

CHAPTER Factors

SPRING 2020



Unite

for Bleeding Disorders

Saturday, June 13, 2020

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

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Association**





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- **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

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FROM THE EXECUTIVE DIRECTOR



As we welcome in 2020, we also welcome a new office, new events, and new members! In this issue of Chapter Factors we highlight some of these items. However, I must admit I am most excited about welcoming new individuals and families who have signed up on our website to become members of MHA over the past few months. It means I have the privilege to meet and support people effected by bleeding disorders. It means MHA is reaching those who may be newly diagnosed or never been part of a support network! It means our family is growing! That is exciting!

We all remember what it is like to be new—anxious, afraid, worried. But we also remember the mom who reassured us that we weren't alone, the dad who greeted us with a firm handshake and left us encouraged, the nurse who gave us confidence to 'infuse' alone at home, the inspiring speaker who didn't let their bleeding disorder control their life-- the kid who survived climbing and jumping from the highest piece of furniture in the room (after which their parent threatened to kill them if they did it again). Through the support and interaction of others like us, those feelings turned to hope, confidence and strength.

Currently, new members are welcomed with a phone call, personal email and/or a follow up letter that includes our Welcome brochure which highlights MHA's events, programs, resources, and more. The brochure has been a great tool in welcoming new people, but also for bringing awareness about the community. I want to encourage you to help us make a difference in the lives of others--to keep a copy or two of the Welcome brochure and share them when you have that unexpected opportunity to meet someone newly diagnosed, tell a new family about of our events, invite a financial donor to sponsor your fundraising team, and/or educate someone about bleeding disorders who is not part of the community.

The Welcome brochures will be at our events for you to take and share. Or, you can call the office and ask for extras to be mailed directly to you.



Sincerely,
Angela Brown
angela.brown@midwesthemophilia.org

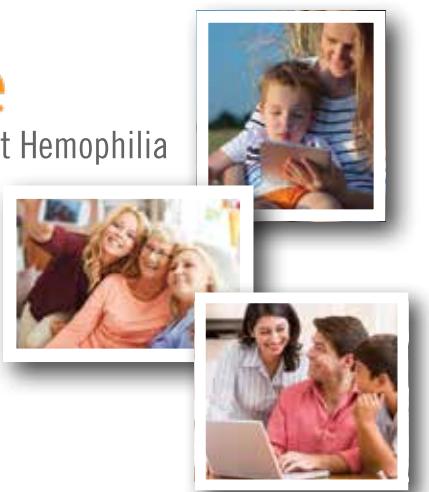
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QUICK NOTES

Springfield Town Hall Meeting Recap

The Executive Director, Board representatives and Springfield area community members met January 18, 2020 at the Springfield Library Center at the first ever town hall meeting to hear from membership on how MHA can better serve the local families and individuals.

Included in the agenda were welcome & introductions, review of MHA's mission and how we accomplish that mission, followed by open discussion based on the following question, "How and what can we improve to better serve the needs locally?"

The overall consensus was to make our communication more personable, to work on the decommodification of the community, and be creative with bringing awareness to bleeding disorders to the general public.

We look forward to the upcoming Town Hall meetings in Kansas City, Wichita and Garden City! We realize not everyone will be able to make these meetings and we want to have as much input from you, our members, so an



online survey will be available on our website soon after all the in-person town hall meetings are completed.

Helping Hands Fund

We are excited to announce that a *Helping Hands Fund* is being developed by the Board of Directors. This past December, a one-day fundraising campaign we called, *#GratefulTuesday* on *#GivingTuesday*, was implemented to help jump start the fund. During that campaign nearly \$1,000 was raised for this program.

Guidelines and applications are still being developed, but the general idea of the program is to exist for the sole purpose of providing emergency financial assistance to those persons who have been physically, emotionally, and financially affected by a bleeding disorder.

The goal is to gather funding through direct donations, fundraisers, and/or grants to establish a solid financial baseline in order to activate and open the application process by December 2020 (or earlier). If you are aware of any resources or want to make a personal contribution, please contact Angela Brown at the MHA office at 816-479-5900. You can also utilize the UNITE Your Way program (see page 12 of this newsletter) and designate the donations towards the *Helping Hand Fund*.



