

CHAPTER *Factors*

SUMMER 2023



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Association**



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Chapter Factors is published by:

**The Midwest
Hemophilia Association**

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FROM THE EXECUTIVE DIRECTOR



I recently ran across an amusing story while searching for some kind of thought, idea, or encouraging words to share with my nephew who was graduating. I decided to share the story here. I hope you enjoy it.

One night four college students were out partying late and didn't study for the test which was scheduled for the next day. In the morning, they thought of a plan. They made themselves look dirty with grease and dirt. Then they went to the Dean and said they had been at a wedding last night and on their way back the tire of their car burst and they had to push the car all the way back. So they were in no condition to take the test.

The Dean thought for a minute and told them they could take a re-test in 3 days. They thanked him and said they would be ready by that time.

On the third day, they appeared before the Dean. The Dean said that as this was a special condition test, all four were required to sit in separate classrooms for the test. They all agreed as they had prepared well in the last 3 days. The test consisted of only 2 questions with a total of 100 points: 1) What is your name? (1 point) 2) Which tire burst? (99 points). Moral of the story: Take responsibility or you will learn your lesson.

Author Unknown

Have a great summer!

Angela Brown

angela.brown@midwesthemophilia.org



Midwest Hemophilia Association
board meeting
2023

MHA's Board of Director meetings are open to the public.
If you would like more information about attending and/or have interest in serving on the Board of Directors, please contact the office at 816-479-5900.



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**





QUICK NOTES

MHA to Hold Free Raffle for Gettin' in the Game Jr. National Championship

Calling all parents and guardians of 7-18 year olds! MHA would like to nominate two of our youth to represent the MHA chapter at the 2023 Gettin' in the Game Junior National Championship in Henderson, Nevada, October 6-18th. Be watching our social media channels and your email inboxes for details on how to add your child on MHA's "Wheel of Names" which will randomly choose this year's winners. Nominees will take part in baseball, basketball, golf, or swimming activities to learn the fundamentals and enhance their skills in that sport, learn about the importance of physical fitness in managing a bleeding disorder, receive instructions on proper stretching techniques and good athletic form, and show off their abilities in a national competition with fellow nominees from around the country. Hotel, airfare, and onsite meal costs sponsored by CSL Behring. *Nominees must be diagnosed with a bleeding disorder.

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national sports competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game Athletes who themselves have been diagnosed with a bleeding disorder.



Online Registration Open!

MHA will co-host the annual women's retreat with Hemophilia of Iowa, Gateway Hemophilia Association, and the Nebraska Chapter of NHF. Ladies 18 years+ who live in the coverage area of the four host chapters and have been diagnosed with a bleeding disorder, are carriers, spouses of a person with a bleeding disorder, and/or parents of a child with a bleeding disorder are welcome to attend.

You don't want to miss the opportunity to learn, grow, and support each other. Sessions will focus on bleeding disorders, treatment options, and relaxation! There is a non-refundable \$20 registration fee which helps offset the cost of your room, meals, and conference materials. Registration closes September 9th.

Scan to Register!



MHA Hosts 25th Annual Golf Tournament

MHA will celebrate its 25th year of hosting their annual golf tournament fundraiser at Winterstone Golf Course, in Independence, Missouri, on Friday, September 22, 2023. To add to the celebration a NEW award will be added for the "Best Dressed Golfer". Get your golf team together and join us for a fun and friendly competition on the greens! Don't play golf? Help us spread the word! Contact the MHA office, 816-479-5900 or info@midwesthemophilia.org, for brochures you can give out and share on your social media platforms. See page 8 of this issue for more details.

Congrats to Team Educating for Evan

Team Educating for Evan were 1 of 5 winners across the country of a \$250 Amazon gift certificate from the Unite for a Bleeding Disorders CVS registration drive. Congrats!!



HFA Names New CEO

The Board of Directors of Hemophilia Federation of America (HFA) unanimously selected Dan Kelsey as HFA's new Chief Executive Officer (CEO) on April 7, 2023. Mr. Kelsey joined the HFA team on April 12 and kicked off his work at the annual Symposium in Orlando, Florida.



