[BIOMATRIX]

NEWS

DEDICATED TO MAKING A DIFFERENCE

Winter 2023
VOLUME 18 | ISSUE 1

Special Women's Issue!

VOLUME 18 | ISSUE 1
Winter 2023

ABOUT [BIOMATRIX]

BioMatrix Specialty Pharmacy is removing burden, improving health, and making life easier for patients with chronic, difficult to treat conditions.

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving quality of life for patients and producing positive outcomes along the healthcare continuum.

Our services include the clinical monitoring, tracking, and management tools required by today's healthcare stakeholders while providing individualized patient support leading to better health outcomes.

MISSION + VISION

The **MISSION** of BioMatrix is to improve outcomes through individualized specialty pharmacy services empowering patients to live each day to its fullest potential.

Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

INTEGRITY – Our professionalism, strength, and stability come from our resolve to operate honestly, morally, and with a higher purpose to meet and exceed the expectations of all.

DEDICATION – Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close family feel.

Our **VISION** is to set the standard for exceptional care, maximizing the health and satisfaction for each patient served.

COMPASSION – We are sensitive to each individual's unique situation. Our ability to listen, empathize, and support those we work with distinguishes our business practice.

ENRICHMENT – We understand that in order to perform at our best, we must always seek to learn and grow while using our knowledge to assist and empower others.

ENTHUSIASM – Our confidence in the services we provide is illustrated by the energy, drive, and passion we exhibit in all we do.

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter
Editors: Susan Moore and Justin Lindhorst

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.

Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

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A NOTE FROM THE EDITOR

Dear Readers

Happy New Year! As we begin our 18th year of *BioMatrix News*, we are thrilled to continue providing the bleeding disorder community with informative, inspiring, and educational articles. We have come a long way since our first edition. Over the years these pages have shared a multitude of personal stories from within the bleeding disorders community. Our goal has always been to uplift, inspire, and strengthen the ties of our wonderful community.

This issue focuses on women with bleeding disorders. For many years women in the community have struggled to be heard regarding their symptoms and obtaining proper treatment. I know the struggle personally. Despite family history of hemophilia and many bleeding symptoms, it took a life-threatening episode after the birth of my third child before I was officially diagnosed with hemophilia. Much in part to the many brave and resolute women who are willing to come forward and share their stories, progress is being made, albeit much too slowly.

On page 18, we explore our recently unveiled *Bleeding Disorders Patient Navigation* program. The New Year always brings a bevy of challenges as it relates to securing and maintaining access to products and services that keep us healthy. If you're having insurance issues, we may be able to help.

We also introduce to you our 2022 BioMatrix Scholarship Award recipients. These young people in our community are truly inspirational! We proudly congratulate each of you!

Lastly, our community-favorite *Living A Spectacular Life 2023 Calendar* is now available! Despite the challenges we encounter, the photos are a reminder of the resilience and beauty of our community. If you'd like to obtain a free calendar, please refer to page 4.

All of us at BioMatrix wish you a spectacular New Year filled with good health, grand adventures and wonderful memories!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
maria.vetter@biomatrixsprx.com

GENDER EQUALITY IN BLEEDING DISORDERS

BY DANIELLE NANCE, MD

Bleeding symptoms in women have been documented since ancient times and, in modern literature, recognized since the early 1900s.

Women with a genetic mutation for hemophilia have a 40-60% chance of having bleeding episodes during their lifetime requiring treatment and an 80% chance of having heavy menstrual bleeding. Due to X chromosome inactivation, one normal X chromosome is not always enough to produce a full amount of factor.

Even in the same family, the severity of bleeding symptoms in women varies a lot because of X chromosome inactivation, and we know now that bleeding symptoms don't correlate with factor levels the same way they do in men. Treating bleeding symptoms in women when their factor levels are 30-50% is not always reimbursed by insurance. This can be confusing to treating physicians who were taught to treat based on "the numbers." Treatment with intravenous medication is seen as invasive and therefore seen as "too difficult" or too expensive to use unless the bleeding is severe.

In men, even a minor bleed is no longer tolerated. Bleeding symptoms in women are often minimized or even dismissed by medical providers. As we understand more about bleeding symptoms and access to medical treatment becomes more widespread, more and more women are being offered treatment for their bleeding symptoms.

Why should any bleeding be endured in women? Women have the increased burden of bleeding from their ovaries, uterus and reproductive organs during pregnancy, delivery and postpartum.

This issue is dedicated to women who bleed and celebrates the stories of those who have courageously talked about their personal symptoms and challenges. As women, we can help improve care for all by continuing to report bleeding symptoms and insisting on getting imaging with CT scans, MRIs, and ultrasounds to document pain and find out if the discomfort and swelling are from bleeding.

As a physician who treats women with bleeding disorders, I ask that each woman keep a calendar and write down symptoms of bleeding, especially the ones that disrupt home, work and leisure activities. Bring the calendar with you to your clinic appointment. If treatment is refused, be brave enough to ask why and ask for more studies so you can learn about your body and how to better care for yourself. Not all pain is from a bleed, and not all pain needs to be treated. Pain provides a signal for investigation. The more we know about symptoms, the better we can work through them towards better health.

May joy be with you in your journey.

ABOUT THE AUTHOR

Dr. Danielle Nance is a hematologist at Banner MD Anderson Cancer Center in Gilbert, Arizona. As a physician of more than 17 years, Dr. Nance shares, "I seek to bring accessible, expert care to each of my patients. I believe in advocacy for patients with rare diseases, access to care and insurance, and improving the patient experience."

2023 CALENDAR "LIVING A SPECTACULAR LIFE"

Now Available!

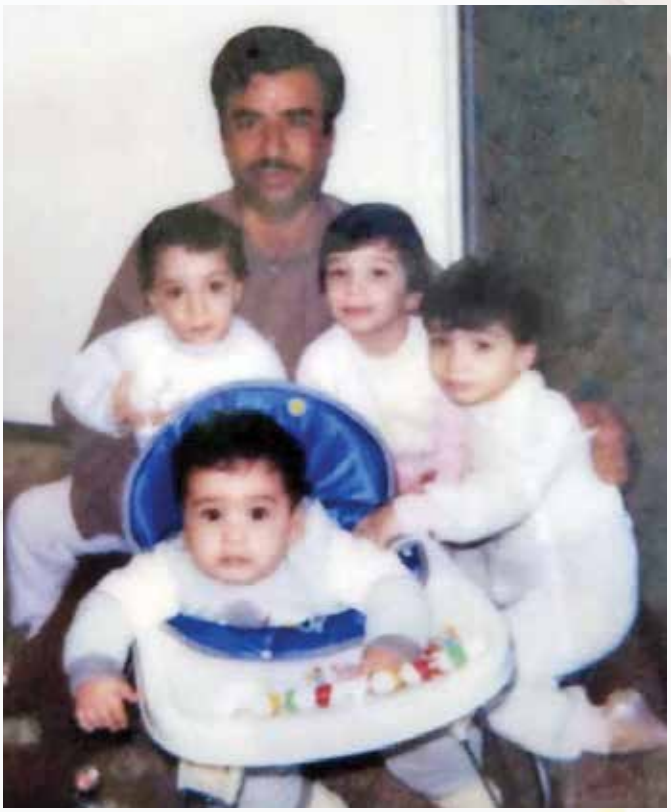
Our celebration of the bleeding disorders community in a photo calendar began 10 years ago. Our goal has been to show that even with the unexpected twists and turns that come with managing a bleeding disorder, life is nothing short of spectacular!

Get your free copy while they're still available! Contact your Regional Care Coordinator or email your request to: info@biomatrixsprx.com

HIS BLOOD... THE INK INSIDE MY VEINS

BY SAWSEN JAMALEDDIN

The aroma of ginger and garlic swirls in and out of my nostrils, tap dancing inside a wok of hot oil, overpowering the sterility of bleach that has inhabited our house for the past year. The two women in our small kitchen are dressed in matching blue uniforms. They are stirring and whispering as the flame of the oven rises and relaxes against the hum of the microwave vent. The one with brown curly hair notices me and smiles. The other is so tall that I question the ceiling. But I have stopped questioning their presence. Hunger is stronger than my curiosity. Fear is better than knowing.



Sawsen with her father, triplet sisters and little brother

The tall one moves the wok back and forth with a grace that reminds me of a swaying palm tree. "How was school?" she asks, sprinkling small conversation between us, her eyes as warm as the heat fogging up the windows. I have no words to respond. At ten years old, my tongue refuses to work with my mind. Years of a lisp and speech therapy and I still can't form the question that is on my mind. What is wrong with my father? I know she knows what I don't.

She was there the day I opened my parent's always-closed bedroom door and ran inside with a set of BIC pens that I bought for my father's upcoming 43rd birthday. When I neared his bed, I did not recognize the skeletal body in front of me. Brown eyes that resembled mine opened, disoriented, turning into droplets of despair when he blinked at me. His dark skin looked faded in the light of sun, the cascading rays revealing an IV that protruded from his arm. He resembled a prisoner of war, starved, resigned. All I wanted to do was bandage the pain, cover his bones with my skin, drape my eyes from seeing, from imprinting the image of my father in front of me.

"Who is she?" he asked staring at me. Shock stood numbly between us. The set of pens fell from my hands, unwilling to write the tragic chapter unfolding.

It was then that I noticed movement in the corner, the tall woman making her presence known, as she stood up from the opposite side of the room and rushed to pick up the set of BIC pens off the floor. She put the jumbled pens in my palm and ushered me out of the room.

Weeks later, my father lost the war of life.

The kettle sputters and seethes. I turn the stove off and pour the water into a floral cup that has survived my move into wifehood. I open the white canister to get a tea bag when I suddenly feel a rush of liquid run down my legs. The vinyl tile in the small kitchen has become a pool of amniotic fluid. At twenty-two years old, I am going into labor for the first time. It seems that my unborn daughter is as patient as boiling water.

"Ahmad," I call out to my husband of less than a year, "it's time!" He sprints out of the room, then stands frozen by the murky water in front of him, a look of excitement and fear crisscross across his face. The ride to the hospital took less than ten minutes, but once we got there, labor seemed endless. After more than twenty-four hours of what-the-hell-was-I-thinking screaming, along with spurts of meconium leaking from my womb, an emergency c-section was the only option to deliver my baby safely.

Once the epidural was given, everything became hazy. All I remember before the blackness is hearing the doctor's panicked voice in the background, "She's losing a lot of blood." When I woke up, it took me a while to orient myself to where I was. My husband was seated in a chair facing the window. My mother was seated beside him. My newborn daughter was in a bassinet beside my bed. I tried to move my arms to pick her up, but my limbs felt like spaghetti. Pain ricocheted throughout my body. I stifled my scream when a nurse came in and handed me pain medication. Then the doctor walked in.

He congratulated us and then explained I had lost a lot of blood during surgery. "I'm wondering if you have von Willebrand disease?" he questions me. Von-what? I thought. It was the first time I had heard that word. I shook my head no.

"You lost a lot of blood. I would like you to have a blood transfusion," he advised. My mother stood up. "No," she shook her head adamantly, "No blood transfusion." Why not? I wondered for a fleeting second until brain fog and pain clouded my curiosity that I said nothing. The doctor sighed, "We'll try an iron infusion instead." My mother nodded for the both of us.

Depending on who you ask, childbirth seemed like a small pinch compared to a wisdom tooth extraction. Once my teeth were extracted, strong painkillers were prescribed, and I devoured them like M&Ms until I became aware that the more I took, the more my mouth bled. When the pain finally eased without medication, gauze pads still had traces of blood more than a month after the procedure.

During the follow-up appointment, I asked the dentist if the ongoing mouth bleeding was normal. "Everyone is different," he answered. Instead of demanding he investigate my concern, I walked out with more gauze. It took another month for the bleeding to stop. I have never had another tooth extraction. However, I did have three more children. Motherhood is a dizzying merry-go-round.