NOW Conference Registration Open

Be part of the National von Willebrand Disease Conference dedicated exclusively to those affected by the disease to be held on May 29-31, 2020, in Phoenix, Arizona. With funding by a grant from CSL Behring, the Arizona Hemophilia Association is excited to organize this national conference focused specifically on von Willebrand Disease.





Participants will be given the opportunity to come together with other individuals around the country with vWD to network, gain knowledge and have fun! Those who attend will be given the tools necessary to start their own local vWD Support Group, allowing the information gained from the conference to be shared at the local chapter level.

Attendees must have von Willebrand Disease and/or be a caretaker of someone who has it. The conference is funded to accept a limited number of participants. Families are welcome and there will be educational activities and daycare for children.

For information and registration, visit arizonahemophilia.org/now/. Should you have any questions and/or problems, contact Vickie at (480) 270-8812.

Dr. Wicklund to Retire in Summer

The Kansas City HTC announces plans for Dr. Brian Wicklund to retire in the summer of 2020. Other physicians at the clinic will absorb Dr. Wicklund's patients. MHA would like to thank Dr. Wicklund for his dedication to the bleeding disorders community and wish him well in his retirement!

Camp Wilderness Registration is Open!

Here we gooooo! Camp Wilderness registration is NOW OPEN for all gamers ages 7-17. Camp will return to Lake Doniphan Conference & Retreat Center in Excelsior Springs, Missouri on July 27-31, 2020. To save your camper's spot, register today at <http://app.campdoc.com/register/wilderness>.

The mission of the MHA Summer Camp is to provide campers with a safe camping experience and the opportunity to meet other young people with rare bleeding disorders.

Campers will receive onsite

medical care and education related to hemophilia and other bleeding disorders.

Campers will have the opportunity to meet new friends or renew old friendships, and participate in a variety of traditional camp activities including fishing, biking, swimming, and crafts.

On-site medical and nursing personnel to perform first aid, factor infusions and medication administration as needed. Personnel will include physicians, fellows, medical residents, advanced practice nurses, registered nurses and pharmacists. Safety is priority one. Local ambulance and emergency service providers are made aware of the location of the campground and the dates for the camp.

Summer camp counselors must have two references and pass a thorough background check. They must be 19 or older and physically able to accept the responsibility of caring for the campers.

For more information or to support MHA's Summer Camp, visit midwesthemophilia.org.



2020 EVENTS CALENDAR

April 2-5

YETI Conference

April 4

Garden City Town Hall & Education Day

Heritage Inn & Suites

April 5

Wichita Town Hall

Westlink Branch Library

April 23-26

HFA Annual Symposium

Baltimore, MD

June 13

UNITE For Bleeding Disorders Walk

Olathe, KS

July 18

Springfield Education Day

Discovery Center of Springfield

July 27-31

Camp Wilderness

Lake Doniphan Conference & Event Center

Excelsior Springs, MO

August 4-8

NHF Bleeding Disorder Conference

Atlanta, GA

September 18

22nd Annual Golf Tournament

*WinterStone Golf Course
Independence, MO*

September 19-20

28th Annual Family Education Weekend & Awards Ceremony

*Marriott Kansas City
Overland Park, KS*

October 24

Trivia Night Fundraiser

November 7

Wichita Education Day



Looking for College Money?

From our inception as an organization in 1990, Midwest Hemophilia Association has always believed in education.

One way we encourage our younger community members to continue their education is by providing scholarships to assist with the costs of secondary education. If you are sending a child to college or attending college yourself, please make note of these scholarships available to the bleeding disorder community.

Applications are available online at midwesthemophilia.org. Visit the Scholarship section located under the Resources tab drop-down menu.

Additional scholarship opportunities are available with National Hemophilia Foundation and Hemophilia Federation of America. Visit their websites at hemophilia.org and hemophilafed.org for more information.

