BIOMATRIX Specialty Infusion Pharmacy News

Summer 2025
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Dedicated to Making a Difference

"May your life be like a wildflower growing freely in the beauty and joy of each day."
— Native American Proverb

Special Women's Issue!

VOLUME 20 | ISSUE 3
SUMMER 2025

About BIOMATRIX

As an independent specialty infusion pharmacy, we provide injected and infused medications not typically found at your neighborhood pharmacy. These medications are costly, involve unique shipping and handling, and require patients to receive training or home nursing support to safely take the medication at home.

Because of the high level of care required to handle these complex infused or injected medications and the conditions they treat, we support our patients at every step. From prescription intake and insurance clearance, through medication delivery, training, and beyond, we are committed to our patients' success.

Our Promise

Every day, in every interaction, we are a specialty infusion pharmacy dedicated to making a difference.

Fine Print

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore, Justin Lindhorst, and Jeanette Kizer-Jones

The purpose of BIOMATRIX NEWS is to provide information such as current news, upcoming events, educational matters, personal stories, and a variety of opinions and views on topics of interest to the bleeding disorders community. The information and opinions printed in this newsletter do not necessarily reflect the views and opinions of the partners, employees, or others associated with BIOMATRIX NEWS or that of BioMatrix.

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BIOMATRIX
Specialty Infusion Pharmacy

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Securing access to prescribed therapy, resolving insurance issues, and dealing with medically related challenges faced by members of the bleeding disorders community.

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For more information, visit:
bit.ly/bd-patientnavigation

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A Note from the Editor

Welcome to our special summer issue of BioMatrix News, focusing on women and bleeding disorders!

Over the years, issues related to bleeding disorders in women have slowly begun to gain recognition. Progress is being made, but we still have a long way to go in ensuring that women receive timely, accurate diagnoses and appropriate treatment. Many women, including myself, have experienced hardships and challenges on their path to receive proper care.

I have two brothers with severe hemophilia. As a teenager, my factor level was 18%. Despite experiencing numerous symptoms, such as excessive bruising, prolonged injuries, heavy menstrual cycles, and bleeding after wisdom teeth extraction, I was not accurately diagnosed until I was 33 years old. By that point, I had previously undergone two C-section births, one of which was a son with severe hemophilia. I also experienced excessive bleeding during and after an ectopic pregnancy, and most significantly, I lost more than half my blood volume as I laid in a recovery room following the C-section birth of my third child.

After years of being told that women can't have hemophilia, it was only then that I realized I needed to advocate for a proper diagnosis beyond just being labeled a *carrier*. When my lab results came back, my Hemophilia Treatment Center physician somewhat reluctantly confirmed that I have mild hemophilia and should "probably" receive factor as needed. Finally! Two years later, I had a fourth C-section and welcomed a second child with hemophilia. Since then, I have undergone several surgeries, both minor and major. With clotting factor on board, excessive bleeding has not been a complication. I would never compare my experiences to those of my brothers and sons; however, had my bleeding symptoms been taken more seriously and had I been properly diagnosed and treated sooner, I may have avoided some residual issues.

It is essential to raise awareness and support one another in our journeys. I hope others are encouraged to seek the answers they deserve. Together, we can work towards better recognition, diagnosis, and treatment for all women affected by bleeding disorders. Please share your story with us so we can publish it for our readers. By sharing and supporting one another, we can emphasize the need for ongoing dialogue within the medical community and help pave the way for improved diagnoses and treatments.

Thank you for reading. Enjoy your summer!

Maria Santucci Vetter
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THE *Future of Care* FOR FEMALES WITH A BLEEDING DISORDER

BY JOANNA DAVIS, MD

As 2025 takes hold, it is a good time for growth, reflection, and resolve. As parents – especially mothers – our time always seems directed to paying close attention to our children and family. But what about us? What about moms, sisters, wives, daughters, aunts, and grandmas? What do *we* need?

We should always take some time to focus a little on ourselves and our needs. Creating "me time" for that visit to the salon, the mall, or the library is critical. However, I am specifically referencing the need for the women in our community to have awareness and knowledge about their bleeding disorders, to develop a voice to be heard, to stand up for their needs, and to make things happen.

The science of bleeding disorders has come a long way, accelerating over the past 10 years. Gene therapy, once a daydream, is a reality. Subcutaneous prophylaxis is possible and effective for so many. Increasing numbers of infants, children and adults with bleeding orders are leading "normal" lives – playing sports, attending college, pretty much like everyone else. Since every human being has some medical issue, why is having a manageable bleeding disorder any more or less devastating or embarrassing than having asthma or diabetes?

Women's bleeding issues require the same attention that is paid to the needs and challenges of our fathers, husbands, and sons. And we – the moms, the aunts, the teens – must be the agents of change.

There is still a lack of awareness on the part of many in the medical community that women can and do have bleeding disorders and that some of the most common issues that force a woman to go to the doctor, such as heavy periods and iron deficiency anemia (fatigue, paleness, dizziness, shortness of breath), can be understood by the evaluation for, and identification of, a bleeding disorder. This recognition results in appropriate management and stronger, healthier women.

It's very easy and reassuring to keep reiterating, "Everyone in my family bruises easily, has nosebleeds, and heavy periods, so this is normal." What is normal? While caring for our children or spouse with a bleeding disorder, we

need to acknowledge and embrace that WE may also have a bleeding disorder and must seek care for ourselves as well.

WHAT CAN WOMEN DO?

Become familiar with symptoms that can point to a bleeding tendency and insist that your physician listen and act! As with everything female, reproductive bleeding is a hallmark.

PAY ATTENTION TO:

- Periods that last at least 7 days
- Periods that require a change in sanitary product every 1-2 hours for a few (or all) of the days
- Soaking through pads, doubling up pads and soaking through clothing or bedding
- Passing grape-sized clots
- History of recurrent nosebleeds – particularly nosebleeds that started as an infant or toddler
- Unexplained bruising in odd places (chest, back, hips) without trauma
- Fatigue, shortness of breath, pallor
- Postoperative bleeding that was worrisome to healthcare providers and raised the need for a transfusion or required a return to the operating room

TRACK YOUR PERIODS:

If you're technologically savvy, many good menstrual tracking apps are available. Otherwise, there's the good old-fashioned calendar page. Pay attention to patterns of interval, duration, and intensity. Are you using aspirin or Advil for pain? If so, how much and how often? What supplements are you taking? Excessive garlic, ginger, or ginseng intake can cause a coagulation defect and lead to bleeding.

FIND A KNOWLEDGEABLE AND SUPPORTIVE PROVIDER, CLINIC, OR MEDICAL TEAM:

- There are nearly 150 Hemophilia Treatment Centers in the United States. For a complete list including contact information, visit the CDC at www.cdc.gov.
- Specifically inquire if your HTC has either a dedicated women's program in conjunction with an OB/GYN or works closely with a provider who has an interest in women with bleeding disorders. If not, speak directly with your physician and provide facts and resources.
- Work with your HTC team to encourage the development of clinical studies focusing on or including women.

FIND COMMUNITY SUPPORT:

- Many organizations offer excellent resources and education for women's issues.
- Attend chapter and advocacy meetings.
- Inquire about "meeting" other women in the bleeding disorders community. We can serve as our own mentors!
- Take time for yourself to question, learn, and act.

FAST FACTS

- 1 out of every 6 mild hemophiliacs are women.
- Women can have joint bleeds.
- In some studies, 50% of women/girls with heavy periods were found to have a bleeding disorder.
- 15–20 % of women with iron deficiency may actually have a bleeding disorder.
- Pregnancy and birth control pills can normalize the clotting system in women with hemophilia A and von Willebrand Disease Type 1, so that lab tests that fall within the "normal" range for the lab are actually falsely elevated to normal. Everything may seem fine following childbirth. However, 2-4 days after delivery, a woman with hemophilia A or vWD may begin to experience postpartum hemorrhaging when the hormones that kept factor levels high, drops off.
- There can be a delay of months to years in identifying a female with a bleeding disorder, when compared with a boy/male with similar issues. The average age of a female being properly diagnosed with a bleeding disorder, not too long ago, was around 33. Fortunately, with increased awareness, more women are being identified in their teens. However, years still exist between the first symptom and diagnosis.

VISIT THESE LINKS FOR MORE INFORMATION:

- Let's Talk Period: check out https://letstalkperiod.ca/self-bat/eng/ for a simple bleeding assessment tool, which will let you know if you or your relatives have a pattern suggestive of a bleeding disorder
- National Bleeding Disorders Foundation https://www.bleeding.org/
- The Foundation for Women and Girls with Blood Disorders https://www.fwgbd.org/
- World Federation of Hemophilia https://wfh.org/
- CHES Foundation-LadyBugs/SHEmophilia/Hermanas de Sangre https://ches.education/intro

Times change. Information changes.

The Hemophilia Treatment Center network is and has been reaching out to educate providers and practitioners, but we need to be in partnership with you - your words, your experiences, your voices!

ABOUT THE AUTHOR:

Dr. Joanna Davis received her undergraduate degree from Barnard College of Columbia University and her MD from the Albert Einstein College of Medicine. After completing a residency in Pediatrics at Montefiore Hospital and Jackson Memorial Hospital, and a Fellowship in Pediatric Hematology/Oncology at the University of Miami, Dr. Davis joined the faculty at UM. She developed the Pediatric Hemophilia Treatment Center in 1987 and has committed both the Adult and Pediatric programs to outreach and education. She remains the Director Emerita of the Hemophilia Treatment Center.

Dr. Davis has raised awareness and education for thousands through various methods, such as bilingual children's booklets, book chapters, scientific articles, and educational grants. Identifying and treating women with bleeding disorders is a particular focus of her practice.

The University of Miami HTC has recently completed investigator-initiated research studying joint ultrasound findings in women with bleeding disorders. Additional registries and projects are ongoing. Dr. Davis is also committed to mentoring young physicians and is proud to have trained several new healthcare professionals who have enthusiastically joined the bleeding disorders community.

You know who she is. She's the hematologist, social worker, or nurse who cares about your total wellness, not just your treatment. She's your coworker, neighbor, or friend with hemophilia B who stands up for herself and other women like her. She's your sister, daughter, mom—the woman who is always there for you. **Together, they're the Heroines of Hemophilia B.**

Share your stories at

HeroinesofHemophiliaB.com

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MEDEXUS PHARMA

MENSTRUATION AND TRACKING

WHAT CAREGIVERS AND PEOPLE WITH BLEEDING DISORDERS NEED TO KNOW

BY JEANETTE KIZER-JONES, MA, ED

We all know someone who menstruates, and at any given time, around 800 million people worldwide are experiencing menstruation.[1] If you care about yourself or someone who menstruates, this information is for you — which means it's relevant to everyone!

Menstruation and heavy menstrual bleeding (HMB), also known as *menorrhagia,* have been significant topics in the bleeding disorders community in recent years. This focus is crucial, considering the urgent need to support women with a bleeding disorder who have faced years of neglect and mismanagement.

Since 90% of females with an underlying bleeding disorder experience HMB,[2] it's essential to learn more about menstruation and how to track for HMB to make a positive difference in the lives of all genetically female individuals. However, many still feel hesitant to discuss menstruation due to stigma, societal suppression, and sexism.[3]

Here's the truth: *menstruation is natural*, not taboo, and it's essential to openly discuss. It is a fundamental part of life, and it is why everyone is alive today. We need to break the stigma surrounding this important topic.

Individuals with HMB face an increased risk of anemia, painful menstruation, hospitalizations, blood transfusions, limitations in daily activities, missed time from work or school, and a reduced quality of life.[4] As a community, we should strive for a better experience for those we care about.[5]

Let us explore the research and its significance to our community. A key issue is the diagnosis age gap between males and females regarding bleeding disorders. One effective approach to address this gap is tracking menstruators for heavy menstrual bleeding, as it is the most common symptom experienced by individuals with bleeding disorders.[6] If our goal is to help more females receive earlier diagnoses, educating healthcare providers and community members on how to screen for HMB could be beneficial. Multiple studies indicate that between 15% and 30% of those with HMB have an underlying inherited bleeding disorder.[7]

Additionally, some studies suggest that about 1% of all females may have a bleeding disorder, and as many as 1 in 10 people with HMB could have an underlying bleeding disorder.[7,8] Many menstruators will eventually visit an obstetrician/gynecologist (OBGYN), making it important to educate OBGYNs about these issues. However, most young menstruators first consult with pediatricians, and unfortunately, many of these providers have limited knowledge about HMB. As a community, we need to educate ourselves to inform others, including our healthcare providers, family, and friends.

