

# KHF Hemosphere

## 2023 Kentucky Unite Walk

This Walk and Community Event celebrates the fundraising efforts of our Walkers and Walk teams. Thirteen teams from across Kentucky and several individual walkers participated in our tenth annual Walk at E. P. “Tom” Sawyer State Park. The Walk commenced with the Pinwheel Ceremony and Laura Webb, Walk Committee member and former Board President, led the way. Afterwards, Walkers were able to enjoy freshly grilled hot dogs and hamburgers prepared by board president, Eric Marcum, and board member, Travis Price. Facepainting, pumpkin painting, balloon animals, costume contest, trick or treat were activities that delighted the many kids who came.

The Walk competition for first place was very close. Top Teams were in first place, Team LEVI from Cynthiana with \$2,624; in second place Team XL from Louisville with \$2,590; and in third place Team Jack from Louisville with \$500. Each of the top three winning Team Captains received an inscribed glass award. All top three team members received a medal and a commemorative KHF to-go cup. The top three individual fundraisers also received an inscribed glass award. The recipients were in first place Dianne Hardman with \$2,590, in second place Levi & Hunter Hill with \$2,399; and in third place Cory Meadows with \$500.

The Walk celebration was so much fun and enjoyed by all who attended. We appreciate all our sponsors who contributed so generously to our fundraising total. They were Silver Level Sponsors CSL Behring, Novo Nordisk, and Octapharma; Bronze Level Sponsors BioMarin, Kosair for Kids, PhRMA, Sanofi, and Takeda; and Kilometer Sponsors Biomatrix and Republic Bank & Trust. We also thank our volunteers who contributed enthusiastically to the Walk’s success. They were Eric Marcum, Laura Webb, Travis Price, Pam Price, Sharen Harmon, Nick Mazat, Milton Kamala, Connie Thacker and Kayden, Patrick and Jennifer Dunegan, Glen and Deborah Hitt. The Walk raised a total of \$27,256 for KHF’s programs and services for Kentucky’s bleeding disorders community.



# Special News

## Study Suggests Patients Preferences Evolving Along with Treatments



In recent years, the arrival of novel hemophilia treatments that are effective and less burdensome to administer have opened up new possibilities for the consumers of these therapies. This begs the question – How might this evolving landscape be impacting treatment preferences for people with hemophilia?

Investigators sought answers to this question in a new study, “Patient and Caregiver Preferences for Haemophilia Treatments: A Discrete-Choice Experiment,” which was published in the journal *Haemophilia*. The study was informed by a literature review and a survey open to adult males with hemophilia age 18 years and older, and caregivers of teen/adult males with hemophilia age 17 years or younger.

The surveys, which were submitted online from February to April 2022, generated a sample of 151 affected adults and 151 caregiver respondents. Each respondent evaluated hypothetical hemophilia treatment profiles defined by six attributes via a discrete choice experiment (DCE). The DCE was used by the authors to quantify preferences and learn more about trade-offs individuals consider when making decisions about available treatments.

Respondents answered questions based on six attributes: number of annual spontaneous bleeds; ability to live a more active lifestyle; how a medicine is prepared/administered; frequency of administration; risk of an inhibitor; risk of hospitalization due to treatment side-effects.

The burdens of treatment administration (intravenous and subcutaneous) and storage were also explored through a best-worst (BWS) scaling exercise, used to assess an individuals’ priorities. It captures extremes including best and worst items, most and least important factors, biggest and smallest influences.

“In the BWS exercise, adult respondents and caregivers had overall similar preferences regarding the burden of treatment administration features, reported the investigators “Both samples found frequent and longer IV infusions most burdensome and a Sub-Q injection every 2 months least burdensome.”

DCE results indicated that both adult patients and caregivers preferred treatments that enabled a more active lifestyle and are associated with a lower inhibitor risk. Notably, both groups valued an active life more than reducing spontaneous bleeds.

“These findings suggest that adults with haemophilia and caregivers of children with haemophilia are willing to make tradeoffs for potential improvements in lifestyle not offered by clotting factor concentrates, bypass agents or activated factor VIII mimetics,” explained the authors.