NHF Hosts Multiple Unite Walk Trainings

In order to assist local chapters with planning and organizing their local Unite for Bleeding Disorders, NHF is hosting



Sip! Sip! HOORAY for MHA!

Live Music, laughter, drinks with friends and family, delicious food, and great silent auction items were all part of the Midwest Hemophilia's first ever wine and bourbon tasting fundraiser, "Sip! Sip! Hooray for MHA!" The event took place at Llywelyn's Pub in Lee's Summit, Missouri, with live music provided by Ashlynn Grey & Willkie Jay and a special guest performance by Ryan Wornall and Stephanie Born. Together everyone helped raise over \$2,000 for our Emergency Financial Assistance and Academic Scholarship funds. Thank you to everyone who came out to support us.

A special thanks to our planning committee: Stephen DiCapo, Dave Todd, and Anne Parrott. Also thank you to our event sponsors: CSL Behring, Medexus Pharma, Bayer, George King Bio-Medical, InfucareRx, and Octapharma.



multiple mini-training groups across the country. MHA participated in Chicago in March hosted at Takeda's U.S. headquarter facilities in Deerfield, Illinois. Six chapters gathered to learn, collaborate, and share ideas. (photo below)

If you are interested in joining the 2024 MHA Unite walk committee, please contact the MHA office, 816.479.5900. We would love to develop a strong working group to make our Unite walk better than ever!!



CALENDAR OF EVENTS

JULY

- 10 Young Women's BD Clinic (KC HTC)
- 10 Community Outreach Program: KC
- 23 Camp Wilderness Staff Training
- 24-28 Camp Wilderness

AUGUST

- 4 Community Outreach Program: KC
- 5 Board Meeting
- 10 Community Outreach Program: Topeka
- 17-19 NHF BDC

SEPTEMBER

- 19 Community Outreach Program: Springfield
- 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 BINGO for Bleeders Fundraiser

NOVEMBER

- 4 Springfield Education Day
- 18 Community Outreach Program: Wichita

DECEMBER

- 2 MHA Holiday Celebration



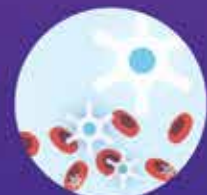
Get to know
the science
behind:



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

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Men's Retreat 2023...

A change in latitude, a change in **attitude!**

By John Carleton

Margaritaville was again the site for our second Mens Retreat. On March 24-26 fifteen men from Gateway and Midwest Hemophilia gathered for a weekend of information, bonding and relaxation. Dr. Blinder was our keynote speaker and shared the history of hemophilia from ancient Russia to the present. The presentation was informative and, based on the response of attendees was very well received. It is always a good thing to remember our past and the many challenges our community has overcome.

During the afternoon we were divided into teams and played a form of Family Feud engineered by BioMarin and emceed by Charles Spalding from the BioMarin team in California. Most of the questions revolved around the issues and challenges shared by those in the bleeding disorder community. The program was enjoyed by all and provided food for thought and later discussions.

Saturday evening was highlighted by our signature event... the infamous Chili Cookoff. The men were divided into five teams and provided the ingredients to make chili. Once finished, a team of highly qualified judges awarded certificates for the Best Chili, Best Presentation, and Most Unique. I [John] was one of the judges, and with the help of two of the wait staff, determined the winners. We certainly felt that by virtue of eating everyday of our lives we were "highly qualified" to judge. We ended up feasting on everyone's chili and assorted sides provided by Margaritaville.

Events of this sort do not happen without a lot of work behind the scenes. A BIG thank you to Angela Brown and Bridget Tyrey for all of the prep work and organization. BioMarin funded the retreat last year and again this year. None of this could have happened without their generous support.

I think we are well on our way to making this a yearly gathering. The only thing missing were the numerous men in both organizations that could have participated. If you're one of those men remember the theme of Margaritaville...A change of latitude, a change of attitude!