- **GEORGIA NORTHWAY SCHOLARSHIP**
DEADLINE: MAY 1, 2020

Offered by Midwest Hemophilia Association and Truman Heartland Foundation, this scholarship is available to high school seniors and college students diagnosed with a bleeding disorder who are pursuing an undergraduate degree. Established in 2003 when MHA was named an estate beneficiary of Georgia Northway, the fund has awarded \$269,188.44 in 108 scholarships to over 38 students. The fund should have \$23,000 to \$25,000 available for grants in the 2020-21 school year.

- **MIDWEST HEMOPHILIA ASSOCIATION SCHOLARSHIP**
DEADLINE: JUNE 1, 2020
- **MARK DUDLEY SCHOLARSHIP**
DEADLINE: JUNE 1, 2020

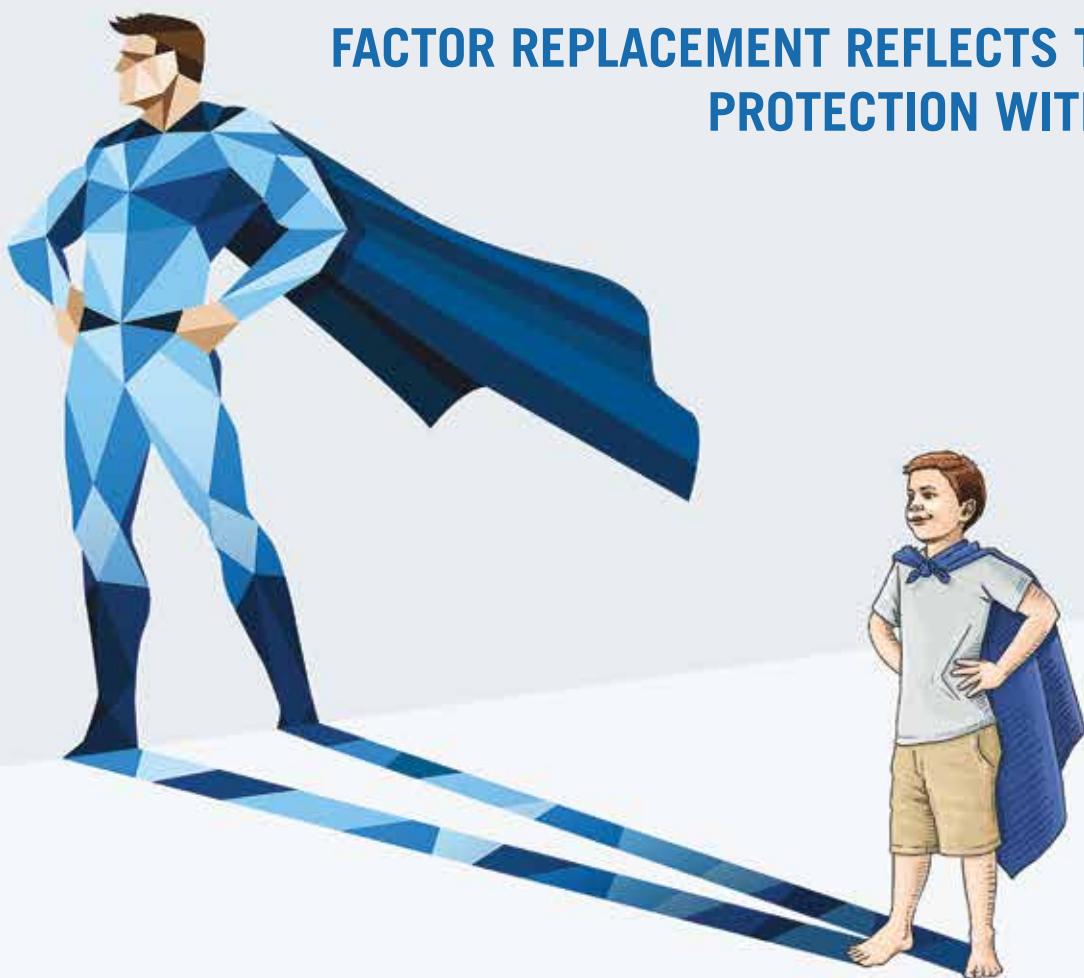
The Midwest Hemophilia Association offers two separate \$1,000 scholarships for post-secondary education to students with a bleeding disorder living in the organization's service area of Western Missouri and Kansas. The Midwest Hemophilia Association Scholarship has been offered for the past 25+ years. In 2016, the Board authorized a second scholarship, the Mark Dudley Scholarship, in honor of our past board treasurer. These two scholarships together have awarded over \$30,000 in educational funding. The scholarships may be used for college or trade school during the 2020-2021 school year. Funds may be used at the discretion of the recipient (i.e. books, tuition, room and board, etc.)