The paper also acknowledged limitations. The sample generated from the survey included English speakers exclusively and respondents were predominantly white, highly educated. In addition, the survey was only available online, which would exclude individuals/families who do not have internet.

The authors posit that this study underscores the importance of a shared decision-making (SDM) approach to hemophilia care. Through SDM, healthcare providers and patients/caregivers may arrive at decisions that factor in the current treatment landscape and individual preferences.

### Citation

Garcia VC, Mansfield C, Pierce A, Leach C, Smith JC, Afonso M. Patient and caregiver preferences for haemophilia treatments: A discrete-choice experiment. *Haemophilia*. 2024 Jan 10. doi: 10.1111/hae.14928. Epub ahead of print. PMID: 38198352.

This article is a synopsis provided by the National Bleeding Disorders Foundation (NBDF). Any questions about the article featured here should be directed to the publishing journal and/or the study authors. This content is for general information only. NBDF does not give medical advice or engage in the practice of medicine. NBDF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or HTC before pursuing any course of treatment.



## New Study Looks at Hemophilia Survival Rate Disparities

Results of a new study published in the journal *Haemophilia* are illustrative of persistent health disparities existing within the U.S. hemophilia population.

The data that informed the study was drawn from National Vital Statistics System (NVSS), which generates comprehensive statistics on births and deaths in the United States. The authors looked at the NVSS' 1999–2020 Multiple Cause-of-Death data set to learn more about rates of hemophilia-related death (rHD).

Investigators ultimately identified 3,115 males associated with a rHD. Data showed that approximately 76.1% of deaths occurred in White men (2370), 13.3% in Black men (413), 7.4% in Hispanic men (233), 2.2% in Asian men (69), and 0.9% in American Indian/Alaska Native men (28), while race and ethnicity data were missing in two cases. A review of the data revealed a noteworthy reduction in overall age-adjusted rHD rates for all race and ethnic groups, with a decrease from 1.37 per 1 million males in 1999–2004 to 0.76 per 1 million males in 2015–2020.

This improvement in rHD rates, driven in part by the evolution of treatment and access to better therapies, represents a positive overall trend. However, the most recent decade's worth of data (2010–2020) also revealed a troublesome disparity as Blacks and Hispanics showed a median rHD of 56 years, putting them significantly behind their white counterparts who experienced a mean age of 68 years.

“Our observation that Black men had a lower median age at death and that HIV continues to be a leading cause of death among Black males with hemophilia listed in their death certificate in both earlier and recent years could signal ongoing survival disparities among Black people with hemophilia and an HIV infection,”

While the data suggest that HIV has a major impact on rHD in Black males, further research is necessary to identify additional inequities contributing to poorer health outcomes in underserved populations.

“Reported haemophilia-death rates improved in males across all race/ethnicities, but rates were higher for Black versus White males. Given the inherent limitations of the current study's data source, further investigation of survival rates and disparities in haemophilia is needed,” the authors concluded.

The study, “Racial and ethnic differences reported in haemophilus death rates in the United States,” was published online in *Haemophilia* on September 23, 2023.

Source: *The American Journal of Managed Care*, September 23, 2023



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# Event News

## 2023 Poinsettia Fundraiser

Many thanks to our faithful volunteers for helping us make our annual poinsettia fundraiser once again a success! In total, we sold nearly 1,000 plants. This year's poinsettias were beautiful in vibrant colors of red, pink, and winter white. Everyone was very complimentary regarding the quality of our poinsettias, and all our customers seemed pleased. Our primary supporters of this fundraiser are Louisville and southern Indiana churches and businesses as well as churches in Owensboro, Lebanon Junction, Shelbyville, and Lexington. We extend our gratitude to all supporters and to our volunteers who promoted this fundraiser and took orders from family members, friends, co-workers, neighbors, and fellow church members. They are Sharon McMahan, Sadalia Sturgill, Eric Marcum, Deborah Hitt, Myra Loeser, Dr. Joseph H. Cieslak, and April Zimmerman. Proceeds from the poinsettia fundraiser benefit our programs and services for Kentucky's bleeding disorders community.