**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.

25TH ANNUAL MHA GOLF TOURNAMENT

**@WINTERSTONE GOLF COURSE
INDEPENDENCE, MO**

FRIDAY, SEPTEMBER 22, 2023

7AM CHECK IN | 8AM TEE TIME





HFA Symposium

**April 13-16, 2023
Orlando, Florida**

Over 1,000 children and adults attended the Hemophilia Federation of America's Symposium in Orlando, Florida, April 13-16, 2023. This year's theme was "Past. Present. Future." There was a variety of educational sessions presented in both English and Spanish which covered topics such as: Spouses & Partners, Mild Matters, VWD, Lean on Me physical therapy, Aging with HIV, Women with Hemophilia, Inhibitors 101, Overcoming Insurance Barriers, and much more. Also highlighted was special Guest, Robert C. Cooper, Blood Brother and multi-award winning writer, director, and executive producer who brought Episode 8 of his "Unspeakable" series for a screening. Based on first-person experiences, "Bad Blood" written by Vic Parsons and "The Gift of Death" by Andre Picard, "Unspeakable" is a mini-series that chronicles the emergence of HIV/AIDS and hepatitis throughout Canada during the 1980-90s and the tragedy that resulted after thousands with bleeding disorders were infected by tainted blood. A follow-up rap session called, "Unspeakable" Let's Talk About It, followed with a panel Q & A.

Some new interactive activities were also offered this year, one of which included an Art Lounge where attendees could express themselves and tell their stories through multiple art mediums such as quilting, journaling, sculpting, and coloring. Another hand-one activity was the Memorial Video Booth where people could record a special memorial message for a loved one. Symposium closed with their annual award ceremony and entry to SeaWorld!

Be sure to mark your calendars to attend HFA Symposium 2024 to be held in Indianapolis, Indiana, April 11-13th!





JOB READINESS GRANT

The Job Readiness Grant provides up to \$1,000 for a skills course, certification, or training.

The grant can also cover materials needed to access the course such as a computer, specialized uniform, or supplies.

Applications are processed as soon as they are received with payments and materials provided within one month of applying.

CONTACT US

If you have questions or need assistance, please contact the Helping Hands staff at:

helpinghands@hemophiliafed.org
202-675-8894

USE THE QR CODE TO APPLY!



HELPING FORWARD

EXAMPLE TRAININGS:

- Phlebotomy technician certification
- Customer service
- Dog groomer
- Medical billing and coding
- Salesforce administrator
- Veterinary assistant
- Marketing and event planning
- Fitness and nutrition coach
- Peer support specialist
- Foreign language
- Project management
- SQL certification
- Course plus subscription
- Electrician apprenticeship
- And many many more!

ELIGIBILITY

- Have a diagnosed bleeding disorder or are a carrier
- An adult between 18 to 64 years old
- Seeking assistance for a skills course, certification, or training program (college courses considered)
- Not a past recipient of a Job Readiness Grant, an HFA board member, an HFA staff member, or the immediate family members of HFA board or staff members.

APPLICATION

- ✓ Complete the brief online application
- ✓ Provide a brief statement about the barriers to employment you have faced and how the specific course, certification, or program will help you gain or keep sustainable employment
- ✓ Proof of a bleeding disorder
- ✓ Your resume
- ✓ Documentation of the course, certification, or program cost
- ✓ A reference letter (optional)

Registration Open For Family Education Weekend!

**September 23-24, 2023
Sheraton KC @ Crown Center**

**You don't want to miss
Family Education
Weekend 2023!**

FEW is an opportunity for the entire family to connect with others, learn valuable information, and find support relative to bleeding disorders. MHA's annual conference will include a keynote speaker, educational breakouts, an exhibit hall, childcare, youth & teen programs, raffles, a chance to win a trip to NHF's 2024 BDC, and plenty of time for fun! Be sure to register today!



**Scan To
Register!**



**To register, please visit
www.midwesthemophilia.org**

*Deadline to register is Friday, August 25th, 4:00pm (CST)
to guarantee a hotel room.*

Congratulations

TO OUR 2023 GRADUATES



Arreana Mendoza

PARENTS: Sarah & Antonio Garcia
GRADUATED FROM: Rockhurst University
FUTURE PLANS: Go back to school to get her Masters
MESSAGE TO GRAD: We are so proud of you!!!



Daytonna Moore

PARENTS: Lori and Chad moore
GRADUATED FROM: North Callaway High School
FUTURE PLANS: Nursing school



James Hensley

PARENT: Lisa Hensley
GRADUATED FROM: Manhattan HS
FUTURE PLANS: Virginia Tech Honors program
MESSAGE TO GRAD: Super proud of this young man. I have learned more from him than he has from me. He continues to inspire me every day. Being his parent has made me a better person. I am so proud of all he has accomplished, the grace with which he has faced challenges and the outstanding man he has become. He is my superhero!



