CHAPTER Factors

SPRING 2022

Midwest Hemophilia Association

Unite
for Bleeding Disorders

SATURDAY, JUNE 11, 2022

@ Heritage Park – 16050 S Pflumm Road, Olathe, Kansas

Additional incentives for Team Captains include one-of-a-kind Unite shoelaces, car magnet, socks, or a beach towel. Anyone raising $500+ will be inducted into the Factor Club!

Scan the QR code to start a team, join a team, or donate today! Then plan to celebrate with us as we walk to honor our bleeding disorders community–past, present, and future.

This family-friendly event is open to the public and will include breakfast, yard games, playground equipment, & fun for everyone! Dogs on leashes welcome!

Registered participants who make a $25 minimum donation will receive the 2022 UNITE for Bleeding Disorders T-shirt!

SPRING 2022 • Volume 32 Number 1

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

FROM THE EXECUTIVE DIRECTOR

In January, the Board of Directors held their first meeting of 2022, starting with introductions of the newest board members, followed by collaborative planning to ensure our chapter is running well and community needs are being met, and also transitioning some of the officer seats. Heather Ince was voted in as the new President and Nora Ancel, Vice President. Mareena Snarey will continue as Treasurer while Hannah Brown, one of our new (but familiar to the community) board members, was voted in to take the role of Secretary. Currently, 9 people make up the Board of Directors. Our bylaws allow for up to 15. We welcome recommendations, referrals, or for anyone interested in joining the board to contact the MHA office, 816-479-5900, or filling out a board application on our website.

Because you, our bleeding disorders family, are important to us, MHA is motivated to persevere through the continued health issues affecting us all by provide opportunities for our community to gather and connect while doing what we can to keep people healthy. We have a full 2022 calendar, with a World Hemophilia Day celebration, Community Outreach Programs, Camp Wilderness, Wichita Education Day, Dodge City Education Day, Springfield Education Day, FAB (Females And Bleeding) Conference, FEW (Family Education Weekend), Unite for Bleeding Disorders walk fundraiser, Trivia Night, the annual Golf Tournament, and a **NEW** *Men's Retreat!* We hope to see as many of you in-person as possible at one, some, or all the events! Make sure to visit the MHA website for more information (www.midwesthemophilia.org). Also follow us on Facebook, Instagram, and Twitter to stay connected.

Stay healthy!
Angela Brown
angela.brown@midwesthemophilia.org

2022 Board of Directors meetings are open to the public and scheduled for the following dates: March 26 (KC), May 14 (Ozark), July 16 (Ozark), September 18 (KC), November 12 (Ozark). 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.

QUICK NOTES

Shine Up Your Boots and Saddle Up!

As a member organization of HFA, MHA wants to share the invitation to attend HFA's 2022 Symposium on April 20-23, 2022 in San Antonio, Texas.

With a family-friendly atmosphere and agenda, this symposium is a great opportunity to participate in quality education programs, connect with your bleeding disorders community from across the country, and celebrate together.

HFA is excited to host its first in-person Symposium since 2019. Since everyone may not be comfortable traveling just yet, some sessions, such as the keynote presentations, will have an online component.

Visit *https://www.hfasymposium.org/* for details and registration information.

HEMOPHILIA FEDERATION OF AMERICA SYMPOSIUM

The History Behind Bleeding Disorders Awareness Month

Bleeding Disorders Awareness Month has been observed each March since 2016, after being designated as a national health observance by the U.S. Department of Health and Human Services. BDAM aims to increase awareness of inheritable blood and bleeding disorders among the public, as well as bring them to the attention of policymakers, public authorities, industry representatives, scientists, and health professionals.

Prior to BDAM, March was known "Hemophilia Awareness Month" – a designation confirmed by President Ronald Reagan in March 1986.

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, 2022.

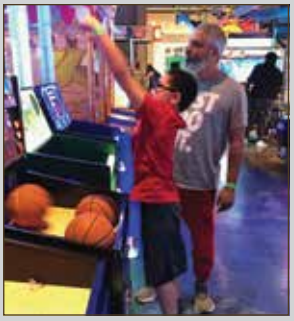
For applications plus links to other scholarships available for the bleeding disorder community, visit the MHA website at *https://midwesthemophilia.org/applications-and-registrations/*.