STEP ONE:
Learn general menstruation information

Young women can begin menstruating as early as ages 8 to 14 years, and their cycles may initially be irregular but should eventually stabilize. A normal menstrual period should last no longer than 6 days, with a volume loss of less than 80 ml (approximately 2.7 oz).

Menstrual blood consists of endometrial tissue, cervical mucus, and vaginal secretions. The color of menstrual blood can vary from bright red or orange to dark brown and even black, depending on how old or oxygenated the blood has become. The texture can also differ significantly, ranging from gritty, stringy, or clotted to slippery, thin, or watery.[9,10,11]

When a person menstruates, the uterus creates a wound as the lining is shed. If someone has a clotting issue that prevents proper healing, they may experience prolonged and heavier bleeding, which can be indicative of a bleeding disorder.

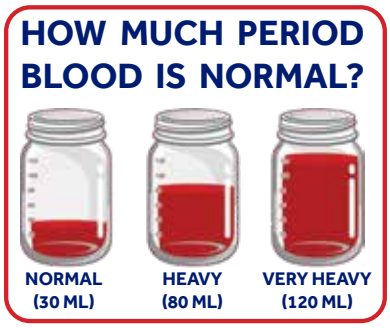
STEP TWO:
Recognize the general signs of heavy menstrual bleeding or a bleeding disorder

Ask yourself the following questions and share the answers with your health provider:[12,13]

- When did you get your first period? An early onset can signal a potential issue.
- How long does your period last? If your answer is longer than seven days, this may be a warning sign.
- Have you experienced flooding or gushing? If so, you know this can lead to very embarrassing situations.
- Do you need to change your period products often due to heavy bleeding? Most menstruation products are designed for those with regular menstrual flow, not for individuals with HMB.
- Have you experienced significant bleeding following a miscarriage, childbirth, a minor procedure, or surgery? Answering 'yes' to this question could indicate a possible bleeding disorder.

STEP THREE:
Understand and identify heavy menstrual bleeding

It's crucial to note that HMB is NOT considered normal. Just because other menstruators in your family have had heavy periods does not mean it is acceptable for you to experience the same.[6,14,15]



Officially, a loss of 80ml (2.7oz) or more is classified as HMB. This standard was established in the 1960s and has remained unchanged.[16] This measurement is the most vital indicator for determining HMB.

Key Indicators of HMB:

1. ***Menstrual bleeds lasting more than 7 days:***
   Even if your bleeding lasts fewer than 7 days, if you are losing more than 80ml (2.7oz) in a single cycle, you are still experiencing HMB.[17]
2. ***Passing clots larger than a dime or quarter:***
   Clots can sometimes resemble grape or strawberry jelly and may even exceed the size of a coin.
3. ***Flooding or gushing of blood:***
   This can occur when someone gets up after lying down, stands after sitting, after a meal, or even when sneezing or coughing. Such incidents can lead to leaks or completely saturating a period product.
4. ***Soaking or filling a period product every two hours or less:***
   It is essential for school-aged menstruators to have extra period products available and easy access to bathrooms. Consider adding this need to your child's 504 plan.
5. ***Needing to wear more than one period product at a time***:
   Some individuals may use a combination of products, such as a tampon and a pad, a pad and period panties, or other combinations. This is a clear sign of HMB.
6. ***Disturbed sleep:***
   Heavy periods should not wake you up during the night. If this happens, consider using period underwear (some are disposable), which may help.
7. ***Limiting activities:***
   If your period prevents you from attending work, school, social events, or affects intimacy, this is not considered normal.[18]
8. ***Low iron and/or ferritin levels:***
   Blood test detecting low iron and/or low ferritin levels may be an indication of significant blood loss.

STEP FOUR: Track HMB

Tracking HMB is essential because it can lead to earlier diagnoses for individuals with bleeding disorders.[9,19] Healthcare providers need honest accounts of a menstruator's experience to consider prescribing any kind of medication.

The practice of tracking menstruation dates back approximately 20,000 to 40,000 years. The famous Ishango bone, discovered in 1960 in what was then the Belgian Congo, is an example of this practice. The baboon bone is etched with markings that may have been used to record menstrual cycles for the purpose of procreation.[20] This early tracking system eventually contributed to the development of our modern calendar systems.

Ishango Bone, Royal Institute for Natural Sciences of Belgium

The Pictorial Blood Assessment Chart (PBAC) was introduced in the 1990s to improve the evaluation of bleeding in hematology. Initially, it was designed for researchers to quantify blood volume loss more effectively.[17] Before this, participants would bring in used, dried products that were rehydrated and weighed, which was not very practical.[21]

The PBAC allows for an equative score by calculating the number of products used based on their saturation levels, while also considering the frequency of flooding incidents and clots. **A score above 100 indicates heavy menstrual bleeding**. Although the PBAC system isn't perfect, it remains the best tool available in the community.

Over the years, researchers have worked to enhance the PBAC, focusing on improving the quantification process by considering the varying absorption abilities of different period products and striving for greater accuracy in measuring volume loss.[22] Recently, a user-friendly version of the PBAC has been adopted.

Many national and international bleeding disorder organizations offer a standard weekly PBAC that can be printed. Although other period tracking apps are available, they do not provide the information necessary for proper testing and diagnosis of a potential bleeding disorder. At one time, there was once a specialized app available in the U.S., but its availability ceased after Roe v. Wade was overturned due to concerns about the privacy of digital period tracking data.[23] The currently available PBAC tracking systems can be kept as private as the user wishes.

Here are some websites where the PBAC version you need can be found:

- HFA offers both a printable and digital form that includes a guide with options for daily, weekly, monthly, and annual tracking (see the sample below). The digital weekly version even performs calculations for you: www.hemophiliafed.org/resource/menstruation-tracking/
- NBDF provides the "Better You Know" program, which includes both a printable form and a workbook: www.betteryouknow.org
- WFH has a printable version as well as numerous educational resources available at: elearning.wfh.org/resource/women-and-girls-with-hemophilia/

Pictorial Blood Assessment Chart (PBAC): Per-Cycle

Date:

Hemophilia Federation of America™

This menstrual chart and scoring system is meant to help you track your period and discuss your circumstances with your healthcare provider. It is not meant as medical advice.

Pad/Tampon/Clot	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8	Total Tallies	Multiplying Factor	Row Total
									0	x1	0
									0	x5	0
									0	x20	0
									0	x1	0
									0	x5	0
									0	x10	0
Small blood clots (= dime)									0	x1	0
Large blood clots (> or = quarter)									0	x5	0
Flooding									0	x5	0
Total PBAC Score											0

How to use the PBAC:
- Record the number of tampons and sanitary pads used each day during your bleeding episode by placing the number under the day and next to the box representing the amount of bleeding you see each time you change your pad or tampon.
- Record clots by indicating whether they are the size of a dime or a quarter coin in the small and large blood clot row under the appropriate day.
- Record any incidences of flooding (accidents) by placing a tally mark in the 'flooding' row.

Scoring the Chart
At the end of your bleeding episode tabulate the "Total Tallies" in each row. Next, multiply the "Total Tallies" in each row by the "Multiplying Factor" at the end of the row, for the "Row Total." Then sum the "Row Total" for the final, "Total PBAC Score."

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STEP FIVE:
Use logs

Use your logs to receive better care and potential treatment for heavy menstrual bleeding. Sharing this vital information with healthcare providers can make a significant difference. Many menstruators with bleeding disorders may be prescribed various medications to help manage HMB.[24,25,9,26,27,28]

Treatment options for HMB include the following. Consult with your physician for the option that is best for you:

- ***Hormone Therapy:*** This is often one of the first methods considered by providers. It's important to note that hormone therapy is not the same as birth control.
- ***Antifibrinolytics:*** Medications such as tranexamic acid or aminocaproic acid can help slow or reduce blood volume loss.
- ***Intrauterine Devices (IUDs):*** These devices can alleviate HMB by temporarily stopping menstruation.
- ***DDAVP:*** This medication has been prescribed in certain cases to help manage bleeding.
- ***Factor Replacement:*** Unfortunately, factor replacement therapy often tends to be a last resort, even for women with a diagnosed bleeding disorder.
- ***Iron Supplements or Infusions:*** These can help address iron deficiency caused by heavy menstrual bleeding.

FINAL STEP:
Share what you've learned

Now that you know how to help yourself or someone else struggling with HMB, don't hesitate to spread this knowledge. You may encounter someone who is unaware that their experiences are not normal or who might have an undiagnosed bleeding disorder.

Remember, knowledge is power. We hope to hear about your success in helping yourself or others. Happy menstruating!

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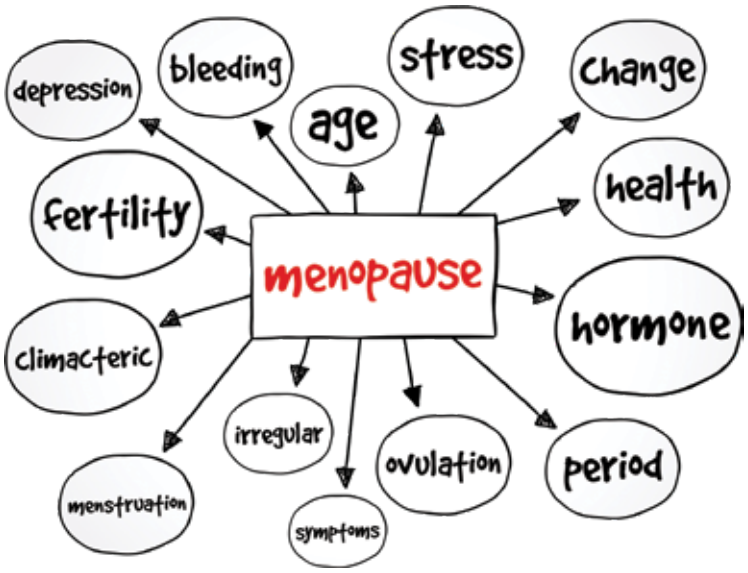
Menopause: Aging for Women with a Bleeding Disorder

BY JEANETTE KIZER-JONES, MA, ED

"Aging is not lost youth but a new stage of opportunity and strength." — Betty Friedan

By the time a woman has finished menstruating, she will likely have experienced an average of 450 cycles. So, it's no surprise that many feel ready and relieved when menopause begins. However, many are unaware of the complexities of this transitional process and are often surprised by the onset of unexpected symptoms.

Like menstruation, menopause has been left undiscussed in everyday conversation due to the stigma surrounding the very personal topic of menstrual health. As a result, while common symptoms such as hot flashes and night sweats are known, there are many more that deserve attention, especially for individuals with a bleeding disorder. Let's explore this often-neglected topic and learn how to provide better care for ourselves or someone we care for.



UNDERSTANDING MENOPAUSE

Menopause comprises three stages: pre/perimenopause, menopause, and post-menopause.