James Snarey

SPOUSE: Mareena Snarey
GRADUATED FROM: Brigham Young University- Idaho
FUTURE PLANS: Continue Working in the IT field
MESSAGE TO GRAD: You ROCK!! Thanks for enduring to the bitter end to achieve your degree.



Sarah Garcia

SPOUSE: Antonio Garcia
PARENTS: MaryJane & Boneyfacio Mangaser
GRADUATED FROM: MCC
FUTURE PLANS: Continue schooling to become a registered dietitian



Shawn Wornall

PARENTS: Kelly & Ben Wornall
GRADUATED FROM: Saint James Academy
FUTURE PLANS: Attending University of Kansas, the School of Engineering
MESSAGE TO GRAD: We're incredibly proud of you & your accomplishments!



Shelby Lingle

PARENTS: Ryan and Jessica Lingle
GRADUATED FROM: North Platte High School
FUTURE PLANS: Attending Kanas Wesleyan University to pursue a degree in Athletics Training. Shelby will run Cross Country and Track for the Univetsity
MESSAGE TO GRAD: We are so proud of you and all your hard work kiddo!



Thank you every donor, walker, team captain, team, sponsor, & volunteer who helped make this year's Unite for Bleeding Disorders walk a success! United, you raised \$24,952 for MHA!!

For anyone who would like to continue (or start) to raise funds, the Unite Walk website will remain open to accept donations until December 1, 2023!

Anyone reaching a milestone towards the incentives prizes and/or Factor Club requirements will receive prizes while supplies last!!

To find out how you can host your own backyard UNITE celebration before the end of the year, contact the MHA office.

Unite

for Bleeding Disorders





MHA



ADVOCACY

Angela Brown, Executive Director of MHA, attended NHF's Washington Days held on March 8-10, 2023 in Washington DC to meet with legislators on behalf of MHA's members affected by bleeding disorders. Washington Days is an opportunity for the bleeding disorders community from across the United States to educate legislators about issues that matter to them.

She was not alone in her efforts as nearly 400 advocates of all ages and diagnosis representing 52 chapters and 45 states plus Puerto Rico also joined the efforts. During the 250+ meetings on Capitol Hill this year, advocates shared about what daily life is like living with a bleeding disorder as well as the continued need for funding federal programs such as the Center for Disease Control & Prevention (CDC), the Health Resources and Services Administration (HRSA), the National Institute of Health (NIH), and the National Heart Lung and Blood Institute (NHLBI).

Advocates were also seeking additional legislative champions to support the HELP Copays Act (H.R. 830), a bi-partisan bill that would ban insurance accumulator adjustment programs. House members were asked to co-sponsor H.R. 803 while Senators

were asked to introduce a companion bill. Introduced by U.S. Representative Buddy Carter (R-GA) and Congresswoman Nanette Barragan (D-GA), the bill clarifies the Affordable Care Act's definition for cost sharing to ensure payments made "by or on behalf of" patients counts towards their deductibles and out-of-pocket costs. If passed it would close an essential health benefit (EHB) loophole, making any covered item or service of the EHB package, so that all cost sharing counts.



UPDATE:

House: The House version of the bill, H.R. 830, is now up to 38 co-sponsors!

Senate: The Senate version of the bill was introduced in early May! S. 1375 was introduced by Senators Marshall (R-KS), Kaine (D-VA), Murkowski (R-AK), Ernst (R-IA) and Markey (D-MA) and since then, Senators Warren (D-MA) and Mullin (R-OK) have been added as co-sponsors.



ACY



MISSOURI ALL COPAYS COUNT COALITION

As part of the Missouri All Copays Count Coalition, MHA Missouri Advocacy efforts have extended beyond our initial advocacy day in February to attempt to get HB 442, a bill that would prevent many insurance policies from implementing Copay Accumulator Adjustment Programs (CAAPs). MHA advocates returned multiple times to Jefferson City in March, April, and May seeking support and providing testimony on the Senate side. Despite their efforts and the bill passing out of the Senate General Laws Committee and being put on the Senate calendar for debate, time simply ran out as this legislative session was adjourned late Friday, May 12.