A year after my daughter was born, my nephew also made his entrance, granting me the title of Aunt. It was a year of new beginnings, but it was also a year of numerous hospital visits. I couldn't understand the unexplained bruises that riddled my nephew's small body. It reminded me of a past life, one I couldn't quite put my finger on.

After a light fall from a bunk bed when he was five years old, an egg-shaped bump on my nephew's kneecap formed, making it hard for him to walk. My sister took him to the hospital to get some answers. After waiting nervously for some news, my mother called to share the diagnosis. "The doctors think he has hemophilia," she said reluctantly. Although it was the first time consciously hearing that word, it felt oddly familiar. "Your father had hemophilia," she explained, but didn't elaborate.

That night I googled the word: *Hemophilia. Bleeding disorder.* I searched for the cure. *Incurable.* The next day my younger brother and I drove to the hospital together to visit my nephew. "You know Dad had hemophilia, right?" He asked, not waiting for my answer. Something about the way he braced his hands across the headrest made me sit up straight and pay attention to what he was about to say. Although he was younger than me by two years, he was closer to my mother, and I knew whatever he was going to say was going to be insider information. "You know how Dad died, right?" I said nothing. This question was something I'd been wondering about since the day he took his last breath. "He got HIV from a tainted blood infusion."

Staring out at the twirling hands of a turbine while my father drove, his hands clutching the steering wheel so tightly his olive-colored knuckles looked as faded as the clouds that traveled with us. I never asked where we were going. I was simply happy to miss a day of school, excited to bask in my father's presence since he was always on the go, even when it seemed like his limp made it hard for him to go the distance. For as long as I remember, my father always walked that way. It was more pronounced when he was standing for a long time. He never complained and I never questioned it, thinking he was just born that way.

But there are things I wish I had questioned then, things that my young mind wondered about, like the vials of medicine in his closet that were neatly stacked beneath his coats, the times he spent a few days in the hospital and came home without an explanation. Or the nurses who used to go into my parent's room before I went to school, and when I would return, the smell of Asian food would waft through the house – sometimes I wonder if that is where my love for Chinese food came from.

Was I trying to hold on to the time my father was alive? To the moments when I didn't need answers because he was still alive, and that was all that mattered? Or was I too afraid to wander into the truth for why there were nurses around the clock, and instead, chose to comfort myself with the food they fed me and my siblings? Sometimes I wish I could pause and rewind the years to get the information that medical records no longer contain. I wish I could ask my father just one question: Can you tell me all about you so I can know more about me?

After more tests, my nephew was diagnosed with severe hemophilia. He needed clotting factor. It was then that I examined my lifetime of symptoms. The excessive bleeding. The unexplained bruises. The joint pain. I requested genetic testing for myself as well as testing for my factor VIII level, along with my children. My children were cleared genetically and their factor levels came back normal. But I held the mutation gene. My factor level came back at 42. I knew then that I too needed factor. I also knew that I too had hemophilia. Not only was it factored in my blood, but in my joints, the result of years without proper diagnosis and treatment.

However, getting diagnosed as a woman with a predominantly male bleeding disorder is like trying to convince a giraffe it is of average height. Or like trying to convince your blood to clot by just shouting at it. The struggle to be heard and be taken seriously is absurd, but painfully real.

Sitting in various waiting rooms has given me a newfound appreciation for HGTV and the Food Network. It has also given me an abundance of patience that seems necessary when dealing with a bleeding disorder. The last hematologist I visited when I was thirty-six told me it was a "mystery of life" why my joints ached. She gave me the classic carrier status associated with being the daughter of a severe hemophiliac. She discarded the results of my genetic mutation, discarded my low factor VIII level, discarded my low ferritin level, and basically told me my symptoms were imaginary.

If only that were the case, then I'd will my blood to clot, I'd will my restless legs at night to stop shaking, heck, I'd will Starbucks to deliver a few shots of espressos on the spot. And I'd request a lot of ice. Because my chronic anemia demands a cold wake-up call in the morning. The truth is if I were a boy, all these symptoms would ensure a quick diagnosis. Hemophilia. And swift treatment. Factor. But my double X-chromosome warrants a shoulder shrug and the concerned-for-my-mental-health stare from various hematologists.

During the pandemic, I learned about the Hemophilia Federation of America and joined my first virtual session. It was then I realized that my story was like many women with bleeding disorders. We have been made to feel like we don't matter. We are often overlooked and underheard. When I finally received a referral to get diagnosed, I was ecstatic. But the catch was that the clinic was hundreds of miles away from my house. I knew it was the only option for me as a woman to get diagnosed.

Once I arrived at the clinic, I felt reassured. After asking me a few rounds of questions and performing lab work, I was sent home with hope. Once the results came in, I was relieved. *Mild hemophilia*. It was the truth I had waited for; it was the written proof validating years of pain.

But the reality is that getting diagnosed is not enough. Treatment must be implemented. Words of reassurance that I am fine from healthcare professionals do not stop the bleeding. They do not change history.

Sawsen, Leena, and Dahab age 3, Abed age 1

The Hemophilia Holocaust took my father. If more care isn't taken, more lives are at risk by not getting the proper treatment.

At thirty-nine years old, my joints ache. My body hurts. You can often find me resting in bed, reading a book, or complaining how depleted of energy I am. I feel a lot of my exhaustion is due to having to fight twice as hard with medical professionals, to warrant a proper diagnosis for my bleeding disorder and to receive treatment. It should not have taken hundreds of miles, and numerous hospital visits to find a doctor who acknowledges women with bleeding disorders.

It is time that a woman is taken seriously. She knows her body. If she is seeking help from a medical professional, it is not because she likes to watch paint dry while watching DIY home remodeling shows, no matter how nice the shade, or watch how to cook pasta while wearing an adult diaper, praying the blood doesn't leak through her clothes until she can meet with a doctor, only to leave empty-handed searching for the nearest restroom to assess the damage.

It is time the past stops bleeding into the present. It is time a woman is given the red-carpet treatment in the bleeding disorders community because she bleeds just as much as a man, if not more.

ABOUT THE AUTHOR:

Sawsen Jamaleddin is American by birth and Palestinian by heritage. Sawsen earned her Bachelor of Arts in educational studies from Western Governors University and is a substitute teacher. She lives with her husband and four children. She enjoys writing and traveling and is excited at finally being able to connect with women who share her history in the world of bleeding diagnosis. Sawsen was reintroduced to her family history of hemophilia when she was 29 years old. She is passionate about advocating for women in the bleeding disorders community.

MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
[von Willebrand factor (Recombinant)]

Erica
VONVENDI Use: On-Demand & Surgery

- VONVENDI® is the **first and only treatment approved for routine use (prophylaxis)** in adults with severe Type 3 VWD who previously received on-demand therapy
- VONVENDI is **also approved for on-demand and surgical bleed management** in adults with all types of VWD
- VONVENDI **replaces VWF** (the main issue behind VWD), and **may be used with or without recombinant factor VIII** as instructed by your healthcare provider

Are you ready to ask about VONVENDI for your VWD? Visit VONVENDI.com to learn more, and talk to your healthcare provider.

VWD=von Willebrand disease; VWF=von Willebrand factor.

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- treat and control bleeding episodes
- prevent excessive bleeding during and after surgery
- reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy

Detailed Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider.

Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What else should I know about VONVENDI and von Willebrand Disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?
You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
Please see the VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.

Takeda

Important facts about VONVENDI® [von Willebrand factor (Recombinant)]

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

vonvendi [von Willebrand factor (Recombinant)]

What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery
- Reduce the number of bleeding episodes when used regularly (prophylaxis) in adults with severe Type 3 von Willebrand disease receiving on-demand therapy.

Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

What should I tell my doctor before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: headache, nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, joint pain, joint injury, increased liver enzyme level in blood, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

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

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at https:\\www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf or call 1-877-TAKEDA-7 (1-877-825-3327).

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

US-VON-0657v1.0 04/22

Takeda

New HEMOPHILIA CLASSIFICATIONS FOR Women

BY DAVID CLARK, PH.D.

We now recognize women can also have hemophilia and it is imperative to define diagnostic criteria that apply to them. This is needed for insurance coverage of their treatment as well as their own recognition and self-respect. Imagine if you had to limp around on your damaged joints from doctor to doctor to find one to take you seriously. Too many women in our community have had just that experience. Now, we can give names to their conditions.

An international group of twelve hemophilia treaters and patient advocates has taken on this project under the Scientific and Standardization Committee (SSC) of the International Society on Thrombosis and Haemostasis (ISTH). The project was mainly supported by the NHF, HFA and the Coalition for Hemophilia B from the U.S., as well as other hemophilia organizations around the world. There was no commercial support. The results were published in an article in the Journal of Thrombosis and Haemostasis on July 31, 2021. [See the complete citation at the end of this article.]

The results are shown in the table on the following page. The same classifications are used for both hemophilia A and B. For factor levels up to 40%, women receive exactly the same diagnoses as their male counterparts. They are classified as severe/moderate/mild based on their factor levels. Above 40%, the tables turn. Men with factor levels above 40% are not considered to have hemophilia in many countries. However, women who are carriers with factor levels above 40% can still have a bleeding diagnosis. The first thing to recognize is that the term "carrier" is now being returned to its proper definition. Carrier is a genetic description – it does not define a bleeding disorder. A woman is a carrier because she carries a mutated factor VIII or IX gene on her X chromosome that she can pass on to her offspring. She may or may not have a bleeding disorder. Carriers can have normal levels of factor VIII or IX.

Next, we need to discuss the international standard of 40% upper limit for hemophilia. In the U.S., we commonly use 50% as the upper limit for hemophilia and the lower limit for the range of normal factor levels. We recognize men with clotting levels up to 50% may still have mild hemophilia and may need treatment. In the rest of the world, men with levels of 40 – 50% are not considered to have hemophilia.

This gets more complicated because we know women can bleed even at levels up to 60%. We don't know why they still bleed, but the study's authors have recognized this and have given women two more categories. If a carrier has a level above 40% and does not have bleeding

DIAGNOSTIC CRITERIA FOR FEMALE CARRIERS OF HEMOPHILIA A AND B

Factor Level % of Normal	Diagnosis/Classification	
	Women	Men
Less than 1%	Severe hemophilia	Severe hemophilia
1% to 5%	Moderate hemophilia	Moderate hemophilia
More than 5% to less than 40%	Mild hemophilia	Mild hemophilia
40% or more	Symptomatic carrier of hemophilia (If genetically a carrier and have bleeding symptoms.) Asymptomatic carrier of hemophilia (If genetically a carrier but do *not* have bleeding symptoms.)	Normal

symptoms, she is classified as an "asymptomatic carrier." However, if a carrier has a factor VIII or IX level over 40% (with no upper limit) but still has bleeding symptoms, she is classified as a "symptomatic carrier."

This fuzziness in the over 40% levels could lead to situations where it is now the men who could have trouble getting treated. Going by the international classification, a man with a 50% factor VIII or IX level would not be considered to have mild hemophilia, even if he has bleeding symptoms. Yet, if he were a woman with a 50% level and bleeding symptoms, she would be a symptomatic carrier who might have a better chance of being treated.

In addition, all of the categories are just approximations. It is the best we can do with our current state of knowledge. We know that about 15% of people (men and women) do not bleed according to their category of mild, moderate or severe, as determined by their factor level. For instance, some people classified as severe bleed like moderates. Some people classified as mild bleed much more heavily.

Another term seen is *obligate carrier*. This is also a genetic description, not a bleeding diagnosis. If you are genetically female (have two X chromosomes) and your father has/had hemophilia, you are an obligate carrier. That means you carry (have inherited) your father's mutated factor VIII or IX gene. That's just how genetics works. You may or may not bleed. Of course, the genetics can always mess up – that's how we get hemophilia in the first place. However, it is extremely unlikely that when your father passes along his mutated factor VIII or IX gene, there is another mutation that actually fixes the gene.