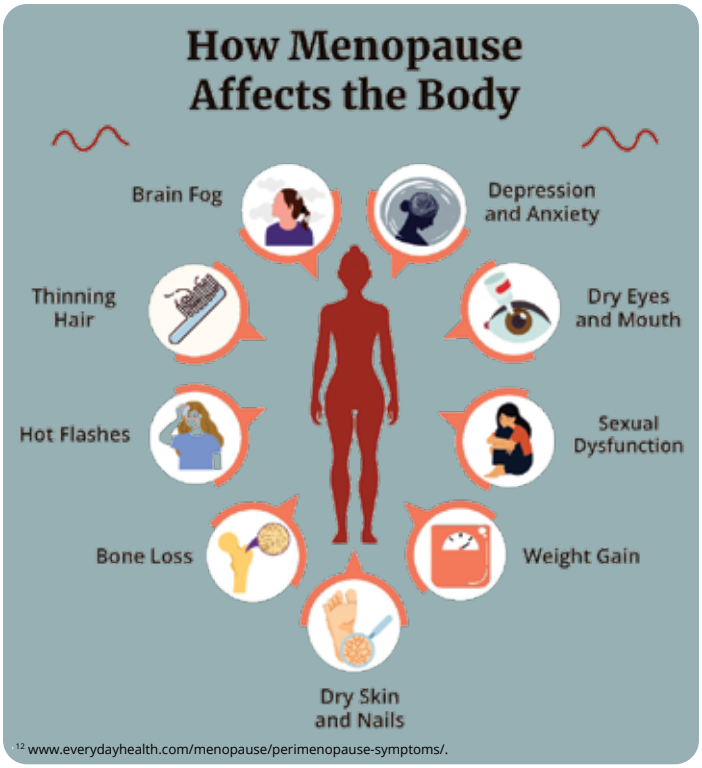
Pre/Perimenopause

Pre/perimenopause typically begins around ages 40 to 50, though rarely, it can start earlier. Research indicates that earlier onset of menstruation may correlate with an earlier start to this stage and the subsequent stages.[1] It is essential to note that some females with a bleeding disorder begin menstruation at a younger age than average,[2] and thereby, may experience the start of menopause at an earlier than average age as well.[3]

This initial phase can last anywhere from three to ten years, and during this time, many challenging symptoms may begin to appear and worsen with passing time. Although hormone levels are starting to decline, pregnancy is still possible, making it important for those who do not wish to conceive to consider their preventative options.[1]

Menopause

Menopause officially begins after a woman has not experienced a menstrual cycle for 12 consecutive months. While a rare return to menstruation can occur, menopause is only recognized after one full year has passed without a period.[3] The average age for menopause is 51,[4] although this can vary due to health, cultural, and environmental factors.



[12] www.everydayhealth.com/menopause/perimenopause-symptoms/.

Menopause occurs when the ovaries have released all the eggs they once stored. Since the menstrual cycle regulates the monthly release of these eggs,[5] menstruation ceases once the ovaries are empty, and conception is no longer possible.[1]

While menopause is a natural process, approximately 1 in 8 females may experience premature menopause due to illness, other disorders, medications, or surgical interventions[5] — commonly referred to as *surgical menopause*.[6] This ratio is likely higher within the bleeding disorders community, where many women in previous generations were not treated for heavy menstrual bleeding and were often encouraged to undergo some type of hysterectomy to manage their symptoms. Although less frequent today, this practice can still be common.[7,2]

Post-Menopause

Post-menopause is the final stage and marks the end of most, but not all, of the troubling symptoms associated with pre/perimenopause. [8] During this stage, new symptoms may arise while others may fluctuate. The transition from menopause to post-menopause is relatively short and confirms the end of both fertility and menstruation.[8] Hormonal declines are most significant during this time, leading to increased health risks for females, such as heart problems, bone weakness, diabetes, and more.[9,10]

Throughout these three stages, various symptoms can occur, each with special implications for individuals with bleeding disorders. Recognizing, tracking, and communicating these symptoms to healthcare providers is essential to ensure better care.[4] While many symptoms are attributed to decreasing estrogen levels, others may stem from different origins. Abruptly entering menopause can increase the severity of symptoms.[5]

SYMPTOMS OF MENOPAUSE

- **Hot Flashes:** Affect 35-75% of women and are caused by changes in the hypothalamus. This vasomotor symptom involves the contracting and expanding of blood vessels, which can lead to heart palpitations and chills.[11] Hot flashes typically last from one to five minutes and can occur up to ten times a day, lasting anywhere from six months to ten years.[3] Recommended lifestyle changes include dressing in layers, lowering environmental temperatures, carrying a portable fan, drinking cold beverages, and avoiding hot drinks, alcohol, caffeine, and spicy foods.[11]

- **Night Sweats:** Similar to hot flashes, night sweats involve extreme sweating that can leave one heavily drenched. It's advisable to have an extra set of sheets and clothing on hand. Cold drinks and ice packs can help alleviate symptoms.[12,6]

- **Weight Gain:** Common during menopause, though it doesn't affect everyone. On average, women may gain about 1.5 pounds per year, which can increase health risks over time. This weight gain is often attributed to a slower metabolism and increased hunger due to lower estrogen levels, which affect the body's fat storage systems. Regular low-impact exercise is encouraged.[12]

- **Mood Changes:** Approximately 23% of women experience depression, anxiety, and mood swings.[12] Some may feel sad about aging, while others may experience these feelings due to changes in the brain, nervous system, or lack of sleep.[13] Transitioning through menopause can be stressful. Engaging in a new hobby can help keep the mind occupied and reduce feelings of anxiety.

- **Sleep Disruptions:** Insomnia and sleep disturbances can result from night sweats, frequent urination, anxiousness and intrusive thoughts.[14] While medication may sometimes be necessary, there are many natural alternatives, such as melatonin, chamomile tea, and cannabidiol (CBD).[13] Developing healthy bedtime habits—avoiding mobile devices and television screens at night and steering clear of caffeine and alcohol—can also be beneficial.

- **Hair Loss and Skin Changes:** Hair thinning and brittle nails may occur due to decreased levels of estrogen and progesterone. Additionally, rising levels of male hormones known as androgens can lead to unwanted hair growth on the chin and upper lip.[12] Many women experience dry skin and other epidermis issues since skin can lose about 30% of its collagen during the first five years of perimenopause, followed by a decrease of about 2% each subsequent year for the next two decades.[15] An increase in acne may also be noted.

- **Mucosal Tissue Changes:** As with many mucosal tissues, dry eyes and dry mouth can occur.[3] Utilizing eye drops and specialized mouthwashes may help alleviate discomfort.

- **Bladder Issues:** Frequent urination and recurring urinary tract infections (UTIs) are common among

women during menopause. Signs of a UTI can include difficulty urinating, painful urination, fever, chills, cloudy or foul-smelling urine, and pain in the flank, abdomen, pelvic area, or lower back, as well as pain during intercourse.[16]

- **Sexual Dysfunction:** Can often occur in women, leading to issues such as vaginal dryness, increased tightness, painful intercourse, and changes in sexual desire, either a decrease or, in rare cases, an extreme increase.[12] Thinning of the vaginal wall can make it fragile and less flexible, increasing the risk of bleeding from injury, tears or lacerations during sexual activity.[5,3]

- **Bone Loss:** Around the age of 35, women may begin to experience bone loss (osteoporosis) as the rate of bone loss surpasses the rate of bone formation. This process accelerates during menopause.[12]

- **Cognitive Changes:** Memory loss and difficulties with concentration are common but generally temporary.[13]

- **Heavy Menstrual Bleeding:** A significant concern for many women in the perimenopause stage is the increase in heavy menstrual bleeding.[17,4] Especially significant to the bleeding disorders community, it's essential to track this bleeding to allow healthcare providers to offer better care for those with bleeding disorders. Using the Pictorial Blood Assessment Chart (PBAC), which is designed for use in hematology and gynecology, is recommended to help quantify blood volume loss from heavy bleeding.[3] This condition can lead to iron deficiency anemia and low ferritin levels.[2]

WOMEN WITH BLEEDING DISORDERS

When considering women with a bleeding disorder, several additional factors come into play. While vaginal bleeding may improve when actual menopause begins, other bleeding problems are likely to persist.[18] As estrogen levels fall rapidly, all mucosal tissues will start to thin, which can increase the risk of nosebleeds, mouth bleeds, gastrointestinal bleeding, and bleeding during intercourse due to lacerations. Lubrication and specialty creams can be beneficial to prevent some of these potential issues. For example, estrogen cream can thicken mucosal tissues and may even assist in reducing recurrent nosebleeds.[3]

Estrogen also plays a significant role in regulating clotting factors. While some factor levels, such as factors VII or VIII, and von Willebrand factor, may increase with age,[11,4] others crucial to the clotting cascade — like fibrinogen (FI), factor IX, and antithrombin III — may decrease following the onset of menopause due to lower estrogen levels.[19] Consequently, clotting time tests may also increase, such as prothrombin time (PT) and activated partial thromboplastin time (aPTT).[19] Given this delicate balance, it is essential to collaborate closely with both a hematologist and a gynecologist to determine the safest approach to estrogen replacement therapy (if desired) to mitigate thrombosis risk.

Any vaginal bleeding after menopause is complete is *not* normal and may indicate a more serious underlying issue that warrants investigation by a healthcare provider.[20] Potential causes of post-menopausal bleeding may include a bleeding disorder, infection, endometriosis, fibroids, endometrial hyperplasia, polyps, ovarian cysts, vaginal or vulvar hematomas, uterine cancer,[11] thyroid abnormalities, or uterine atrophy, which collectively account for about 60% of such bleeding. Additionally, some vaginal bleeding could be mistaken for bleeding originating in the urethra, bladder, or gastrointestinal tract.[21] All surgical procedures carry a risk of hemorrhage, making a hematology consult essential for establishing a plan to prevent excessive bleeding.

TESTING AND TREATMENT

Various tests may be necessary during the stages of menopause. While blood tests can determine whether menopause has begun,[6] there is no specific test to confirm the onset of perimenopause transition.[5] Some women will eventually require a pelvic ultrasound (internal or external). In some cases, an endometrial biopsy is performed to test the tissue of the vaginal lining, and in other situations, a hysteroscopy or dilation and curettage (D&C) may be recommended.[21]

It's important to note that these procedures can cause bleeding. If post-menopausal bleeding occurs, a thorough medical investigation is recommended to establish an accurate diagnosis.[20] In severe cases, exploratory surgery might be considered as a last resort. For individuals with bleeding disorders, it will be critical to check factor levels throughout all stages, especially before any planned procedure or surgery, as estrogen levels can cause fluctuation in clotting ability.[4]

The most common treatment for menopausal stages is hormone therapy.[18,4] For decades, the risks and benefits of hormone therapy have been debated and researched.[6] Today, many believe that the benefits outweigh the risks. Potential risks include heart problems, stroke, blood clots, and breast cancer.[6] Estrogen and progesterone are commonly prescribed in various forms, such as pills, patches, creams, injections, and sprays.[11]

Hormone therapy can help alleviate hot flashes and night sweats, as well as many perimenopause symptoms. It is considered safe to use within 10 years of menopause,

up to age 60. In most cases, hormone therapy is used for short intervals and is frequently reassessed as natural hormone levels fluctuate.[3]

Joining or gathering a group of supportive women going through similar experiences can greatly improve yours. As taboos surrounding menstrual topics are removed, so should menopause accordingly. As has always been known in our bleeding disorder community, we learn the most from each other, so you are encouraged to talk about it. Here are several helpful resources for people experiencing menopause:

- *My Meno Plan* – sponsored by NIH, a nationwide research network of doctors and menopause scientists: https://MyMenoPlan.org/
- *Let's Talk Menopause* – a nonprofit organization invested in changing the conversation around menopause so women get the information and healthcare they need and deserve: https://www.LetsTalkMenopause.org/
- *Society for Women's Health Research* – guided to make women's health mainstream, provides a *Menopause Preparedness Toolkit*: https://swhr.org/
- *The Menopause Society* – providing healthcare professionals the tools and resources they need to improve the health of women during the menopause transition and beyond: https://menopause.org/
- *Rock My Menopause* – stamping out the taboo around menopause: https://RockMyMenopause.com/

In conclusion, navigating the complexities of menopause can be particularly challenging for women with bleeding disorders, as they may face unique symptoms and health risks during this transitional phase. They must remain proactive in managing their health during this time of transition, as both physiological changes and their medical history can significantly affect their well-being.

By understanding the complexities of menopause, the

impact of declining estrogen levels, and the importance of communication with healthcare providers, women with a bleeding disorder can empower themselves and ensure that their individual needs are met, ultimately enhancing their quality of life during and after menopause.

