BIG RED FACTOR

2023—Issue 3

Nebraska Chapter
NATIONAL
BLEEDING
DISORDERS
FOUNDATION

Inside this issue:

Nebraska Chapter
National Hemophilia Foundation
www.nebraskanhf.org

I am delighted to announce an exciting transformation for our organization. As we transition from the National Hemophilia Foundation to the National Bleeding Disorders Foundation, we want to emphasize that our mission and unwavering commitment to serving the bleeding disorders community remain steadfast. This rebranding initiative is a testament to our evolving understanding of the broad spectrum of bleeding disorders and our dedication to inclusivity. We believe this change better reflects the diversity of our community and the many individuals we support. As we move forward through the remainder of 2023 and into 2024, our focus on education, advocacy, and support remains resolute, and we are eager to embrace this new chapter while continuing to make a positive impact. Thank you for your ongoing support and partnership as we grow and evolve together.

Maureen Grace

Maureen Grace, Executive Director
Nebraska Chapter
National Bleeding Disorders Foundation

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

Staff

Executive Director
Maureen Grace

Senior Program Manager
Sarah Arrieta

Advisory Board of Directors

President - Joe Mickeliunas
Vice President– John Ashley
Secretary - Suellen Colin
Treasurer– Bob Dick
Zach Fischer
Dale Gibbs

The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

2023

Remaining Events

November 4th
Industry Symposium

December 6th
VWD Education Dinner
With Octapharma
Lincoln, NE

December 9
Winter PING and
Holiday Gathering
Lincoln, NE

2024

Upcoming Events

February 10th-11th
Couple’s Retreat

February TBD
Nebraska Advocacy Day

March 6-8th
Washington Days

combined health agencies drive
MEMBER CHARITY

REBRAND UPDATE

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

In 1948, the foundation got its start as simply “The Hemophilia Foundation” – then in 1956, the foundation formally incorporated into what is known today as – the National Hemophilia Foundation. Even then, it was important to capture the organization’s expanding footprint across the U.S.

Now, in 2023, the time for change has come again.

Because of our longstanding name, the National Hemophilia Foundation is best known for helping people with hemophilia and also for serving the individuals and professionals who care for that community.

However, in the foundation’s many decades, we have also long served those facing other blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Over the past 75 years, our powerful combination of research, education, and advocacy has improved the lives of people and families with a range of conditions – yet our name and image has not reflected that.

Now, as the National Bleeding Disorders Foundation (NBDF), we can be more inclusive of *everyone* we serve. Although hemophilia remains a major focus, our name ensures that all people with VWD and rare and ultra-rare deficiencies know that they can find a home within NBDF.

Although we’re adopting a new name and a new look, our work will not change in the short term. We remain dedicated to supporting our network of over 50 chapters across the country and channeling funds into blood and bleeding disorders research. And we will continue to educate and support families with these disorders as we work tirelessly to protect access to health care on the state and local level.

Over the long term, our new name will challenge us to explore how we can harness our resources and networks to help people facing other blood and bleeding disorders – because after all, bleeding disorders *are* blood disorders. In the same way that the National Hemophilia Foundation evolved to help people facing blood and bleeding disorders beside hemophilia, we can evolve once again to assist more families in need. Many rare blood and bleeding disorders don’t have a national support and advocacy network like ours — and together, we have a historic opportunity to change that.

As the National Bleeding Disorders Foundation, we will use our longtime legacy to inspire a future where even more people have access to the treatments and support they need to thrive. We will remain true to our core vision while raising awareness, expanding reach, and continuing to build upon 75 years of history, hope, and progress.

Harvest Festival

The 2023 Harvest Festival, held at Roca Berry Farm on Saturday, October 21st, was a day filled with warmth, connection, and laughter for the bleeding disorders community. This event, generously sponsored by Bayer, Hemabiologics, CSL Behring, Novo Nordisk, ARJ Infusion, CVS Specialty, Octapharma, and Superior Biologics, showcased the incredible power of unity and support. Families affected by bleeding disorders came together to enjoy a day of pure fun and relaxation.