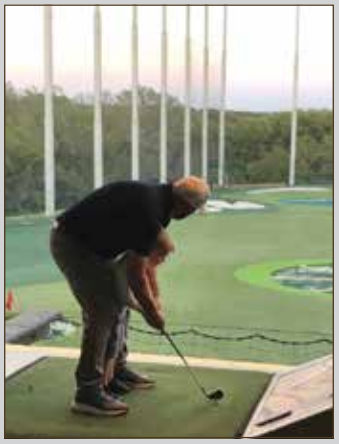
Attend a C.O.P. near you in 2022!

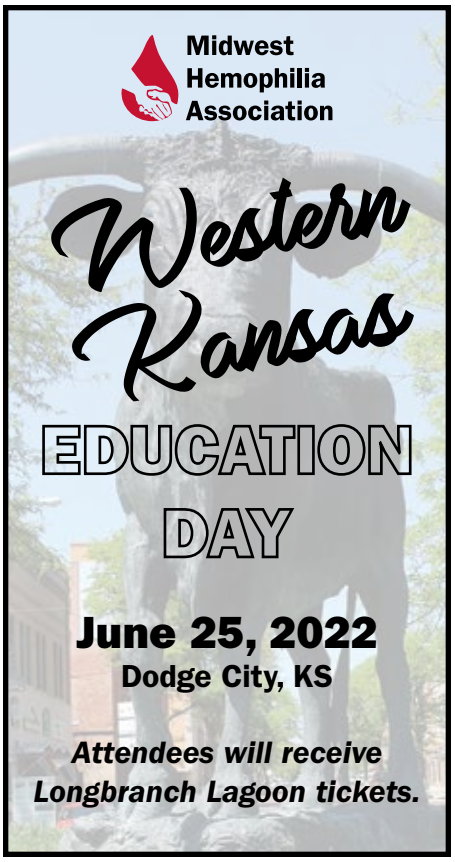
Community Outreach Programs (C.O.Ps) are a way we stay connected throughout the year in between our "big" events. We try to host them in various areas around Kansas and Missouri to make it easier for travel. Usually sponsored by an industry company, they typically include a great meal, a brief education presentation, and sometimes a fun activity. It's an opportunity for you to take a break, get to know other MHA members, learn something new, discover possible resources, and support each other.

We are continually adding C.O.Ps to our calendar as the year goes on so be watching for an invite!

SCENES FROM 2021 C.O.Ps







CALENDAR OF EVENTS

MARCH

1-2	NHF Virtual Washington Days
5	Community Outreach Program: Wichita, KS
7	Missouri Virtual Advocacy Day Training
9-10	Missouri Virtual Advocacy Days
26	Community Outreach Program: Overland Park, KS

APRIL

2	Community Outreach Program: Kansas City, MO
9	World Hemophilia Day Celebration
20-23	HFA Symposium, San Antonio, TX

MAY

4	Community Outreach Program: Kansas City
13-15	Men's Retreat: Osage Beach, MO
21	Wichita Education Day

JUNE

11	UNITE for Bleeding Disorders walk: Olathe, KS
15	Community Outreach Program: Wichita
25	Western Kansas Education Day: Dodge City

AUGUST

1-5	Camp Wilderness
9	Trivia Night Fundraiser
25-28	NHF BDC: Houston, TX

SEPTEMBER

16	24th Annual Golf Tournament
17-18	Family Education Weekend (FEW)

OCTOBER

6	Community Outreach Program: Wichita
14-16	FAB (Females And Bleeding) Conference
18	Community Outreach Program: Joplin
22	Springfield Education Day

- **More than 20 years* of experience—**the first recombinant treatment for individuals with hemophilia B
- **Designed with viral safety in mind.** More than 150 quality control tests are done on each batch of BeneFix
- **The convenience of the BeneFix Rapid Reconstitution (R2) Kit** with a range of vial sizes
- **Ask your doctor about BeneFix dosing** options to meet your needs

*FOR **ONCE-WEEKLY** PROPHYLAXIS AND **ON-DEMAND** USE*

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

PP-BEN-USA-0642

December 2021

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-14.0, revised September 2021.