ABOUT THE AUTHOR

Jeanette Kizer-Jones, MA, ED, is a Territory Account Executive at BioMatrix Specialty Pharmacy. With a master's and two bachelor's degrees in education, she is a passionate advocate for issues related to bleeding disorders. Additionally, she is a certified Mental Health First Aider. Before joining BioMatrix, Jeanette managed education for HFA and its *Blood Sisterhood* program. She previously held a position with her local bleeding disorders organization. Earlier in her career, Jeanette taught academic English to international university students. Jeanette resides in a historic town in Oklahoma with her children and pets. She enjoys anthropology, cinema, and music, but her favorite pastime is traveling. Jeanette, along with her son and daughter, has an ultra-rare bleeding disorder known as platelet-dense (delta) granular deficiency.

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STORIES IN EVERY STITCH:
THE JOURNEY OF THE STITCHES DOLL PROJECT

BY KATHLEEN GERUS-DARBISON

Like most people, my life's path has been somewhat convoluted due to circumstances beyond my control. In 1981, at the age of 23, I was working as a waitress while attending college when I met Michael, a sweet and funny young man who I quickly felt drawn to. Every Friday night for six weeks, he returned to the restaurant before finally mustering the courage to ask me on a date. I, of course, said yes.

On our first date, he shared that he had hemophilia. Having faced my own health challenges, I wasn't particularly concerned. A few months later, we were living together and planning our wedding. Our daughter, Stephanie, was born about a year after we married. Life was on a steady track, but that didn't last long.

In early 1985, during an appointment at the hemophilia treatment center, my husband was asked to participate in a CDC study on blood transfusion safety, which included our daughter and me. We had never received a transfusion, but he assured me it was standard practice. After blood samples and personal questions, we were supposed to receive follow-ups, but we never heard back.

Curious, I reached out in December and was asked to bring my family in for an appointment the following day. There, we learned the blood supply had been tainted with HIV, and both Michael and had I tested positive, our daughter was negative. While there was uncertainty about whether she would remain negative, it offered us a small glimmer of hope. The prognosis for Michael and I was grim; most people with the virus died within 18 months to two years. We were advised to keep this information quiet due to the stigma and fear surrounding the new virus.

To say the devastating news changed our lives would be an understatement, but we persevered as best we could. With little information about HIV available, we tried our best to educate ourselves while keeping our situation secret. Over the next years, national news stories about violence against HIV-affected families caused me great concern, but Michael was reluctant to discuss it. One thing was sure: it wasn't the time to be openly public about being infected.

Women representing all aspects of our bleeding disorder community

In 1989, to find a supportive outlet to speak openly and discuss our concerns and fears, I co-founded a women's group within the local bleeding disorder community. A social worker helped connect me with another spouse of a man with hemophilia and HIV. With the support of the HTC and the local hemophilia chapter, we gathered over 25 women at our first meeting, creating a safe space to discuss our fears about HIV alongside issues like grief, stigma, and practical matters such as health insurance.

Michael, Kathleen and Stephanie

In 1990, I began working as an educator at a local AIDS prevention agency, speaking in various settings to raise awareness. This role was invaluable, allowing me to inform others while also giving me the opportunity to learn more about my condition in a supportive environment without fear of reprisal. During this time, my husband began facing serious health issues that required medical attention and many doctor visits. Although he had initially opposed my starting a support group for women, he eventually recognized the importance and began hosting men's groups at his workplace, which became highly supportive once they learned of our situation. Tragically, he passed away from HIV-related lymphoma in October 1992 at just 33 years old.

Our daughter, Stephanie, was eight when Michael passed away. Though we initially kept our illness from her, as she grew older, she began asking questions. Although she was young, she understood that I was also suffering from HIV-related health issues. We felt it was better to be honest with her, which led to her developing separation anxiety and fear of losing us. She experienced behavioral and academic issues at school due to stigma, and struggled with anorexia. Though she never contracted HIV, with her father's passing and the uncertainty of my health, Stephanie bore the heaviest burden.

"GYPSY"
I made my doll a gypsy because I feel like I'm coming and going constantly. I feel my life has changed dramatically. I went from living a normal life with few worries to a person hoping and praying constantly to see the next day. — Yonkers, NY

"CINDY"
I am a mom with a little girl and we are living with AIDS/HIV. I sometimes want to give up on life but my baby gives me hope, strength and courage. I am strong and we will go on. Regardless of our problems, we are human and we are somebody!
— New York City

"PRETTY IN PINK"
I stand for all my sisters who came into my life that had HIV/AIDS. They touched me so much with their stories, kindness and love. I will never forget them. I'm in the fight to find a cure.
— St. Louis, MO

"GRACE FOR GRATITUDE"
After being diagnosed with HIV, I was afraid, angry, lonely, and depressed. Support groups can offer important help by allowing you to blow off steam in a safe place. And accept you without being critical. — Flint, MI

"SHEILA LEE"
Strong women can be strong leaders. It is the only way women will gain any ground in the HIV/AIDS epidemic. By addressing the contributing factors of the HIV/AIDS epidemic, women become a powerful force in systemic change. — Greensboro, NC

By 1999, AIDS had become a widespread topic in the news, instilling fear in many. It had decimated the hemophilia community. My colleague, Candice Moench, and I decided to create workshops for girls and women with HIV. We wanted to create an engaging and artistic way to reach affected women and provide them a safe space to share their stories. This led to the *Stitches Doll Project*, aimed at helping women cope with their diagnoses while raising awareness in the broader community about HIV.

The doll forms are customized by the women with fabric, buttons, markers, ribbon, and all kinds of embellishments. We ask, "If your doll could talk, what would she say?" The responses are powerful and moving. This simple project quickly gained recognition through news stories and articles in POZ and A&U magazines, two publications dedicated to HIV/AIDS issues.

Initially, we were able to purchase dolls through our organization. However, when I left my job at the AIDS prevention agency, I continued the project from my basement with the support of my second husband, Bill, my mom, and my sister. For years, my dear hemophilia community friend, Jackie Lucas, sewed and donated all the doll forms, while others contributed ribbon, fabric, buttons, and beads. Today, we raise funds locally to purchase the doll forms.

A couple of years later at a workshop with the bleeding disorders community, a friend suggested expanding the project's mission to include women with bleeding disorders. I immediately agreed, leading to our next collection named the *ClotNot Club*.

This evolution garnered great attention through our community, allowing me to host workshops at local, regional, and national events and showcase completed dolls. With funding secured, we traveled to various meetings and hemophilia camps across several states to work with young girls affected by a bleeding disorder and the sisters of affected boys.

Through social media, I connected with others interested in the project, ultimately leading to an invitation in 2014 to India's first educational workshop for women with bleeding disorders. Over two transformative weeks, we provided vital information and support, introducing doll-making as a way to empower women in New Delhi and Puri. We provided essential information about bleeding disorders, discussed ways to earn income from home while caring for their affected children, and supported their psycho-social needs through doll-making. During my trip, I met Fatima, a hemophilia mom from Iran, who later replicated our efforts there, and Andrea from the Philippines, who did the same.

These international connections inspired a women's booth at the 2016 World Federation of Hemophilia (WHF) Global Summit in Orlando, Florida, marking the first time women had a dedicated space in the exhibit hall of a global meeting. Our project expanded further at the 2018 WFH conference

Three lovely ladies from the Philippines at the 2018 WFH Summit in Scotland.

Kathleen, Cheryl, and Fatima at Hemophilia Federation of India

Mary B. constructed the quilt from squares sent to her.

Chimwemwe C. of Malawi

Kim C., President of Malaysia Hemophilia Society

Naja S. of Denmark

Gurmeet K. (right) of India converses with a booth visitor

With Andrea from the Philippines

Jeanne White-Ginder

in Scotland, where we offered quilt square making alongside doll workshops. Stitches dolls created by women globally are now part of a traveling exhibit, and the project continues to grow through local fundraising and volunteer dedication. The dolls and their poignant stories can be viewed on our website, the Stitches Doll Project: http://stitchesdollproject.org/.

The doll project has been incredibly successful and continues to operate independently, relying on donations of supplies and the unwavering support of individuals who recognize its importance to our community. Over time, the project has expanded to address other areas of concern for women, including survivors of hemophilia, HIV/AIDS, sexual and domestic abuse, at-risk youth, transgender discrimination, and orphans, preserving the invaluable stories of girls and women.

As I reflect on the tumultuous journey we've traveled, I am reminded of the strength that can arise from vulnerability and the importance of community in times of crisis. The challenges we've faced have shaped us in ways I could never have anticipated. Though the shadows of loss and fear remain, they are accompanied by the warmth of support and love that has fortified our spirits.

Stephanie and I continue to honor Michael's memory, finding solace in the truth that, while his absence is deeply felt, our bond as a family has emerged even stronger. Together, we carry on, advocating for awareness, acceptance, and hope—turning our trials into lessons and our fears into bridges toward a brighter future.

ABOUT THE AUTHOR

Kathleen Gerus-Darbison holds a Bachelor's degree in Psychology and a Master's degree in Sociology. She is a professor of Sociology at Macomb Community College in Warren, Michigan. She remarried in 1998 and lives near Detroit with her husband, Bill.

Believe Ltd.'s most recent film, *"On The Shoulders of Giants"* showcases the *Stitches Doll Program* and highlights the importance of women's voices. To view the film, visit: https://www.ontheshouldersfilm.com/.

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A LESSON IN *Advocacy* AND *Empowerment* FOR WOMEN WITH A BLEEDING DISORDER

BY LINDA "LEW" E. WYMAN-COLLINS, BSN, RNC-NIC

This year, I will turn 68. I have mild hemophilia A, a platelet disorder, and Ehlers-Danlos Syndrome. Growing up, I bruised easily, and my menstrual cycles were heavy and prolonged. When I expressed concern to my doctors, they assured me my cycle was "normal," as similar experiences were noted in my family, and attributed my bruising to my fair skin and red hair. I also had been experiencing gastrointestinal bleeding, which left me chronically anemic, severely impacting the quality of my life.

2024 Bleeding Disorders Awareness Month Proclaimation from Mayor David Billings of Fate City, TX

With Texas State Representative, Katrina Pierson, 2025

As an active young person involved in gymnastics and competing in track and field, I now realize that I was dealing with untreated muscle and joint bleeds, particularly in my left knee. An auto accident in my early twenties left me with permanent pain in my neck.

When I was 24, I gave birth to a baby boy who bled significantly from his circumcision, and the wound took weeks to heal. Although I asked a lot of questions, he was not initially diagnosed with hemophilia. At 17 months, however, he was hospitalized with a swollen, painful knee. He was being treated for possible juvenile arthritis or osteomyelitis. In the middle of the night, a young hospital resident took time to really listen to my concerns and review the symptoms I shared. He ordered clotting tests, and my son was soon diagnosed with severe hemophilia A. Following his diagnosis, I was identified as a possible carrier.

At 35, I was scheduled for an inguinal hernia repair. Noticing the carrier diagnosis of hemophilia in my records, the anesthesiologist refused to clear me for surgery until I consulted with a hematologist. I made an appointment with a hemophilia treatment center, and it was discovered that I also have a platelet disorder. I was prescribed a dose of intravenous DDAVP for the surgery, yet there was no recommendation for treatment for the muscle and joint bleeds or the heavy menstrual cycles that persisted.

With Texas State Senator, Bob Hall, 2015

With Texas Congressman, John Ratcliffe, Washington Days, 2018

2025 Bleeding Disorders Awareness Month Proclaimation with Mayor David Billings and Fate City, Texas, Council

My bleeding tendencies later led to the diagnosis of Ehlers-Danlos Syndrome, a connective tissue disorder affecting joints and organs with symptoms that include easy bruising, joint instability, and an increased risk of bleeding. It took another five years for me to be diagnosed with mild hemophilia A, but I did not gain access to clotting factor for another 17 years.

For far too long, I endured undiagnosed bleeds and heavy menstrual cycles until another hematologist accurately diagnosed me and prescribed on-demand doses of clotting factor. Now with proper therapy in place, I have undergone several major surgeries without complications.

