

CHAPTER *Factors*

SPRING 2023



**Midwest
Hemophilia
Association**



LEARN MORE AT
HEMGENIX.COM

Patient portrayal;
HEMGENIX not intended for women

HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC.
HEMGENIX® is a registered trademark of CSL Behring LLC.
©2022 CSL Behring LLC. 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring.com www.HEMGENIX.com USA-HGX-0300-NOV22

CSL Behring

Chapter Factors is published by:

The Midwest Hemophilia Association

1471 W. South St, Suite F, Ozark, MO 65721

PO Box 412866, Kansas City, MO 64141

(816) 479-5900

www.midwesthemophilia.org

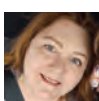
EXECUTIVE DIRECTOR



ANGELA BROWN

angela.brown@midwesthemophilia.org

**BOARD OF DIRECTORS
2023 OFFICERS**



HEATHER INCE

PRESIDENT

hince2013@gmail.com



NORA ANCEL

VICE PRESIDENT

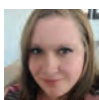
nora.e.ancel@gmail.com



MAREENA SNAREY

TREASURER

treasurer@midwesthemophilia.org



HANNAH BROWN

SECRETARY

hbrown.31622@gmail.com

2023 BOARD MEMBERS



DAKOTA ROSENFELT

dakotarosenfelt@gmail.com



KIM ROSENFELT

krosenfelt@hotmail.com



CODY YORK

cyork1121@gmail.com

This material is provided for your general information only. The Midwest Hemophilia Association does not give medical advice or engage in the practice of medicine. The Midwest Hemophilia Association under no circumstances recommends particular treatments for specific individuals. In all cases, it is recommended that individuals consult a physician or local treatment center before pursuing any course of treatment.

Brand names of treatment products are provided for information only. They are not an endorsement of a particular product or company by MHA. Acceptance of advertising for products and services in Chapter Factors in no way constitutes endorsement by the Midwest Hemophilia Association.

© Copyright 2023 by Midwest Hemophilia Association

FROM THE EXECUTIVE DIRECTOR



Advocacy efforts started early this year. We usually make our presence known with our matching red ties during Bleeding Disorders Awareness Month in March. However, experience has taught us it is better to connect with our legislative representatives early so we visited the Capitol in February. Included in our advocacy efforts this year is a collaboration with the Missouri All Copays Count Coalition which includes twenty-four different organizations supporting the same legislation. Thank you to the 15 MHA community advocates, 13 GHA community advocates, NHF Advocacy Leaders, and leaders from the Arthritis Foundation, National MS Society, and other stakeholders who were able to attend in person and continue to connect with your legislators! Your work is ongoing!

Advocacy is a year-round effort. Sharing patient stories, collaborating with stakeholders, and ensuring access to care for our bleeding disorders community is vital to MHA. We are learning and growing in our efforts and invite anyone who would like to participate to contact the office. Our voices together can make a difference!

Stay healthy!

Angela Brown

angela.brown@midwesthemophilia.org

***NOTE:** 2023 Board of Directors meetings are open to the public and scheduled for the following dates: April 1, June 17, August 12, and October 12. Changes to these dates may be necessary due to scheduling conflicts and will be updated on our website calendar as soon as they are available.*



MHA offers assistance to our community members experiencing financial hardships who live in our geographical coverage area of Kansas and western Missouri and/or for current patients of the Kansas City Regional Hemophilia Treatment Center.

If you or someone you know is experiencing financial hardship, the program guidelines and application form can be found on our website, midwesthemophilia.org, or by scanning the QR code below.



**MHA
Financial
Assistance**



Sadly, AmazonSmile has notified its eligible organizations (including MHA) that because their AmazonSmile program has not grown to create the impact they had originally hoped, they have closed the program as of February 20, 2023. MHA will still be able to seek support from Amazon customers by creating our own wish lists.

QUICK NOTES

Know A 2023 Graduate?

Parents and loved ones who have a child or spouse graduating in 2023 from high school, college/university, or trade school are encouraged to contact the MHA office by May 1, 2023 to submit information so MHA can celebrate our community graduates in the next Chapter Factors issue. Self-submissions are also welcome!

Camp For Kids Chooses MHA's Camp Wilderness for Matching Funds

Last year, Luke Saulsberry, MHA Camp Director, initiated a relationship with Camp Four Kids and Camp Wilderness was approved to receive up to

\$1500 in donation matches through the Camps For Kids program. In 2023, we are excited to announce Camp Wilderness has been approved for up to \$5,000 in matching funds through the same program!

