

KHF Hemosphere



KHF had an Active Fall

KHF kept busy as summer turned to fall with our Annual Meeting, Family Camp, and another successful Walk. There are photos throughout the newsletter and more information starting on page 4.



Special News

New Document to Help Residential Substance Use Disorder Placement for Individuals with Bleeding Disorders



Historically, many residential substance use disorder (SUD) facilities have denied admittance to individuals with bleeding disorders – the basis of these denials are most often the use of self-administered, intravenous medications such as factor replacement therapies. The lack of access to residential addiction treatment facilities, can have very serious, even fatal outcomes for bleeding disorder (BD) patients in acute need of help with their addiction.

Results of a national survey of hemophilia treat center (HTC) providers suggest that the majority of attempts to place patients at a residential addiction treatment facility or at mental health facilities have met with failure. However, interviews with HTC providers who have bucked this trend and secured residential placements have helped generate a document that provides best practices and resources for HTCs endeavoring to successfully refer a BD patient. It is a comprehensive resource that is meant to encompass the various referral stages, including things to consider prior to making a referral, during the referral process, and in the event of a denial.

Best Practices For Accessing Residential Substance Use Disorder Treatment For Individuals With Bleeding Disorders is a product of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), whose mission is to advocate for access to appropriate SUD and mental health (MH) treatment facilities for all individuals with BDs. The Coalition plans to develop a similar document centered on access to MH facilities.

Please note that the Coalition is very eager to collect as much information as possible relevant to denials for residential SUD treatment, so that they can continue to refine best practices and enhance support for individuals with BDs. To get more information, go to https://www.newenglandhemophilia.org/wp-content/uploads/2022/08/BD-SMUHAC_Best_Practices_FINAL.pdf. Refer to the contacts at the bottom of page eight for contact details.



BD SUMHAC was formed via a partnership between the New England Hemophilia Association (NEHA), Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and BD community members. Sponsoring organizations include NHF, NEHA, and the HTC at Rush University Medical Center.

Special News



KHF Activities Calendar

2022 was packed full of fun and information!
2023 will be even better if you join us.

2023

January 15 Deadline for Applications to KHF's Scholarship Fund for Spring Semester

February KHF Advocacy Day (Exact Date TBD)

NEW! March 4 KHFiesta, a fun event with a Latin Flavor! (Dinner, Entertainment, Gaming, Silent Auction, Grand Prize Drawing)

March 8-10 NHF's Washington Days (national advocacy effort)

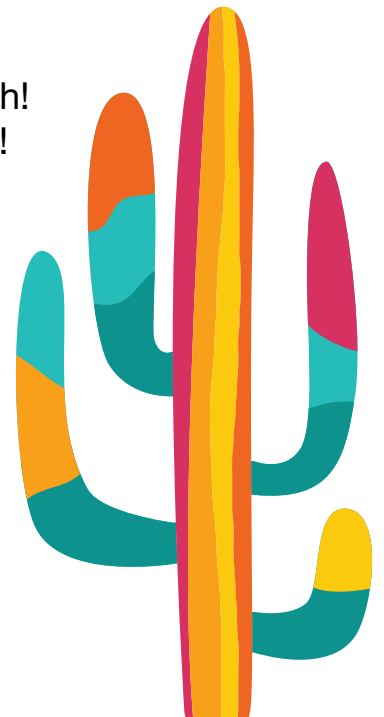
New in March!



It's a Latin-infused night of friends, fortune, fun, and music with Casino-style gaming for real money. Test your skill and luck with Black Jack, Poker, Roulette, and more. Proceeds benefit KHF which serves those in Kentucky with bleeding disorders.



Mark you calendars for Saturday March 4th!
Watch your mailbox for invitation in 2023!