By participating in national and local bleeding disorder educational events, I learned to advocate for myself and became much better at demanding proper testing, diagnosis, and treatment. The years of being undiagnosed and inadequately treated led to significant damage in my large intestine, knee, hip, ankles, wrists, and thumb joints. I am currently recovering from a total left knee replacement, for which an advanced artificial knee designed for stabilization was used due to the absence of cartilage.

Unfortunately, much of the medical community still operates under the assumption that only males can have a bleeding disorder. Doctors often perceive women merely as carriers who do not require treatment. Treatment should be based on documented factor levels and bleeding tendencies, rather than gender. While organizations have made progress in educating about bleeding disorders, a significant gap remains in the proper treatment for women.

2023 Fate City, Texas, Bleeding Disorders Awareness Month Proclaimation

Over the years, I have actively engaged in education and advocacy for women with bleeding disorders at local, state, and national levels. My mission is to educate women and healthcare professionals, including hematologists, primary care doctors, OB/GYN physicians, and dentists about the signs and symptoms of bleeding disorders in women and to advocate for timely diagnosis and appropriate treatment. Women must advocate for themselves more vocally and not allow themselves to be dismissed. I do not want other women and girls to endure the suffering I have experienced.

Through my journey of advocacy and education, I have witnessed firsthand the transformative power of knowledge and self-advocacy. It is crucial for women with bleeding disorders to connect, share their experiences, and demand the care they deserve. Together, we can dismantle the misconceptions surrounding these conditions and ensure that no woman has to endure unnecessary suffering.

I remain committed to empowering others, raising awareness about the unique challenges women face, and fostering a supportive community where every woman's voice is heard. Let us work together to pave the way for better diagnosis, treatment, and ultimately, a brighter future for all women affected by bleeding disorders.

ABOUT THE AUTHOR

Linda "Lew" E. Wyman-Collins, BSN, RNC-NIC, is a mother, wife, aunt, sister, and daughter of someone with a bleeding disorder, as well as a person with a bleeding disorder herself. As a nurse with extensive experience in neonatal intensive care, she has been recognized as a Dallas/Fort Worth Great 100 Nurses. Lew has served on the Board of Directors for Hemophilia Federation of America (HFA), was a Blood Sisterhood and Symposium Chair, Medical/Professional Advisory Board member, and is a founding member of HFA's Focus on the Feminine. She has also served on the Texas State Bleeding and Clotting Disorders Advisory Council and is a member of Equity in Bleeding Disorders Care for Women and Others. Additionally, Lew frequently presents at national and international conferences and has authored numerous articles on hemophilia and women with bleeding disorders in industry magazines and journals. You can often find her attending bleeding disorders conferences, where she serves as an infusion suite nurse.

X-INACTIVATION / LYONIZATION AND SKEWING: How Females May Possibly Manifest X-Linked Bleeding Disorders

BY JEANETTE KIZER-JONES, MA, ED

In case you have not heard, WOMEN BLEED, TOO! This powerful message has been a rallying cry in our bleeding disorder community for quite some time. It emphasizes the important fact that females are not merely "carriers" of bleeding disorders; they can and do experience bleeding symptoms that deserve proper medical care.

While this understanding has been gaining traction among healthcare providers and community members, some still argue that women are *just* "carriers" and therefore do not need testing, care, or treatment. This perspective overlooks the many known examples of female bleeders. To address this skepticism and encourage acceptance of the crucial truth, our goal is to share knowledge and educate others in the community regarding a possible explanation.

Let us begin with the term "carrier" and clarify that males with hemophilia are carriers as well, passing the hemophilia gene to every daughter, but not to sons. In its broadest sense, being a "carrier" refers to someone who possesses a genetic abnormality in their DNA and can pass it on to their offspring. Any gender can carry a genetic disorder.

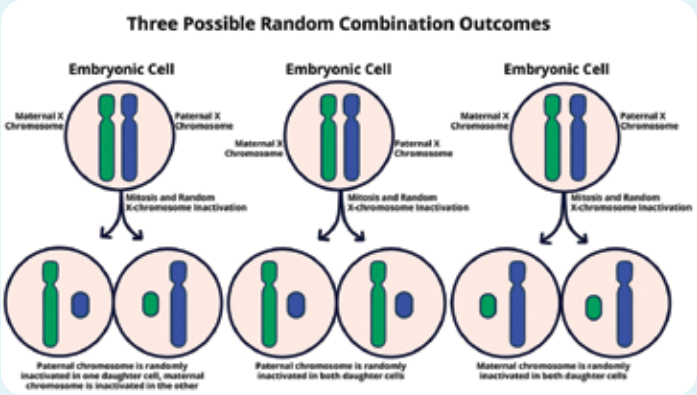
Traditionally, physicians believed that a female carrier would not exhibit any symptoms. If she did, she would be classified as a *symptomatic carrier*. However, these symptoms were downplayed and attributed to other reasons, and the assumption was that since a woman has two X chromosomes, treatment was not necessary. However, we now know that this perspective is outdated. Referring to a female as a "carrier," although technically correct, places her in a category that has been scientifically and systematically misunderstood for decades, which can create barriers to her care.[1,2]

Most of what medical providers have learned about bleeding disorders, testing, factor levels, and related topics is based on the male experience. Consequently, diagnosing females was traditionally challenging. The International Society of Thrombosis and Hemostasis (ISTH) currently recognizes a diagnosis of hemophilia in females with factor levels below 40%. They still use the term "carrier" in their descriptions, including a bleeding phenotype (an observable characteristic) above 40%.[3] This means some females may exhibit bleeding symptoms beyond the typical testing ranges without receiving an official diagnosis. Without a diagnosis, it is difficult for females to access appropriate care, especially when dealing with healthcare providers and insurance companies.

Research has shown that a risk of bleeding exists between 40%–70% in various types of hemophilia, and a chromogenic assay would provide more accurate factor levels in females.[4,5,6] Additionally, genetic testing would support a more definitive diagnosis. Given that the terminology surrounding this issue can cause delays and disruptions in care, it has been suggested that we refer to "carriers" as "females with a bleeding phenotype." This terminology may provide a more accurate description.[7]

It is essential to recognize that all bleeding matters and warrant investigation. Females may carry genetic differences from males, but they have the advantage of possessing two X chromosomes, making them less likely to experience severe bleeding symptoms, although not impossible. This understanding leads us to the important question: how do females develop the bleeding disorder they carry?

Let's first discuss how females can develop X-linked disorders. Females can manifest sex-linked disorders similar to males, as seen in certain bleeding disorders. Females have two X chromosomes, which is where the



hemophilia gene is found. A genetic abnormality can be carried on either X chromosome or, in rare cases, both. Previous understandings suggested that females would not be affected by X-linked disorders because they possess a healthy X chromosome to compensate for the affected one. However, in 1961, Mary F. Lyon discovered X-inactivation (XCI), also known as lyonization. This finding established that females are actually mosaic (a process where one of the two X chromosomes in a female cell is randomly inactivated early in embryonic development), meaning that different cells may have different X chromosomes activated.[8,9,10,11] Specifically, early in female development, during the initial cell multiplication, each cell randomly either activates or inactivates one of its two X chromosomes.[12]

Dr. Mary F. Lyons

An active X chromosome is loosely packed, allowing genes to produce proteins actively, which makes symptoms of a disorder more likely. In contrast, an inactive X chromosome is compacted, resulting in fewer proteins being generated and thus reducing the likelihood of symptoms. However, symptoms can still occur since an inactive X is only about 85% inactivated.[11] Researchers have found a method to visualize XCI in female cells, revealing a unique mosaic pattern.[13]

Currently, XCI is not fully understood, partly because it is unpredictable. The process is random, think of flipping a coin, with each cell (XX) resulting in one X being active (heads) and the other inactive (tails). While the probability is roughly 50:50, the outcome can range from 0:100 to 100:0.

Calico cats are an example of X chromosome inactivation. The orange and black patches are caused by cells that have been inactivated.

This variability in XCI is known as skewing, easily observable in female calico cats.[14] Each fur color cell chooses which color to activate or inactivate, resulting in fur that displays both orange and black. This explains why some calico cats may appear predominantly orange or black, showcasing a wide range of color representation.

Similarly, females with bleeding disorders experience varied expressions (or penetrance, when a genetic disorder has a wide range of manifestations) of XCI due to skewing, which affects their phenotype (e.g., bleeding severity).

Skewing can be random, influenced by other genetic abnormalities, or related to a growth advantage, meaning it can change as females age. In rare instances, XCI may also occur in specific organs, such as the blood or liver, which can impact bleeding disorders.[11] Thus, instead of functioning like a simple light switch that turns each X on or off, the mosaic expression in females behaves more like a dimmer switch, with each X chromosome expressing varying degrees of intensity.

Although the concept of XCI is well-known, it has not been fully integrated into the practices of all providers who might encounter someone with a bleeding disorder. Many X-linked disorders can present symptoms in female carriers, who often face challenges in accessing testing, diagnosis, and care. A significant resource for these individuals is *Remember the Girls*, a non-profit organization that supports females affected by X-linked conditions. (https://rememberthegirls.org/) They focus on educating the community about various disorders, including hemophilia, and advocate for greater female representation in research and funding.

Additionally, the *Foundation for Women and Girls with Blood Disorders* (https://www.fwgbd.org/) works to educate providers about the unique needs of females with blood disorders by providing grants to support research initiatives focused on women. Shared communities foster support and provide necessary resources for both patients and providers, contributing to improved care for females. While many organizations are striving to support women with bleeding disorders, the space for funding is becoming increasingly competitive. Nevertheless, collective efforts from the entire community and beyond are essential to enact meaningful changes that enhance care for females experiencing bleeding disorders.

This leads us to our final question: How can females with bleeding disorders access the care they need? While females who carry a bleeding disorder are affected by it, the only way to determine the extent of their needs is

through data collection. Females or their caregivers should track their bleeding patterns.

Various tools are available for this purpose, including printable logs, digital trackers, and convenient smartphone apps.[15,16,17,18] It is essential to note all instances of bleeding, including menstruation. Tracking this data will help healthcare providers understand the patient's bleeding phenotype. With this information, patients and caregivers can encourage providers to gather more data by testing for bleeding disorders, especially if there is a known family history. If a female experiences heavy bleeding and no other cause is evident, she should be tested for a bleeding disorder.[19]

Testing can help patients and providers understand the genetic background of bleeding disorders within a family. It's important to note that two partners can carry the same or different bleeding disorders, which may lead to more severe expressions of bleeding.[20] While tests for X chromosome inactivation (XCI) are not available, there are many other tests to determine if a bleeding disorder exists, and its type. Some tests may be covered by insurance, while others, especially specialty sub-tests, may not be. Often tests are denied by insurance because of incomplete or inaccurate documentation by the clinician.

For example, the chromogenic assay is often available, but not always covered by insurance; other genetic tests may be even more costly. However, engaging in research might provide opportunities for access to genetic testing. Genotyping, a laboratory process that analyzes an individual's DNA to determine their genetic makeup and can reveal mutations inherited from their parents, can be valuable when the opportunity arises. Additionally, conducting testing more than once is important, as fluctuations can occur. Annual testing of factor levels can reveal valuable trends over time.[6]

In conjunction with tracking and testing, educating providers is crucial for advancing care and overcoming barriers that females face. It is encouraging to see national organizations offering continuing education credits to providers, and it is even better when patients can share these professional resources and opportunities with them. Despite increased awareness, there is still much work to be done to address knowledge gaps. While it can be frustrating to encounter uninformed individuals, it's often more effective to share knowledge and educate others. By doing so, we can enhance care for the females who need it most.

As we continue to advocate for better understanding and recognition of women's experiences with bleeding disorders, it is crucial to highlight the importance of individualized care and diagnosis. By reframing how we discuss "carriers" and acknowledging the unique challenges that females face, we can work toward a healthcare system that is more inclusive and responsive to their needs. Just as the patterns of X-inactivation in female cells can be unpredictable, so too can the expressions of bleeding disorders.

There is still more to discover that we do not yet understand, and absolutely more research is needed to explain why women are bleeding.