- **INDUSTRY PARTNER SCHOLARSHIPS**

MHA has been contacted by multiple industry partners with information about the scholarship opportunities offered by their organizations to people living with bleeding disorders. A listing of these scholarships can be viewed on the MHA website. Visit the Scholarship section of midwesthemophilia.org located under the Resources tab down-down menu.



FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.^{1,2} With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.²⁻⁶

Brought to you by Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.⁷

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. 2. Canadian Hemophilia Society. Factor replacement therapy. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/>. Accessed May 18, 2018. 3. Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. 4. Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. 5. Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. 6. Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*. 5th ed. New York, NY: WH Freeman; 2002. <https://www.ncbi.nlm.nih.gov/books/NBK22589/>. Accessed May 18, 2018. 7. Shire. Shire's 70+ year commitment to the hemophilia community. <https://www.shire.com/en/newsroom/2018/january/7sossj>. Accessed June 6, 2018.

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Unite

for Bleeding Disorders

Saturday, June 13, 2020

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



UNITE FOR HOPE.
UNITE FOR COMMUNITY.
UNITE TO MAKE A DIFFERENCE.

WE ARE WITH YOU EVERY STEP OF THE WAY!

- ◆ One-on-one fundraising coaching with chapter staff
- ◆ Personal walk website to tell your story and ask for donations
- ◆ Sample letters/emails to recruit your family and friends

The Unite for Bleeding Disorders walk brings our community together. It UNITES families with bleeding disorders and chapters with family, friends, neighbors and coworkers to support important programs and services to help people with hemophilia, von Willebrand disease, and other rare bleeding disorders in our community.

REGISTRATION IS OPEN!

Visit www.uniteforbleedingdisorders.org and click “Find a Walk”. Search for walks in Kansas. Once on the local page, click Register Now to form your team!

The 2020 MHA Unite for Bleeding Disorders Walk is earlier this year, so **NOW** is the time to start forming your team and sending out your fundraising messages!

Teams account for about 80% of the monies raised in walks. They represent companies, organizations, families, schools and clubs, and can range from as few as five walkers to hundreds. Forming teams is a great way to build company morale and camaraderie among co-workers. Families and friends can join together to walk for a common cause and increase community spirit.

Matching gifts are a great way to increase donations. Check to see if your company will match

employee contributions and encourage your donors to do the same. To take part in a matching gifts program, request an application from the benefits manager or human resources department. Then send the completed form to your local chapter. They will verify receipt of your gift and complete the process.

Tips to get started are at your fingertips on the Unite website. There you can watch tutorials on how to send a fundraising email, share on social media, customize your personal fundraising page, search for matching gifts and much more!

100% of every dollar raised directly supports our local chapter's advocacy and education events. Register today to get started now!



DOWNLOAD OUR MOBILE APP

Simply search by Unite For Bleeding Disorders

(you must first register for our walk at UniteForBleedingDisorders.org and then you can activate your mobile app.)



MHA Welcomes CHANGES IN 2020!

With the start of the new year, it's time to celebrate changes in the bleeding disorders community, not only locally but nationally as well.

New Year, New Location!

First of all, MHA is excited to announce its new office location in Ozark, Missouri! We are located inside the Ozark Chamber of Commerce Carl G. Hefner Enterprise Center. As a tenant, we have access to the building media center, kitchenette plus conference room that provides MHA great space to hold small meetings. Ozark is located just south of Springfield and north of Branson. If you are ever in the area, please feel free to stop by for a visit! This is where most mail and written

communication should be sent unless otherwise specified. We will continue to keep the regular activity and events in the same locations.