Efforts will continue throughout the summer to connect with legislators while in their local/home offices and resume in September when they reconvene. Please reach out to the MHA office if you have been directly affected by an accumulator in your insurance plan. Please contact the MHA office if you have experienced the negative effects of a CAAP and/or you would like to get involved in advocacy with the chapter (Kansas OR Missouri side)

The problem: Copay Accumulator Adjustment Programs (CAAPs). Patients with complex and chronic illnesses often rely on copay assistance programs to afford the specialty medications essential to their health. These funds from manufacturers and nonprofit organizations help patients afford their treatments--medications that rarely have generic alternatives. Increasingly, health insurance companies are using "copay accumulator adjustment programs" which exclude copay assistance payments from counting toward a patient's annual deductible or out-of-pocket maximum. In effect, the insurer demands double payment of out-of-pocket costs: first from the copay assistance and then again from the patients.

Copay accumulator adjustment programs harm patients by undermining access to life-saving prescription drugs, making it more difficult for people living with chronic illnesses to adhere to a treatment plan.

Visit AllCopaysCount.org



Rep. Wright exchanges a witty comment to Stephen D., MHA Advocate.



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

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Hemophilia Community Liaison

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816-830-1813



SUPERIOR BIOLOGICS

Inhibitor Risk Paper Informed by Genotyping Project

Between 2013-2017, the “My Life Our Future” (MLOF) project offered eligible individuals with hemophilia free genotyping, which is historically hard to access, expensive, and not covered by insurance. Conducted through the laboratory analysis of a single blood sample, genotyping can reveal the specific genetic mutation responsible for a patient’s disease such as those located in the factor VIII and factor IX genes in the case of hemophilia A (HA) and hemophilia B respectively.

MLOF was a partnership between the hemophilia community, the National Hemophilia Foundation, American Thrombosis and Hemostasis Network (ATHN), Bloodworks Northwest, and Bioverativ/Sanofi (formerly Biogen). Individuals who participated in the program could also opt – via informed consent – to have a blood sample with their de-identified genome sequence data deposited into the MLOF Research Repository. Investigators could apply for access to the database to support their research, with acceptance contingent upon their ability to demonstrate both scientific merit and ultimate benefit to patients.

Ultimately, samples from more than 6,000 individuals were included in the repository to help advance the scientific understanding of the disorder. MLOF was a boon to researchers, particularly to those looking to better understand the genetic differences that affect bleeding severity and reactions to certain therapies. One such example is a new paper “Race, Ethnicity, F8 Variants, and Inhibitor Risk: Analysis of the ‘My Life Our Future’

Hemophilia A Database,” published in the *Journal of Thrombosis and Haemostasis*.

Armed with ample collection of samples generated by MLOF, the authors of the paper sought to investigate some existing hypotheses related to inhibitor risk amongst individuals with HA.

A total of 4169 subjects were included in the primary analysis, 2,443 with severe HA and 1726 with mild or moderate HA – this analysis examined several key variables including demographic, clinical, factor VIII gene (F8) sequence data. Investigators found

*...genotyping
can reveal the
specific genetic
mutation
responsible
for a patient’s
disease...*



inhibitor incidences of 30.3% in those with severe HA and 7.9% in the mild/moderate group. In the severe group, 1075 (44%) had an intron-22 inversion mutation of the F8 gene, and of those, 388 (36.1%) developed an inhibitor.

The result of a crossing over between two linked gene pairs of the same chromosome, intron 22 inversions account for nearly 50% of severe hemophilia A cases. Investigators sought to determine whether inhibitor risk associated with these type mutations are

similar to those associated with other large structural changes in the F8 gene. They ultimately found no difference in inhibitor risk amongst those severe HA participants with an intron-22 inversion vs other large structural changes in the F8 gene.

The authors also looked at another hypothesis informed by earlier research which suggested that increased inhibitor risk could be caused by specific mutations known as non-HA causing, non-synonymous single nucleotide polymorphisms (nsSNPs). Often associated with disease, nsSNPs are caused by a change to the amino acid sequence of a genetically encoded protein. In fact, the analysis showed that nonpathogenic ns-SNPs in the F8 were not associated with inhibitor development.