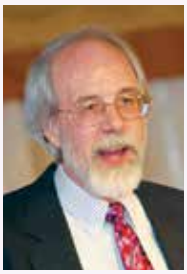
One interesting point in the article is the estimate that for every male with hemophilia, there are 1.6 female carriers. Since many of these female carriers might have bleeding problems, there may actually be more women with hemophilia than men. Tell that to your doctor who says women don't get hemophilia!

This is all based on averages, and no one is average! That's why you always have to talk to your doctor about your individual case. No one should bleed, no matter their factor levels.

REFERENCE

van Galen Karin PM, et al., A New Hemophilia Carrier Nomenclature to Define Hemophilia in Women and Girls: Communication from the SSC of the ISTH, Journal of Thrombosis and Haemostasis, 19(8), 1883-1887, 2021. https://pubmed.ncbi.nlm.nih.gov/34327828/

ABOUT THE AUTHOR



David Clark, Ph.D. is an independent consultant to the biotechnology, plasma and tissue industries. He has 35+ years of experience in the development and manufacturing of plasma and tissue products, including factor VIII and factor IX concentrates, primarily with the American Red Cross. Dr. Clark holds a Ph.D. in chemical engineering from Cornell University.

LIVING WITH HEMOPHILIA:
HOPE FOR HELP

BY ASHLEY GREGORY

Anthony and Nicholas were born in 1998, and although I had no family history of bleeding disorders, I now had twins with severe hemophilia A. I became informed about their condition and as they grew, stayed in close contact with our hemophilia treatment center. Also in 1998, NHF launched Project Red Flag, which advocated for women with bleeding disorders. I remember being curious because I had experienced puzzling symptoms throughout my time, but life would take a darker turn and it would be several years before I could revisit this topic.

One day Anthony didn't seem right; he was lethargic and not eating. I took him to our pediatrician who suspected the flu. I remember looking directly at her and saying, "Shouldn't we infuse him since his head is hot, but he has no fever?" She said, "No, just take him home." Instead, we took him to the emergency room where we learned he had a brain bleed. Despite heroic surgical efforts and finally infusing factor, my son died the next morning – he was only 11 months old. Thus began a slow tumble into despair that our family would not emerge from until well into the next decade.

During subsequent years, researchers were learning that women with the hemophilia gene exhibit unexplained bleeding symptoms and need treatment. Some doctors began successfully working with women to determine how to manage symptoms using factor replacement; they were learning that despite "normal" factor levels, women who experienced unexplained bleeding responded well to factor treatment with no adverse reactions. It was unexplained bleeding that pulled me back into a search for a diagnosis.

While volunteering at my local foundation, I heard women discuss similar untreated symptoms around inexplicable bleeding. It didn't take long to realize there was a common problem. Women in our community, like me, were experiencing puzzling bleeding that was not addressed despite reporting these symptoms to their doctors. The concerns were usually explained away with comments like, *sometimes these things happen, sounds like all the women in your family are like this*, or *this is just your normal*. Were we being ignored, or did the doctors simply not believe us?

This led to a personal investigative journey to seek a diagnosis and treatment while, at the same time, pursuing a career in advocacy and education in bleeding disorders. I began attending local, regional and national programs that provided comprehensive education about my bleeding symptoms and brought me in contact with physicians who were successfully treating women's bleeding issues using all the medications available to men with bleeding disorders.

I learned about lyonization, which is when one of the two X chromosomes in every cell of a female is inactivated. Lyonization can cause an effective X chromosome to stop working, allowing the other ineffective X chromosome to take over, producing lower factor levels. This led to an even greater understanding of my particular bleeding disorder as a woman with two X chromosomes. Thanks to Dr. Barbara Konkle and the *My Life, Our Future* genetic analysis project, I learned that some mutations present a high factor level but bleed like a severe! I finally learned that connective tissue disorders can also be present in persons with bleeding disorders, which can then exacerbate bleeding.

Empowered with this knowledge, I confidently entered the HTC near me and presented the information I had gathered, along with my symptoms and history. I trusted I would be heard and cared for. I could not have been more wrong. I even brought my mother along who had been by my side through all my pain and could attest to my history.

The treatment center told me my factor levels were too high for my swollen ankles and knees to be caused by hemophilia, and my petechiae were birthmarks.

My unexplained bleeding history was useless in gaining a diagnosis here. I was also seen by the genetics specialist who told me I lacked enough markers to have a connective tissue disorder. I was left with the option to do nothing or to have a synovectomy on my right ankle to see what fluid it contained. Based on my past, I instinctively knew without infusing factor prior to the procedure, the healing process would be long and painful. I declined the surgery in pursuit of a better option.

It was time to try a new approach. I crossed state lines and met with an expert clinician I had met at a national symposium. After a thorough medical evaluation, complete history review of symptoms, physical evaluation and lab workup, I was diagnosed with hemophilia A (symptomatic carrier) and hypermobility syndrome – a connective tissue disorder meaning my joints stretch further than normal. Aminocaproic acid (Amicar®) was prescribed for mucosal bleeding and clotting factor for muscle and joint bleeds. An emergency medical card was prepared with my treater's name, contact number and diagnosis. A medical alert bracelet was ordered for me, and I was instructed to contact the treatment center and treat on-demand as needed.

Imagine my delight to find when I treated a bleed as my hematologist instructed, my whole body felt better; things that had hurt my entire life stopped hurting; my petechiae cleared and the swelling in my knees and ankles subsided. Then, as the factor left my body, the pain and baffling bruising would return.

I was able to access treatment from the out-of-state HTC for a short time, and I was emboldened to treat my hemophilia the same way I was as a mother in treating Nicholas' hemophilia. Since I had been infusing him for years, infusing myself was easy, and I kept a log of bleeds and treatments. I was amazed at the overall improvement in my energy and stamina when using factor!

Moving forward to 2022 – Through my out-of-state HTC, I was able to access free trials of factor products, but those have ended. I am no longer able to have treatment for my bleeds. The system that pays for factor for persons with bleeding disorders requires an in-state doctor to write the prescription. So far, I have not found a doctor in my state who is knowledgeable about the particular genetic mutation that causes me to have a high factor level yet bleed severely. I am now a woman without a treatment center and without treatment.

My chronic pain and suffering affects not only me, but my family as well. Because of my health, we are not living our best life. In spite of this, I am grateful for my experiences, to my sons born with hemophilia, and to Anthony who didn't survive due to the lack of knowledge that prevails to this very day. This lack prevents his mother from treatment and medication.

I am grateful to Nicholas, who bears witness to the stark contrast of gender care in hemophilia. I have built a career advocating for those like me who are unable to access the care we know is needed. I am appreciative for all of these experiences, but I would also like to be grateful for access to treatment for all women with hemophilia. It is my hope this will be a reality soon.

TIMELINE HIGHLIGHTING A FEW SYMPTOMS THROUGH THE YEARS:

- Age 4: my first memory of severe pain in my knees. I had no words to describe the pain and it went unattended.
- Age 9: moved to a home in a hilly area. I had pain that brought tears and immobility. Diagnosed with pre-patellar chondromalacia and was instructed to avoid hills and stairs, and to rest, ice and elevate. The constant pain kept me sedentary.
- Age 10: my menstrual cycle began with extreme pain, heavy clots, bruises under my eyes and sheer exhaustion. Soaked through sanitary pads and ruined sheets. At school, it seemed I was in the bathroom more than in class. Treatment for this would never come. I spent my menstruating years suffering the effects of anemia.
- Age 15: cut my ankle on a jagged piece of wood. The wound kept oozing and reopening, taking a year to fully heal.
- Age 16: worked long shifts standing on a hard restaurant floor, in constant pain, fatigued, with swollen knees and ankles. When sitting, I would draw my legs up under my body to prevent my ankles from dangling as the pain was unbearable. Tired and hurting all the time. By the time I became sexually active, I bled with intercourse regardless of my cycle.
- Age 21: diagnosed with gout in my toe. I now recognize this was a bleed.
- Age 25+: with each of my first 3 pregnancies, I experienced anemia, 2nd trimester spotting, petechial hemorrhaging around my face during childbirth and prolonged postpartum bleeding. 2nd pregnancy brought throbbing pain behind my left eye leading to a spinal tap that would not clot causing a week-long leak of cerebrospinal fluid. 3rd pregnancy resulted in prolonged healing of c-section incision.
- Age 27: wisdom teeth extraction bled for weeks.
- Age 28: at the ER with excruciating knee pain. Was told there was nothing to be done.
- Age 32: sons Anthony and Nicholas were born via C-section. A bleed at the incision caused excruciating pain; bleeding and severe bruising in my groin and down my legs.
- Age 35: diagnosed with fibromyalgia.
- Age 45: diagnosed with tendinosis (Related to connective tissue disorder).
- Age 53: finally diagnosed as a symptomatic carrier of hemophilia A and connective tissue disorder reaffirmed. Was prescribed factor, Amicar® and physical therapy.
- Age 56: free factor trials end; I no longer have access to treatment.

TIME TO RETHINK WOMEN AND BLEEDING DISORDERS:

Stop THE UNNECESSARY SUFFERING!

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

As a woman with hemophilia A, a platelet disorder and Ehler's Danlos Syndrome (EDS), the bleeds I experience are more in line with moderate to severe hemophilia. At age 65, I suffer with various medical complications and side effects from receiving a later-in-life diagnosis. I did not obtain a diagnosis or proper/adequate treatment for most of my life. The pursuit of equal or compatible treatment that my blood brothers receive has been a struggle.

Throughout my life, dental work and cleanings caused extensive bleeding. Impacted wisdom teeth caused me needless mouth pain for many years, but because of how easily my mouth bled, no one wanted to extract them. Finally at 52, I found an oral surgeon who agreed to remove them with treatment prior to procedure. I experienced senseless tooth and mouth pain for so many years. Now I treat with DDAVP nasal spray prior to all dental appointments, and bleeding is minimal.

When I was 11 years old, I began having gastrointestinal bleeding. Physicians believed I had colitis; the treatment was dietary changes and medications. The mucosal lining of my lower intestine is permanently damaged from years of uncontrolled bleeding. Now with a proper diagnosis, I am able to effectively treat with clotting factor, desmopressin (DDAVP®) and tranexamic acid (Lysteda®).

All my life, I have bruised very easily and when my menstrual cycles started, I bled heavily with large clots for more than seven days every month. When I voiced my concern to my doctors, I was told my cycle was "normal" because my mother and grandmother also had heavy cycles, and that being a fair-skinned redhead added to the bruising. In retrospect, my mother and grandmother both had undiagnosed bleeding disorders. Due to the prolonged bleeding each month, I had chronic anemia, which greatly affected my quality of life.

In 7th grade I injured my knee during gym class. When I look back at that injury, it was clearly a muscle and joint bleed. As I grew older, my left knee deemed itself my target joint. It is chronically swollen with decreased range of motion; x-rays reveal the knee joint is now bone-on-bone. Steroids and gel injections only offer temporary relief, and I am now considering a knee replacement. Had my joint bleeds been treated properly when I was younger, the extensive joint damage could have been avoided or at least lessened. I now wear rib, back, knee and thumb braces due to impaired joints.

Current studies are revealing a correlation between Factor VIII deficiency and bone health, and I have been diagnosed with osteopenia. Women with a bleeding disorder are developing osteopenia and osteoporosis at an earlier age.

In 1983, when my oldest son was diagnosed with severe hemophilia A at 17 months, scientists had not yet discovered the gene where the mutation occurred. When DNA testing became available, I was tested and the results showed I had the same gene mutation as all 3 of my children, yet despite my bleeding history, I was labeled as *just* a "symptomatic" carrier.

At 35, I had an inguinal hernia repair scheduled but at that time, wasn't being seen by a hematologist. After reading in my medical record that I was a carrier, the anesthesiologist refused to clear me for surgery until I was seen by a hematologist. I went to a hemophilia treatment center and was tested and was diagnosed with a platelet disorder.