Pfizer

By Matthew Barkdull

If asked what comes to mind when the term "hemophilia" or "bleeding disorder" is mentioned, most would say something about uncontrollable bleeding or bruising. When it comes to how I see a bleeding disorder, I think of it equally as a genetic medical condition and a financial condition. Bleeding disorders immediately force individuals and families into the cold and confusing world of insurance, with all the foreign babble that accompanies it.

Because it's human nature to heavily rely on professionals (or even armchair experts) when we're unsure how to navigate through the landmines of insurance, families are at the mercy of good, poor, or "meh" advice. Please indulge a few personal flashbacks:

In 2002, I got my first salary-based position that provided several benefits, including health and life insurance. When my wife and I pored through the life insurance policy, we found that it was just enough to bury me in a plywood coffin when I kicked the bucket. Not knowing much about "how the real world works" in terms of life insurance, we scheduled a visit with my company's financial advisor. I told him that I'd like to purchase more life insurance. After I had answered some questions about my severe hemophilia diagnosis and an earlier kidney transplant, the advisor quickly said that I could not qualify for more life insurance. "Your best bet is to save a ton of money throughout your career!" he said, nailing that discussion closed.

Publication: Pulse 2020
Column: Transitions

As a result, I became a disciple behind the "Got a medical problem? Don't bother applying for life insurance!" philosophy. But I terminated my discipleship 17 years later, when a good friend and brilliant financial adviser contested my views, saying that there were many possibilities to protect my loved ones if I kicked the bucket. The upshot? If I pass away at age 65, my plan now guarantees that my beneficiaries will be mostly financially independent as they go on through life. Not bad for a guy who not only has severe hemophilia, but is a former three-year dialysis patient, recipient of two kidney transplants, cancer survivor, and severe West Nile Virus survivor—and has been infected with hepatitis C. My friend taught me the fine art of looking outside the box.

Another interesting experience involves medical insurance. I was born in the 1970s, when hemophilia treatment was still trying to get its footing, and when health insurance companies could cap coverage with lifetime maximums and limit or deny coverage because of the infamous pre-existing condition clause. Consequently, I was given the advice to always work for a company that was large enough to offer outstanding medical benefits and absorb the cost. It was unthinkable to venture off to be my own boss and start my own business, as my father had done throughout his life. I carried this belief until I lost my job at a company where I'd been employed for over 16 years. During my first year of unemployment, I tried without success to find another permanent job within a large company. For years, I had been contemplating a business idea, but never dared to pursue it because of my social and medical conditioning. As time went on without resources, I felt I was ready to go against the grain and open up my own organization, despite the hardship of not knowing how I'd ever cover my factor or my family's medical needs.

> *"It was unthinkable to venture off to be my own boss and start my own business, as my father had done throughout his life."*

In the past, I had asked nonprofessionals and nonexperts about getting medical insurance as a small business owner. Their recommendations were all over the map. But when I started working with financial professionals, as well as experts within the hemophilia community, I became more and more comfortable, feeling there was more consistency in these recommendations. Being self-insured is a pricey ordeal with its own set of challenges, but after counseling with the executive director of my local hemophilia chapter, I was astounded at the resources she gave me. Pages and pages of resources, both in-house and outside of the chapter, showed me that I had little knowledge. The result? I was able to get my business underway, while national and local resources covered premium and deductible expenses to bless me and my family.

These are only two examples, out of dozens I could have used to illustrate important financial principles you need to understand when taking a step into unfamiliar territory—which is often saturated with misinformation, preconceived beliefs, and pop culture advice. The overarching financial principle I wish to emphasize: Always think outside the box.

A few recommendations that will aid you and your family:

1. Never accept a single opinion or recommendation at full face value.

Years ago, I was employed as the health officer at a very large, international nonprofit organization. One of my tasks was to work with worldwide medical institutions and other service providers to solve many kinds of problems patients were facing. During that time, I learned a valuable lesson: Never rely on one person's answer, opinion, or recommendation at full face value. This is different from assuming everyone is trying to snow or mislead us; they simply may not understand the full picture. This principle leads to the second principle.