Camps For Kids works to assure that no Kansas City area child will be turned away from summer camp because of low income or physical or developmental disability. The organization was founded by Marjorie Powell Allen in 1981 after the Federal government discontinued a program providing summer camp to children with disabilities or financial need at no cost to their families. Camps For Kids believes that camp offers opportunities for children to enjoy a sense of independence, meet and make new friends, and experience fellowship



and a feeling of community through the unique and potentially life-changing experience of summer camp.

Camps For Kids matching funds program is a unique opportunity for camps to effectively double their fundraising efforts, leveraging both their donor's gifts and staff/volunteer time. Camps For Kids is not aware of any other organization providing this type of support to help assure that no Kansas City area child will be turned away from camp. 100% of the financial support provided to the network camps is directed to campers from the Kansas City area. The matching funds program is a collaborative effort by area supporters to encourage donations to camp programs for children and youth, who have special medical, developmental or financial needs.

Contributions made between April 1st and July 31st (2023) will be matched up to \$5,000 for MHA's camp. To find out more information and/or make a donation please visit: www.campsforkids.org

Scholarship Reminder

Don't forget! There's still time to apply for the MHA Academic Scholarship and the MHA Mark Dudley Scholarship. Applications are due June 1, 2023.

For applications plus links to other scholarships available for the bleeding disorder community, visit the MHA website at <https://midwesthemophilia.org/applications-and-registrations/>.



one family World Hemophilia Day 2023

WORLD HEMOPHILIA DAY APRIL 17

Sharing the power of protection.

Get ready for our One Family program.

WHD Celebration • April 18th, 6:30pm
@Grand Street Cafe on the Plaza
RSVP by April 7th at www.midwesthemophilia.org/events/

A Midwest Hemophilia Association & Sanofi Event

sanofi

© 2022 Genzyme Corporation. All rights reserved. Sanofi is a registered trademark of Sanofi or an affiliate. MAT-US-220817-v1.0-11/2022



Wichita and Western Kansas EDUCATION DAY

June 23-24, 2023

In order to better steward our resources, MHA will be combining our Garden City/ Dodge City Education Day (aka Western Kansas Educ. Day) into one weekend event for the foreseeable future. We will be amping up the fun to include a mini-Unite for Bleeding Disorder walk celebration, great opportunities to connect and learn together, as well as programming options for youth and teens. Childcare will be provided for children 3 months to Pre-K.

We recognize travel may be an issue for our western Kansas folks, so we are offering a complimentary Friday night hotel room that will be provided for our members living outside a 60+ mile radius of Wichita. Space is limited so register early. Details and registration information can be found on our website:

www.midwesthemophilia.org

CALENDAR OF EVENTS

APRIL

- 1** Board Meeting & HopeConnection Event
- 10** Young Women's BD Clinic (KC HTC)
- 13-16** HFA Symposium (Orlando)
- 18** World Hemophilia Day Celebration (KC)



MAY

- 3** Sip! Sip! Hooray for MHA! Wine & Bourbon Tasting Benefit
- 6** Community Outreach Program: KC
- 16** Community Outreach Program: Springfield

JUNE

- 3** UNITE for Bleeding Disorders Walk
- 8** Community Outreach Program: (KC)
- 13** KC HTC Outreach Clinic - Western KS
- 14-16** KC HTC Outreach Clinic - Wichita
- 17** Board Meeting
- 23-24** Wichita & Western KS Education Day

Unite
for Bleeding Disorders

JULY

- 10** Young Women's BD Clinic (KC HTC)
- 23** Camp Wilderness Staff Training
- 24-28** Camp Wilderness

AUGUST

- 10** Community Outreach Program: Topeka
- 12** Board Meeting
- 17-19** NHF BDC



SEPTEMBER

- 19-22** KC HTC Outreach Clinic - Springfield
- 22** 25th Annual Golf Tournament
- 23-24** Family Education Weekend

OCTOBER

- 7** Board Meeting
- 9** Young Women's BD Clinic (KC HTC)
- 13-15** F.A.B. Conference (Women's Retreat)
- 17** KC HTC Outreach Clinic - Joplin
- 24** Trivia Night Fundraiser

NOVEMBER

- 4** Springfield Education Day

DECEMBER

- 2** MHA Holiday Celebration





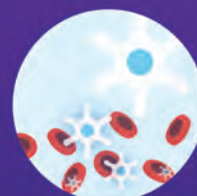
Get to know
the science
behind:



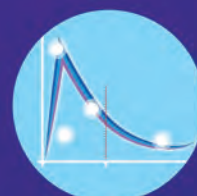
Blood clotting



Factor activity levels



Hemophilia and
hemostasis



Pharmacokinetics

Your education connection.