Shortly after, I was identified as having EDS and was then prescribed DDAVP via IV for any surgery or invasive procedure. Tranexamic acid and aminocaproic acid (Amicar®) helped with menstrual cycles and mucosal bleeds. In my late 40's, I was finally properly diagnosed with a bleeding disorder and received appropriate treatment for chronic anemia; yet I was not given access to clotting factor for another 17 years.

Unfortunately, the majority of the medical community is often still under the notion that only males can have a bleeding disorder. The assumption is women are only carriers and do not need treatment. However, rather than basing care on gender, treatment should be based on documented factor levels and bleeding tendencies.

Our national organizations, non-profits and pharmaceutical companies have done a great job at educating the community on bleeding disorders in men *and* women. Yet, there still remains a missing piece on *prescribing* proper treatment for women. Education needs to be expanded at the medical school level to instruct doctors-in-training to recognize that women can and do bleed. In the meantime, women need to advocate for themselves with a much louder voice and not allow themselves to be dismissed. In the 25 years I have been active in the bleeding disorders community on a national level, I have not seen much change in the timely diagnosis and adequate treatment for women. This needs to change.

ABOUT THE AUTHOR

Linda "Lew" E. Wyman-Collins, BSN, RNC-NIC is a mother, wife, aunt, sister, daughter of someone with a bleeding disorder and has a bleeding disorder of her own. As a nurse, she has much experience in neonatal intensive care and was recognized as Dallas/Fort Worth Great 100 Nurses. Lew served HFA formerly on the Board of Directors, Blood Sisterhood Chair, Symposium Chair, Medical/ Professional Advisory Board member, and is a founding member of HFA's women's group *Focus on the Feminine*. She has served on Texas State Bleeding and Clotting Disorders Advisory Council and is a member of *Equity in Bleeding Disorders Care for Women and Others*. Additionally, Lew has presented frequent at national and international conferences and has authored numerous articles on hemophilia and women with bleeding disorders in industry magazines and journals.

ADVOCATING FOR THE WOMEN IN MY LIFE

BY ANONYMOUS

As with many young couples, my wife and I were thrilled and terrified when we first learned we were going to become parents. Although we had been married for three wonderful years, we were not sure we were ready for the responsibility that comes with bringing a new life into this world. But as with most parents, even after 16 hours of induced labor, we both could not imagine our lives without our son. As all first-time parents believe, our son was perfect, but over the next few days, we noticed his coloring was somewhat pale. After multiple calls to the pediatrician and a visit to the hospital, our son was diagnosed with jaundice and spent several days in the hospital. Worried, but still in awe of this new life, we brought him home to begin our new life as a family.

At four months, we noticed a small bruise on his knee, but the pediatrician told us it was nothing to worry about and so we didn't. After a few days, the bruise was not dissipating, and we noticed it looked swollen so we took him to the local children's hospital. What followed was a terrifying sequence of tests, mistakes and follow-up visits until we were finally told our son had severe hemophilia A. Neither of us knew anything about hemophilia and we spent his early years learning and searching for answers.

When our second son was born, we knew exactly what we needed to do. He was tested at birth, and he too was diagnosed with severe hemophilia A. This time we felt slightly more confident about how to handle his diagnosis. Having two sons with hemophilia allowed us to see firsthand the similarities and differences this condition presents in every patient.

During this period my wife and I began to discuss her bleeding issues and how debilitating her menstrual cycle had been throughout her life. We launched a dialogue about her concerns with our son's hematologist and were told her difficulties were not related to a bleeding disorder. Over the next few years, we settled into parenthood and life with a bleeding disorder and all the ups and downs that come with raising a family. As a couple, we had decided not to have more children, primarily due to the probability of having another child with a bleeding disorder.

As our children grew so did the problems with my wife's menstrual cycle. After multiple attempts to have her tested at the HTC to no avail, my wife discussed her issues with her gynecologist. After learning about her family history of bleeding disorders, her gynecologist submitted an order for a blood test to check her factor levels. The HTC was forced to review the results of the blood tests and it was determined she had 25% factor VIII which classified her as having mild hemophilia. The HTC told her she was considered, in their opinion, a symptomatic carrier. Although this was not the ideal diagnosis, we were content her issues were finally being acknowledged even though no medication was recommended or prescribed.

Our plan to not have more children did not work out as four years after our second son was born, we were given a delightful surprise in the form of a beautiful daughter. Naturally, we were concerned about our daughter's potential for having bleeding issues like her brothers and mother. When we brought this up to our hematologist, we were told in no uncertain terms that girls are only "carriers" and there was no need to be concerned. We asked if she could be tested regardless to learn her factor levels but we were told the test was not medically necessary and as such, not covered by our insurance. We accepted the information, albeit with some apprehension, and continued our familial journey.

After the birth of our daughter, my wife continued to have bleeding difficulties that only increased in severity. Ultimately, she was diagnosed with uterine polyps due to years of excessive bleeding that was never treated appropriately. Her gynecologist stated the only way to effectively treat her condition was with a complete hysterectomy.

It was a difficult time for my wife, not only because of the surgery but also due to the lifetime of hormone therapy that would become necessary. In addition to the frustration of this new circumstance came the knowledge that if she had been treated as a hemophiliac, like our sons, some of this would likely have been avoided.

My wife and I immediately turned our attention firmly to the health of our daughter. We both agreed we would do anything necessary to avoid our daughter having to live through the same bleeding issues and consequences that her mother endured. My wife joined a women's bleeding disorders support group to learn more about bleeding issues in general and to connect with other women in the community. We attended educational programs and began

to prepare ourselves for the struggle we knew was coming.

When our daughter became a woman, we knew exactly what to do. The month after her first menstrual cycle she was seen by her gynecologist and we explained how debilitating the cycle had been along with our family history of bleeding disorders. The gynecologist immediately ordered blood tests to determine her factor levels. An HTC appointment was scheduled to review the results of the tests. At the appointment, we were told that her factor levels classified her as a symptomatic carrier. When we asked about the severity of her menstrual cycle, we were told it was relatively normal for some women to have excessive bleeding. After discussing my wife's history with the doctor and her eventual surgery, the hematologist ordered Stimate® and Amicar® to be used as necessary.

The HTC told us we would receive a diagnosis card in the mail to verify her condition. When the card was received, it stated our daughter was diagnosed with von Willebrand disease. I called the HTC to ask about her hemophilia A status and was told the diagnosis on her card was correct. I questioned which blood test showed a deviation in her von Willebrand factor and none could be found.

I politely requested a corrected diagnosis card be sent and the clinic agreed. The following week we received a new card listing the diagnosis as mild hemophilia A and von Willebrand disease. Our daughter has done well with her treatment over the years.

Several months ago, our daughter was recommended for a minor surgical procedure to remove a cyst. Naturally, the surgeon requested a medical clearance to be completed by her hematologist before surgery. During the HTC visit, her first in a few years, the hematologist informed us that the surgery should not be an issue as she was a von Willebrand's patient and no treatment should be necessary. Even though our daughter is a teenager she asked me to be with her during the exam and I felt the need to correct the hematologist about her diagnosis. I asked if she could show me the test results that supported the diagnosis, and she answered that no tests were available in her chart.

The hematologist turned to my daughter and made the following statement, "There is no reason to worry. Women do not have bleeding issues." At this point, my daughter looked at me somewhat confused, as if to ask, "Are you sure I have a bleeding disorder?" I must admit I felt a wave of frustration towards this "specialist" and concern, not only for my daughter, but for all the other young women who are potentially meeting with hematologists around the country and receive this same statement – this brush-off and lack of treatment, making them feel as if everything being experienced is either made up or unimportant, and neither is true.

...we were told in no uncertain terms that girls are *only carriers* and there was no need to be concerned.

I spent the next few minutes discussing my experience with women living with bleeding issues and the number of women that I know personally who require prophylactic intervention due to their condition. The doctor quickly backtracked and stated she meant that women who are bleeders are rare, to which I stated, "Hemophilia is rare." The doctor decided to confirm my daughter's diagnosis by ordering a panel of blood tests to check her levels.

A few weeks later, my daughter and I were at the HTC to review the results of her blood tests. This time we were seen by the clinic's medical director, who reviewed the tests and explained the results did show that our daughter was a "carrier" of hemophilia A and due to her factor VIII level of 36%, she may need some treatment before surgery. I mentioned that if her diagnosis was simply as a carrier, our insurance might give us some difficulty reimbursing for factor. The doctor agreed and stated he would make a note in her chart that a 36% factor level constituted a mild hemophilia A diagnosis. To finally hear those words come out of an HTC hematologist about my daughter was an affirmation of what we believed all along.

I felt elated that we were finally able to confirm what my wife and I had known since the first set of blood tests were performed several years prior. At the same time, my heart sank thinking about all those young girls and women who have battled bleeding issues their entire adult lives and do not have access to someone who can and will advocate for and with them. To classify a woman as a "carrier" is to put her in a box and say she is fine. Technically anyone who has hemophilia, male or female, is a carrier. Think about it - men with hemophilia carry that chromosome to every daughter he fathers. Ergo, men, too, are carriers. We need to continue to work and advocate until everyone, regardless of their gender, receives the same level and quality of care possible.

Patient Navigation in the Specialty Pharmacy Space

BY SHELBY SMOAK, PH.D. AND JUSTIN LINDHORST, MBA

The bleeding disorders community has long endured health–system related challenges.

Attending college in the early 2000s, I secured my first private insurance policy offered to students attending the university. After attempting to order factor, I was contacted and told that my policy included exclusions for pre-existing conditions and that I'd have to wait a year before the plan would cover my medication.

> **The reality for patients is that accessing prescribed specialty therapy is challenging.**

After one grueling year of jumping through many hoops to maintain access to my lifesaving medication, I finally placed my first factor order through my insurance company. Six months after that, I hit the "lifetime max" on the plan and was forced to find coverage elsewhere. Before the passage of the Affordable Care Act, lifetime caps and pre-existing condition exclusions were some of the primary health-system related roadblocks experienced by members of the bleeding disorder community.

Today step-therapy, copay accumulators, and high out-of-pocket costs threaten or delay our access to prescribed therapies. The fact is people with chronic health conditions such as hemophilia and VWD face a range of challenges navigating our fragmented healthcare system. Patient navigation programs can help.

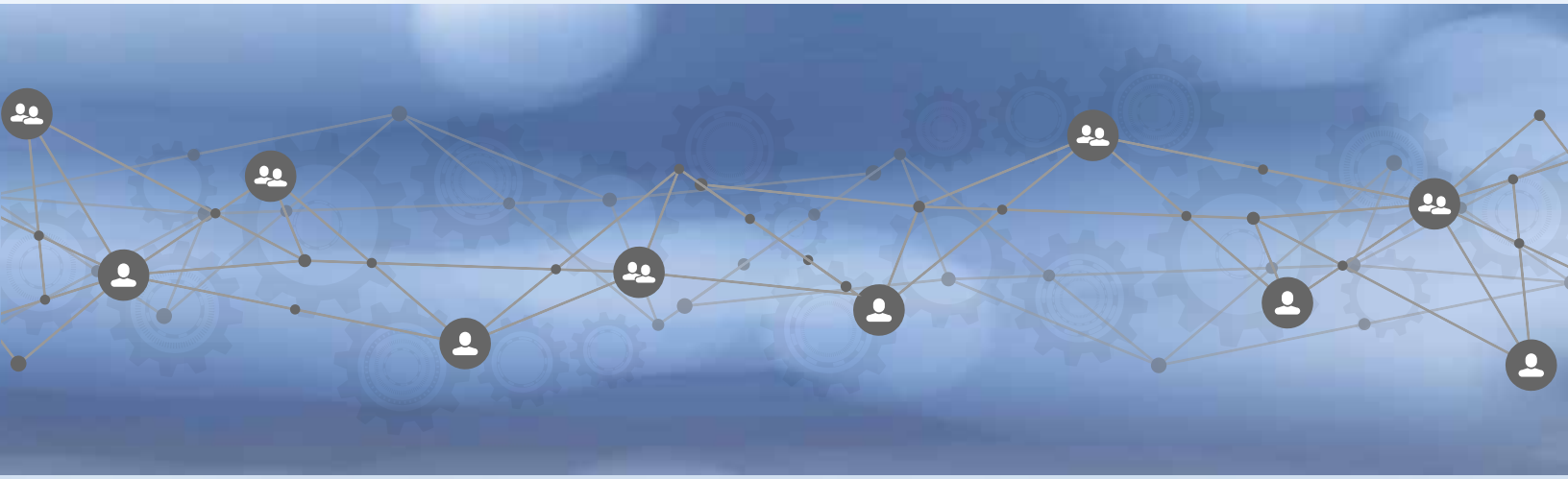
Patient navigation has been defined as, "Individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care."[i] Patient Navigators are peer, non-medical and medical professionals who assist patients to coordinate support across the healthcare system. This support can include education, removing financial and other barriers to care, assisting with insurance coverage, facilitating access to community resources, and providing emotional support.[ii] Research indicates patient navigation services using peer, medical, or non-medical staff are effective at resolving health-system barriers and result in improved outcomes and increased patient satisfaction.[i, iii]