The Roca Berry Farm provided the perfect backdrop for a day of family-focused activities. Children's laughter echoed across the pumpkin patches as families picked their favorites, and the excitement of hayrack rides added to the sense of togetherness. The aroma of freshly baked apple pies filled the air, while attendees enjoyed delicious treats and indulged in the fall spirit.

The day concluded with a sense of unity and empowerment, reminding everyone that together, we are strong, and together, we can create cherished memories that will last a lifetime. The 2023 Harvest Festival was not just a celebration of the season, but a celebration of the enduring bonds within the bleeding disorders community.

Getting in the Game 2023

October 6 – October 8
Henderson, Nevada
https://www.csljnc.com/

Nicolas Quiroz (Omaha) and Greyson Lovell (Lincoln) represented Nebraska at this year's Getting' In The Game hosted by CLS Behring in Henderson, NV earlier this month. Nicolas played basketball and Greyson chose Golf. They were able to work with professionals in their respective sports with other kids ages 7-18 with bleeding disorders from across the country. Both boys had a wonderful time and were thrilled to be able to attend. Keep your eyes peeled for our nomination process for 2024!

Teen Program Update

2023 NENBDF Teen Council Service Project – Medical Field/Children's Hospital

Teens were asked to pick a career or industry that they would like to know more about, and the teens chose nursing and the medical profession. We worked together to create the 2023 service project partnering with Children's Hospital. We held fundraisers and collected donations for the completion of this project. There are key elements to our project:

Ask A Nurse Program – This is the educational component to the project. Teens created videos asking nurses and CNAs questions about their education and profession. The nurses and healthcare workers created response videos for the teens that participated in the program. We will host a watch party in the future so teens can watch all the videos together and learn a little more about what it's like to be a nurse, and the nurses that care for kids with bleeding disorders at Children's Hospital.

Care packages for nurses & patients – This is the service portion of the project. The chapter came together to create care packages both for nurses and healthcare workers that participated in the Ask A Nurse Program, as well as for kids staying as patients at Children's Hospital. These packages will be delivered on November 8th by a few representatives of the NBDF Teen Council.

2024 NENBDF Teen Council Service Project Ideas: We will be collecting ideas for careers to learn about for our next service project. If you have a youth in your household age 12 – 19 that would like to participate in the Teen Council, please have them submit their ideas for a career topics for our next project to Sarah Arrieta at sarrieta@hemophilia.org.

Youth Resume Writing & Public Speaking Workshop for Ages 12 and Up

November 6, 2023 6 - 8 pm

Bring a copy of your resume.
Don't have one? It's okay, we'll make one together.
Register online at
www.nebraskanhf.org
8031 W Center Rd, Suite 301
Omaha, NE 68124

Join us for tacos as we brush up on our professional skills.
Contact Sarah Arrieta with questions at
sarrieta@hemophilia.org or
(402)889-0572

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

Unite

for Bleeding Disorders

OCTOBER 7

RAISED NEARLY $30,000

Unite for Bleeding Disorders

Nebraska Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

2023

Thank you to our Local Walk Sponsors:

Takeda
The Hemophilia Alliance
BioMarin
Bayer
sanofi
CSL Behring
Deloitte.
BlueCross BlueShield Nebraska
Genentech

Thank you to all our 2023 Walkers!
We had an absolute blast.
Save the Date for September 29, 2024

2023

INDUSTRY SYMPOSIUM

NOVEMBER 4TH, 2023 9 AM - 2:30 PM

AKSARBEN HILTON GARDEN INN

Join us for education about products to treat bleeding disorders, followed by an Omaha Maverick's hockey game.

Contact Sarah Arrieta with questions or concerns at 402-889-0572 or sarrieta@hemophilia.org

2023

HOLIDAY PING

PARENT INFORMATION NETWORKING GROUP

You're invited for some holiday cheer to celebrate this special time of year!