Our Community Relations and Education (CoRe) Managers are hosting events from coast to coast to dig into two important topics in hemophilia today: **the clotting cascade** and **factor activity levels**.



Register to attend today.

Scan and filter by hemophilia to find an event near you.
rareblooddisorders.com

© 2022 Genzyme Corporation. All rights reserved.
Sanofi is a registered trademark of Sanofi or an affiliate.
MAT-US-2209318-v1.0-11/2022

sanofi



Board Members from left to right on furniture: Cody York, Heather Ince-President, Mareena Snarey-Treasurer, Kim Rosenfelt, Nora Ance-Vice President, Dakota Rosenfelt. Seated on floor: Angela Brown, Executive Director. Missing: Hannah Brown, Secretary.

Board Training Retreat Recap

By Mareena Snarey

Shortly after the Groundhog pronounced six more weeks of winter, the members of the Midwest Hemophilia Board of Directors met for their first ever Board Retreat Training in Branson, Missouri. With guidance from Kristi Harvey-Simi and Nick Kallinicou from Chapter Development of NHF, we had discussions about the roles and responsibilities of each Board member, priorities the Board should be focused on, and action items to implement in assisting our local bleeding disorders community.

The retreat began on Friday night with pizza and board member introductions. Our visiting NHF leaders noticed right away that we enjoy being around each other and are open to share information freely. (In fact, they said we were their favorite board to work with. But shhh... don't tell others. They might get jealous of how awesome we are.)

Saturday morning started the meetings in earnest with comparing board members to parts of a car – who is the hood ornament, giving a polished appearance to the community, or who is the engine, driving the organization forward? (Hint: neither one is me).

For the next several hours discussions and learning continued on all kinds of topics and top priorities. By early evening, with completely fried brains, we adjourned the meeting and took a break before heading to dinner at the Branson Landing.

Sunday morning, we gathered again for a quick official



board meeting and recap of action items that would be immediately implemented to better serve the community. The Board Retreat training was a great opportunity to get to know the other board members better and make plans for the future. And most importantly, it was a fun weekend of proving to Mr. Groundhog that more winter does not necessarily mean cold and boring. Our board is anything but boring!



Thanks to Kristi Harvey-Simi and Nick Kallinicou from NHF's Chapter Development for leading our training!

Note: There are currently 7 seats filled on MHA's Board of Directors. We have room for up to 8 more. If you would like more information about serving on MHA's Board or know someone who may be interested in serving, please contact any current MHA Board Member. Their email information can be found on the second page of the newsletter. Board Applications can be found at www.midwesthemophilia.org.



START PLANNING YOUR TRIP TO #BDC2023!



Did you hear? Your favorite event of the year is back!

Registration for the 75th Annual Bleeding Disorders Conference is officially open!
Sign up now to receive early-bird registration pricing
for this August's event in National Harbor, MD.
Plus, don't forget to submit for the Awards of Excellence program
or apply for a travel grant ASAP!

Sip! Sip! Hooray! for MHA

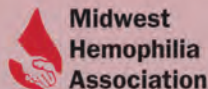
Join us for our
**1st Annual Wine & Bourbon
Tasting Benefit**

Great Wines, Bourbon & Food

Live Music

*Silent Auction with Wine & Bourbon
memorabilia*

Details & Tickets
www.midwesthemophilia.org



**Wednesday, May 3, 2023
6:00 pm**

**Llywelyns Pub
301 SE Douglas St
Lee's Summit, MO**

START THE CONVERSATION START THE CONVERSATION **START THE CONVERSATION** START THE CONVERSATION START THE CONVERSATION START THE CONVERSATION

BLEEDING DISORDERS AWARENESS MONTH

March is Bleeding Disorders Awareness Month. Throughout the month, the U.S. inheritable blood and bleeding disorders community will be starting the conversation to inspire a national conversation around these rare conditions that affect thousands of patients and families nationwide.