Within the last decades, our understanding around the positive impacts of patient navigation programs has grown. Witnessing the various forms it can take and the many different professionals who give patient navigation a voice, patient navigation continues to be a sound way to close the gaps in healthcare access and, as researchers in *Cancer* put it, "a strategy to improve outcomes."[iv] The goal of patient navigation has remained steadfast: "to facilitate timely access *for all* [emphasis added] to quality standard care in a culturally sensitive manner."[v]

The reality for patients is that accessing prescribed specialty therapy is challenging. Given that eighty-two percent of surveyed patients reported delays in accessing meds, a clear problem exists.[vi] Over half of pharmacists surveyed indicated spending 1–2 hours with patients, especially when it involves complex medications.[vii] An article in *Journal of the National Medical Association* calculated an even higher average of 2.5 hours per patient spent helping individuals reduce barriers to care.[viii]

Today, chief among these delays are insurance issues and costs associated with medications. Pharmacies have observed these obstacles and witnessed the fragmentation of the healthcare system into compartments that do not always work well together. To reduce disruptions in treatment access, specialty pharmacies like BioMatrix are embracing patient navigation as the next evolution in high touch patient care.

Sometimes a little emotional support can go a long way. Emotional support provided by patient navigators can bolster patients as they overcome barriers. Relationship-building thus forms another root in the success of patient navigation programs. As one researcher notes, relationships between patient and navigator influenced



the outcome, adding, "The process [of patient navigation] has at its core relationship-building and instrumental assistance."[ix]

Successful patient navigation appears to be closely tied to the patient navigator's ability to build strong patient relationships and provide effective emotional support. Patient navigation can be conducted by a clinician or trained layperson. A study examined a broad range of patient navigation programs using either clinicians or trained laypersons as the primary patient navigator. The researchers concluded that, "The type of navigator used was not found to affect patient outcomes." The study indicated successful outcomes were tied more closely to relationship building and providing effective emotional support versus professional background.[x]

Patient navigation programs have proven themselves as a gateway to improved outcomes. Patients are also being more proactive and seeking avenues to gain the access to care; ninety percent of those surveyed said exactly that.[xi]

BioMatrix has assembled a team of caring experts with years of bleeding disorder specific experience in insurance processing, social work, and education to help patients successfully resolve health system, nonclinical barriers to care. These services are offered at no cost and are available to any member of the bleeding disorder community regardless of product, pharmacy affiliation, or insurance coverage. We welcome patients to contact us so we can work together to reduce and overcome barriers to care: info@biomatrixsprx.com

REFERENCES

i. Blackley, K., Burriss, H., Cantril, C., Kline R., Pratt-Chapman M., Rocque G., Rohan, E., Shulman, L. (2019). Patient navigation in cancer: The business case to support clinical needs. Journal of Oncology Practice. 15,11 585-590. DOI: 10.1200/JOP.19.00230

ii. McBrien KA., Ivers N., Barnieh L., Bailey JJ., Lorenzetti DL., Nicholas D., Tonelli M., Hemmelgarn B., Lewanczuk R., Edwards A., Braun T., Manns B. (2018). Patient navigators for people with chronic disease: A systematic review. PLoS One. 2018 Feb 20;13(2):e0191980. DOI: 10.1371/journal.pone.0191980.

iii. Meade CD., Wells KJ., Arevalo M, Calcano ER., Rivera M, Sarmiento Y., Freeman HP., Roetzheim RG. Lay navigator model for impacting cancer health disparities. (2014). Journal of Cancer Education. 2014 Sep;29(3):449-57. doi: 10.1007/s13187-014-0640-z.

iv. Freedman, Harold M., and Rian L. Rodriguez. "History and Principles of Patient Navigation." Cancer. 10 July 2011. https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.26262

v. Freeman, Harold M. "The Origin, Evolution, and Principles of Patient Navigation." Cancer, Epidemiology, Biomarkers, and Prevention. 21.10 (2012). https://aacrjournals.org/cebp/article/21/10/1614/69026/The-Origin-Evolution-and-Principles-of-Patient

vi. Cover My Meds. "2022 Medication Access Guide." PDF

vii. IBID.

viii. Lin, Chyongchiou J., et. al. "Factors Associated with Patient Navigators' Time Spent on Reducing Barriers to Cancer Treatment." Journal of the National Medical Association. 110.11 (2008). https://www.sciencedirect.com/science/article/abs/pii/S0027968415315078

ix. Jean-Pierre, Pascal., et al. "Understanding the Processes of Patient Navigation to Reduce Disparities in Cancer Care: Perspectives of Trained Patient Navigators From the Field." Journal of Cancer Education. April 2010. https://link.springer.com/article/10.1007/s13187-010-0122-x

x. McVay, Sheri., et. al. "The Effect of Different Types of Navigators on Patient Outcomes." Journal of Oncology. April 2014. https://www.jons-online.com/jons-categories?view=article&artid=3665:the-effect-of-different-types-of-navigators-on-patient-outcomes&catid=18

xi. Cover My Meds. "2022 Medication Access Guide." PDF.

BIOMATRIX PROUDLY ANNOUNCES THE 2022 MEMORIAL SCHOLARSHIP RECIPIENTS!

Each year, BioMatrix provides six $1,000 scholarships for bleeding disorders community members seeking higher education. Since 2013, our scholarships have honored the memory of several individuals who impacted the bleeding disorders community in unique ways. BioMatrix partners with the Hemophilia Federation of America for administrative support and independent, third-party evaluation of applicants.

It is with great pleasure we announce the 2022 recipients of our Memorial Scholarship Program. Thank you to everyone who applied — we wish you great success in your bright future! Without further ado, we introduce you to our scholarship recipients!

MICHAEL CAGGIANO

Freshman at University of Miami; Engineering
BioMatrix Ron Niederman Memorial Scholarship

In high school, Michael discovered his love for hockey. Despite his diagnosis of severe hemophilia, he wanted to play, so with his medical care team, made adjustments to effectively manage his bleeding disorder and joined his school's team. This experience led Michael to create a website, HemoTalk.com, where he interviews inspiring people with a bleeding disorder, spreads awareness, and offers support and encouragement to others living with a bleeding disorder. Michael has hope as he shares, "My schooling could prompt me to develop critical therapeutics for those with bleeding disorders like gene therapy or subcutaneous injection technology."
Congratulations, Michael!

BRIAN DUVAL

Senior at University of Nebraska; Finance/Political Science
BioMatrix Mike Hylton Memorial Scholarship

As someone with severe hemophilia, Brian has much experience under his belt as he pursues a career in rare disease advocacy. In high school, he spoke at his state capitol and participated in NHF's Washington Days. Currently Brian serves on the Hemophilia Foundation of Minnesota/Dakotas Board of Directors and is a policy and government relations intern for Hemophilia Federation of America in their D.C. office. "Advocating for such a personal cause and making the voice of the bleeding disorders community heard by policymakers has been crucial in shaping my career goals."
Congratulations, Brian!

JUSTIN EICHERMULLER

Graduate Student at Florida State University; Master's in Public Administration
BioMatrix Mark Coats Memorial Scholarship

When Justin was diagnosed with hemophilia, the doctors painted a picture of a very restrictive life, which his family refused to accept. Though he couldn't always participate in school sports, he volunteered to help his team. As an advocate, Justin has served on a youth council at his Hemophilia Treatment Center, has mentored young children with a bleeding disorder, and seeks out opportunities to raise awareness of hemophilia in his job. "Individuals should not be defined by a medical condition but by what they do with it."
Congratulations, Justin!

LIDIA GRANDE-RUIZ

Senior at Cal Poly Humboldt; Film
BioMatrix Millie Gonzalez Memorial Scholarship

For an educational video series, Lidia was asked to speak about her diagnosis and experience living with von Willebrand Disease and how it affects family and friend relationships. The experience made a lasting impact, helping her realize the importance of sharing her story and how film can help others. As such, she was inspired to pursue film as a career with the hope that sharing her stories about her bleeding disorder will offer support to the community. "I learned that a well-produced film could cause a chain reaction raising awareness and helping others feel motivated, connected, and not alone."
Congratulations, Lidia!

NICHOLAS LEACH

Freshman at Belmont University; Biochemistry and Molecular Biology
BioMatrix Tim Kennedy Memorial Scholarship

As a 4-year-old, Nicholas began playing soccer before he was diagnosed with hemophilia. Due to his love for the game, he wanted to keep playing despite the diagnosis. Nicholas learned to self-infuse at a young age and was able to continue playing soccer through high school by successfully managing his medical treatments. "I play soccer because I love it, and this love has brought me through highs and lows. At the end of the day, I will be remembered not for hemophilia but as an athlete who followed his passion and overcame his obstacles."
Congratulations, Nicholas!

JOSIAH WALKER

Sophomore at James Madison University; Engineering
BioMatrix Joe Holibaugh Memorial Scholarship

Given his severe hemophilia and risk of painful bleeding episodes, Josiah grew up with a sense of caution. Understanding that sports would not be ideal for him, he joined a local robotics team where he soon became a leader, teaching and managing other students in designing their 120-pound competition robots. Through this experience involving technical skills and teamwork Josiah was inspired to pursue engineering. "Hemophilia has gone from a stumbling block to a steppingstone for my future adventure — in education, career, and life."
Congratulations, Josiah!

The 2023 school-year application will open in March 2023 and be accepted through August 1, 2023.

Beginning March 2023, apply online: scholarship@biomatrixsprx.com

Joe Holibaugh (1971-2006)
$1000 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor

Tim Kennedy (1962-2011)
$1000 Scholarship
For MEN with hemophilia

Millie Gonzalez (1953-2001)
$1000 Scholarship
For WOMEN with hemophilia or von Willebrand Disease

Ron Niederman (1950-1999)
$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mike Hylton (1945-1998)
$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mark Coats (1956-1963)
$1000 Scholarship
For MEN and WOMEN with hemophilia

BIOMATRIX ON THE *Move*

Our Regional Care Coordinators and Education Team have been out in full force meeting with our bleeding disorders community members live and in-person all over the country! Additionally, we continue to offer on-line sessions with a wide variety of educational topics and fun activities to choose from. Interested in scheduling an session for your group either in-person or virtually? Please contact your RCC or message the Education Team at: education@biomatrixsprx.com.

Ashley, Sheila, Angela and Genni

TENNESSEE

Cyndy Coors

We all know about the difficult challenges our nurses have had over the last couple of years, so what better way to show our appreciation and make them feel special than to provide them with a ***Luncheon and Activity*** program!

BioMatrix was honored to do so September 8th for our local HTC nurses at the Pediatric Cancer and Blood Disorder Center in beautiful downtown Chattanooga. We leaned into the talents of our very own Michelle Stielper and her *Beading Your Journey* program. After enjoying lunch together, the nurses created beautiful bracelets that held special and personal meaning to them. Not wanting to be excluded, hematologist Dr. Avery Mixon joined in on the fun!