Emphasizing research, awareness, and education will not only empower females within our community but also pave the way for advancements in treatment and care. Together, we can dismantle outdated beliefs and ensure that every woman receives the recognition and medical attention she deserves. Let us champion the message that all bleeding matters, and every voice counts in the quest for equitable healthcare.

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BIOMATRIX ON THE *Move*

The BioMatrix Education Team and Territory Account Executives have been busy attending community gatherings and hosting educational events across our great country. Our team offers a wide and expanding menu of educational topics and fun activities to choose from, including on-line sessions. Interested in scheduling a session for your group of any size either in-person or virtually? Contact your Territory Account Executive or message the Education Team at: education@biomatrixsprx.com.

NEW MEXICO

Jeanette Jones and Felix Jacques Garcia

2025 marks the return of the in-person ***Family Education Weekend*** in New Mexico! We haven't had our community together for five years, leaving a tremendous longing in our hearts. This year, Sangre de Oro (SDO) collaborated with the Nebraska Chapter, NBDF, to ensure that not another year went by!

SDO worked diligently to keep the March 21–23 event small and intimate, but with support from pharmaceutical and pharmacy sponsors, including BioMatrix, they happily welcomed more than 100 community members to the Albuquerque Marriott, At our booth, "Zitty," our little stuffed zebra, made a surprise appearance and posed for photos with attendees to raise awareness for rare diseases such as bleeding disorders.

The younger kids enjoyed playing a youth-friendly version of BioMatrix *Friendly Feud*, learning about bleeding disorders while teens participated in a meaningful discussion about what it means to be a blood brother or sister's keeper.

A special thank you goes out to Maureen Grace, Executive Director of the Nebraska chapter of NBDF, and her staff for their invaluable help in making this event a success. We also want to express our gratitude to all the volunteers from SDO. The New Mexico community can't wait to see what's next!

Dave and Lakeia visit the BioMatrix booth to pose with Zitty the Zebra

Keira and Melissa

Adriana, Aiden, Alyssa, and Jon

Robert gets an infusion from Nurse Christina

Robert

Zitty the Zebra

Brayley and Isaac

Caleb hamming it up with Zitty, the Zebra!

Ruth

VIRGINIA

Terry Stone and Michelle Stielper

What a warm and welcoming day as the Hemophilia Association of the Capital Area (HACA) greeted its members and treated everyone to an impressive lineup of presenters and updates at the ***Annual Chapter Education Day***! Taking place March 22nd at Northern Virginia Community College's Ernst Cultural Center in Annandale, the event attracted a nearly full house. Matt Delaney from the National Bleeding Disorders Foundation kicked off the day with an *Advocacy Update*, providing valuable information and reminding attendees to stay connected, as no one can predict the future!

Michelle and Luke play peek-a-boo

Dr. Gary Kupfer from Georgetown shared insights into *Emerging Therapies*, discussing the most current treatments and what is expected to be available in the near future. It was enlightening to learn that new therapies continue to expand patient care options.

Bill Wilbert, Social Worker from BioMatrix and part of the Patient Navigation Dream Team, presented a session on *Financing a Chronic Illness*. He offered tips and guidance on available resources to help families manage their expenses when medical bills arise. Industry representatives were present to support and educate families, creating an atmosphere of fun and fellowship among the close-knit HACA community.

Many thanks to Brenda Bordelon, Executive Director, and Robin Monin, Chapter Administrator, for rolling out the welcome mat and making it a great day for everyone!

ILLINOIS

Eva Kraemer

The gang is all here!

People are multifaceted individuals whose identities extend beyond their bleeding disorders, a sentiment recognized by BioMatrix and Octapharma. On March 22nd, we hosted an ***Educational Dinner*** program titled *Finding Your Harmony* at El Norte in Gurnee. Throughout our lives, we often face stress and anxiety, which can impact our overall health. This program explored how to recognize bodily signs of anxiety and discussed techniques to help mitigate it, such as deep breathing exercises. After fostering a friendly and relaxed atmosphere, we played *JeoParody*, our fun version of Jeopardy, where we tested our knowledge of bleeding disorders.

BioMatrix is dedicated to supporting the Illinois bleeding disorders community by offering various programs for learning and sharing experiences. We thank Octapharma for their continued support and partnership. And many thanks to the great community members who joined us!

OHIO

Shelia Biljes

Kristine, Arwynn, Jen and Connie enjoying lunch and friendship

Spring has finally arrived, and the snow in Ohio has melted! March 25th was the perfect day to gather in the garden room at Clementine's Victorian Restaurant in Olmsted Falls for a ***Ladies' Educational Lunch*** with Octapharma and BioMatrix. The room was filled with wonderful women, lively conversations, and warm hugs as they enjoyed an array of specialty sandwiches and unique salads. Moe Hoque, Territory Representative for Octapharma, spoke about their new *Female and Bleeding* program. He also shared information about Octapharma products available to the community.

Shelia and Marie

Thank you to Octapharma for sponsoring this wonderful event!

FLORIDA

Marcy Foertsch

Rahbin and Carol

BioMatrix and Bayer teamed up for a fun ***Educational Dinner*** at Maggiano's Little Italy in Tampa April 3rd. The evening began with Maya Bloomberg, APRN, of University of Miami Health System, who gave an interactive presentation about Bayer's product, Jivi®. After a lively question-and-answer session, we enjoyed a spirited round of BioMatrix *Advocacy Trivia*, which always sparks great conversations. We're excited to continue engaging with and supporting our community throughout the years to come!

CALIFORNIA

Gabriella Griffin, John Martinez and Eva Kraemer

Anthony shows off his putting skills

Early signs of spring permeated the Sheraton San Diego Resort March 27th as the Hemophilia Federation of America (HFA) hosted our bleeding disorder community for a weekend of education and community building at the ***2025 Symposium, "Navigating the Future Together***."

John and Robert

The Symposium featured an impressive lineup of educational sessions, many designed to foster open discussions on topics relevant to our community. One of the most poignant events was the *Forget-Me-Not Celebration of Life*, which honored individuals who lost their lives due to bleeding disorders. This presentation was both powerful and cathartic.

Gaby and Maria give HFA a thumbs up!

During exhibit hours, the BioMatrix booth became a lively hub as families gathered to learn about our company's wide range of resources. We also organized a golf challenge in which participants could earn points for their respective chapters. Groups from different chapters showcased their skills at our putting green, with each round's winner earning 10 points for the chapter of their choice. By the end of the weekend, the chapter with the highest point total received a $500 donation from BioMatrix. Competitors of all ages enjoyed the golfing challenge and appreciated the chance to support their chapters. After a close contest, the Hemophilia Foundation of Southern California emerged as the winning chapter!

The much-anticipated final evening event was at an outdoor venue overlooking San Diego Bay. Everyone enjoyed food, music, games, and engaging conversations, while some found warmth from the chilly night air by dancing the night away.

Rigo Garcia accepts the winning prize for the Mini-Putting contest

On Sunday, the hotel lobby buzzed with everyone engaging in last-minute conversations and exchanging heartfelt goodbyes with old and new friends... until we meet again!

FLORIDA

Chip Hearn and Tina McMullen

Patients, families, caregivers, healthcare professionals, and advocates gathered under the sunny spring skies of central Florida for The Coalition for Hemophilia B ***2025 Annual Symposium***, held April 9-13 at the Renaissance Orlando at SeaWorld. The event's program boldly proclaimed, *We Meet You Where You Are*, in bold font just below the number 35 — symbolizing the Coalition's service to the community since 1990.

Chris always travels with a smile!

BioMatrix Specialty Pharmacy was proud to sponsor the 2025 Symposium, demonstrating our ongoing commitment to the hemophilia B community. At our booth, we engaged with attendees and provided information about our many resources and services.

We featured interactive activities, including rounds of hemophilia-themed *JeoPardy*, which created a lively and competitive atmosphere. Participants also had the chance to join in a raffle for a themed gift basket filled with handcrafted items, adding an element of fun to the educational experience.

A key focus of the symposium was the exploration of groundbreaking treatments. Gene therapy was highlighted for its potential to address hemophilia B at its genetic root, offering hope for a long-term solution. Discussions on hemostatic rebalancing therapies showcased innovative approaches targeting natural coagulation inhibitors, presenting alternatives to traditional factor replacement.

The symposium emphasized inclusivity by offering tailored sessions for various groups within the hemophilia B community. Program sessions addressed the unique challenges faced by women with bleeding disorders, providing a platform to discuss ongoing issues and advocate for better recognition and care. Men's and women's empowerment rap sessions fostered peer support and shared experiences, reinforcing the importance of community solidarity.

Recognizing the value of engaging younger members, the symposium featured activities for teens and children. A teen lounge served as a space for relaxation and connection, while various programs, including scavenger hunts, empowerment sessions, and educational workshops, catered to their interests and needs. These initiatives aim to empower the younger generation and integrate them into the broader hemophilia B community.

This year's symposium culminated in a celebratory evening and *Totally 80's Dance Party*. Neon colors and hairspray were in abundance as everyone danced the night away to the biggest hits of that decade. This festive atmosphere underscored the resilience and unity of the hemophilia B community, honoring our collective journey and looking forward to continued progress.

The Annual Symposium not only celebrated 35 years of the Coalition's dedication but also reinforced its commitment to advancing care, fostering inclusivity, and empowering all members of the hemophilia B community. As always, BioMatrix Specialty Pharmacy was pleased to support this mission. "*Engage, Support, Serve*" – our personal and professional commitment is to always put the patient first!

Thea and son, Callan, win the BioMatrix raffle basket! Pictured with BioMatrix TAEs, Chip and Tina

Callen, Thea and puppy, Daisy, snuggled warm and cozy with blankets from the BioMatrix raffle basket!

Good friends, Jeron and Tina share a hug

Say *Hemo-B!* Tina with Lucas and Sebastian

The girls are back in town!

Milinda is ready to rock!

Brooke learns to infuse!

Nick and Jackson

TENNESSEE

David Tignor

Fun in the sun! Andrea and Treleisha

With the sound of a really loud air horn, the race began! The Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) held the ***7th Annual Blazin' for Bleeders 5K Run/ Fun Walk*** and the ***2025 Spring Fling*** at Gateway Island in Murfreesboro on Saturday, April 12th. Despite a bit of wind, the sun was shining brightly as everyone gathered. Awards were handed out, and the fantastic runners were celebrated in every age group, with lots of photos being snapped and shared.

Andre

Beckett and Mason

This year, THBDF added a new twist with the *Spring Fling*! After the race, we enjoyed a delicious lunch from Slick Pick BBQ, along with refreshing shaved ice. BioMatrix sponsored breakfast and coffee for everyone, and there were games and face painting for the kids, making it a family-fun day!

We can't wait to come together again for this wonderful THBDF community fundraising event in 2026!

FLORIDA

Marcy Foertsch

Harold and Kara, with children, Lilly and Leo

BioMatrix and Sanofi invited members of the local bleeding disorders community to join us for an ***Educational Dinner*** on *World Hemophilia Day*, celebrating inclusion and our dedication to the community. We gathered at the delightful Fogo de Chão Brazilian Steakhouse in Orlando, where BioMatrix's Education Advocate, Jeanette Kiser-Jones began the evening with an engaging presentation called *Women Bleed Too*, which shed light on advocacy and the importance of supporting an underserved population in our community.

Following tasty appetizers and a lively question-and-answer session, Sanofi Core Manager Eric Burgeson took the stage to share an interactive introduction to Altuviiio® while dinner was served.

Before we knew it, the night came to an end, and our wonderful guests began to head home. We're so thankful for the strong connections we've built in our community and can't wait for more opportunities to engage, support, and serve together in the future!

FLORIDA

Chip Hearn and Hector Heer

Hector greets visitors

Foundation Hope & Life hosted a fantastic and well-attended event on April 19th at the Sheraton Hotel in Miami, celebrating the 12th annual ***Light of the World*** program. This program brings families together to applaud progress in our bleeding disorders community while recognizing and remembering those we have lost. Despite facing tragedy and loss, our community's resilience and ongoing advocacy efforts have contributed to advancements in the safety, efficacy, and monitoring of our nation's blood supply. BioMatrix was proud to support this event and looks forward to future partnerships with the Foundation.