## Year-End Family Event



The Year-End Family Event is a popular gathering time to celebrate the season. Our many guests were excited to experience our new venue for this event, the German-American Club in Louisville. The festive atmosphere combined with our activities resulted in a great event that was enjoyed by adults and kids alike. Bake contest, "ugly" hat contest, silent auction, door prizes, gifts for kids by Santa Claus and Mrs. Claus, DJ Axel's music, and delicious hors d'oeuvres melded to a memorable holiday celebration. Tammy Carter won an air fryer for winning 1st place in the bake contest with her Pineapple Dream Cake. Pat Tharp placed 2nd with her Strawberry Cake and won an Advanced George Forman grill. Myra Loeser placed third with her Chocolate Fudge Cake and won a 4-qt. slow cooker crockpot. The "ugly" hat contest was won by Nathaniel Beard with the most creative entry, who received a \$25 Amazon



gift card for his "antler-bicycle helmet-hat" creation. Blake Males also won a \$25 Amazon gift card in a drawing among Nathaniel's supporters. Every year a high point at this event is to thank the many volunteers who help us throughout the year and to present them with a token of appreciation. Many thanks, especially, to our day-of-event volunteers who were essential to the event's success. They were Patrick and Jennifer Dunegan, Connie Thacker and Kayden, Myra Loeser, Pam Price, Glen Hitt, and Milton Kamala. We also had the honor to recognize Glen Hitt as our "Volunteer of the Year" for his many efforts to engage his fellow Shriners in our fundraising activities. We thank our exhibitors who sponsored this event and who helped make this wonderful celebration possible. They were Novo Nordisk, BioMarin, InfuCare, Optum RX, Sanofi, Takeda, Pfizer, CSL Behring, and Octapharma.



## 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](mailto:info@kyhemo.org) to make a request.

# Event News



## Kentucky Hemophilia Foundation Membership

July 1, 2023 – June 30, 2024

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

### Individual/Family Memberships, \$20

Jim Huff  
Colleen Keith  
Roy Mallory  
Travis Price  
Nita Wayne-Zehnder

### Supporting Memberships, \$35

Judy Hayes  
in memory of Jason Hayes  
Stacey Powell  
Sarah Richardson

### Patron Membership, \$50

Danny & Maritza Adams  
John & Leah Graham  
Victoria Huff  
Cory W. & Whitney Meadows

### Sustaining Memberships, \$100

Megan Davidson  
Glen & Deborah Hitt  
Dr. David & Leslie Houvenagle  
Charles & Cheri Music  
Laura & Glenn Webb

### Benefactor Memberships, \$250

Paula Bias  
Barbara W. Grayson

## 2024 KHF Activities Calendar

- Mar. 2** KHFiesta Fundraiser
- Feb. 22** Kentucky Advocacy Day
- May 18** Family Day at the Louisville Zoo
- June 10** Golf Scramble Fundraiser
- July 21-25** Summer Camp
- Sept. 7** Summer Family Event/Annual Education Meeting
- Sept. 27-29** Family Camp
- Oct. 19** Kentucky Unite Walk
- Dec. 15** Year-End Family Event



# More News

## Winter 2023/2024

November 2023 – February 2024 Donations

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

### Donors, \$830-\$960

Constellation  
for Walk  
Dianne Hardman  
for Walk

### Donor, \$750

CSL Behring

### Donors, \$200-\$300

Bill Stopher  
Mr. & Mrs. Henry W. Boyd, III  
Greg Fiscus  
Louisville Oral Surgery & Dental Implants  
for poinsettias

### Donors, \$100+

Kroger Community Rewards  
Colleen Keith  
Keith L. Peterson

### Donors, \$50 - \$95

Mr. & Mrs. John E. Graham  
Stan Hankins  
for poinsettias  
Kimberly-Clark  
Cheri J. Music  
Mr. & Mrs. James A. Ray  
Summit Heights Fellowship Class  
in honor of Andrew & Tyler Marcum  
Linda Surratt  
Nancy Ward

### Donors, up to \$49

Dolores T. Davis  
in honor of Andrew & Tyler Marcum  
Deborah Hitt  
for poinsettias  
Jim Huff





## WE'RE IN THIS TOGETHER.

**Sunday 2:16 pm**

Jogging in the park  
with his girlfriend

Ben, living with  
hemophilia A

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](https://bleedingdisorders.com)



## 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](http://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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