December 9, 2023 2-4 pm
at the Auld Pavilion Recreation Center
1650 Memorial Drive,
Lincoln, NE 68508
Contact Sarah Arrieta with questions
at (402) 889-0572 or
sarrieta@hemophilia.org

Nebraska Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

Men’s Retreat

In a heartwarming display of camaraderie and empowerment, men within the bleeding disorders community recently gathered at the picturesque Platte River State Park for the 2023 Men's Retreat. This extraordinary event, facilitated by the dynamic duo of Kevin Harris and Brian Rodgers with TRAILS to Healthy Living, left a lasting impact on all who participated.

TRAILS to Healthy Living, often described as "a lifestyle-focused company that delivers interactive programs centered around health & wellness, mental fortitude, wilderness first aid, and community development," provided the perfect backdrop for the retreat's diverse activities.

The men who attended the retreat had the opportunity to partake in a range of exhilarating experiences, each designed to foster a sense of unity, empowerment, and personal growth. Rifle shooting allowed participants to tap into their focus and precision, while horseback riding instilled a deep sense of connection with nature and the animals, creating a unique bond among the group.

One of the retreat's highlights was the campfire talks, which provided a safe and welcoming space for the men to share their stories, experiences, and challenges. These candid conversations helped build a sense of community, reinforcing the idea that they are not alone in their journeys.

In keeping with the theme of empowerment, an educational presentation, generously sponsored by BioMarin, offered valuable insights and information to the participants. This presentation added a layer of knowledge and awareness, equipping these men with the tools and resources they need to lead healthier, more fulfilling lives.

The success of the 2023 Men's Retreat is a testament to the incredible sense of brotherhood within the bleeding disorders community. It's evident that the attendees were not merely participants but a vital support network for one another. The sense of unity and camaraderie fostered during this retreat is a powerful reminder of the strength that emerges when individuals come together with a common purpose.

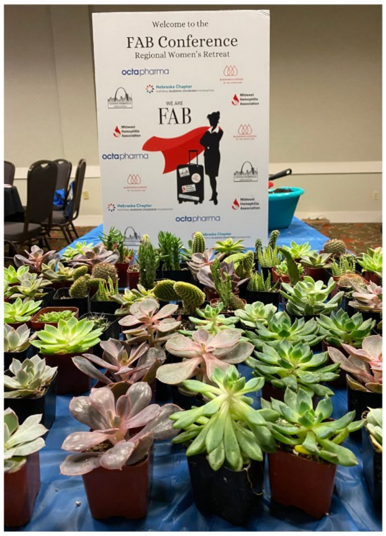
A heartfelt thank you goes out to all the men who joined this new and impactful event. Your presence and active participation were instrumental in making the retreat a resounding success. It is through your willingness to share, engage, and learn that we can continue to grow and thrive as a community.

As we move forward, let us remember the lessons and experiences gained at the 2023 Men's Retreat. May the bonds formed and the knowledge acquired serve as a source of inspiration and motivation in our collective journey toward better health, wellness, and personal development.

Thank you to everyone who made this event possible, from the organizers to the sponsors, and, most importantly, to the incredible men who embraced this opportunity for growth, connection, and empowerment. Your commitment to the well-being of the bleeding disorders community is truly remarkable, and together, we are making a difference.

FAB Women’s Retreat

Our third annual FAB (Females and Bleeding) was held October 13-15th at Margaritaville in Lake of the Ozarks. This event is co-hosted by Nebraska NBDF, Gateway Hemophilia Association, Midwest Hemophilia Foundation and Bleeding Disorders of the Heartland supported by Octapharma. 60 women from 4 states came together to discuss Mental Health, joint health, the challenges and wins of living with a bleeding disorder. One of the highlights of the morning was the Women with Bleeding Disorders Panel. Brave women shared their personal stories, struggles, and triumphs. Their narratives resonated deeply, reminding everyone present that they were not alone in their journey. Conversations, connections and friendships were made or reestablished over succulent planting, water aerobics and finished the night with a fun slumber party full of games, pizza and a lot of laughter. We look forward to being back in 2024 to continue to offer this dynamic programming to adult women across the Midwest.