Inheritable blood and bleeding disorders can present from a genetic mutation, or a random mutation. Conditions like hemophilia, von Willebrand's disease, sickle cell disease, rare platelet disorders or factor deficiencies and others, can be extraordinarily challenging to manage day-to-day, as well as quite expensive. This Bleeding Disorders

Awareness Month, it's important to raise the profile of these chronic conditions faced by people in our very own community.

Everyone – whether a patient, caregiver, loved one, or advocate – deserves accessible support and resources unique to them. It is up to us all to start the conversation about blood and bleeding disorders. Talk about it, share, and learn from one another – to your leaders, and to your neighbors.

- Advocate for transformational research and novel treatments
 - Raise public awareness by conducting friendly calls, virtual presentations, more
 - Educate yourself and enable others to better recognize signs and symptoms of a blood or bleeding disorders
- We can and must create more affordable and accessible

treatments for the inheritable blood and bleeding disorders community by raising awareness and providing education. By raising our voices, we can have an impact, together. Get more information about how to make a difference by visiting hemophilia.org.

***By raising our
voices, we can
have an impact,
together.***

LETS TALK ABOUT...

N P O V W S M E J V S K
I I C H A N G E A X U U
X W F K C A F U J S P Q
E X A D V O C A C Y P I
L U W C O T U Y A S O T
I U A F H I I D A C R D
J F R U F M F I N D T H
H J E R P M I B L O W P
M E N T A L H E A L T H
X C E X M U A P R O X I
A U S J R O D Z B D Z R
W A S P K K U Q D X J P

BLEEDING DISORDERS AWARENESS MONTH

Nurses AND NACCHOS

The 21st annual NACCHO conference, made possible through generous funding from Pfizer and Sanofi and hosted by the Arizona Bleeding Disorders, was held January 5th - 8th. NACCHO (North American Camping Conference for Hemophilia Organizations) is the only camping conference dedicated to summer and family camps that serve children of the bleeding disorders community. NACCHO brings together camp directors and counselors from bleeding disorder camps around the world to learn from experts, share with one another and collaborate on new programs and activities for camp. We continued our efforts by inviting attendees from across the globe, to participate in this conference. Attendees came from Turkey, Romania, Egypt, and India.

Why host these national conferences? We see that part of our role is to contribute to the bleeding disorder community on a national level as well as a local level. We benefit from sharing with other chapters and feel that if all chapters gain knowledge and are better able to serve their local community, we are all better off locally and nationally.

The theme this year was The Gift of Camp. Speakers included a keynote presentation from GutMonkey (Pat Torrey and Joe Torrey), an opening keynote from Anne Henningfeld focusing on the Gift of Camp for ALL and many informative breakout sessions. It is such an honor to be able to host the NACCHO conference and be a partner in building and improving our camping community to better serve our children and families.

— Reprinted with permission of the Arizona Bleeding Disorders

Hi! My name is Veronica. Megan and I are the two Nurse Coordinators with the KC Hemophilia Treatment Center. I have been with the HTC since October 2019, Megan since August 2021. We were lucky to attend NACCHO (North American Camp Conference for Hemophilia Organization) in early January. This was my second time attending in person and as usual it was rewarding. Thankfully, NACCHO continues to be a wealth of knowledge for camp staff and a resource for myself and thousands of other attendees to deliver the best camp experience for our kids every year! We flew into Phoenix, Arizona on Friday; checked into our respective rooms and the conference began almost immediately with an icebreaker activity and introductions. We were then served dinner and dismissed for the evening.

On Saturday morning, after breakfast there were several breakout sessions offered. Each breakout session had different experts presenting education around their area of expertise related to camp. The first breakout session, myself and Megan attended was a discussion on the importance of having emergency preparedness kits for camps. The Hemophilia Foundation of Michigan presented stories of the importance of having an emergency response pack. These were amazing and something Megan and I would like to advocate for MHA to have for our camp.

The next breakout session was led by Tracey Gaslin, PhD APRN. Tracey is a leader in camp healthcare,

specifically hemophilia camps. Each year she discusses new and leading healthcare changes to improve camps across the country. At this breakout session, Tracey discussed the importance of a comprehensive health screening form. Tracey encouraged medical staff to discuss important and often forgotten aspects of their campers' healthcare with parents prior to and upon arrival to camp. She also discussed the importance of cultivating a safe environment for campers to develop social interactions with other campers.

The third breakout session on Saturday we attended was a discussion

on self-advocacy. The leader of this discussion gave examples of games and activities camp staff can lead to encourage self-advocacy and self-empowerment for campers. The leader of the discussion also encouraged camp staff to teach their campers how to deal with potential adverse reactions when attempting to advocate for self.