The analysis also confirmed earlier studies suggesting an increased risk for FVIII inhibitor development in both Black/African American and Hispanic HA patients, relative to White non-Hispanic individuals with HA in the U.S.

Investigators signaled the potential implications of this study, and future research, in helping to inform therapeutic plans that better anticipate inhibitor risk.

“It is hoped that future studies, e.g., whole-genome sequence analyses to detect genetic variations contributing to inhibitor risk, will identify specific, clinically actionable genetic correlates indicating increased susceptibility to, or protection from, hemophilic inhibitor development and possibly suggesting novel therapeutic interventions to promote immune tolerance to FVIII,” concluded the authors.

Citation Ahmed AE, Pratt KP. Race, ethnicity, F8 variants, and inhibitor risk: analysis of the “My Life Our Future” hemophilia A database. *J Thromb Haemost*. 2023 Apr;21(4):800-813. doi: 10.1016/j.jtha.2022.12.017. Epub 2022 Dec 26. Erratum in: *J Thromb Haemost*. 2023 Apr 25;: PMID: 36696179.

Visit the *Journal of Thrombosis and Haemostasis* to view the abstract.

NOTE: Corrigendum to ‘Race, ethnicity, F8 variants and inhibitor risk: Analysis of the “My Life Our Future” Hemophilia A database’ [*Journal of Thrombosis and Haemostasis* Volume 21, Issue 4, April 2023, Pages 800-813]

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.

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 section features the text '2023 CAMP WILDERNESS' in large, bold, black letters. To the right is a logo for 'CAMP WILDERNESS' featuring a sun and mountains. Further right, it says '30TH ANNIVERSARY' in a stylized font, with 'YOU DON'T WANT TO MISS THIS...' below it. The middle section is divided into four colored squares: green (top left), yellow (top right), red (bottom left), and blue (bottom right). The green square contains the text 'MONDAY JULY 24 - FRIDAY JULY 28' and 'NEW DATES'. The red square contains a QR code and the text 'DON'T FORGET TO REGISTER HERE'. The blue square contains a small Mario character and the text 'CAMP ALUMNI CELEBRATION Friday July 28, 2023 @ 11AM'. The yellow square contains the text 'REMINISCE COMMEMORATE SHARE STORIES SPECIAL AWARDS'. The bottom of the poster features a green grassy field and a brown dirt path. The Midwest Hemophilia Association logo is in the bottom left corner.

COMMUNICATING *with the HTC*

by Veronica Vann

How often do you communicate with your Hematologist about your bleeding disorder? When you go to your annual comprehensive clinic, have you forgotten everything you wanted to talk to your doctor about? Have you forgotten all the bleeds you have had in the past year?

We often run into these issues with our patients and their families. And let's be honest, a lot can happen in a year! To help you remember bleed reports to share with your doctor, we recommend getting an app or emailing us directly! It really helps your HTC troubleshoot your needs if you communicate your bleeding episodes to your doctor as soon as possible. Sometimes in discovering frequent or spontaneous bleeding episodes, we, as your HTC, realize your factor or treatment product doses need to be adjusted, you may need to be dosed more frequently, or we might need to discuss other treatment product options that might