The Loras Goedken Outstanding Leadership Award

Our very own Joe Mickeliunas was honored at the 2023 Bleeding Disorders Conference for receiving ***The Loras Goedken Outstanding Leadership Award.*** Congrats to Joe for being recognized nationally for the amazing work he has done in the past 6 years at the Nebraska Chapter. Your dedication to Elliott, the community and making a difference have not gone unnoticed.

This year's winner, Joe Mickeliunas, is a shining example of what makes a kind, impactful, and dedicated leader. His fellow chapter members say that he is one of a kind and has the power to change the world! As a teacher by profession, he uses his education skills to raise awareness for bleeding disorders.

Additionally, he is a dedicated father to his son, Elliott, who has hemophilia. Elliott was diagnosed as an infant. Joe and his wife, Jenny, found this diagnosis shocking, as many parents do. But they quickly got involved with the community and found solace, support, and a passion for furthering research and fundraising.

Sickle Cell Event– September

On Saturday, September 23rd, an inspiring event unfolded at the Kroc Center in Omaha, where the forces of knowledge and community came together to create a day of learning, support, and connection. Sickle Cell Education Day, organized in partnership with Children's Nebraska and Nebraska Medicine, brought together over 73 individuals affected by sickle cell, uniting children, teenagers, and adults in a space where they could gain valuable insights and draw strength from one another. The event featured informative sessions tailored to the different age groups, ensuring that each individual had access to information relevant to their journey. To cap off this empowering day, a family carnival provided a delightful setting for all to come together, celebrating resilience, togetherness, and the power of knowledge in the fight against sickle cell. It was a day that served not only to educate but also to foster a sense of belonging and support within the community.

Sickle Cell is a blood disorder that affects dozens of families in the Omaha area. Nebraska NBDF offered support for planning and execution of this first time event. We understand the overwhelming need for support in this community, and while we are not equipped to take over Sickle Cell support fully as an organization, we are looking for ways to support this community through Children's Hospital. We hope to incorporate affected teens into our teen program and see how we can grow our support of those affected by SCD.

Board Update

Board & Committee Recruitment

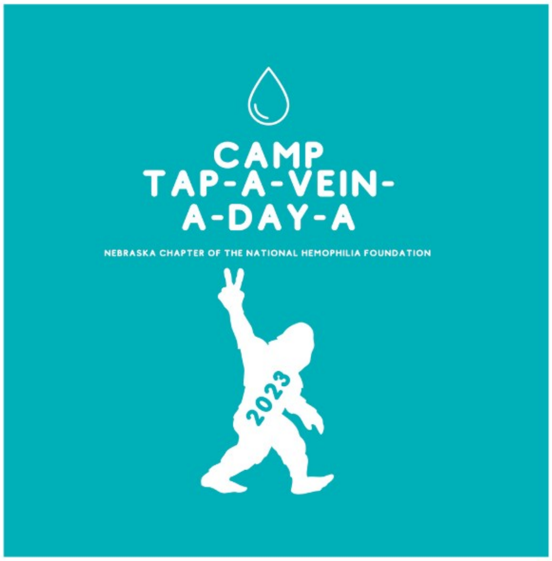
The Nebraska Chapter of NHF is looking to expand our Advisory Board of Directors. We are currently recruiting both affected and unaffected board members. We specifically are looking for members with diverse backgrounds including those who reside in rural areas, Spanish speaking or bilingual, individuals comfortable in the rare disease space, those with financial or accounting backgrounds, community connections or a knack for fundraising. This list is not exhaustive. If you know someone who would be a good fit for our Board and Chapter, please reach out to Maureen at mgrace@hemophilia.org.