2. Educate yourself.

And not just online, where everyone is taking a stab at a problem. Surround yourself with experts; get second opinions. It's okay to be persistent because often, even the most well-meaning professionals may not take as much interest in helping you as you do yourself. If you find a pattern of people answering similarly, you're probably receiving good advice.

3. Learn to ask questions.

I never pretend to know what I'm doing if I honestly don't know. So ask questions of those you're working with. If the financial or insurance expert is describing something with which you have little familiarity, feel free to ask questions as often as you need to. Most people find it helpful to set expectations early: "Hey, just a quick warning. I'm really a novice when it comes to insurance. I'll probably be asking a ton of questions to make sure I'm understanding everything. I'd assume you're cool with this." And most of the time, they are!

Insurance of any kind has become a necessity in our lives, especially within the bleeding disorder population. It's critical that we not only understand insurance, but that we learn to build a team and to advocate for ourselves and our loved ones. My experience is that when I've been willing to take a risk and reach out for information and support, I've never regretted doing so.

Matthew Barkdull, MBA, MS, LMFT, MedFT, provides education, assessment, coaching, advocacy, and support through his organization Wholeness Integrated Solutions, PLLC. WIS works with individuals, couples, families, and institutions to assess and empower problem-solving within the Eight Dimensions of Wholeness: biological, psychological, social, spiritual, nutritional, economical, educational, and environmental. For a free consultation, please call Matt: 385-434-8136.

COMMUNITY CONNECTIONS

Everyone has a story to tell or experience to share. This section of Chapter Factors features community members who make up our Midwest Hemophilia Association family. It is our goal to connect, encourage, and inspire the reader whether they are new to the community or seasoned members.

This Issue's COMMUNITY CONNECTIONS *participants*

MA

Martin A. (right)

AD

Ashley DiCapo (middle) with siblings and parents

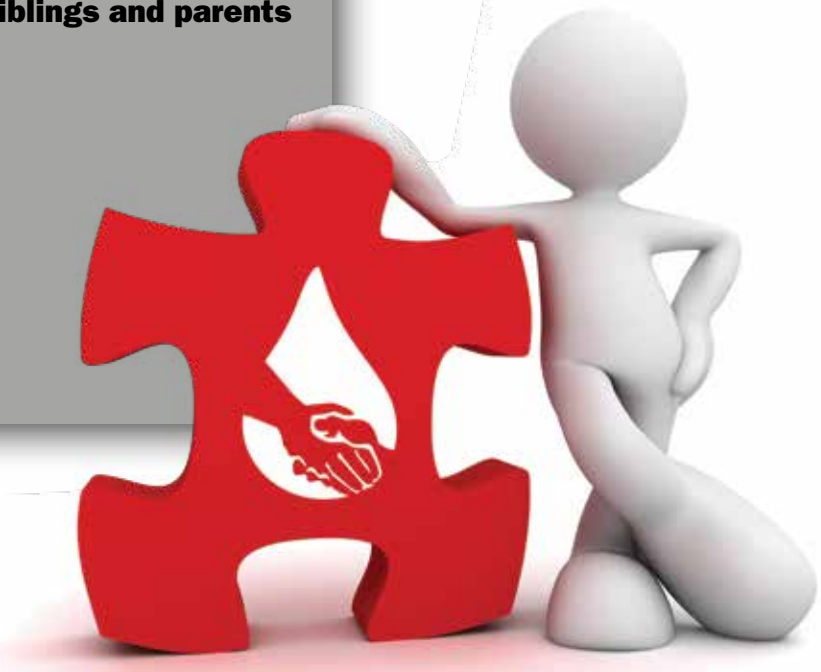
Q: What is your attachment to the bleeding disorders community?

MA: *Diagnosed with a bleeding disorder*

AD: *Diagnosed with a bleeding disorder; Sibling of someone with a bleeding disorder; Daughter of someone with a bleeding disorder*

Q: What has been your greatest challenge related to your bleeding disorder?

MA: *Until the beginning of ACA implementation (2010) when lifetime caps and pre existing conditions were removed by federal law. Maintaining health coverage and accessing treatment was the biggest problem between 1985 (first job with insurance, I started working in "78") and 2010 I went through more than 4 million dollars of benefits and 3 lifetime caps. During this time I tried to ration my factor usage to make benefits last longer, thus I was not on prophylaxis and incurred a lot of joint damage which I am reminded of every day.*



Q: What has been your greatest success as related to our community?