DELAWARE

Tina McMullen

Milestone Bracelets with the gang!

Brandywine Valley Hemophilia Foundation, along with Sanofi and BioMatrix, welcomed community members at Newark's Christiana Hilton Hotel April 23rd to take part in a ***Celebration of World Hemophilia Day***.

Arthur – just a boy and his grapes and crackers

We own an unbreakable bond formed by our experiences living with a bleeding disorder and the true friendships that have blossomed from these shared journeys. We're truly a family! Everyone had a great time creating *Milestone Bracelets*, with each bead color representing different aspects of life with a bleeding disorder. The instant camera selfie station with DIY photo frames was a huge hit, capturing fun moments throughout the evening. April 17th is dedicated to raising awareness of bleeding disorders, and this special event was a wonderful celebration of World Hemophilia Day, cherishing our strong connections.

Wyatt and Paige proudly share their frames

Samantha, Matt and Chris enjoying great conversation!

Thank you to the Brandywine Valley Hemophilia Foundation for organizing this special event and to all the attendees for making it an incredible evening. A big thank you to Executive Director, Gail Novak, for putting this special event together and to all the attendees for making it such an amazing evening!

TEXAS

Jeanette Kizer-Jones

Claudia, Leo, Levi and Elijah

Mucho gusto! It was a beautiful Sunday evening in Dallas, when Texas Central Bleeding Disorders hosted a wonderful gathering April 27th bringing our Spanish-speaking community members for a ***Community Education Meeting***, en Español. We met at Pappasito's Cantina, which provided the perfect backdrop for the joyful event. We are incredibly grateful for the support from Texas Central in promoting access to bleeding disorder education for everyone. Along with our

sponsoring partner, Bayer, we were able to provide essential resources.

Erika Bocanegra, who has over 20 years of experience as a social worker at a hemophilia treatment center, presented a session that covered several topics. *How to Prepare for Emergencies*, *The Importance of Wearing a Medical ID*, and *Mental Health Support for Families Living with a Bleeding Disorder* were among the topics. Following her presentation, we engaged in a special BioMatrix rendition of bleeding disorders *Loteria*. Game winners received a stuffed zebra as a fun way to help raise awareness for rare diseases! Attendees also enjoyed taking fun family photos with 'Buddy,' the blood drop mascot.

Big smiles from Vickie and Yolanda

Ismael, Elva & Ismael Jr

Muchas gracias to everyone who joined us! We look forward to reuniting with everyone again at the Texas Bleeding Disorders Conference in June. Nos vemos pronto! (See you soon!)

TENNESSEE

LeAnn Wilson and David Tignor

The Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) hosted an exciting ***Family Fun Night*** May 1st, featuring go-kart racing at Nashville's K1 Speed!

Amanda Wilson finishes her laps

Happy observers, Treleisha & Millie Jean

While enjoying a delicious meal, representatives from CSL Behring, HEMA Biologics, and BioMatrix shared information about their products and services and passed out fun goodie bags.

Izabella & dad Zach

After a safety demonstration, it was time for the main event! Participants were divided into three groups, and racers sped around the track 12 times. The go-karts were fast, turns were tight, and tires screeched! Competition was fierce! Races were timed to determine the final three brackets, where 15 more laps were raced to establish the winners.

And the winners are... Chad, Brad and Zach!

Fans gathered to watch the exhilarating races. Onlookers smiled ear to ear with excitement as they cheered on the racers! This unique and fun event provided an excellent opportunity for community members and their families to come together, enjoy each other's company, and have a blast racing! Thank you, THBDF!

PUERTO RICO

Gabriela Griffin, Chip Hearn and Hector Heer

The Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado hosted its ***2nd Annual MOIN Conference*** May 2-4 at the Embassy Suites Hotel in San Juan. Bringing together over 200 attendees, it was nothing short of absolutely amazing! Families reconnected and made new friends while engaging with industry representatives and learning about the latest innovations in bleeding disorders.

Chip, Jose and Javier

Fel and Hector

The event kicked off on a high note, giving families an opportunity to mingle with industry reps, ask questions, and dive into the latest innovations in the bleeding disorders community. The BioMatrix booth had a fantastic time engaging with everyone who stopped by!

Chip and Tyler

Saturday was packed with valuable information aimed at enhancing health outcomes for patients and their families. We were thrilled to have John Martinez from BioMatrix lead a youth session introducing our *Camera On* program that showcased the positive impact of art on managing stress. The crowd also enjoyed a lively game of *100 Latinos Dijeron* and wrapped up the day with music, food, and laughter.

Gaby with Rose and mom Gina, who won the raffle prize!

Sunday kicked off with a film debut – *Triatleta con Hemofilia* (Triathlete with Hemophilia), showcasing a local triathlete who motivates the community to stay active despite their diagnoses. As the conference concluded, families expressed their excitement for the next gathering.

Noelia and Keyshla visit with Gaby

A heartfelt thank you to chapter Executive Director, Anthony Llanes Rodríguez, and all the dedicated volunteers for making this incredible event possible! We can't wait for next year!

PLAYBILL

4TH ANNUAL MEN'S RETREAT | MAY 2–4, 2025 | DELAWARE

BY RICHARD VOGEL

THE REVIEWS ARE IN, AND THE 4TH ANNUAL MEN'S RETREAT WAS A HUGE SUCCESS!

- ☆ Ronnie S. said, "Thank you for a great retreat experience, full of new knowledge, friends and good food. Your events are fantastic, and I look forward to enjoying more!'
- ☆ David M. yells, "Educational Informative!"
- ☆ Angel M. states, "Sharing advice and personal experiences with other hemophilia brothers is helpful and fun."
- ☆ Matt S. shouts, "It was the perfect mix of education, socializing, free time and fun!"

CAST

- ☆ Gail Novak, *Brandywine Valley Hemophilia Foundation*
- ☆ Richard Vogel and Terry Rice, *BioMatrix Specialty Pharmacy*
- ☆ Justin Lively, *HEMA Biologics*
- ☆ Grant Belsham and Christian Harris, *Medexus Pharma*
- ☆ Paul Brayshaw, Peter Marcano, Claudio Sandoval, MD, and Michael Zolotnitsky, PT, DPT, *Octapharma*
- ☆ A Cast of *Fantastic Guests*!

SCENE

Spring 2025 – As the warmth of early spring envelops the bustling boardwalk, the Men's Retreat unfolds in all its glory. Hosted by Brandywine Valley Hemophilia Chapter with the sponsorship of BioMatrix, HEMA Biologics, Medexus, and Octapharma, this gathering at the Atlantic Sands Hotel in Rehoboth Beach promises a weekend filled with education, camaraderie, and unforgettable connections.

ACT I — *Arrival and New Beginnings*

The spotlight shines on a diverse group of men arriving from across the East Coast. Some reunite, while others forge fresh friendships over a welcome dinner that sets the tone for the weekend. As Act I draws to a close, Christian Harris of Medexus takes the stage. A creative soul with a flair for fashion from Nike, he engages the audience in a playful sewing activity, turning vital infusion techniques into an easy-to-remember skill—how to sew a straight stitch—leaving everyone with a smile.

ACT II — *Energizing Discussions*

The curtain rises to reveal the men enjoying a sumptuous buffet breakfast of eggs, bacon, fresh fruit, and decadent pastries. Justin Lively sparks discussion with insights into HEMA Biologics and the revolutionary benefits of SEVENFACT® for inhibitor patients. As the lights come up, Terry Rice, Director of Bleeding Disorders Sales for BioMatrix, shares a poignant soliloquy on *Finding Your Harmony*. He delves into the crucial differences between anxiety and stress, encouraging attendees to reshape their thought processes and enhance their well-being. With emotions running high, the guests are left with a sense of connection as Act II concludes.

Intermission: *Lefty's Ally and Eats*

Guests enjoy food and fun, featuring axe throwing and the thrill of virtual Top Golf, fostering even more camaraderie.

ACT III — Exploring Advancements

As the scene opens, men are seated for a lavish buffet dinner featuring crab cakes and sliced steak. Dr. Claudio Sandoval leads a compelling dialogue on *Emerging Therapies*, offering a fair and balanced assessment of innovative rebalancing treatment options. Engaging questions and thoughtful discussions permeate the evening, as the men voice concerns and insights that resonate long after the curtain falls.

EPILOGUE — *Reflections and Connections*

In this final act, the men share heartfelt reflections on the weekend, exchanging contact information and pledging to stay connected. As bonds are forged and promises made for future gatherings, the spirit of the retreat lingers—a testament to friendships built on shared experiences that will endure a lifetime.

☆ ***Join us next year for another transformative experience!***

FLORIDA

Marcy Foertsch

Paulette and Tony

Meeting on May 15th at the charming Donatello Italian Restaurant in Tampa, BioMatrix joined forces with Sanofi for an ***Educational Dinner*** dedicated to understanding the profound impact of bleeding disorders on women. BioMatrix's Jeanette Jones delivered an engaging and informative presentation via video conference. Following Jeanette, Sanofi's Community Relations Manager, Eric Burgeson, introduced inspiring peer speakers, Allison and her son Emilio, who shared the heartfelt story of their bleeding disorder journey.

The lively atmosphere fostered camaraderie and left folks with valuable resources for their journeys. We look forward to having more meaningful conversations!

DELAWARE

Richard Vogel

The gang's all here!

Play ball! Sponsored by Octapharma and BioMatrix, the Brandywine Valley Hemophilia Chapter hosted a special evening May 16th at Wilmington's Daniel S. Frawley Stadium for its members. The event featured an exciting ***Baseball Game*** between the Wilmington Blue Rocks and the Jersey Shore BlueClaws.

Since the Brandywine group is incredibly community-oriented and everyone seems to know each other, the 2-hour rain delay wasn't a problem at all. It was our chance to chat, catch up, and enjoy delicious ballpark food together. Once the game began, everyone returned to their seats to watch. When the home team Blue Rocks scored a run, their mascot, Mr. Celery, made his way onto the field. Yes, that's right—Mr. Celery! Legend has it that when the team was first established, it didn't have a mascot. A local high school offered them costumes from a drama production featuring fruits and vegetables that they had, and thus, Mr. Celery was born.

Rich Vogel & Gail Novak

As if the sight of Mr. Celery wasn't entertaining enough, Friday night fireworks added an extra thrill to an already fantastic evening with our bleeding disorders community. And to top it all off, the home team won the game 7 to 2!

PENNSYLVANIA

Tina McMullen

Makaya

May 16-18 was a fantastic weekend at Hershey Lodge for bleeding disorder patients and their families at the first-ever statewide ***Conference*** held jointly by the Eastern and Western Pennsylvania Bleeding Disorder Foundations.

Guests enjoyed exploring the exhibit hall and all it had to offer. Claw machine games at the BioMatrix Booth offered a chance to win mini stuffed animals!

Brooklyn, Charlie and Oliver

Lisa, Jenna and Michelle

Jordan wins the BioMatrix basket!

Keith, Matt, Kim, Tina and Chris

The first evening featured a scavenger hunt to win a two-night stay at the Hershey Lodge and tickets to Herseypark! Day two featured an impressive 24 educational sessions on various topics, including the experiences of women and girls with hemophilia and maintaining contact with treatment centers. An exhibit titled *HFA's History of Bleeding Disorders Timeline* was also highlighted. On the third and final day, breakfast and three additional sessions were offered, followed by announcements of raffle and scavenger hunt winners.

Thank you to Kara Dornish, Sara Pilacik, and the planning committee for this remarkable event attended by over 400 people, including 119 children. Organizing this event was no small feat! We are deeply grateful for your ongoing commitment to the community!

VIRTUAL – EN ESPAÑOL!

John Martinez, Eva Kraemer, Gabriella Griffin, and Felix Jacquez Garcia

On May 17th, the BioMatrix Translation Committee proudly hosted an engaging all-Spanish ***Virtual Educational Event*** featuring our innovative program, *Encontrando Su Armonía (Finding Your Harmony)*. This transformative session centered on unraveling the intricacies between anxiety and stress, exploring how these emotions can profoundly impact health and everyday life.