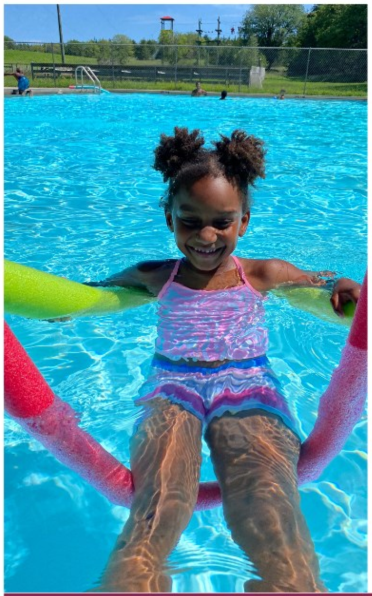
Additionally, there’s always room on committees for non board members at all. If you want to get involved and help with Advocacy, Programs and Education, Fundraising and Events or more. We will be hosting monthly virtual committee meetings for the following programs and events:

⇒ Family Education Weekend
⇒ Family Camp
⇒ Infusion: Bloody Mary Mix Off
⇒ Unite for Bleeding Disorders Walk

Please join us for these virtual meetings to help us make these programs and events even more dynamic. Keep an eye out on your email and social media for the dates for these meetings. If you would like a reminder– please reach out to Sarah at sarrieta@hemophilia.org

Thank you to our Industry Sponsors who support our programming, advocacy and outreach efforts throughout Nebraska for all bleeding disorders.





Thank you for a wonderful Family Camp!
We look forward to seeing you next August.

Family Camp Update

This year, the picturesque Carol Joy Hollings Camp in Ashland, Nebraska played host to an unforgettable event that brought families closer together while creating lasting memories - the 2023 Bigfoot Adventure Family Camp. Nestled in the heart of nature, this camp offered an exceptional opportunity for families to connect and bond in a beautiful outdoor setting.

But what made this year's Family Camp truly extraordinary were the incredible teen counselors from our very own NENBDF Teen Council. These dedicated young leaders didn't just facilitate the camp; they played an essential role in creating an atmosphere of warmth, learning, and fun for families.

One of the highlights of Family Camp was the chance for these talented teen counselors to showcase their leadership skills. They took on various responsibilities, such as helping prepare delicious meals in the camp's kitchen. Whether it was cooking up a hearty breakfast, a savory lunch, or a scrumptious dinner, these teens were up to the task, making mealtime a memorable experience for everyone.

For the adventure seekers, there was a thrilling ropes course and a zipline that provided a rush of adrenaline. Families soared through the treetops, building not just courage but also unforgettable memories. Additionally, the camp offered swimming, paddle boats, and a refreshing escape into the water, perfect for cooling off on warm summer days.

Of course, no camping experience is complete without the classics. Campers gathered around a crackling campfire, where they sang songs and roasted marshmallows for s'mores. It was a delightful, cozy experience that helped create bonds and lasting memories. And for those who wanted a tangible keepsake, tie-dying T-shirts provided a creative and artistic outlet for self-expression.

The 2023 Bigfoot Adventure Family Camp was an inclusive experience, catering to family members of all ages. It offered an opportunity for parents, grandparents, children, and even the youngest of campers to come together and enjoy the great outdoors. The diverse activities and the friendly atmosphere ensured that there was something for everyone to enjoy, making it a truly family-centric adventure.

In a world that often seems dominated by screens and busy schedules, the Family Camp at Carol Joy Hollings Camp in Ashland, Nebraska, served as a reminder of the beauty of connecting with loved ones in the heart of nature. It was a weekend of bonding, adventure, and shared experiences that families will treasure for years to come. The 2023 Camp Tap-A-Vein-A-Day-A was not just a camp; it was an unforgettable journey of togetherness and discovery, reinforcing the importance of family bonds in our lives. Thank you our sponsors who made this experience possible, Takeda, CSL Behring, Brother’s Healthcare, CVS Speciality, Infucare RX and Sanofi.