Event News

Annual Meeting aka Summer Family Event

The Summer Family Event featured several important educational sessions, children's activities, and new board member election. This event took place at the beautiful Hyatt hotel in downtown Louisville. The event started with an exhibit period during which our attendees had the opportunity to chat with industry representatives to stay abreast of current and future treatments and services. We then welcomed Matt Delaney from the National Hemophilia Foundation (NHF) as our keynote speaker. His presentation was entitled "Federal and State Advocacy: Updates and Opportunities" and consisted of a description of the current legislative landscape for Kentuckians within the state and on the federal level. He also provided helpful information to dispel any fears regarding advocacy. After a hearty breakfast, breakout sessions addressed one's "Inner Strength: Developing a Relationship with Your Body," presented by Tai Chi expert, Rick Starks, and "Fueling Your Future with Smart Choices," presented by Morgan Cook. Children's activities were facilitated by Connie Thacker from Christian Fellowship. During lunch, community member Aisha Irvin was elected to KHF's Board of Directors, and we expressed our gratitude to Cory Meadows and Bradley Woods who rotated off the Board. The event concluded with a door prize drawing, which included two Nintendo Switch Lite systems. Many thanks to our volunteers, exhibitors, and sponsors for their participation and support. Our main event sponsor was Novo Nordisk. Speaker sponsors were CSL Behring, NHF, and Takeda. Exhibitors were Accredo, BioMarin, CSL Behring, CVS Caremark, Genentech, HEMA Biologics, Novo Nordisk, Paragon Hemophilia Solutions, Pfizer, Sanofi, and Takeda.



2022 KHF Family Camp

Our Family Camp this year lent itself to the most wonderful Halloween flavored activities. In addition to all the outdoor fun, such as campfire and s'mores at the lake, playing gaga ball and capture the flag, canoeing, archery, basketball, cornhole and more, participating families enjoyed an interactive cooking lesson led by Chef Mike. This team effort resulted in a delicious macaroni and cheese dish and chicken strips, which were accompanied by a green salad. Halloween decorations, pumpkin painting, and a costume contest that required substantial creativity and humor set the stage for a great Halloween season. Kids were thrilled interacting with their parents



and siblings and other families in a stress-free and fun environment culminating in a dance party during the last evening. All activities took place at Cedar Ridge Camp where KHF holds its annual summer camp for kids and teens as well. Lodging was provided in a nearby hotel. The weather was great during this end of summer/beginning of fall weekend and allowed for lots of time being spent outside. This was a large effort and a labor of love by several of our Camp Committee Members. They are Justin Lindhorst; Missy Frey, RN; Rania Salem, RN; Travis Price and Sam Johnson. We extend our appreciation to them and our sponsors who were CSL Behring and HEMA Biologics.



9th Annual Unite Walk

A sunny fall day greeted our Walk teams early on Saturday, October 22, 2022, at E. P. “Tom” Sawyer State Park once again. Sixteen teams from the greater Louisville area, Bowling Green, Vine Grove, and Cynthiana gathered for our Ninth Annual Unite for Bleeding Disorders Walk and community event. Everyone’s spirits were high

as Venus Marcum, our Walk Committee Chair, led the teams on their Walk route after the pinwheel ceremony, which set the stage for unity, hope, and resilience. In the meantime, Eric Marcum and Travis Price fired up the grills and provided our walkers, volunteers, and exhibitors with scrumptious hot dogs. These freshly grilled hot dogs, chips, cookies, and beverages hit the spot and were enjoyed by all. Parents had the opportunity to visit with national and local sponsors, while their children enjoyed face painting, pumpkin painting, photo booth, pinata smashing, and other fun kids’ games.

The popular Halloween costume contest featured three winners: Tag Poynter, the “Scary Werewolf;” Shreeyan Jadhav, the “Ninja Pirate;” and a lovely young lady, perfectly embodying a “Brats Doll.” Leading up to the awards ceremony, adults enjoyed the drawing for door prizes. Peer to peer fundraising had been competitive among the top teams during recent weeks. Winners were determined by their leaderboard standing right before the Walk. The 3rd place Walk team winner was Team Roblynn from Louisville with Constance Wheat as Team Captain. They raised \$850. The 2nd place Walk team winner was Team XL from Louisville with Dianne Hardman as Team Captain. They raised \$1,425. The 1st place Team winner was Team Tag & Trey’s Turtles from Bowling Green with Monica, Tag, and Trey Poynter as Team Captains. They raised an incredible \$4,825, which since the time of the Walk has increased to \$5,925.00. Their secret “weapon” was husband and dad, Josh Poynter, who single-handedly raised most of this amount from donations by co-workers and other workplace supporters. Congratulations and much gratitude to all teams but especially to Team Tag and Trey’s Turtles. Theirs is the highest team amount raised since the start of our Walk. Each team member of the top three teams received a handsome medal and an insulated lunch cooler. All winning team captains received a very nicely inscribed glass award to commemorate and show our appreciation for their leadership and hard work.