A big thank you to each of these nurses and Dr. Mixon for the excellent care they give their bleeding disorders patients, and we hope our *Beading Your Journey* brought some well-deserved happiness to their day!

Nurse Donna and Dr. Mixon

Nurses Janna, Jackie, Maggie and Sheila

Nurse Raquel

Jose and Gail

Nancy and Chris

Rob, Arthur, Tara and Walter

Tina, Gerald and Becky

DELAWARE

Tina McMullen

Brandywine Valley Hemophilia Foundation held their annual ***Baseball Education Event*** in Wilmington, September 9th, with BioMatrix and Octapharma having the honor of sponsoring an afternoon program at Timothy's Riverfront Grill. After a brief discussion of BioMatrix's specialty pharmacy services, Patient Experience Manager with Octapharma, Paul Brayshaw related his company's services and community support programs.

After lunch, we headed across the street to the Daniel S. Frawley Stadium to watch the Wilmington Blue Rocks take on the Hudson Valley Renegades before the first pitch was tossed.

Due to some cancellations, we had a few extra tickets, so Board President Gail Novak's husband, Robert, approached two gentlemen in line to purchase tickets. Robert told then about the Brandywine Foundation and their efforts to support the bleeding disorder community and offered them the extra tickets. Later, the men sought out Robert and Gail to thank them for the tickets and surprised them with announcing that they had made a donation to the foundation!

Another surprise awaited attendees – since the game tickets were booked so early, each person in our group would receive a free baseball cap. I was thrilled for our participating families, and now I will be even easier to spot in my Blue Rocks cap!

Mr. Celery (Gail's favorite mascot) appears each time the Blue Rocks get a home run. We got to see him 5 times with the Blue Rocks defeating Hudson Valley by a score of 5–4! Families socialized, cheered on their team and enjoyed fireworks after the game. Thank you to Gail, Paul and all the Brandywine Valley families who attended this fabulous event!

VIRGINIA *Women's Event!*

Terry Stone

The weather was mostly in our favor as the ladies of Hemophilia Association of the Capital Area (HACA) gathered for an ***Annual Women's Weekend Retreat*** September 9–11th at the beautiful Meadowkirk Delta Farms in Middleburg to invoke their inner peace and tranquility. The pastural view of meadows and mountains from our private dorm-style accommodations set the stage for a weekend chock-full of quality girl time, enriching education and creative art time to fill our spirits and catch up on life.

Keeping with tradition, the opening session kicked off with HFA speaker Anna Bell, LICSW, LCSW-C, LISW, navigated the conversation of *Emotional Intelligence* where we discussed how to be more self-aware in our personal relationships and interactions, and how that makes us better overall communicators. Later in the day, Anna also facilitated a rap session addressing caregiver trauma and challenges.

Additional sessions included NHF's presenter Maria Tovar-Herrera offering an engaging talk about "Reproductive Health, Menstruation, and Menopause." Also, our very own Terry Rice, BioMatrix Director of Education & Advocacy, presented on the topic of *Financing a Chronic Illness*, offering guidance on how to safeguard your family's financial health. For the limber ladies or those who want to be, yoga was in session in the field under the tree with Marsha Banks-Harold of Alexandria, VA's PIES Fitness Studio.

Saturday evening's Art Program was a fun and festive time creating decorative birdhouse keepsakes led by BioMatrix's Regional Care Coordinator and Art Educator Michelle Stielper. From the same table of supplies came an explosion of beautiful masterpieces of classic, mystical, farmhouse, and unique styles that all have special places in HACA homes around the northern Virginia or DC metropolitan area...They all turned out amazing!

Many thanks to HACA for hosting this annual retreat!

ILLINOIS

Eva Kraemer

Let's face it, life can be challenging and learning how to finance a chronic illness can be overwhelming. BioMatrix and Novo Nordisk hosted an ***Educational Dinner – Financing a Chronic Illness / 6 Financial Tips for Adults*** at Maggiano's Little Italy in Oak Brook September 14th.

Novo Nordisk's Natalie Borzick discussed the importance of knowing your relationship to money and how to better manage it. BioMatrix's Shelby Smoak, PhD, continued the discussion with how medical debt can impact credit scores. He also talked about copay assistance and support programs, FSA and HAS plans, life and auto insurance and short- and long-term disability. Lot of lively conversation was had, making this type of interaction so beneficial especially. Making this occasion even more special was celebrating Jonathan's 12th birthday! BioMatrix is committed to the Illinois bleeding disorders community and creating this kind of networking.

Happy Birthday, Jonathan!

NEW YORK

Richard Vogel

As summer came to an end in upstate New York, the Bleeding Disorders Association of Northeastern New York (BDANENY) held their ***Annual Meeting*** at Liberty Ridge Farms in Schaghticoke September 18th. Community members turned out for a day of fun, information and comradery on this beautiful, warm day.

Manufacturers and specialty pharmacies set up information booths in the open air. Members strolled through, gathering information. It was good to see many familiar families! Everyone was invited to lunch in the old red barn where we devoured smoked BBQ brisket and chicken, all prepared right there on the farm.

Pat Torrey of Gutmonkey presented a session on Mindset. He spoke about two types of mental attitudes: *Fixed* and *Growth*. Fixed mindset, when you feel your outlook cannot change and you tend to focus on the familiar. You stay within your comfort zone are quick to say, "I can't do


Patrick Torry

that." Growth mindset is when individuals are more likely to step outside the box and challenge themselves. If they fail, they are more apt to say, "I can't do that...*YET*." Pat went on to demonstrate this concept with juggling squares. He showed us how to juggle using squares of light material since they floated slowly to the ground. Most people were able to master juggling. I couldn't... *YET*.

It's always good for families in the bleeding disorders community to get together to talk, share stories and relax, and there is no better place in late summer than Liberty Ridge Farms. Thank you to BDANENY for giving our community this opportunity.

FLORIDA

Marcy Foertsch

On the evening of September 21st, BioMatrix and Bayer partnered to bring an ***Educational Program*** to the bleeding disorder community at Tampa's Seasons 52 restaurant. The well attended program began with a presentation by Bayer's Hemophilia Community Executive Barbara Arebola who spoke about securing healthcare with a chronic bleeding disorder. Following her informative presentation was BioMatrix's Director of Education Terry Rice who presented an engaging and interactive discussion on *Awareness for Advocacy*. Terry highlighted the importance of being one's own best advocate by establishing clear communication with physicians and providers and by using apps like MicroHealth to track infusions and bleeds. With a seasoned presenter like Terry, history was brought in to demonstrate the wins of a lifetime of advocacy.

The group was energetic as they asked about insurance and advocacy and shared their own stories and experiences of advocacy. Feedback was overwhelmingly positive with attendees looking forward to the next program they would be able to attend! Thanks to Bayer for partnering with us and thank you to our Tampa community members who were able to join us!


RCC Gaby Griffin with raffle winners, Reynaldo, Carolina, Jaqueline, and RCC Hector Heer

CALIFORNIA

John Martinez, Gaby Griffin and Hector Heer

Familia in Spanish is a word that means something different to everyone. In the bleeding disorders community, we use the word "family" to describe the members of our community.

The Latino bleeding disorders community members often use familia to describe relationships with others who walk in our same shoes. As we place a high priority on socializing, the lack of in-person events over the past couple years has been quite distressing. Our familia has yearned for opportunities to reunite and enjoy each other's company. So, after many virtual conferences, we were able to reunite face-to-face to celebrate what connects us and participate in a wide variety of educational and entertaining activities.

Community member Ana pauses for a photo with RCC Gaby Griffin

The four hemophilia foundations in California, the Hemophilia Foundation of Southern California, Hemophilia Foundation of Northern California, Central California Hemophilia Foundation and the Hemophilia Association of San Diego County gathered in Anaheim September 23–25th for the ***6th Annual Familia de Sangre***.

Familia de Sangre is the largest Spanish language conference in the US focusing on providing education and support to Latino families. With over 600 attendees, the level of anticipation and excitement was palpable as we arrived that Friday afternoon. Warm exclamations of delight were heard as families began reuniting in the hotel lobby as they checked in.

Following the opening ceremony Friday evening, families continued connecting with friends and industry sponsors as they strolled through the exhibition hall. The evening continued with lively mariachi music entertaining the joyful crowd.

Saturday morning began with a presentation during breakfast, followed by sessions covering various topics from hemophilia care basics to the future of new treatments. The afternoon brought more presentation options and time with industry sponsors. We sure were busy at the BioMatrix booth with visitors who were eager to participate in our raffle!

After the sessions wrapped up, families enjoyed the rest of the day and evening at Disneyland. Adults and children alike spent hours appreciating the sights and sounds of the park and encountering each other at the park's many attractions. After enjoying a Sunday morning breakfast and a rousing closing presentation, bittersweet goodbyes and heartfelt embraces were had. Familia de Sangre 2022 was a brilliant success and BioMatrix was honored to have been a part of the experience. Thank you to all who took the time to visit our booth and to the four foundations for organizing this spectacular event!

RCCs Gaby and Hector welcome visitors!

Stephanie speaks "goat"

Starr has a new little friend!

OHIO *Women's Event!*

Shelia Biljes

It's officially sweater weather in Ohio! The crisp fall air has arrived, and every farm is open for visitors to experience pumpkin spice season. The ladies of Northern Ohio joined Novo Nordisk and BioMatrix for a fun ***Ladies Educational Lunch*** at Majestic Meadows Alpaca Farm in Medina September 23rd. While guests enjoyed boxed lunches and sweet tea, Novo Nordisk's Judy Doyle presented *Being Your Own Advocate*. The topic offered a chance for the moms with young school-aged children to share how they have had to advocate for their kids early in the school year. Other moms told stories of advocating with their healthcare providers. Judy reminded everyone that as caregivers, we should not forget to advocate for ourselves as well!

Following the educational session, we were directed to the farm's main barn to enjoy the alpacas, donkeys and tiny pigs. These sweet animals are not shy of visitors! In fact, some came in a little closer than appreciated by a few of the guests, but still won over the hearts of everyone immediately. Resident camel Gus loves to be photographed and made himself available for many selfies. At another barn, much excitement ensued as goats of all sizes gathered to meet the visitors (or eat from the grain they carried, however you want to look at it!). It was such a fun day outdoors at the farm. Thank you to Novo Nordisk and Judy for cosponsoring this event!

Charlene

Cheryl pets the soft fur

Amber "It tickles!"

Marie doesn't seem sure...

Eve loves piggie!

ILLINOIS

Eva Kraemer

After a three–year hiatus, 100 dedicated community members, family and friends came out to Bleeding Disorder Alliance Illinois (BDAI) ***Unite Walk*** October 1st in Brookfield's Woods Forest Preserve. It was amazing to be together again! BioMatrix, a proud fundraiser for this event, is always delighted to participate. BDAI is dedicated to improving the quality of life for persons affected by hemophilia and other inherited bleeding disorders through advocacy, consumer services, education, and research. This event allows everyone an opportunity to get together to support the Illinois bleeding disorder community, making this fundraiser successful on all levels!

RCC Eva Kraemer with Alan, Julian and Elliott

PENNSYLVANIA

Tina McMullen

The Eastern Pennsylvania Bleeding Disorder Foundation (EPBDF) held its ***Annual Meeting*** October 6th at Sheraton Valley Forge Hotel in King of Prussia. Before the event got underway, approximately 200 attendees took the opportunity to socialize with other attendees and visit with industry representatives in the expansive exhibit area.

Tommy, RCC Tina McMullen and Vickie

The presentations started with opening remarks by Board President Leonard Azzarano, followed by Executive Director Sarah Pilacik, who gave a six–month report of the Foundation's events. Keynote speaker J. Nathan Hagstrom, MD, MHCM, FAAP, a physician with Lehigh Valley HTC, spoke about his history in bleeding disorders medicine and gave an update on gene therapies in hemophilia.