Participants were treated to a rich discussion filled with practical tips and dynamic techniques for navigating challenging situations, alongside the discovery of new skills to manage anxiety and stress effectively. The feedback was overwhelmingly positive, with attendees valuing the chance to not only learn but to connect and share personal experiences in a supportive environment.

We look forward to hosting another enriching community-building program for our Spanish-speaking families affected by bleeding disorders soon! Stay tuned for more information!

Matthew likes to drive fast!

TENNESSEE

Cyndy Coors

What an incredible ***Family Night*** we had in Chattanooga! Hosted by the Tennessee Hemophilia & Bleeding Disorders Foundation and sponsored by CSL Behring and BioMatrix, families gathered May 17th for a delightful evening. We enjoyed delicious pizza and enjoyed exploring the Creative Discovery Museum!

Families had a blast as they climbed the outdoor multi-pod tree house, showcased their creativity in the art space, tinkered with cool tech, and dove into hands-on projects in the STEM Zone. The natural science exhibit sparked curiosity, and the Little Farmhouse section was a hit with our young ones, allowing them to learn about the joys of farm life.

Fun was had by all! Thank you to Executive Director, Amanda Wilson, for organizing another fantastic event!

Eleanor goes for a ride!

Time for Fun!

Games on page 31

1=B, 2=D, 3=D, 4=C, 5=C, 6=B, 7=B, 8=A

5	1	8	4	2	6	7	9	3
7	6	2	9	3	1	4	5	8
9	3	4	7	5	8	2	6	1
1	4	7	3	8	9	6	2	5
2	8	9	5	6	7	1	3	4
3	5	6	2	4	1	9	8	7
8	9	5	6	1	3	2	7	6
4	7	1	8	9	5	3	4	2
6	2	3	1	7	4	8	9	5

1	4	9	6	2	8	3	7	5
8	9	5	6	1	7	4	3	2
6	3	7	2	9	4	5	1	8
4	2	3	5	8	7	6	9	1
9	1	7	3	5	6	2	8	4
2	7	8	4	9	1	3	5	6
3	5	6	7	4	2	9	1	8
7	8	4	9	6	3	1	2	5
5	6	1	8	3	9	7	4	2

Upcoming Events

JULY 11–12, 2025 MISSOURI

Family Education Weekend
Gateway Hemophilia Foundation
314-482-5973
https://gatewayhemophilia.org/
Doubletree; Chesterfield

JULY 16, 2025 OHIO

Ladies Luncheon
Hosts: Novo Nordisk and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Coopers Hawk Winery; Avon Lake

JULY 25, 2025 TENNESSEE

55th Annual Meeting
Tennessee Hemophilia & Bleeding Disorders Foundation, www.thbdf.org
RSVP: Amanda Wilson, 615-900-1486
Amanda.Wilson@thbdf.org
DollyWood's Heart Song Lodge & Resort; Pigeon Forge

JULY 25–27, 2025 VERMONT

3rd Annual Men's Retreat
New England Hemophilia Association, 781-326-7645
www.newenglandhemophilia.org
Mount Snow Resort; West Dover

AUG 8, 2025 OHIO

Back-to-School Safety Event
Northwest Ohio Hemophilia Foundation, 419–291–5882
https://nwohemophilia.org/
RSVP: Carla Wells, 734-497-5944
carla@nwohemophilia.org
Maumee Bay Winery; Toledo

NATIONAL EVENT!
AUG 21–23, 2025 COLORADO

77th Bleeding Disorders Conference
National Bleeding Disorders Foundation
212-328-3700, x728, bdc@bleeding.org
https://www.bleeding.org/events/bleeding-disorders-conference
Gaylord Rockies Resort; Aurora

SEPT 9, 2025 TENNESSEE

Axe Throwing
Tennessee Hemophilia & Bleeding Disorders Foundation, www.thbdf.org
Sponsors: CSL Behring and BioMatrix
Contact: Amanda Wilson, 615-900-1486
amanda.wilson@thbdf.org
To Register:
https://form.jotform.com/251604391703149
Craft Axe Throwing; Knoxville

SEPT 12–14, 2025 VIRGINIA

Medical Symposium
Virginia Hemophilia Foundation
804-740-8643
https://vahemophilia.org/
RSVP Online: https://vahemophilia.org/event-program/save-the-date-williamsburg-medical-symposium-at-great-wolf-lodge/
Great Wolf Lodge; Williamsburg

SEPT 14, 2025 NEW JERSEY

HANJ Back to School
Hemophilia Association of New Jersey
732-249-6000, https://hanj.org/
Offshore Restaurant, Point Pleasant

SEPT 19–21, 2025 VIRGINIA

HACA Retreat
Hemophilia Association of the Capital Area, 703-352-7641
https://hacacares.org/
RSVP: Brenda Bordelon, 703-352-7641
director@hacacares.org
Graves Mountain Lodge; Syria

SEPT 27, 2025 DELAWARE

Bleeding Disorders Education Day
Christiana Care, www.christianacare.orgspecialhealthcareneeds
RSVP: Mary Jones-Gant, 302-320-9521
mgant@christianacare.org
John J. Ammon Center; Newark

OCT 11, 2025 OHIO

Family Education Day
Northwest Ohio Hemophilia Foundation
419–291–5882
https://nwohemophilia.org/
RSVP: Carla Wells, 734-497-5944
carla@nwohemophilia.org
Hilton Garden; Perrysburg

NATIONAL EVENT
NOV 6-8, 2025 FLORIDA

HOPE Conference *In-Person & Virtual!*
HOPE Charities, 888-529-8023
www.hopeforhemophilia.org/
RSVP: https://www.hopeforhemophilia.org/hope-conference-2025.html
Hilton Orlando; Lake Buena Vista

NOV 8–9, 2025 MAINE

Fallfest
New England Hemophilia Association
781-326-7645
www.newenglandhemophilia.org/
Samoset Resort; Rockport

Time for Fun!

Hi Kids!

Ready for a CHALLENGE? How much do you know about girls and bleeding disorders? Test your knowledge! Then try a Sudoku puzzle! The answers are on page 30.

1. Who can be born with a bleeding disorder?

A. Only Boys
B. Boys and Girls
C. Only Girls
D. Only Martians from outer space

2. Which of these symptoms may be a sign of having a bleeding disorder?

A. Easy bruising
B. Nosebleeds that happen often
C. Longer bleeding after a cut on your skin
D. All of the above

3. A girl is an "obligate" carrier of hemophilia if...

A. Her mom is a carrier
B. Her brother has hemophilia
C. Her sister is a carrier
D. Her dad has hemophilia

4. If a man with hemophilia has a daughter, which statement below is true?

A. His daughter will *never* have a bruise
B. His daughter will grow taller than him
C. His daughter will be a carrier of hemophilia
D. His daughter must be named Judy-Judy

5. If a mom is a carrier of hemophilia, what are the chances her daughter will also have hemophilia or be a carrier?

A. 10%
B. 25%
C. 50%
D. 100%

6. If a girl has a bleeding disorder, when will she grow out of it?

A. Never
B. 2 years after birth
C. By age 13
D. When she's a grandma

7. If a boy has hemophilia, which of these statements is true?

A. His sister can catch hemophilia from him
B. His sister may or may not be a carrier of hemophilia
C. His sister will automatically have hemophilia
D. His sister will *never* be invited to attend bleeding disorders camp

8. When playing sports, a girl with a bleeding disorder should...

A. Never play *any* sport whatsoever
B. Speak with her parents and doctor before playing a sport, and use proper protective equipment
C. Play whatever sport she wants and not give it a second thought
D. Take up flower-picking or knitting instead

9		8	5			3	7	6
	7	5	3					4
		3	4		6			8
	8						5	3
		1		6		9		
5	2		9	8			4	
1			8		7	4		
			1		9	2	6	7
3	9	7			4	8		5

Sudoku!

Fill in the grid so every row, every column, and every 9 by 9 box contains the numbers 1 through 9.

				8			9	
2			4	9	7			
7	8	9	1	3	6		2	
	5	7	9	1	4			2
	4	2				7	1	
1			7		8	5	3	
	1		5	4	9		7	3
			3	7	1			8
	7			6				

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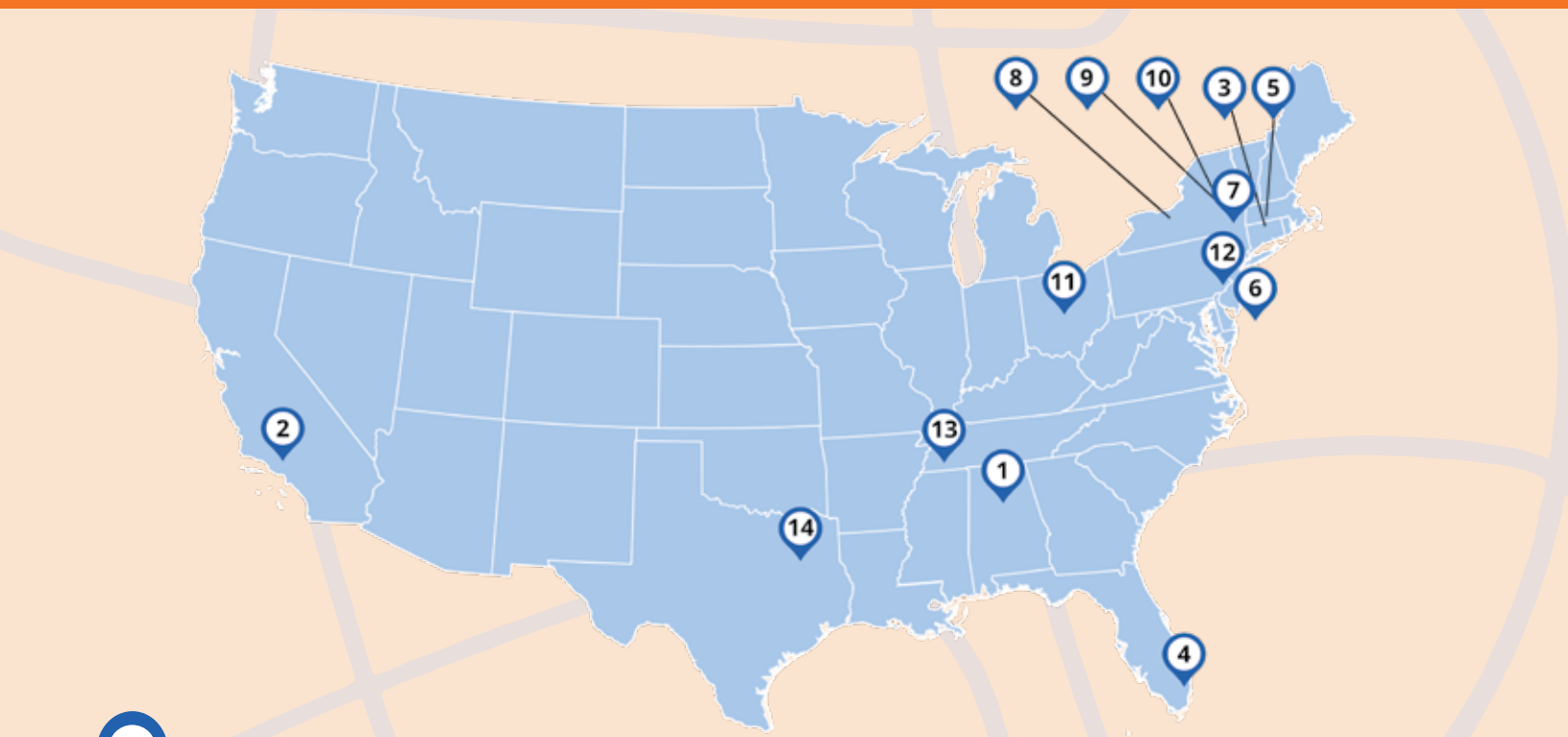

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9. Syracuse, New York
10. Syracuse, New York
11. Dublin, Ohio
12. Garnet Valley, Pennsylvania
13. Bartlett, Tennessee
14. Tyler, Texas

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