We are keeping the P.O. Box 412866 Kansas City, MO 64141 for the time being. Just be aware that it is NOT checked as often as the new physical address. Also, we were able to keep the MHA phone number: 816-479-5900. It has been "ported" to a cell phone purchased and belonging to the chapter. This will improve the accessibility and create quicker communication responses.

2020 MHA Board of Directors

The new year also brings changes to the MHA Board of Directors. Nora Ancel has stepped in as the Board President. Bridget Castro is Vice President and Jaci Colter is Treasurer. Kyrie Smith will be Interim Secretary until the position is finalized. Mareena Snarey and Cody York have joined the Board of Directors. Remaining on the Board are Jennifer Rentschler, Dakota Rosenfelt, and Kim Rosenfelt.

Left: MHA's new office, located in Ozark, Missouri. Below Left: Members of MHA Board of Directors meet in the conference room at the new office. From left, Interim Secretary Kyrie Smith, Executive Director Angela Brown, Board Member Kim Rosenfelt, Board Member Mareena Snarey, Board President Nora Ancel and Board Member Cody York. Below Right: New NHF President and CEO Dr. Leonard A. Valentino.



NHF Welcomes Next President and CEO

The National Hemophilia Foundation welcomes changes as well in the new year. The Board of Directors of the National Hemophilia Foundation (NHF) announced that Dr. Leonard A. Valentino as the foundation's next President & Chief Executive Officer. Dr. Valentino took the helm on February 17, 2020, to advance the foundation's mission of education, advocacy, and research. Dr. Valentino was a standout candidate who was identified through a national process.

"We are thrilled to welcome Dr. Valentino as the next President & CEO at the National Hemophilia Foundation," said Brian Andrew, NHF's Chair of the Board of Directors. "Dr. Valentino is a dynamic leader with experience managing people, research projects, and fundraising efforts, with an extensive and impressive clinical background. He has been an active member of this community and is an ideal fit as the foundation begins a new era of success."

Dr. Valentino brings more than 35 years of clinical and research experience related to bleeding disorders to the role, aligning with the board's strategy of a more research-focused agenda. Prior to his most recent work with Spark Therapeutics, a biotech startup, he founded and led the Hemophilia and Thrombophilia Center at Rush University Medical Center in Chicago, where he successfully balanced a \$10 million budget to support research grants, research and clinical teams – keeping the patient and their families as his core focus. Additionally, he has held leadership roles with key industry groups. In these roles, Dr. Valentino was responsible for managing the global medical teams who successfully led strategic planning for multiple worldwide hemophilia product launches.



The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

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Let's put science to work

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DIFFERENCE —



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from our
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Unite YOUR WAY

**Every Idea. Every Dollar.
Every Drop Counts.**

**UNITE Your Way and use your creativity
to support the bleeding disorders community.**

The National Hemophilia Foundation announces UNITE Your Way, a new do-it-yourself (DIY) fundraising platform where you can be instrumental in providing funds directly to MHA. Whether you're a scout troop looking to earn a patch, a school group searching for a community service project or a women's league wanting to give back, this initiative is for you.

UNITE Your Way lets you turn your passion into a fundraiser – however, wherever, whenever you want. Examples include “donating” a birthday (asking for donations on your birthday to benefit the chapter), an organized bike event to raise funds, or even a baking contest to send a kid to camp. With an online platform dedicated to the fundraiser you choose, and many resources to empower you, you can create your own personal or group fundraiser in the matter of minutes.

Getting started is easy. You'll have

all the tools you need to create and manage your own fundraiser from start to finish. There are templated emails, suggested tips and tricks to maximize fundraising potential, and even social media badges that are earned based on fundraising performance!

UNITE your family and friends by inviting them to support your fundraising. And celebrate your impact with knowing that your efforts will help bring research, treatments, education and support for everyone affected by bleeding disorders.

With UNITE Your Way, you now have a chance to raise awareness and critical funds in a way that makes the most sense for you. Our community is all-in when it comes to ending bleeding disorders. Together, we become a powerful force. And with every idea, every dollar we raise, we're that much closer. Together, we will end bleeding disorders. Ready to get started?

Visit UniteYourWay.org and click on Local Chapter. Select Midwest Hemophilia Association from the list and follow the prompts to start your campaign!



