

KHF Hemosphere

Camp
Discovery



KHF Summer Camp Program for Children and
Teens with Bleeding Disorders and their Siblings



Special News

Paper Features Q&A Resource on Shared Decision Making and Gene Therapy



As investigational hemophilia gene therapies move closer to regulatory authorization, community stakeholders have recognized the acute need for people with hemophilia (PWH) and healthcare professionals (HCPs) to be fully engaged

in shared decision making (SDM). While the concept of SDM whereby patient and provider collaborate to reach informed treatment decisions has gained support in recent years, the arrival of such a paradigm-shifting will present unique challenges and opportunities.

Disparities in health literacy, the proliferation of inaccurate and contradictory content on social media, direct-to-patient marketing, plus the sheer complexity of gene therapy, may prevent a PWH from fully engaging in SDM. While some HCPs may also lack a thorough enough understanding of gene therapy, hindering their full participation in the SDM model. In addition, an HCP's perception of their patient's comprehension of this therapy may not align with their patient's actual understanding, a discordance that further compromises SDM, increasing the potential for delayed treatment decisions and other negative outcomes.

In light of these anticipated obstacles, an international and multidisciplinary group known of as the Council of the Hemophilia Community (CHC) was convened. Composed of independent advisors, HCPs, industry and patient representatives, the goal of the CHC was to fill these information gaps through the development of a resource that would help generate an ongoing dialogue between PWH/HCP, with patient-centricity as its guiding principle.

The CHC held three roundtable meetings between November 2020 and May 2021 wherein they fleshed out a series of questions and answers that would best foster a genuine SDM process amongst PWHs/HCPs. The majority of the decided-upon questions fell under several over-arching categories including treatment regimen/adherence requirements, treatment predictability and variability, treatment durability, and the risk/benefit profile.

Each of the questions were subsequently assigned to the five stages of the patient "decision making journey." These included 1) Pre-gene therapy information seeking 2) Pre-gene therapy decision making 3) Treat initiation 4) Short-term post-gene therapy follow up (less than one year since receiving gene therapy) 5) Long-term gene therapy follow up (more than one year after receiving gene therapy).

A recent paper published online in the journal Patient Preference and Adherence (PPA), describes in greater detail the process of developing the resource and context in which it was created. Read the open-access PPA article.



Paper Features Q&A Resource on Shared Decision Making and Gene Therapy

continued from the previous page

The authors highlight the value of this tool to enhance SDM relevant to hemophilia gene therapy, while also hinting at its potential utility in other disease groups.

“The educational and decision support resources described herein recognize that each patient’s decision journey will evolve throughout their lifetime with their individual preferences at different life stages, and with the emergence of new therapies and a growing evidence base,” explain the authors. “The Q&A resource provides HCPs and PWH with timely, relevant information, facilitates discussions, and empowers PWH to engage in shared decision-making. As gene therapy products enter the market, the themes and questions mapped here should stimulate discussion and aid interactions among HCPs, PWH, and family members, to ensure that they are fully informed and realize the clinical potential of this treatment. While the issues discussed here pertain to hemophilia, they could also be applied to other hereditary diseases with multiple treatment options.”

Access “Hemophilia Gene Therapy: Your Questions Answered” in PDF.

Citation

Wang M, Negrier C, Driessler F, Goodman C, Skinner MW. The Hemophilia Gene Therapy Patient Journey: Questions and Answers for Shared Decision-Making. *Patient Preference Adherence*. 2022 Jun 9; 16:1439-1447. doi: 10.2147/PPA.S355627. PMID: 35707346; PMCID: PMC9191577.

Disclaimer: NHF provides periodic synopses of articles published in peer reviewed journals, the purpose of which is to highlight papers that cover a wide range of topics and speak to a broad spectrum of the inherited blood disorders community. Topics include shared decision making, gene therapy, health equity, and more. NHF hopes you find this content to be informative and engaging.

Any questions about the articles featured here should be directed to the publishing journal and/or the study authors. This content is for general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.



Event News

Camp Discovery

This year's summer camp was phenomenal in several respects. Campers and camp volunteers were excited to resume a full-fledged, in-person summer camp after a two-year hiatus because of the COVID-19 pandemic. We had a packed schedule of activities, which featured a new and exciting "Game of Games" that lasted for the duration of

camp and challenged all our campers. The game promoted team building, problem solving, resourcefulness, finding consensus, and developing a competitive team spirit. "Game of Games" is based on the concept of "Game of Thrones." Campers were placed into "Houses" the first day of camp. Each House had to design a crest and come up with a name and back story. Houses competed for "Influence" throughout the week by playing a custom card game each day. Campers earned influence by completing Influence Cards tasks and challenges. Every team started the day with 5 Influence Cards. Influence Cards could also be found in common areas throughout the campground. Every House chose a "Head of House." The Head of House wore a special pin indicating his or her role and became responsible for enacting the House's will. This included playing Influence Cards including issuing challenges or responses to challenges and settling disputes and tie breakers among the House. The Head of House did not act independently but had to represent the House collectively. Influence was tallied by counselors throughout the day and the final numbers were tallied during a group meeting at the end of the day. New playing cards were then issued, and the Houses decided who would act as their groups' Head of Household the next day. The House with the most influence at the end of the day received 3 extra canteen dollar bonus for all members of the House, front of the line at all meals, no clean-up duties, and the ability to decide camp-wide activities for the evening. The House with the most influence at the start of the "End of Camp Party" would receive a grand prize. House "Bloodthorn" won the grand prize, which consisted of a \$25 gift card for each member of the House. Of course,