We also viewed a very touching video presented by a Patrick Lames Lynch entitled "Let's Talk." In this short film, there are several interviews with people who struggled with mental health at some point along their journey with their bleeding disorder. The video highlighted several people from different walks of life and their struggles with support and diagnosis and how it affected their mental health. This movie is truly a must see. In our opinion, the video helps healthcare staff to understand the daily



**by Veronica Van, LRN,
KC HTC Nurse Coordinator**

struggles of being on the receiving end of care for bleeding disorders.

Then we were given a presentation from international camps. We got to see the progress of camps for countries such as India, Egypt, Turkey, and Romania. It was so awesome to see the progress made and barriers overcome in getting their camp established and then re-established after COVID. The night then ended with dinner, games and fun variety shows.

Sunday morning, we started with a few breakout sessions, I attended a session entitled “Go with the Flow: Period Packs, Conversation Hacks.” In this discussion a woman spoke from her perspective as a person with a bleeding disorder and managing her menses. She gave us the opportunity to build a period pack and educated us on the importance of having these types of conversations for young women with bleeding disorders. This conversation was also really motivating, and I would love to implement this conversation at camp.

Megan attended a breakout session on self-infusion teaching. It was interesting to hear what other camps are doing to make it a fun learning experience for campers. One camp used a bracelet earning system that was a visual



ABOVE: Nurse Veronica prepares the gong for campers who self-infuse at camp (2022).



RIGHT: NACCHO is all about teaching hands-on activities.

BELOW: A small group of attendees enjoys a round table discussion during NACCHO 2023.

for all campers to see who was learning self-infusion and what stage they were at (knowledge of med/dosing, mixing medication and drawing up medication, self-infusing, and last, teaching someone to self-infuse). They felt like it really

motivated the kids to learn. It was also interesting to hear the perspective of people with bleeding disorders and how they feel like the younger generation is not wanting to learn to self-infuse since other injection options have come to the bleeding disorders community. The healthcare providers, counselors, and “older” people with bleeding disorders could all agree that self-infusion teaching is still a needed skill set, and that it’s something that we want to continue to advocate for as well as teaching newer injection options.

Attending this conference always helps to refresh and motivate our team as we head into camp planning. The HTC would like to thank MHA for giving us the opportunity to attend this conference and would like to extend the offer to families to make suggestions on how we can continue to improve camp.



Brittany Slossberg

Relationship builder

About Brittany

Brittany is a Hemophilia Community Liaison who has a passion for creating long-lasting relationships with others. She has built a strong comradery with many patients in the Colorado community.

Connect with Brittany

BTSO@novonordisk.com
(561) 289-3275



Hemophilia Community Liaison

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

©2019 Novo Nordisk Printed in the U.S.A. US19HRBD00089 June 2019



Brothers HEALTHCARE

Rx + 🩺 + ❤️ = 🌊

Welcome

Mimi, Anna & Noel to BROTHERS HEALTHCARE

MIMI LAW: 314.920.3081 | mimil@brothershealthcare.com
ANNA MACDONALD: 760.540.3118 | annam@brothershealthcare.com
NOEL MINOR, RN, BSN: 316.866.0114 | noelm@brothershealthcare.com

BONDED BY BLOOD

BROTHERSHEALTHCARE.COM | 800.291.1089



Your health, your family and your life is our specialty.

What you can expect:

- Coordination with payers, medical providers and factor manufacturers
- Direct collaboration with our clinical team
- Specialty and retail pharmacy products delivered to your door
- Local and national outreach and advocacy
- Expert nursing paired with educational empowerment

Expertise In:

- Hemophilia A
- Hemophilia B
- Von Willebrand's Disease
- Other Bleeding Disorders

Craig MacDonald
cmacdonald@myscrx.com
Phone: 760.485.8281

myscrx.com **SpecialtyCareRx**
Excellence is Our Specialty

Missouri ADVOCACY

Missouri Advocacy Day kicked off with dinner and training for community member advocates on Monday, February 6, 2023, at the Capitol Plaza Hotel in Jefferson City. Bill Robie and Josie Gomez both of NHF presented the issue: Copay Accumulator Adjustment Programs (CAAPs). Melissa Horn from the Arthritis Foundation then shared her personal story of how her insurance plan implemented a copay accumulator and its devastating effects on her family. Finally, special guest, Missouri Representative Dale Wright (R), who sits on the Health and Mental Health Policy Committee and introduced Missouri House Bill 442 (HB442), addressed attendees and spent time talking to many individuals afterwards. HB442, if passed, would prevent many insurance policies from implementing Copay Accumulator Adjustment Programs (CAAPs) and was the heart of this year's advocacy efforts.