The top three highest individual fundraisers were also recognized. In third place was Constance Wheat from Louisville with \$595; in second place was Cory Meadows from Louisville with \$700; and in first place was Dianne Hardman with \$900. They also received a very attractive glass award for their achievements. Walk t-shirts, tote bags, and incentive gifts for individuals who raised \$250 or more added a special touch to everyone’s participation in this important fundraiser. We thank all walkers, team captains, donors, volunteers, and sponsors wholeheartedly for making the 2022 Kentucky Unite for Bleeding Disorders Walk a success. Local Silver Sponsors were CSL Behring and Novo Nordisk; Bronze Sponsors were BioMarin, Kosair Charities, Sanofi Genzyme, and Takeda; Kilometer Sponsors were Biomatrix and Republic Bank and Trust Company. The Walk raised \$27,030 for KHF’s programs and services for Kentucky’s bleeding disorders community.



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+

James Huff

Supporting Memberships, \$35+

Judy Hayes

in memory of Jason Hayes

Sarah Richardson

Patron Memberships, \$50+

Jim & Shannon Hoskins

Vivian Marcum

Charles & Cheri Music

Sustaining Memberships, \$100+

John & Leah Graham

Glen & Deborah Hitt

Dr. David & Leslie Houvenagle

Laura & Glenn Webb

Benefactor Memberships, \$250+

Barbara W. Grayson

Champion/Corporate Membership, \$500+

LTC (R) John & 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!*

September – November 2022

Betty Jo Raney

Steve & Donna Englert

Patricia Graham



More News



Fall Donations

September – November 2022

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

Donor, \$3,200

Forcht Group
for poinsettias

Donor, \$750

CSL Behring

Donor, \$200+

Greg Fiscus

Donor, \$550

JE Dunn Construction Company
Charitable Fund
for Walk

Donor, \$200

Diann Meadows
for Walk

Donors, \$100+

Benevity Community Impact Fund
for Walk
Mary Henson Circle
for Walk
Maria Leshner
for Walk
Mona Lucky
for Walk
Kroger Community Rewards
Ronnie Poynter
for Walk
Laura & Glenn Webb

Donors, \$50 - \$90

Greg Fiscus
Brandy Fox
for Walk
Dianne Hardman
for Walk

Glen & Deborah Hitt

for Walk
Cory W. Meadows
Pam Price
for Walk

Donors, up to \$49

Amazon Smile
Anonymous
for Walk
Jim Huff
Marjorie W. Seely
for Walk

Going through a hard time?

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.



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.



Non Profit Org.
U.S. Postage
PAID
Louisville, KY
Permit No. 883

KENTUCKY HEMOPHILIA FOUNDATION
1850 Taylor Avenue #2
Louisville, KY 40213-1594

WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)
TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.

The Genentech logo is a registered trademark of Genentech, Inc.
©2020 Genentech USA, Inc. All rights reserved. M-US-00008064(v1.0) 10/20

**GENENTECH IN
HEMOPHILIA**

Genentech
A Member of the Roche Group

Jivi
antihemophilic factor
(recombinant) PEGylated-auid

Jivi[®], now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.



Scan this QR code to learn more
about the data at
[JiviExtensionStudy.com](https://www.JiviExtensionStudy.com)

©2022 Bayer. All rights reserved. Bayer, the Bayer Cross, and Jivi are registered trademarks of Bayer. 6/22 PP-JIV-US-1786-1



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



Copyright © 2020 Takeda Pharmaceutical Company Limited. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. US-NON-0136v1.0 03/20