bid to provide their banking centers in the Louisville area with poinsettias, and a special thank you goes to Mr. and Mrs. Terry Forcht for their generous donation in support of this important fundraiser.





Kentucky Advocacy Day

KHF's Advocacy Day in Frankfort was held in person for the first time since the COVID-19 pandemic. Our faithful and passionate group of advocates convened in Frankfort on February 21, 2023, for meetings with their state legislators. The purpose of these meetings has several layers, one is to acquaint legislators with KHF's mission and services,

another is to give them an overview of what it is like to live with a bleeding disorders and resulting needs and concerns. Thirdly, we always thank the Kentucky legislators for the continued funding of the patient assistance program for individuals with hemophilia and similar inheritable bleeding disorders, which is administered by the Office for Children with Special Health Care Needs (OCSHCN). Lastly and most importantly, we asked for their support of HB134 introduced by Kentucky Rep. Kimberly Poore Moser, which would grant certain physicians exemption from pre-authorizations for procedures and services if they have a 90% insurance approval rate. We observed that this piece of proposed legislation, which was spearheaded by the Kentucky Medical Association (KMA), was well-received among the legislators we had the privilege to speak with. It would not only benefit physicians with a good approval record but more importantly patients who would be able to receive needed and timely treatment and care without any delay. We hope that HB134 will pass both the House and Senate and become law in Kentucky for the benefit of so many men, women, and children. Many thanks to our sponsors Takeda, Sanofi, and Pfizer.

2023 KHF Activities Calendar

**13
May**

Family Day at the Zoo • Louisville Zoo, Louisville, KY

19-21

Family Camp • Cedar Ridge Camp, Louisville, KY • for families with children and teens, ages 6-16 with bleeding disorders and unaffected siblings

**12
June**

Play a Round for a Cure Golf Scramble Fundraiser • Glen Oaks Country Club, Prospect, KY

**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

**TBD
Dec.**

Year-End Community Event

More News

Winter Donations

December 2022 – March 2023

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

Donor, \$1,500

CSL Behring

Donor, \$750

Optum Rx, Inc

Donor, \$350+

American Online Giving Foundation
for Walk

Donors, \$100+

Rick L. Barker
Charities Aid Foundation
for 2022 Walk
Michael A. Gatton
in honor of John G. Gatton,
for Camp, for Scholarship Fund
Glen & Deborah Hitt
for Poinsettias
Kroger Community Rewards

Donors, \$50 - \$90

Amazon Smiles
Greg Fiscus
GE Appliances
Dianne Hardman
for 2023 Walk
Dianne Hardman
for 2022 Walk
Ursela Kamala
for 2022 Walk
Gary & Sande Rawlings
James A. Ray
Mason Stout
for Poinsettias
Sadalia Sturgill
for Poinsettias
Jason Wetherington
in honor of Laura Webb at Christmas



Donors, Up to \$49

Anonymous
for Camp
Helen P. Blankenbaker
for Poinsettias
Dolores T. Davis
for Poinsettias
Jim Huff

**Thank
You**

Remember: KHF Cares

Kentucky Hemophilia Foundation continues to provide 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.



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
Nita Wayne-Zehnder

Supporting Memberships, \$35

Judy Hayes
in memory of Jason Hayes
Travis Price
Sarah Richardson

Patron Membership, \$60

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!

December 2022 – February 2023

William G. Barr
Evelyn Barr Kramer

Jackie Gardiner
Ann & Buzz Boyd

Carol Mills Holzknacht Nord
Kathy Brosnan
Susan & James Lewis
Heather M. McDavitt
Olash Medical Associates

Carol Mills Holzknacht Nord, cont.
Lisa & Thomas Palmer
Mary M. & John O. Ridenour, Jr.
George & Debra Schlaughenhaupt
University of Kentucky Utilities Department
Deborah & Herman Wallitsch, Jr.
Paul & Sharon Woodbeck
Gail Yates
Wanda S. Yonts

Lisle Threlkeld
Ann & Buzz Boyd



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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