Advocates met early the next morning and walked to the Missouri State Capitol where they spent most of the day visiting all 163 state Representative offices plus many Senate offices to give information about CAAPs and ask for support of HB442.

Efforts did not go unnoticed as HB442 was assigned to the Health & Mental Health Policy Committee just two

days later on Thursday, February 9th. It was then scheduled for a hearing on the following Monday. Several community advocates submitted written testimony and others, including MHA's Ancel Family, were able to return to the capitol on February 13th to provide in person testimony.

Our endeavors are not finished and you can help! The next step is for HB442 to be voted out of committee for debate and legislators to vote in favor of HB442!! If you live in Missouri, please

consider contacting your Missouri State Representative and Senator via phone or email. Ask them to support HB442! Scan the QR code to find your legislators here:

Thank you to Rep. Wright for introducing the HB442 & Rep. Stephens, Health & Mental Health Committee Chair, for your swift action to get this bill heard. If you have been directly affected by a copay accumulator adjuster/maximizer, please contact Angela Brown immediately at 816-479-5900 or info@midwesthemophilia.org





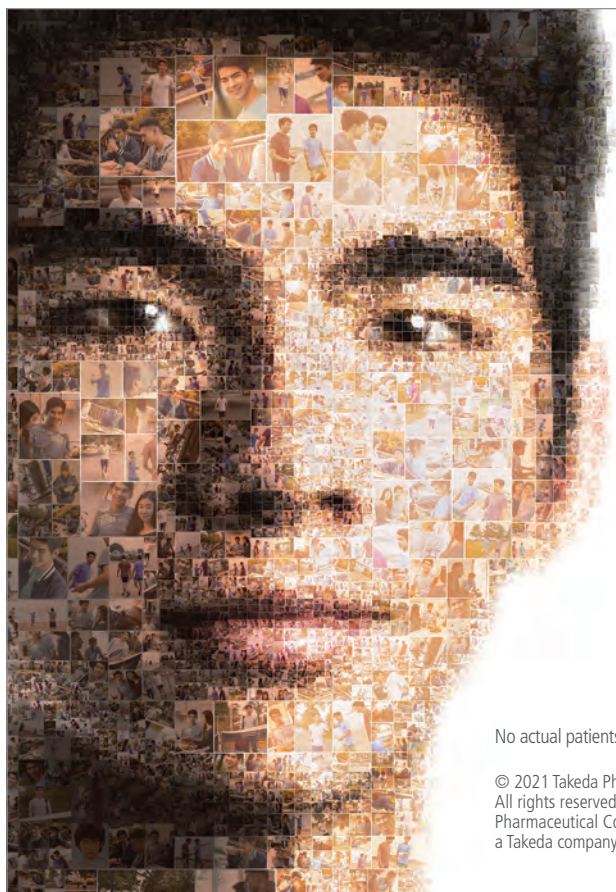
Jivi[®], now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.



Scan this QR code to learn more
about the data at
JiviExtensionStudy.com

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




ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

TALK TO YOUR DOCTOR TO SEE IF
ADYNOVATE[®] MAY BE RIGHT FOR YOU.

For more information, please visit
AdynovateRealLife.com.

No actual patients depicted.

© 2021 Takeda Pharmaceuticals U.S.A., Inc. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088.
All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda
Pharmaceutical Company Limited. ADYNOVATE is a registered trademark of Baxalta Incorporated,
a Takeda company. US-ADY-0326v2.0 05/21



HERE WE GO!

Hey Campers! I want to personally invite you to 2023 Camp Wilderness happening July 24th-28th as it promises to be your best week ever! Be prepared to use your brains and brawn as you work with Mario, Luigi, and Princess Peach to defeat the evil Bowser. I hope you will join us on this most excellent adventure.

We are also planning a wonderful 30th Anniversary Celebration this year and invite ALL Camp Alumni (campers, volunteers, and medical staff) to join us. Lake Doniphan Conference & Retreat Center in Excelsior Springs will once again be our host. Please help us spread the word. If you know anyone who has attended Camp Wilderness in years past let them know we want them back to celebrate with us Friday, July 28th at 11AM!