The evening concluded with an announcement by Assistant Director Lisa Lee about the chapter's scholarship recipients – a whopping 18 scholarships were awarded this year! Chapter leadership did an incredible job of making this year's meeting a huge success!

NEVADA

Kelly Gonzalez

While the sun rose across the pond at Tule Springs in the Northwest part of Nevada October 8th, the Nevada Chapter NHF annual ***Unite Walk*** began. Excited for the occasion, teams came together for the first time since the start of the pandemic.

Crossing the finish line, runners and walkers were met with cheers, given a medal, and popped over to the picnic, named in honor of the late emergency room nurse, Renée Paper (1958–2007), who exemplified the strength of community advocacy.

Renée was a von Willebrand disease and hepatitis C patient and co-authored *A Guide to Living With von Willebrand Disease* with Laurie Kelley. As a fierce advocate for the bleeding disorder community, she founded Nevada's first hemophilia treatment center and patient organization, both of which continue to this day. Interesting to note is that November 1st is *Renée Paper Day* in Nevada!

Kelly and former NV NHF staff Kaley

Jamie visits with Kelly and Maureen

Emily and Lisa joined Jamie and Kelly

Thank you to all those who attended, donated, sponsored and/or participated in the Unite Walk. And to Nevada Chapter NHF for organizing this event!

OHIO *Women's Event!*

Shelia Biljes

The best day ever is one way to describe Northern Ohio Hemophilia Foundation's ***Women's Retreat – A Full Day of Crafts, Food, Nature and Education*** sponsored by BioMatrix, Octapharma and HEMA Biologics was held October 15th at WJ Green Cabin in Berea Metroparks. Filling the lodge with smiles, the women enjoyed a cozy fire and began the day with a tasty breakfast sponsored by Medexus represented by Nora Latcovich.

We were honored to have Lalitha Nayak, MD, accompanied by Susan Hunter, RN, of Cleveland's University Hospital HTC as our guest speakers. Dr. Nayak presented on advances in treatment for women with bleeding disorders. Afterward, it was time for our favorite game – *What's in Your Purse!* A variation of the game revealed the secretive and fun side of the women and led to lots of laughter!

JoJo Carloni's catered a fine Italian lunchtime spread. As we enjoyed our meal, Medexus Patient Advocate Michelle Stielper took the floor with a presentation focused on pain management. Conversation flowed as the group was eager to share their struggles and tips. Michelle then donned her BioMatrix RCC/Art Educator hat and led the ladies into one of our exclusive craft programs where we painted Mandala stones, a soothing and calming activity. Journaling is another great way to organize the mind and relieve stress, and so a session on journaling was included as our time together continued.

Can you guess it was time to eat again? With famous date-nut cupcakes with cream cheese frosting from Dick's Bakery of Berea, Community member Stephanie and Michelle demonstrated the proper way to eat a cupcake! Before the event wrapped up, raffles and games were enjoyed and given the gorgeous weather, many chose to take a walk through the park to enjoy autumn's brilliant colors.

Thank you to the sponsors, and NOHF and to Stephanie for the beautiful cups she hand–made for each lady. A special thanks to Kathy Kole who worked hard all day, serving and clearing meals, and to the ladies who stayed late to help clean, but I suspect it was because none of us were ready to say goodbye!

VIRGINIA

Terry Stone and Michelle Stielper

We're Baaaaaack! After a steady increase of in-person events at smaller venues that put safety first, the Virginia Hemophilia Foundation welcomed back the community with more than 200 strong at Great Wolf Lodge in Williamsburg October 16–17th for a joint event weekend programs including their ***Annual Medical Symposium*** and their largest fundraiser ***UNITE Walk.***

Attendees receive a signed copy of *This is My Something* from BioMatrix RCC and author Terry Stone

Keynote speaker Kevin Todd, Medical Director of the Hemostasis and Thrombosis Center at the Children's Hospital of the King's Daughters (CHKD) presented an engaging talk on emerging therapies filled with newer products, gene therapy, the advancement of sub-q therapies, and a glimpse of an abundance of pipeline options that are very exciting for the bleeding disorders patient population. Other topics during Saturday's Medical Symposium touched on the continuing evolution of gene therapies, product specific talks, women with bleeding disorders and how to engage strategies for successful conversations with providers, as well as programming for the kids. There were familiar faces, and new ones too. Industry was on hand to update everyone on their products and services, and to catch up on all the news with families too.

Evening was time for family and friends at the water park and throughout the lodge with magical adventures. Sunday-funday was more of a celebration as the *Unite Walk* was an inside event with trivia and cool tunes from DJ Cool Shelby Smoak, and lots of fun and togetherness to raise money in support of the Chapter's good work.

It was a weekend to remember and one to be grateful for as life, it seems, is getting back to normal.

ILLINOIS

Eva Kraemer

It's always a pleasure to get together, and what better reason to get together than to talk about infusing? BioMatrix and Bayer hosted an ***Educational Dinner*** at Primo Italian American Cuisine in Gurnee October 19th.

Nurse Rania demonstrates to Daniel how to find a vein while RCC Eva Kraemer looks on

Armando Serrano from Bayer talked about the challenges with self-infusion. Rania Salem, RN, BioMatrix's nurse extraordinaire was on hand to demonstrate how to find a vein and infuse on the Bay-cuff. The evening was filled with lively questions, discussion and demonstration. It's rewarding to be with the Illinois bleeding disorders community and offering this kind of networking.

NEW MEXICO

Felix Garcia

Sangre de Oro (SDO) and Bayer came together for Halloween festivities with a ***Fall Education Event*** October 22nd at the Marriott Pyramid Albuquerque. This was the largest gathering of the year… and maybe the most fun too! Jeff Kallberg, PT, DPT was on hand to lead us through a great demonstration that helped us all understand more about joint bleeds and treatment. After the presentation there was plenty of networking and family time including a costume contest, pumpkin carving competition, dunking for gummy worms and more! BioMatrix was there in support of SDO and welcomed visitors to our booth. We even held a raffle – congrats to Brayley and family on being the new owners of a Blackstone grill! Many thanks to all involved in organizing this tremendous event!

Great costumes were seen everywhere and lots of Halloween fun was had!

Felix poses with raffle winner Nathan; daughter Braylen held the winning ticket!

Jeff Kallberg greets the group

OHIO

Shelia Biljes

Cleveland Browns–20 versus Baltimore Ravens–23, but the final score did not spoil the fun as Bayer and BioMatrix teamed up with the Northern Ohio Hemophilia Foundation (NOHF) for a ***Cleveland Browns Watch Party*** at Brew Garden in Middleburg Heights October 23rd.

Cleveland Fans Unite! Shelia and June

Before kickoff, Bayer Patient Advocate Wendy Perkins presented a program on product advancements, followed by a BioMatrix update on Medicaid and Marketplace plans that have opened their doors to choices in Ohio.

NOHF gave updates as the kids participated in a coloring contest. With good food, entertaining games and

Carter was wishing for a win

Wendy proclaims a TOUCHDOWN!

a house full of friends gathered together, we rooted for our home team and enjoyed the bright afternoon! Hope continues to flourish that next time, the Browns will grace us with a huge victory!


Jordan and Jordan are in on the fun!

OHIO

Shelia Biljes


Three Amigas: Connie, Gloria and Marie

Leaves are falling and cold weather is settling over Northern Ohio. A chilly rain set the scene for our monthly ***Educational Lunch*** and support meeting on October 26th at Tony K's Bar & Grille in Berea. The weather sure doesn't stop our group of women ladies from gathering though!

Genentech's Clinical Education Manager Christine Pelayo, BSN, RN, kicked off the lunch with an overview of Hemlibra before introducing Ambassador Speaker, Maria, who flew in from Waco, Texas to join our group! We were honored! She shared her story of challenges as a single Latino mother of a son with severe hemophilia. Most of us were unaware of the additional challenges faced in the Latino culture. Everyone listened intently, many with teary eyes as she opened her heart. Her story concluded with a sense of strength and perseverance.

We ended this month's meeting with silly games and, as always, the ladies love strengthening their bonds as they spend time together. Thank you, Genentech for being our October sponsor!

OHIO

Shelia Biljes and Moe Hoque


Our *sweet* BioMatrix Team! Michelle Stielper, Moe Hoque, Shelia Biljes and Bill Wilbert


RCC Michelle Stielper assists Matthew with his drawing

The Northern and Northwest Ohio Hemophilia Foundations teamed up for a huge ***Annual Meeting*** at the Kalahari Resorts and Convention Center in Sandusky November 4th–5th. With more than 200 in attendance and industry represented, the ballroom was buzzing with excitement. BioMatrix played a large role in the event starting with an amazing candy buffet booth featuring retro candies for the older generations and many selections for the young. Following dinner and a presentation, everyone was off to the indoor waterpark. Shoes and towels could be left at the BioMatrix Cabana, which was also a place for parents who were not fans of the giant water slides to hangout.

Saturday brought more education and additional diversion, especially for the younger set. BioMatrix's RCC and Art Educator Michelle Stielper led a class on *Anime Drawing*. So much talent in our young ones! It was a weekend full of fun and reunions and we look forward to next year's annual meeting!


Caitlin, RCC David Tignor and Derek


RCC Cyndy Coors, Lily and Bayer rep, Donna


David Tignor with Brantley, Weston and Makenna

TENNESSEE

Cyndy Coors and David Tignor

BioMatrix partnered with Bayer to host an ***Educational Family Dinner*** at Knoxville's Calhoun's Beardon Hill November 10th. Calhoun's dishes up traditional country fare in a rustic barn setting, giving a taste of Tennessee culture and décor, paying tribute to the agricultural roots and great barbecue traditions of Eastern Tennessee. Seated in a private room, we were treated to a delectable BBQ buffet. Bayer's rep Donna Lebrun presented a session which covered Bayer's available products and programs available. We were also available to answer any questions about the services we offer at BioMatrix. Everyone enjoyed the time together, and we are thankful to Bayer for sponsoring our event!

FLORIDA

Justin Lindhorst and David Burgeson

The Florida Hemophilia Association hosted their ***12th Annual Unite for Bleeding Disorders Walk*** November 13th at Markham Park in Sunrise. With the BioMatrix Bleeding Disorders Center of Excellence located just a few miles down the road from the walk venue, BioMatrix participated as a bronze level corporate sponsor and with an official walk team. Prior to the walk, our Plantation office participated in several activities supporting Team BioMatrix including Bingo games, a 50/50 raffle, and a visit from the Executive Director of the


Team BioMatrix!

Florida Hemophilia Association. It was a gorgeous day for strolling through the park, catching up with friends and supporting a great cause! Thanks to everyone who participated. We eagerly anticipate the 13th annual event!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Eric and Alicia, Patsie and Kaleb, Maggie and Carol

CSL Behring and BioMatrix held an ***Educational Dinner*** November 17th at Maggiano's Little Italy in Tampa. CSL speaker Dezarae Morales, RN, of the South Texas Hemophilia Treatment Center offered a variety of information on bleeding disorders issues. Next was CSL Common Factors Advocate Krissy Miller who spoke about her experiences and caregiver insight as the mother of a son with severe hemophilia.

While everyone polished off dinner and mouthwatering desserts, the games began! Guests sorted into teams for a rousing round of BioMatrix Trivia Pursuit: Media Medicine. The categories included Drug Slogans, TV Docs, Movie Docs, Rock Doc Songs and Lit Docs. The winning team took home Yankee Candles for relaxation after the intense competition. Many thanks to CSL Behring for sponsoring this event!

OHIO

Shelia Biljes

Ben with granddaughter Selina

I am thankful for YOU and YOU and YOU! Novo Nordisk teamed up with BioMatrix November 19th to celebrate my favorite event of the year. A gathering to be grateful for each other and what we have. The ***Thanksgiving Family Event*** began with a delicious meal at Brew Garden while Dr. Jennifer Domm presented an overview of Novo products. Hailing from South Carolina, Novo's Advocate Speaker Brandon, shared his story of coping with hemophilia during his early life in Kenya. His health took a turn to a much better direction when his family was able to move to the United States, and Brandon had access to clotting factor. He also spoke about his college years and world travels. He had the full attention of the young men in the group who were inspired by what they heard.