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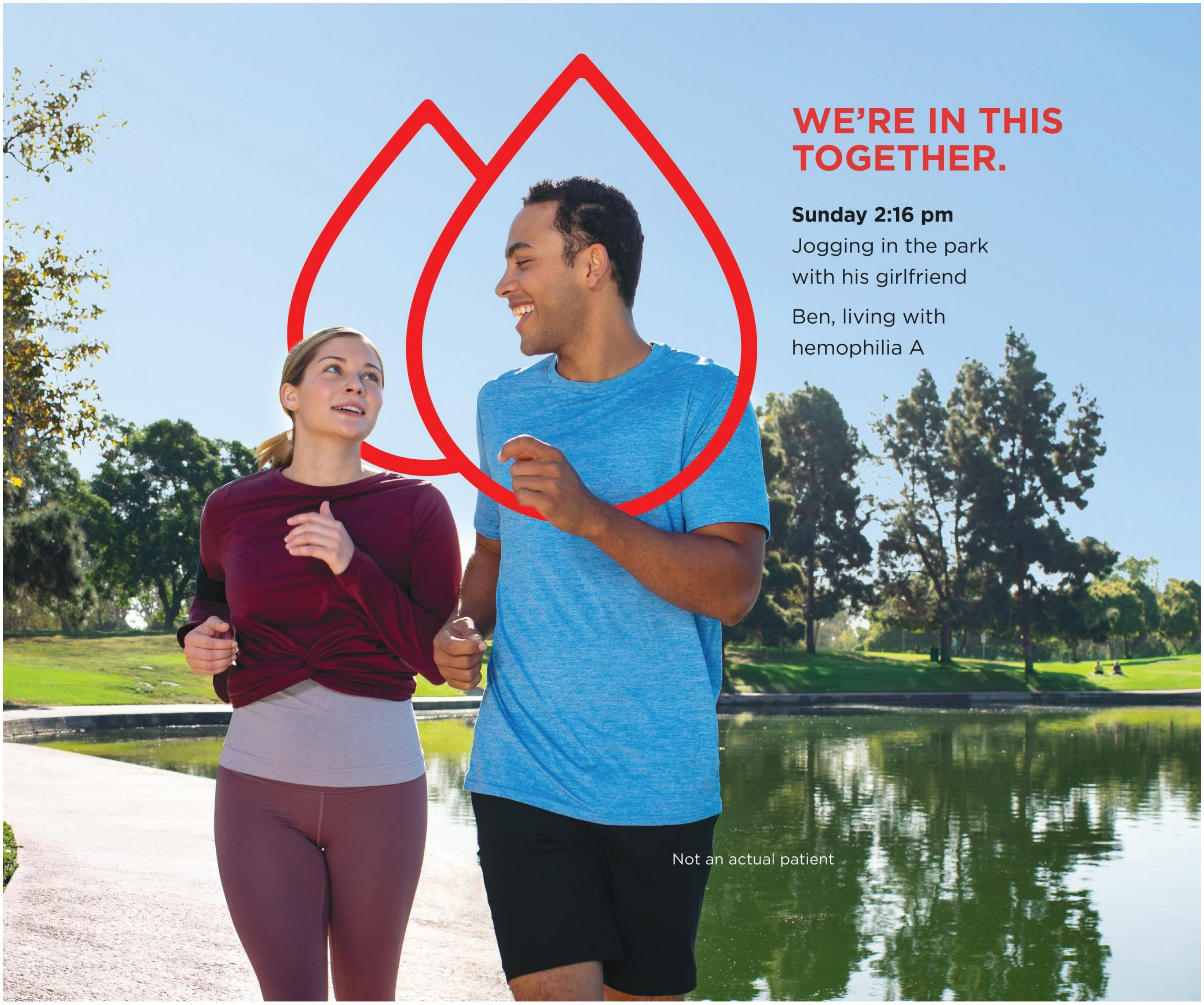
WE'RE IN THIS TOGETHER.
Sunday 2:16 pm
Jogging in the park with his girlfriend
Ben, living with hemophilia A
Not an actual patient

Overlooked Cause of Abnormal Menstrual Bleeding

Author: Martha Frase

Many women accept excessive, prolonged periods as an annoying but ordinary part of being female—putting up with the monthly stress of periods so heavy that they interfere with their quality of life.

But in some cases, the cause of those heavy periods is von Willebrand disease (VWD), the most common inherited bleeding disorder in the US. While men and women are equally affected by VWD, in women, heavy menstrual bleeding is often the major symptom.