As always I look forward to everything that camp provides...life-long friendships, learning new skills, bleeding disorder education, personal growth, independence, and more. I know this year will be extra special with our 30th Celebration! Come be part of the fun and excitement!

If you would like more information about Camp Wilderness or want to be involved in the planning of the Alumni Celebration contact me at campdirector@midwesthemophilia.org. You can also visit MHA's website: www.midwesthemophilia.org for details and information.

Let's-a-go!

-- Luke Saulsberry, MHA Camp Director



A colorful poster for the 2023 Camp Wilderness event. The top left features the text '2023 CAMP WILDERNESS' in large, bold, black letters. Below this, it says 'MONDAY JULY 24 - FRIDAY JULY 28' and '★★NEW DATES★★'. To the right of the main title is a logo for 'CAMP WILDERNESS' featuring a sun and mountains. Further right, the text '30TH ANNIVERSARY' is written in a stylized, bubbly font, with 'NINTENDO AND MARIO THEME IS SET TO BE A BLAST!' and 'YOU DON'T WANT TO MISS THIS...' below it. In the bottom left corner, there is a QR code with the text 'DON'T FORGET TO REGISTER HERE' and an arrow pointing to it. The bottom right corner features the text 'CAMP ALUMNI CELEBRATION' and 'Friday July 28, 2023 @ 11AM', followed by a list of activities: 'REMINISCE', 'COMMEMORATE', 'SHARE STORIES', and 'SPECIAL AWARDS'. The poster also includes images of Mario, Luigi, Princess Peach, and Toad. The background is a mix of blue, yellow, and red.



APPLY FOR MHA'S ACADEMIC SCHOLARSHIPS

2023-2024 Academic Year

Applications open
January 1, 2023

Visit midwesthemophilia.org
or scan the QR code.







REGISTRATION DRIVE

- 1 Register for your local Unite for Bleeding Disorders Walk
- 2 Make or receive a donation of \$25 between March 1-March 31
- 3 Be entered to win one of FIVE \$250 Amazon gift cards provided by  NATIONAL HEMOPHILIA FOUNDATION for all bleeding disorders



REGISTER NOW!
Scan the code to find your local walk

Sponsored by:  **CVS specialty**

FIVE CHANCES TO WIN! IT'S THAT EASY!

World Bleeding Disorders Registry expands to include people with VWD

In 2018, the World Federation of Hemophilia (WFH) launched the World Bleeding Disorders Registry (WBDR), providing hemophilia treatment centres (HTCs) with a simple solution to collect data on people with hemophilia (PWH). Today, the WFH is very proud to announce that the platform has expanded to include von Willebrand disease (VWD). This makes it the first global registry collecting standardized clinical data on people with VWD.

With up to 1% of the world's population suffering from von Willebrand disease (VWD), it is by far the most common type of bleeding disorder. However, significant lack of data on people with VWD remains a major challenge to effectively diagnose and manage this disease. By adding VWD to

the WBDR platform, the WFH will be able to address a major gap in bleeding disorders data. This is an important development for our community, because

“While von Willebrand disease is the most common inherited bleeding disorder, there is a great deal of variability in how VWD is diagnosed and managed around the world. The inclusion of VWD in the WBDR will allow scientists, policy makers, and stakeholders to better understand the ways in which care for VWD is delivered, while helping them work toward improved care and quality of life globally.

— Nathan Connell, MD MPH, WBDR-VWD Working Group, co-author of VWD diagnosis and management guidelines

WBDR data are invaluable for evidence-based advocacy, research, and for improving clinical practice.

Using the registry, healthcare practitioners will be able to address important research questions in the field, patient advocates can conduct evidence-based advocacy initiatives, and people with VWD from across the world can

play an integral role in advancing the knowledge and management of the most common bleeding disorder. The VWD core dataset was developed by a dedicated working group of world renowned experts in the field of VWD diagnosis and management, in collaboration with the WFH von Willebrand Disease and Rare Bleeding Disorders (VWD-RBD) Committee and the WBDR Steering Committee.

The WFH encourages HTCs and NMOs to join this important initiative. By contributing VWD data to the WBDR, you can help us advance the understanding of this bleeding disorder that affects so many people around the world.

HTCs wishing to join the WBDR to collect data on hemophilia and VWD, or NMOs wishing to promote it, can contact the WFH at WBDR@WFH.org.