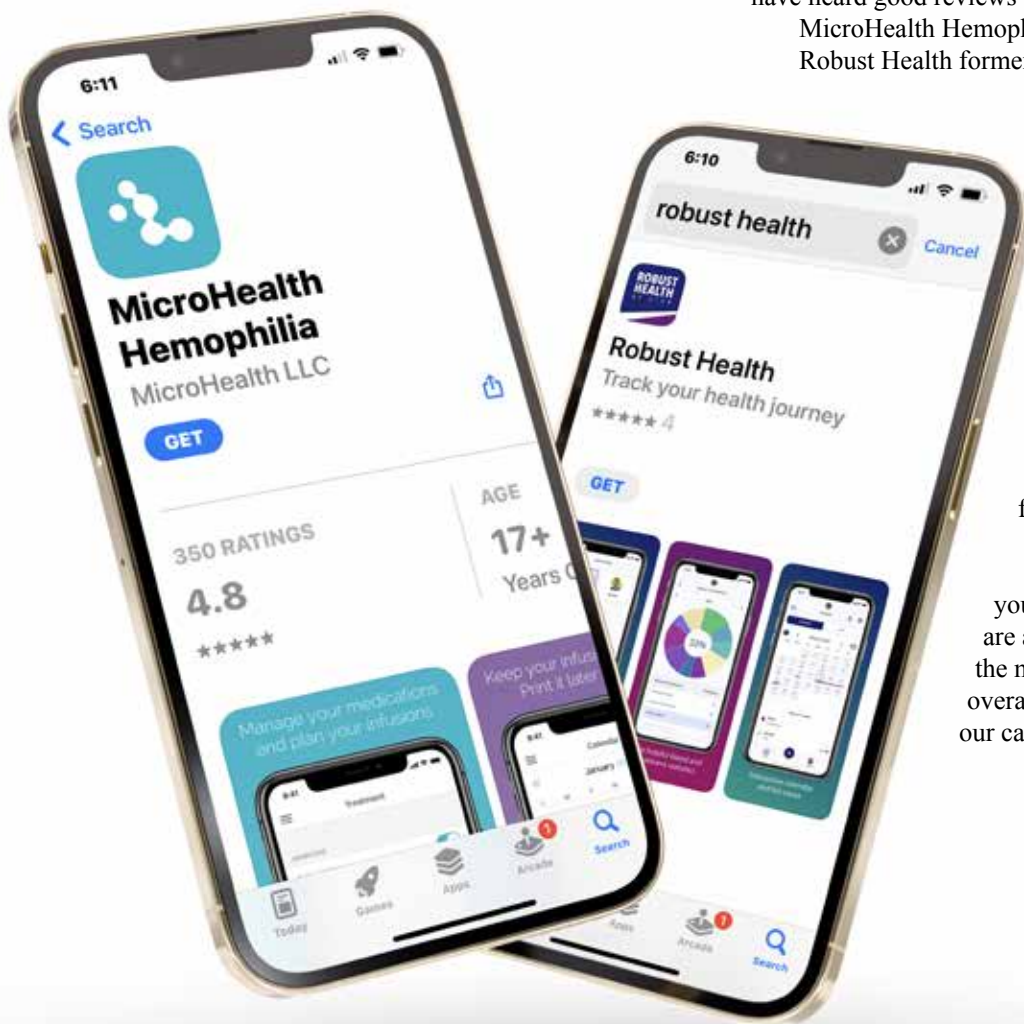
be more beneficial to your current lifestyle. Keeping an open line of communication with your HTC can help discover these issues a lot sooner than waiting until your next appointment.

Your HTC can be reached multiple ways. We are available by phone Monday through Friday 8am to 5pm for any emergency or non-emergency at 816-302-6869. If you have an emergency (such as an active bleed) during this time frame, please let our administrative assistants know you have a bleed and need a Hemophilia provider paged. If you have a question or concern that is not related to an active bleed, you can leave a voicemail for us and one of our team members will get back to you within 24 business hours. We also have an email that is monitored regularly during office hours. Our email is htc@cmh.edu.

In reference to the list of apps, we do not promote certain apps over any others but here is a list of some of the ones we have heard good reviews for:

MicroHealth Hemophilia

Robust Health formerly ATHN Advoy



Apps such as these, allow you to easily share bleed reports also known as “treatment logs” with us. We often need these logs for multiple reasons including treatment plan updates and health insurance requirements of medication authorization approvals. Our team does not communicate with these apps regularly, therefore the patient and their family are still responsible in communicating frequency of bleeding episodes.

Your HTC would love to hear from you regarding bleed related concerns. We are always here to help with guidance on the management of bleeding and improving overall bleeding health of everyone under our care.



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Community Outreach Programs



Recent Community Outreach Programs have highlighted gene therapy, joint health, and exercise.





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.