What's Normal, and What's Not?

It can be hard to tell if you have heavy or excessive bleeding because you've gotten used to it, but in general, periods that last more than seven days is considered heavy menstrual bleeding (HMB).. Other signs of HMB:

- You use more than one pad or tampon every hour
- You need to double up by wearing one pad and a tampon because of heavy bleeding
- You need to change pads or tampons more than once during the night
- You have menstrual flow that repeatedly contains blood clots the size of a quarter or larger
- Your menstrual flow is so heavy that it keeps you from doing the things you would do normally, such as going to work or school

When VWD Is Suspected

Not every woman with heavy periods has VWD, so the diagnostic process for VWD usually begins with a few questions about family and menstrual history, says Andrea Lukes, MD, MHSc, president and CEO of Carolina Women's Research and Wellness Center in Durham, North Carolina. "If someone has had heavy bleeding since her first period, that raises suspicions. A family history of known bleeding disorders, such as hemophilia, would as well," says Lukes, who is also the founder and chair of the Ob/Gyn Alliance, a peer-to-peer network educating ob/gyns.

The initial step to determine if a patient has VWD is to run specific tests that measure VW antigen (the amount of VW protein in the blood) and activity levels (how well the VW protein works), and levels of factor VIII (FVIII).

"The range of normal for antigen and activity will vary from 50% to 150%," says Alice Ma, MD, associate professor of medicine in the Division of Hematology/Oncology at UNC Hospitals in Chapel Hill, North Carolina. "But there's normal, and then there's 'normal.'" The difference is in the patient's story, according to Ma, a hematologist who specializes in treating women with bleeding disorders.

When Retesting Is Required

Because test results can come back normal for a person with VWD due to several factors, such as stress, elevated estrogen levels, pregnancy, use of oral contraceptives and recent physical exertion, retesting can be required. Test results may also be skewed during periods of acute inflammation, such as the perioperative period, and if infections are present. Any of these can temporarily increase the VW antigen and activity levels into the acceptable range.

Abnormal Menstrual Bleeding Continued...

“For a patient with a level of 50% to 60%, but in the setting of a really good story—a history of bleeding and a strong family history of bleeding disorders—I am going to repeat those tests, making sure everything is optimized for the best results,” Ma says.

“I may bring a patient back to be tested again right before menstruating [when hormone levels are lower], or take her off birth control pills or HRT [hormone replacement therapy] for a month or two before repeating the test,” Ma says. “Also, if a patient has just run up the stairs or is nervous, [those factors] can increase levels as well. I will bring her back on another day, make sure she takes the elevator and try to keep her calm.”

Another factor that can affect VWD test results is where the testing is done. “It is best to get the tests done by a hematologist, preferably one associated with a hemophilia treatment center,” Ma says. Commercial labs or clinics may not use optimal methods for handling blood. “If it sits outside in a metal box, the sample could be messed up before it gets to the lab.”

Treatment for VWD

To those undergoing testing or who are newly diagnosed, Lukes offers this assurance: “Once you are diagnosed, it’s the first step to managing the disease. There are lots of options to control its impact. I see a huge sense of relief come over individual women when they finally understand why they have this bleeding disorder and how common it really is.”

For more information on lab testing for VWD and how to prepare for them, visit NHF’s Better You Know website. https://www.betteryouknow.org/women/at-risk/how-to-prepare

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Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.†

In people taking ALTUVIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

†159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

‡Data based on treated bleeds.

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Who should not use ALTUVIIIO?
You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?
Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?
You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full Prescribing Information.

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NEBRASKA CHAPTER NEEDS ASSESSMENT

- **NEW SURVEY DEVELOPED BY SARAH, MARIA, & MAUREEN**
- **CHANCE FOR THE COMMUNITY TO SHARE THEIR OPINIONS & PREFERENCES**
- **HELP US BETTER UNDERSTAND YOUR NEEDS**
- **IMPROVE PROGRAMS & SERVICES**

We need your feedback!

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Your voice matters and will help shape the future of NENHF