Source: Published February 13, 2023 by World Federation of Hemophilia, www.wfh.org.

Community Outreach Programs

continue to be a great way to connect throughout the year with local MHA individuals and families. Be on the lookout for the next C.O.P. near you! Thank you to our industry sponsors.



NHF Responds to FDA's Proposed Blood Donation Changes

On January 27, 2023, the United States Food and Drug Administration (FDA) announced proposed changes to blood donation policies that will likely take effect later this year. The policy change addresses the donation possibilities for men who have sex with men (MSM) that has long been a point of scrutiny/ contention within the bleeding disorders and LGBTQ+ communities. The new policy would call for an individualized risk assessment for all donors, with the same standards for all regardless of their gender or sexual orientation.

The National Hemophilia Foundation (NHF) has long advocated that any policy change should be based in science and ensure there is no additional risk to end users of blood and plasma-derived products. The announcement of the proposed policy change is accompanied by a 60 day comment period whereby individual and organizations may register their concerns and questions to the federal government before the policy change is finalized. NHF looks forward to submitting comments on behalf of the inherited blood disorders community.

“The proposed FDA policy change for MSM donors comes after decades of advocacy from many communities that desire an equitable, reasonable direction that ensures the largest number of healthy eligible donors, and simultaneously fully ensures the safety of blood and plasma donations for end users,” said Nathan Schaefer, NHF’s vice president of public policy. “The United States is now considering implementing a policy that is aligned with scientific advancements in the collection, surveillance, and distribution of blood and plasma. After years of advocacy for a science-based approach, NHF applauds this change that will address the long-standing concerns of discrimination experienced by members of the LGBTQ+ community.”

Similar policy changes have been implemented in other countries in recent years, notably Canada last year. Individuals who wish to submit their concerns and questions to NHF are encouraged to do so via advocate@hemophilia.org.

Source: National Hemophilia Foundation, www.hemophilia.org



Unite

for Bleeding Disorders



11th Annual Walk

Saturday, June 3, 2023

9:30 to Noon (Check-in: 9:30 - 10:00 am)

Shawnee Mission Park-Shelter 1,
7900 Renner Rd, Shawnee, KS 66219

Contact Angela Brown: 816.479.5900

www.uniteforbleedingdisorders.org



**YOU ARE INVITED TO START A TEAM, JOIN A TEAM,
OR MAKE A DONATION.**

Then plan to celebrate with us Saturday, June 3, 2023 at Shawnee Mission Park, Shelter #1 in Shawnee, KS! This day is about more than just about fundraising...it's a day to UNITE for hope, UNITE for community, and UNITE to make a difference. Your dedication and support to this important fundraiser allows us to continue our mission: to improve the quality of life for those affected by bleeding disorders through education, advocacy, and support.

UNITED... WE CAN REACH OUR \$30,000 GOAL!

Registered participants who make a \$25 minimum donation will receive a 2023 UNITE for Bleeding Disorders T-Shirt. Individuals who raise a minimum of \$500 will be inducted into the Factor Club!

**ADDITIONAL INCENTIVES CAN BE FOUND ON THE WALK WEBSITE.
100% OF ALL DONATIONS AND SPONSORSHIPS RAISED GO DIRECTLY TO OUR CHAPTER.**

*Do you know a small business who would like to sponsor the walk?
Contact Angela Brown, 816-479-5900, for details on how to connect.*

MOVING? NEW ADDRESS?

Update your contact information by visiting MidwestHemophilia.org and clicking on the "Become a Member" tab. Once complete, click JOIN and you're done!



Midwest Hemophilia Association

1471 W. South St, Suite F
Ozark, MO 65721

GEORGE KING BIO-MEDICAL, INC.

-Since 1973-

Are you able donate plasma when
you have a severe bleeding disorder?
In many cases the answer is yes!

- WHERE? FDA Licensed Specialty Source
Plasma Centers with a doctor
on staff
- WHY? To continue proper diagnosis
for others & to further research
worldwide
- WHO? We're currently adding FV,
FVII, FVIII, FIX, FX, FXI, FXII,
FXIII, and all types of Von
Willebrand Disease



Our Founder &
Former NHF
President

**Help research &
earn money by safely
donating plasma!**

Contact Us!



11771 W 112th Street
Overland Park, KS 66210
913-469-5464 (KING)
plasma@kingbiomed.com
www.kingbiomed.com



Celebrating **50** years of excellence!
1973-2023