- **UNITE Your Way (UYW) is a different fundraising initiative than the UNITE For Bleeding Disorders Walk.**
- **100% of funds raised go to benefit our local chapter.**
- **This program provides supporters who may not find the right “fit” within our other events, like our golf tournament or trivia night, a chance to contribute.**
- **UYM Champions are provided tools and resources to fundraise, while they create events and fundraise in ways meaningful to them.**
- **Events can be created year-round and can be as big (or as small) as the Champion designs them to be.**



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Dr. Michael Silvey • Dr. Lauren Amos

ADULT PHYSICIANS:

Dr. William Jennings • Dr. Jill Moormeier • Dr. Anuj Shrestha



Amos



Carpenter



Jennings



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Shrestha



Silvey



Wicklund

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202-675-6984 • www.hemophilafed.org

Study Shows Higher Postpartum Hemorrhage in FXI Deficiency Patients Post Cesarean

Researchers from the Beth Israel Deaconess Medical Center in Boston, MA conducted a study on the link between postpartum hemorrhage (PPH) and women with mild factor XI (FXI) deficiency. The results were included in a research poster abstract presented on December 9, 2019 during the 61st American Society of Hematology Annual Meeting in Orlando, Florida.

Since direct-to-consumer genetic testing companies now often screen for FXI mutations, more people are learning that they have a mild form of the disease. While many of these individuals have never exhibited symptoms, they may still be vulnerable for excessive bleeding related to surgery. The investigators from Beth Israel looked at a particularly at-risk group, postpartum women with mild FXI

deficiency, including those who have undergone a cesarean delivery.

Investigators initiated a retrospective analysis that included two groups, a control group that included 200 women who had undergone deliveries between 2016 and 2018, and a second group which included 40 women with mild FXI deficiency.

The FXI deficiency group included 71 deliveries, of which 45 were vaginal and 26 were cesarean. The control group encompassed 200 deliveries, of which 125 were vaginal and 75 were cesarean. PPH was defined as estimated blood loss of at least 1000 milliliters (mL) or reported symptoms of hypovolemia (a decreased volume of circulating blood in the body) related to blood loss within 24 hours post-delivery.