MA: *I retired from working as a 911 operator in 2008 on disability to get on the 24 month waiting list for medicare as I thought it was my only option for future benefits. I spent months researching HIPPA and COBRA laws looking for something that would benefit me, and reaching out to others in the community for ideas or options. I found a rule in federal law that concerned how the high risk plan was to cover the un-insured that I felt was not being handled properly in Missouri. The high risk plan was one I had previously capped out on. And they would not take me back. I finally made a NHF contact that knew a person in health and human services at the federal level, she shared my findings with him(he was 1 step below the director) he agreed with my assessment and issued a letter to the directors of all 50 state high risk plans detailing that if a person had lost their insurance through no fault of their own(fraud or fail to pay premiums) the high risk plan as insurer of last resort in the state had to make coverage available. This was in 2009, I was able to get back on the high risk plan until the ACA began and I could get back on my wife's work plan. This also applied to all states and may have provided coverage opportunities to others in similar situations.*

AD: *Meeting two of my best friends – I was even a part of their weddings and they will be apart of mine.*

Q: What would you want others to know about your situation as a consumer or provider?

MA: *Currently with the medication I use, I have way less bleeds then I have had in a long time even while*

dealing with some poor functioning joints and some break through bleeds.

I have had the opportunity to speak at some national events like NHF and HFA symposiums about my insurance journey, and participated in several lobby days in Missouri as well as a couple in DC.

My first lobbying event was in Wisconsin when I was about 12 and testified in state hearings about insurance and hemophilia home care.

AD: *Although my factor levels are higher than most with a bleeding disorder, I still have many issues regarding it. Mostly stemming from periods.*

Q: Relative to the Midwest Hemophilia Association, what do you see as the greatest benefit of the organization to the community?

MB: *MHA can help the community get to know each other, and encourage us to grow individually as we share our experiences both within the community and as advocates. We have opportunities to educate our local and national officials about the needs of our community. We can support each other if we are aware of each others needs.*

MHA also shares lots of resources that are available in the community as well as events that bring us together.

When I was a child in the 60's & 70's my mom was involved in early hemophilia groups in Wisconsin where I grew up. She would be proud and amazed to see all the changes to our care and future lives.

AD: *Support. As a female, it is hard to get the appropriate help needed; because many still believe females cannot have a bleeding disorder. This association has given many an outlet to vent and express themselves and their concerns.*

Q: Is there someone you feel who has had a major impact on our community?

MA: *Not an individual but accolades to all those who have worked tirelessly to improve our community. Past and current people involved in chapters and national organizations. Individuals who have lobbied and championed our stories and gotten the attention of our leaders and government for the needs of our community.*

Q: Have you or someone in your family been recognized, received an award/certificate, and/or accomplished a goal relative to your bleeding disorder OR at school, work, your local community, etc.? Please share details.

HB: *I was awarded service pins for every 5 years of service while working for the city of Springfield for 25 years.*

I have been a volunteer Pastor in my church for 32 years.

Being involved with the hemophilia community for many years.

I also am involved with the National Alliance of Mental Illness (NAMI) as a family support group facilitator.

I participate in the online Blood Brotherhood meetings when I am available, if your not aware of them ask me.

Q: What else would you like to say/share?

MA: *Hemophilia or other chronic illnesses can help us to understand and have empathy for others who are suffering. I believe that my experiences have made me the person I am today with a desire to help others!*

AD: *This community is more than a source of information, we are a family.*

If you are interested in being a Community Connections participant, contact Angela Brown at angela.brown@midwesthemophilia.org or call the MHA office at 816-479-5900.

Connected to you.

As Community Relations & Education Managers, we're united in our efforts to support and educate the hemophilia community.

SANOFI GENZYME

Reach out to your local CoRe to learn more.
rarebloodddisorders.com
@HemophiliaCoRes
1-855-SGZHEME

Midwest Hemophilia Association

GATEWAY HEMOPHILIA ASSOCIATION

2022

Men's Retreat

Sponsored by: BIOMARIN

MHA & GHA are hosting an educational getaway just for the guys!