campers enjoyed all their other favorite activities and aspects of summer camp: swimming, playing "Capture the Flag," Gaga Ball, ziplining, snow cones, virtual dollars shopping in the "Canteen" for goodies, and the final night dance party. Also, congratulations to Camper Adam who won the coveted "Big Stick" award for injecting his hemophilia medication for the first time at camp. The occasional rain shower and thunderstorm definitely did not dampen or diminish everyone's camp spirit one bit.

We thank all counselors and especially our volunteer leadership staff -Justin Lindhorst, William Black, Travis Price, Missy Frey, RN, and Rania Salem, RN - for providing a safe, educational, and recreational summer camp program once again for our campers. We also thank our sponsors for their generous support. They are Kosair Charities, Takeda, WHAS Crusade for Children, CSL Behring, CVS Health, Bayer, Novo Nordisk, Sanofi, Grifols, and Pfizer.





Women's Summer Brunch

We are planning to have periodic women's programming on Saturday mornings. Get-togethers will focus on education and support. Our kick-off program featured an arts and craft's project that involved decorating welcome mats. The outcome was spectacular, and the process was

fun and stress relieving. Our group of women first enjoyed a healthy breakfast and an opportunity to get to know each other and share their stories before letting their creativity shine. This program was kindly sponsored by Cottrill's Pharmacy and Octapharma.



2022 Fall Semester KHF Scholarships



We are happy to announce that we are awarding three \$500 Scholarships for the 2022 fall semester. The Herb Schlaughenhaupt, Jr. Memorial Scholarship will be awarded to John Graham of Winchester, Kentucky, who attends Centre College in Danville. He is a sophomore and expects to graduate with a Bachelor's degree in Finance and Economics with an emphasis on politics in May 2024.

The Terry D. Turner Memorial Scholarship will be awarded to Isaac Webb of Louisville. Isaac is a sophomore at Bellarmine University with a double major of Music Theory and Composition and Music Technology. Because of his passion and talent for music, Isaac's ultimate goal is to teach music at the university level.



The Theodore (Ted) Bradley Forcht Memorial Scholarship will be awarded to Thomas Beard of Louisville, Kentucky, who is a 2022 graduate of Dupont Manual High School. Thomas attends renowned Purdue University's School of Engineering with a major in Civil Engineering. We congratulate the three recipients for their accomplishments and awards and wish them continued success with their studies.



The application submission deadline for the 2023 spring semester is January 15, 2023. You may obtain application form and guidelines by sending an email to info@kyhemo.org or calling 502-456-3233.

2022 KHF Activities Calendar

- Sept. 30 – Oct. 2** Family Camp, Cedar Ridge Camp, Louisville, KY
- Oct. 22** 9th Annual Unite Walk, E. P. "Tom" Sawyer State Park, Louisville, KY
- November-December** Annual Poinsettia Fundraiser
- Dec. 4** Year-End Family Event, Holy Trinity Clifton Campus, Louisville, KY

More News

Kentucky Hemophilia Foundation Membership

July 1, 2021 – June 30, 2022

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



Individual/Family Memberships, \$20+

Michael & Cathy Johnson
Nita Wayne-Zehnder

Supporting Memberships, \$35+

Judy Hayes
in memory of Jason Hayes
John L. Silletto

Patron Membership, \$50+

Mary E. Marasa

Sustaining Memberships, \$100+

Arthur Hackman
John & Leah Graham
Barbara W. Grayson
D. Spalding Grayson
Dr. David & Leslie Houvenagle

Benefactor Memberships, \$250+

Glen & Deborah Hitt
Ruth Ann LeVay
Eric & Venus Marcum
Laura & Glenn Webb

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!*

June – August 2022

Donald S. Grayson
Helen & Sid Hill



2022 Summer Donations

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

Donor, \$1,500

Sanofi

Donors, \$750

Cottrill's Pharmacy
Veeva Digital

Donor, \$200+

Greg Fiscus

Donors, \$100+

Kroger Community Rewards
Anonymous

Donors, \$50 - \$90

Dianne Hardman
for 2022 Walk

Donors, Up to \$49

James Huff

More News



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 during the ongoing COVID-19 health crisis or due to another type of emergency such as the recent flooding in eastern Kentucky and as a result are 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.

JIVI[®]
ADYNOVATE[®]

Jivi
antihemophilic factor
(recombinant) PEGylated-aug1
LET'S GO

PK (Pharmacokinetics) Study Data



Talk to your doctor
about the study.



Scan the QR code to learn more
about PK at UnderstandingPK.com

PK: Pharmacokinetics

© 2021 Bayer. All rights reserved. All trademarks are the property of their respective owners. Printed in USA. 05/21 PP-JIV-US-1437-1



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