Our finale was creating Thanksgiving centerpieces, each family designing beautiful and incredibly unique works of art. I am so thankful for my hemophilia family as I have watched them share joy and pain with each other in this close-knit community of Northern Ohio.

Cookie decorators: Alaina, Chantel, Chardea, Carmello and Cameron

OHIO

Shelia Biljes

It's the most wonderful time of the year! The children of Northern Ohio will agree to that as the Northern Ohio Hemophilia Foundation (NOHF) kicked off the season with their annual ***Holiday Event***! The Greater Cleveland Aquarium set the scene for the December 3rd event sponsored by NOHF, BioMatrix, Optum RX, Takeda, Medexus, Bayer and Novo.

The BioMatrix booth offered a place to write letters to Santa, cookie decorating, a craft and game - plenty to keep little ones busy while parents shared holiday plans with community friends. After saying "see you next year" to the sponsors, the group was off for an aquarium tour. The event proved to be a wonderful end to a full year of fun and education. Thank you, NOHF!

Jan and Tyler write a letter to Santa

Matthew gets a big Sharky hug!

Sharky fans! Kathy, Tanya, Dawn and Kendra

TENNESSEE

Cyndy Coors and David Tignor

Despite the rain, good cheer overflowed December 3rd as BioMatrix and CSL partnered for a North Pole Express Train Ride! Community members and HTC staff hopped on board the Tennessee Valley Railroad in hopes of finding St. Nick at the other end. Along the hour-long ride, hot chocolate and cookies were served. Upon arrival at the "North Pole," elves were seen playing and frolicking outside Santa's Warehouse. To everyone's delight, Santa boarded the train, visited with excited children, took photos and left everyone with a keepsake ornament!

Photo time for Anthony and Santa!

Afterwards, the group gathered to hear from Chad Mitchell, Manager of Coagulation Products for CSL in the Alabama area and his advocate Kristen Prior, who shared her journey of living with a bleeding disorder. This event was a joyful way to ring the holidays, and we are very thankful to have had this opportunity with CSL. Happy Holidays!

Upcoming Events

JANUARY 29, 2023 VIRTUAL PENNSYLVANIA

Chef Mike Zoom Event! *(4 pm EST)*
Western Pennsylvania Bleeding Disorders Foundation
Kara Dornish, 814-335-4240
https://wpbdf.org

MARCH 26, 2023 NEW JERSEY

Community Connections
Hemophilia Association of New Jersey
732-249-6000, https://hanj.org
American Dream Mall;
East Rutherford

NATIONAL EVENT!

EMPOWERED! AMAZING! TOGETHER!

MARCH 16–19, 2023 FLORIDA

2023 Annual Hybrid Symposium
The Coalition for Hemophilia B
https://www.hemob.org
contact@hemob.org
Renaissance Orlando

NATIONAL EVENT!

HFA '23 Symposium
Past. Present. Future.

APRIL 13–15, 2023 FLORIDA

'23 Symposium
Past. Present. Future.
Hemophilia Federation of America
https://www.hemophiliafed.org
Renaissance Orlando

MARCH 25, 2023 CONNECTICUT

Consumer Medical Symposium
New England Hemophilia Assoc.
781-326-7645
info@nehemophilia.org
www.newenglandhemophilia.org
Hartford Marriott Downtown
Hartford

MAY 19–21, 2023 DELAWARE

Men's Retreat
Country Boy Fishing, BioMatrix, Octapharma and Medexus
Contact: Richard Vogel
732-991-7373
richard.vogel@biomatrixsprx.com
Atlantic Sands Hotel;
Rehoboth Beach

Time for Fun!

Puzzles are on Page 31

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

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

1. **B** – boys and girls can both be born with a bleeding disorder.
2. **A** – an "asymptomatic carrier" of hemophilia is a carrier female who has no bleeding disorder symptoms.
3. **A** – a "symptomatic carrier" of hemophilia is a carrier female who sometimes has bleeding symptoms.
4. **D** – symptoms of hemophilia include easy bruising, longer bleeding after dental work, injuries or surgery, and bleeding into joints and muscles.
5. **D** – symptoms of VWD include frequent nosebleeds, longer bleeding after dental work, injuries or surgery, and easy bruising
6. **C** - a shorter way to say and spell von Willebrand disease is VWD.
7. **A** – one out of every child is born with VWD?
8. **D** – Erik Aldolf von Willebrand was the first doctor to identify VWD.
9. ***TRUE*** – boys and girls can have a bleeding disorder
10. ***TRUE*** – a girl is automatically a carrier if her dad has hemophilia
11. ***FALSE*** – a girl is not automatically a carrier if her brother has hemophilia
12. ***FALSE*** – if a boy has hemophilia, his sister cannot catch it from him.
13. ***TRUE*** – if a girl's mom is a carrier of hemophilia, the girl has a 50% chance of being a carrier too.

Hi Kids! Time for Fun!

Here are a few quiz questions to see what you know about girls and bleeding disorders. Check your answers on page 30! Good luck!

1. Who can be born with a bleeding disorder?
A. Only Boys
B. Boys and Girls
C. Only Girls
D. Only Martians

2. Who is an "asymptomatic carrier" of hemophilia?
A. Carrier female who has no bleeding disorder symptoms
B. Carrier female who has bleeds like a severe patient
C. Carrier female who has bleeding episodes only on Tuesdays
D. Carrier female who has no symptoms but still must use factor

3. Who is a "symptomatic carrier" of hemophilia?
A. Carrier female who sometimes has bleeding symptoms
B. Carrier female who must infuse every week prophylactically
C. Non-carrier female who has a child with hemophilia
D. Carrier female who never has bleeding issues

4. Which are hemophilia symptoms?
A. Easy bruising
B. Longer bleeding after dental work, injuries or surgery
C. Bleeding into joints and muscles
D. All of the above

5. Which are symptoms of von Willebrand disease?
A. Frequent nosebleeds
B. Longer bleeding after dental work, injuries or surgery
C. Easy bruising
D. All of the above

6. What is a shorter way to say and spell von Willebrand disease?
A. vWF
B. VonDW
C. VWD
D. None of the above

7. Out of 100 kids, how many girls and boys are born with von Willebrand disease?
A. 1 in 100 kids
B. 25 in 100 kids
C. 50 in 100 kids
D. 100 in 100 kids

8. Who was the first doctor to identify von Willebrand disease?
A. Robert Will Bond
B. Victor von William
C. Valery Willowbrand
D. Erik Aldolf von Willebrand

9. Boys and girls can both have a bleeding disorder.
TRUE or *FALSE*

10. A girl is automatically a carrier if her dad has hemophilia.
TRUE or *FALSE*

11. A girl is automatically a carrier if her brother has hemophilia.
TRUE or *FALSE*

12. If a boy has hemophilia, his sister can catch it from him.
TRUE or *FALSE*

13. If a girl's mom is a carrier of hemophilia, the girl has a 50% chance of being a carrier too.
TRUE or *FALSE*

14. Girls can have hemophilia A, but not hemophilia B.
TRUE or *FALSE*

15. Girls with hemophilia or VWD are usually not allowed to go to bleeding disorders camp.
TRUE or *FALSE*

16. VWD is more common than hemophilia in both boys and girls.
TRUE or *FALSE*

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

Sudoku!

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

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

BIOMATRIX

Corporate Office

855 SW 78th Ave., #C200
Plantation, Florida 33324

Toll Free: 877-337-3002
Office: 954-385-7322
Office Fax: 954-385-7324

Visit us online:

bleedingdisorders.biomatrixsprx.com
fb.com/BioMatrixBleedingDisorders
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DEDICATED TO MAKING A DIFFERENCE

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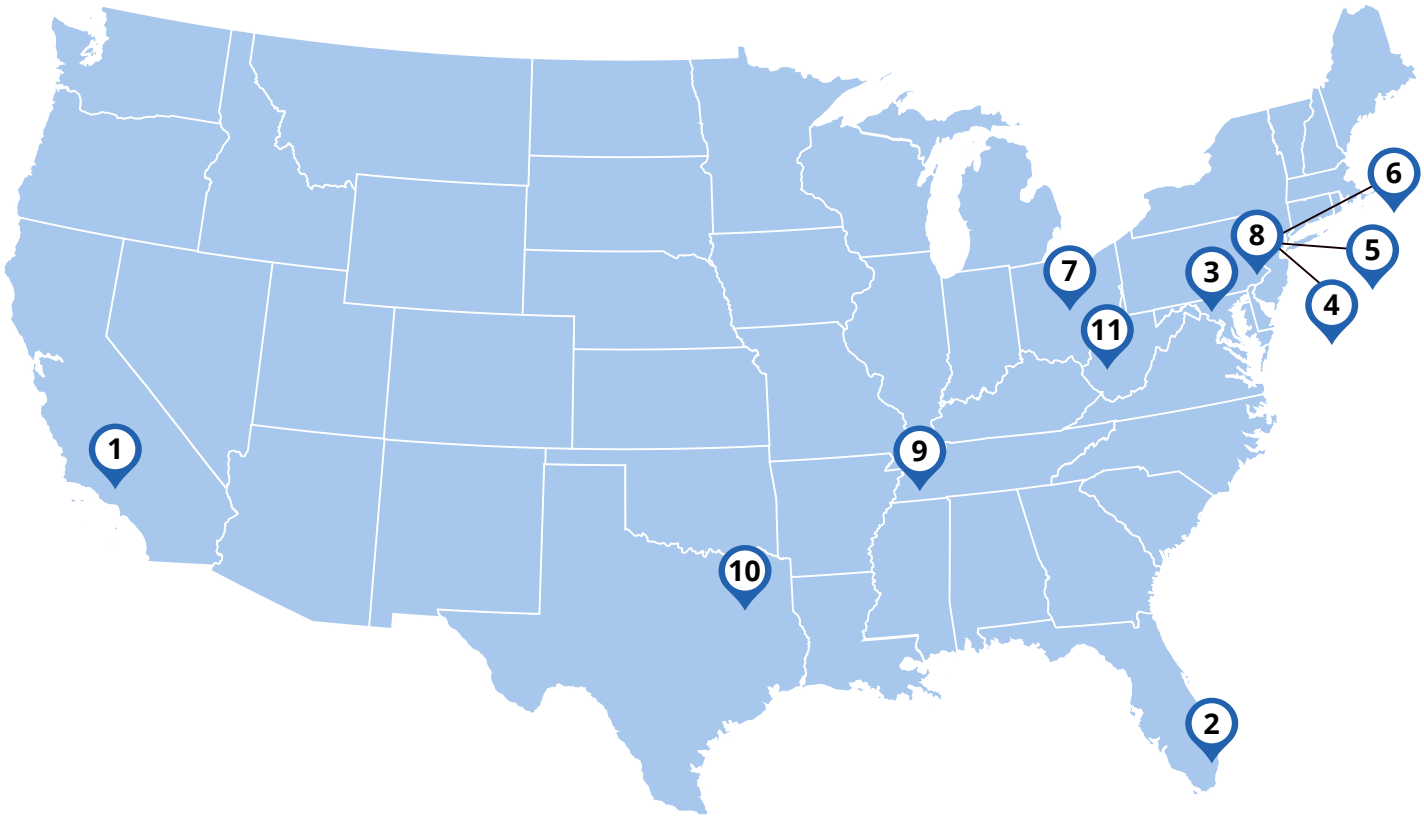

Specialty Pharmacies

1. Canoga Park, California
2. Plantation, Florida
3. Columbia, Maryland
4. Totowa, New Jersey
5. Totowa, New Jersey (Reproductive)
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania
9. Bartlett, Tennessee
10. Tyler, Texas
11. Charleston, West Virginia

BEST AND BRIGHTEST COMPANIES TO WORK FOR IN THE NATION
2019, 2020, 2021, 2022