May 13-15, 2022

@ Margaritaville Resort
Lake Ozark, MO

Come & take part of engaging education, a chili cook-off, boat tour & much more!

Attendees must meet these prerequisites:

- **Live in MHA/GHA service areas**
- **Be 21+ years old**
- **Have a bleeding disorder and/or**
- **Be a spouse, parent/legal guardian of someone with a bleeding disorder**

SCAN THE QR CODE TO REGISTER TODAY!

Registration closes Friday, April 8th. Space is limited so RSVP soon!

** All registrations will be directed to GHA's website.*

AUGUST 1-5, 2022

REGISTRATION IS OPEN!

For more details, visit **www.midwesthemophilia.org.**

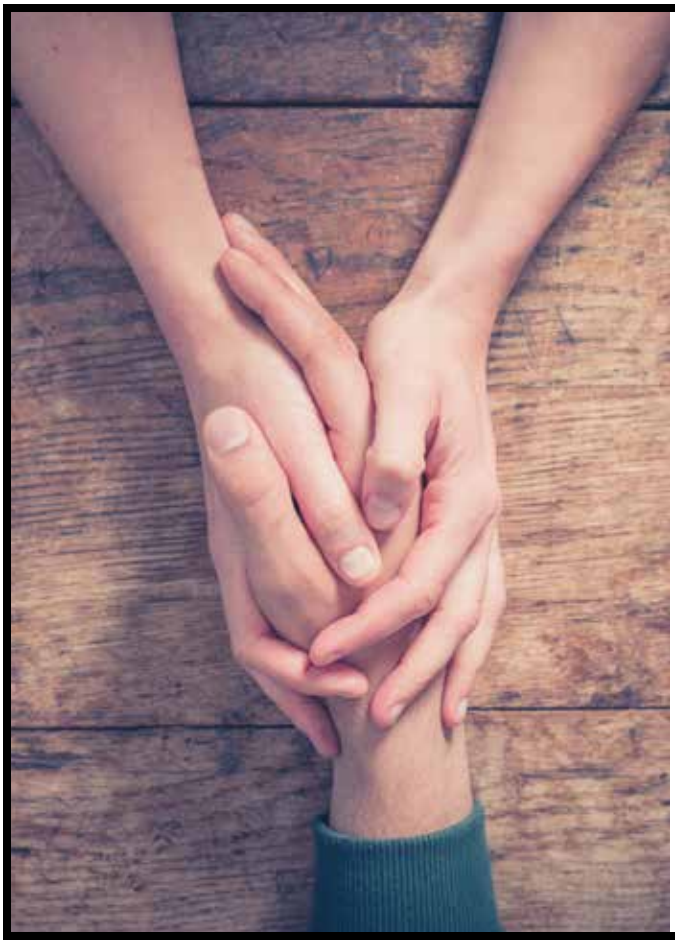
Support MHA

When you shop with PayPal, set your charity to MHA and easily donate when you check out!

STEP 1
Login to your account.

STEP 2
Select Midwest Hemophilia Association from the verified list of causes.

STEP 3
Donate $1 at checkout.



MHA continues to offer assistance for community members experiencing financial hardship for community members living in our geographical coverage area of Kansas and western Missouri and/or is a current patient of the Kansas City Regional Treatment Center.

If you or someone you know is experiencing financial hardship, please visit our website for qualifications guidelines and applications.

Scan this QR code to read about program guidelines and to download an application. Or visit ***https://midwesthemophilia.org/financial-assistance-program/***

MHA Financial Assistance

New Data Analysis Sheds Light on Bleeding Patterns in Young VWD Patients

Historically, data on infants and toddlers (ITs) with von Willebrand disease (VWD), particularly relevant to bleeding patterns, has been lacking. To address this absence of data, a team of researchers from the U.S. Hemophilia Treatment Center Network (USHTCN) and the Centers for Disease Control and Prevention conducted a retrospective analysis of HTC patients with VWD who are less than two years of age. The data were obtained through the USHTCN. The results were published in the journal Blood Advances.

A total of 105 VWD patients two years of age or less were ultimately included in the analysis: of those, 63% were type I VWD, 28% were type II VWD, and 9% were type III VWD. Investigators focused primarily on birth characteristics, bleeding episodes, and complications.