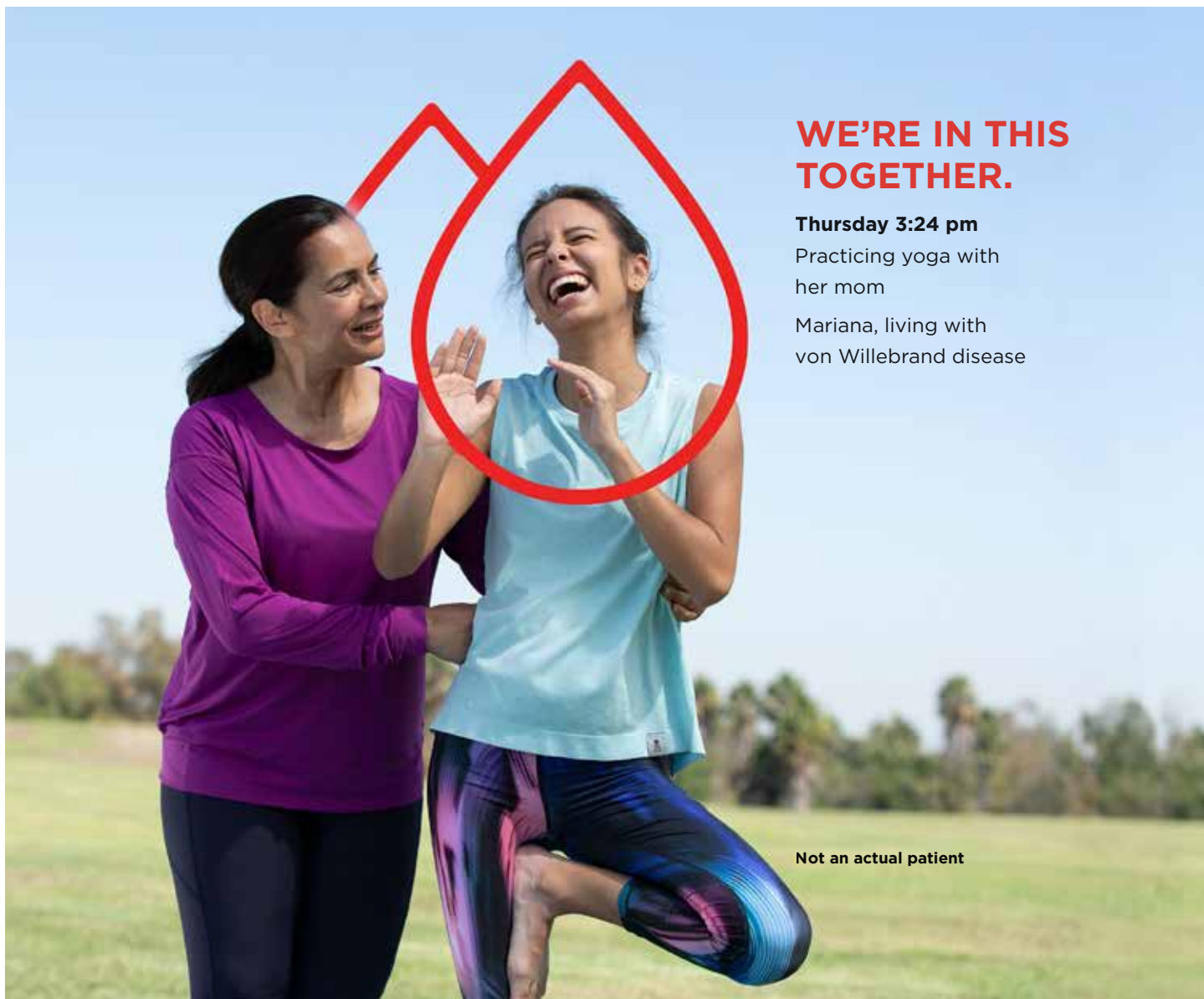
The authors emphasized the need for healthcare providers to "tactfully" provide anticipatory guidance and counseling for these mothers. They also suggested some positive takeaways.

"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





WE'RE IN THIS TOGETHER.

Thursday 3:24 pm

Practicing yoga with
her mom

Mariana, living with
von Willebrand disease

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 adult patients with von Willebrand disease is stronger than ever.

*Not all activities are appropriate for all individuals.
Consult your doctor prior to engaging in any activity.*

 bleedingdisorders.com | 

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STAY CONNECTED!

Update your contact information or join MHA by visiting midwesthemophilia.org or scan the QR code. Click on the "Become A Member" tab.



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