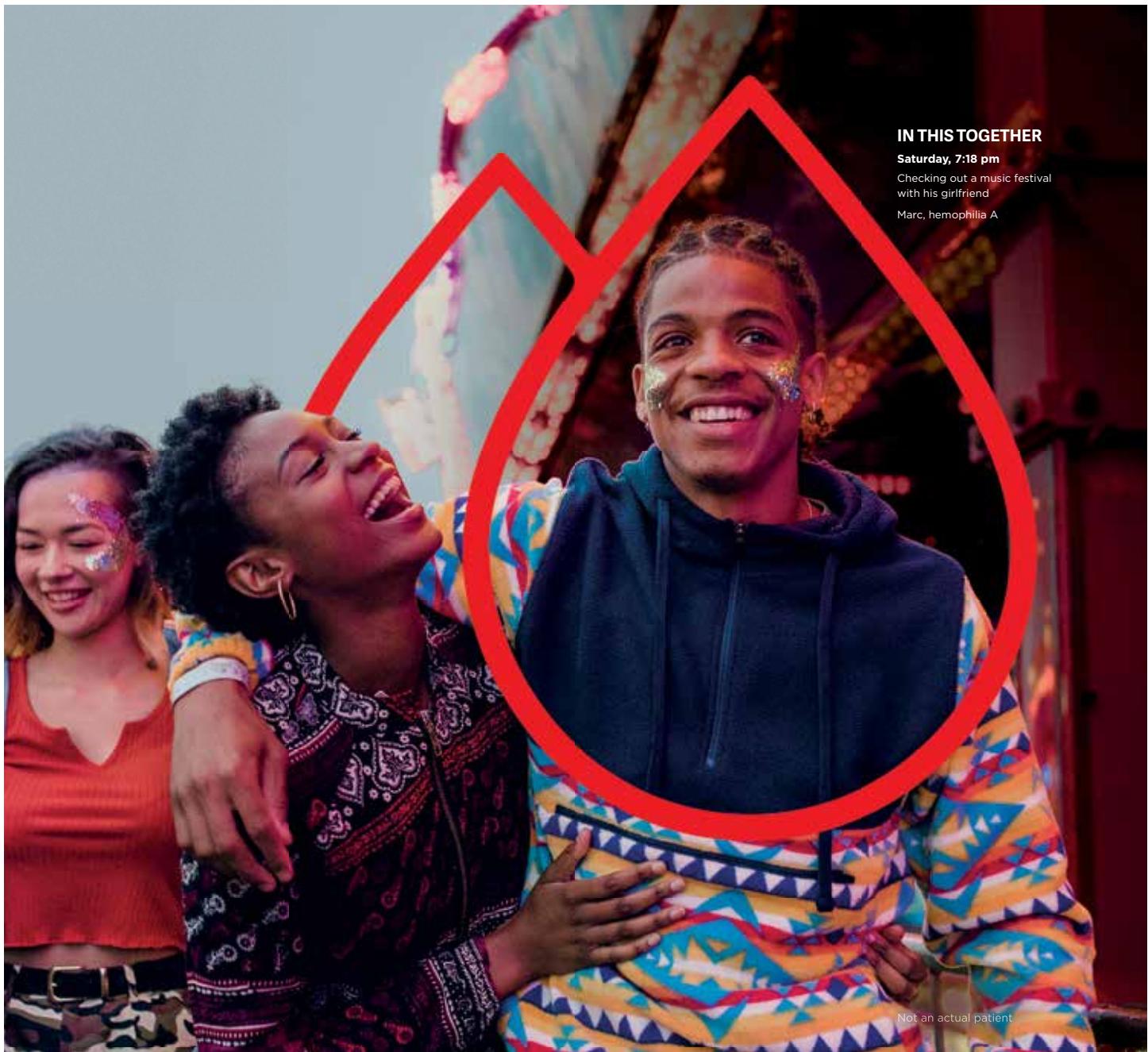
In both groups, median estimated blood loss for vaginal deliveries was 300 mL and median estimated blood loss for cesarean deliveries was 800 mL. Among patients undergoing vaginal delivery, PPH occurred after no deliveries in the FXI deficiency group and after one delivery in the control group. In contrast, women with mild FXI deficiency undergoing cesarean delivery were approximately 2-fold more likely to develop PPH when compared to the control group. The overall rates of PPH among those FXI women who underwent cesarean delivery was 38.4% (10 of 26 deliveries) compared with 18.7% (14 of 75 deliveries).

Investigators ultimately found that a prior history of hemorrhage was the best predictor of PPH following cesarean delivery. In fact, most of the women (7 out of 10) who developed PPH following caesarean had a prior history of bleeding. Notably, only two of the women with PPH received some type of prophylactic care prior to delivery. Among the women 16 caesarean deliveries in the FXI group without PPH, significantly fewer had a history of bleeding.

"In this case control study, we did not observe any cases of PPH among women with FXI deficiency who underwent a vaginal delivery but noted a greater than 2-fold increase in PPH among those women who underwent a cesarean delivery," concluded the study authors. "In those women with a bleeding history, the risk of PPH following cesarean section was nearly 10-fold higher compared to women without a history of hemorrhage supporting the role for prophylactic measures in this high-risk group."

— Source: *Hematology Advisor*,
December 10, 2019





IN THIS TOGETHER

Saturday, 7:18 pm

Checking out a music festival
with his girlfriend

Marc, hemophilia A

Not an actual patient

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever. **Let's make today brilliant.**

bleedingdisorders.com



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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

Keep track of your bleeds, infusions, and activity.

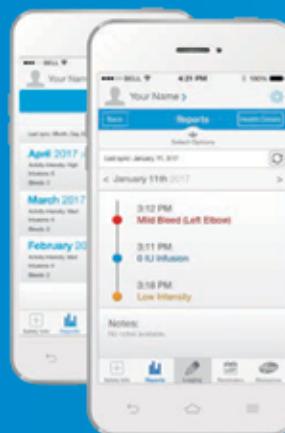
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