A review of birth and delivery data showed that 86% were delivered at full term, 82% were of normal weight, and 89% were considered to be of normal length. 63% of the births were done vaginally, while elective cesarean sections were utilized more often with mothers who were known carriers of VWD.

> Other studies have recommended a multidisciplinary care approach to provide early diagnosis and optimal care for this population

An examination of diagnosis data showed that patients with type 2 VWD were identified sooner, on average, than types 1 and 3. Patients had a mean age at diagnosis of seven months, with little variation by sex. A family history of VWD was also associated with an earlier diagnosis, occurring approximately four months earlier than in those without such a history. In all, family history of a bleeding disorder prompted diagnostic testing for 68% of this population.

The majority of the patients (70%) experienced a bleeding event, with 68% of those having their initial bleed in the first year of life. Initial bleeds most often occurred in the oral mucosa (mucous membrane lining the inside of the mouth), with 32% of patients experiencing this symptom. The second and third most common bleeds were circumcision-related (12%) and intracranial/extracranial bleeding (10%), respectively. Approximately 5% of patients suffered an intracranial hemorrhage, though none was associated with delivery at birth.

Treatment with bleeding disorder therapies was utilized in approximately 64% of the patients in the study, with nearly half (47%) of these receiving plasma-derived von Willebrand factor VIII concentrates. Aminocaproic acid was used in 32% of patients, while 14% received intravenous or intranasal desmopressin.

The authors highlight the central role HTCs play in mitigating risk and ensuring the best possible outcomes for these patients.

"Other studies have recommended a multidisciplinary care approach to provide early diagnosis and optimal care for this population. Specialized HTCs are uniquely positioned to offer such multidisciplinary care, including genetic counselors throughout the prepartum period who work to increase expectant mothers' understanding of the risks associated with having a child with VWD, and adult and pediatric hematologists, obstetrician-gynecologists, genetic counselors, nurses, and social workers throughout the pre- and postpartum period who seek to optimize outcomes and disease management," conclude the authors.

Source: Hematology Advisor, October 4, 2021

Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

The onset of childbirth and the postpartum period are times when women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging as there is sparce clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

The von Willebrand factor in pregnancy (VIP) study was therefore developed to enhance understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD. Investigators for this prospective, multicenter trial will focus on maintaining von Willebrand factor (VWF) levels at a specific target level using VWF replacement therapy, and assessing the impact on bleeding rates during and after childbirth.

The VIP study is being stewarded by a trio of experienced principal investigators including Drs. Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), and Dr. Peter Kouides (Mary M. Gooley Hemophilia Center and University of Rochester). The VIP Study is currently recruiting pregnant women in the U.S. above 18 years of age with VWD of any type.

An exciting component of the VIP is a new companion website, created to keep patients and healthcare professionals informed about the study. It will provide information on VIP's design, patient eligibility, and locations of participating centers.

The site was officially launched on December 10th during an educational webinar that preceded the American Society of Hematology Annual Meeting.

Source: PR Newswire/The VIP Study, November 28, 2021

World Hemophilia Day 2022

Join us for One Family, an immersive experience on joint health in the global hemophilia community.

This **World Hemophilia Day**, connect and learn with your local community in hands-on activities that focus on four key themes:

1. The importance of joint health
2. Hemophilia care around the world
3. Living with severely damaged joints
4. Global hemophilia community support

When:
Saturday, April 09, 2022 10:00 AM - 12:00 PM CDT

Where:
Bristol Seafood Grill
5400 W 119Th St
Leawood, Kansas
66209

RSVP:
Contact your local chapter today.
info@midwesthemophilia or 816-479-5900

A Midwest Hemophilia Association & Sanofi Genzyme Event

SANOFI GENZYME

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

Dedication and Personal Support

Pfizer Rare Disease | RARE DISEASE PATIENT AFFAIRS

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.

Joe Schuch

IL, MO, IA, WI, MN, ND, SD, KS, NE
joseph.r.schuch@pfizer.com
O: 816-419-8699

"I've helped organize patient educational programs for over 10 years—I enjoy creating interactions and sharing knowledge in the community."

My work is guided by:

Compassion—Listening to your needs and addressing questions and concerns that you may have

Commitment—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection—Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others