

BIO MATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**WINTER 2024
VOLUME 19 | ISSUE 1**

“ Write it on your heart that every day is the best day in the year. ”
— Ralph Waldo Emerson

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

We at BioMatrix hope everyone has enjoyed a blissful holiday season. With the start of a new year, from our Regional Care Coordinators to our pharmacists and everyone in between, we are excited to continue serving our patients with compassion, accuracy, and integrity.

As we begin the 19th year of BioMatrix News, we remain dedicated to bringing our readers a wide-ranging selection of educational articles about health and wellness, advocacy, legislative affairs as well as current events, community resources, personal stories and more!

We hope you've enjoyed the past year of our publication. We love being a resource in the bleeding disorders community and we hope it shows in the pages of our newsletter!

Wishing you a splendid 2024!

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

A Moment in Your Spectacular Life

2024
BioMatrix
Calendar



Our 2024 *Living a Spectacular Life* Calendar is available!

Filled with happy photos of community members, it highlights just how amazing life can be, even with a bleeding disorder!

ORDER YOUR FREE CALENDAR!
Contact your Regional Care Coordinator or email us at:

bit.ly/2024SpectacularLife

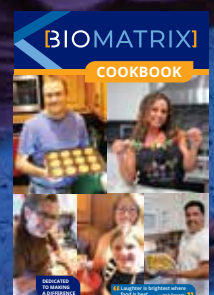
Order Your Calendar Today!

BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our Regional Care Coordinators have provided their very best recipes — from appetizers to entrees and desserts. To get your free cookbook, contact your Regional Care Coordinator or request online:

<https://mailchi.mp/biomatrixsprx/cookbook>





BIOMATRIX PROUDLY ANNOUNCES THE 2023 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 2023 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!



YUSUF BUKHARI

Freshman at Hofstra University; Major: Civil Engineering
BioMatrix Joe Holibaugh Memorial Scholarship

An aspiring civil engineer, Yusuf has always pushed to excel academically. He finished high school in 2 years and applied for college at 15. Even though his greatest passion is soccer, he realizes it isn't something he can pursue professionally given his hemophilia. Yusuf shares, "Though having hemophilia presents many roadblocks in my life, it has also enabled me to grow and learn invaluable lessons, shaping the person I am today. I have learned over the years to truly live life to its fullest without focusing on what I can't do, and instead focusing on what I can do." Congratulations, Yusuf!



JACK DAVIS

Freshman at Texas A&M University; Major: Kinesiology
BioMatrix Mike Hylton Memorial Scholarship

At 3 years old, Jack was diagnosed with moderate hemophilia A. Because contact sports were ill-advised due to his diagnosis, Jack joined and excelled on his high school varsity cross-country team helping the team qualify for the state championships during his junior year. While on a mission trip to Guatemala City, Jack was struck by the joy and gratitude of the Guatemalan people, despite living in the face of great adversity. It taught him to focus outward instead of feeling sorry for himself. "I want to give to others what I have been given – encouragement, support and strategies to overcome difficult circumstances." Congratulations, Jack!



LOUIS DEALBA

Freshman at University of Illinois at Chicago, Major: Civil Engineering
BioMatrix Mark Coats Memorial Scholarship

Growing up as an energetic and athletic child, moderate hemophilia A often got in the way. Though feeling frustrated and angry at times throughout his childhood, Louis found his outlet running on cross country and track teams, eventually winning a team State Championship in his senior year of high school. "Living with hemophilia has been a challenging journey for me, but I have learned to push through the difficulties and pursue my passions despite the limitations this condition has imposed upon me. I want to be defined by my achievements and accomplishments, not by my disorder." Congratulations, Louis!



JAMES HENSLEY

Freshman at Virginia Tech, Major: Sociology and Public Health
BioMatrix Tim Kennedy Memorial Scholarship

Due to experiences living with moderate hemophilia B, James understands the often-dire importance of seeing patients as people first rather than as their primary diagnosis. He is grateful for his mother's tenacious advocacy and credits her for prioritizing his health care. Intending to become a doctor, James shares, "I am focusing on sociology and psychology because part of delivering effective care is understanding your patients and how personal, cultural, and social experiences impact health-seeking behaviors. The rare disease community needs clinicians who understand our fears and challenges." Congratulations, James!



COURTNEY ROWE

Freshman at Montgomery County Community College; Major: Business Administration
BioMatrix Millie Gonzalez Memorial Scholarship

Courtney and her brother were diagnosed at a young age with von Willebrand disease. Growing up, Courtney understood that physical precautions had to be taken to participate in the activities that she enjoys, such as snowboarding. Through the struggles she and her brother endured, Courtney feels she matured quickly while also developing an ability to empathize with others to a greater degree. "I have learned a lot about other people's experiences living with rare diseases and what I have found is that everyone is living with something." Congratulations, Courtney!



RYNE WAGNER

Freshman at Illinois State University; Major: Special Education, Learning and Behavioral Specialist
BioMatrix Ron Niederman Memorial Scholarship

Due to being diagnosed with several health disorders, including moderate von Willebrand disease, Ryne has experienced various challenges throughout his life. One particular challenge is the frequency and severity of spontaneous nose bleeds. It has prevented him from participating in many activities and has sometimes impacted his class attendance. "Yet, as with every other health issue I have been faced with, my von Willebrand disorder has helped me gain valuable life skills and challenged me to rise above my restrictions and succeed in life." Congratulations, Ryne!

What's your favorite recipe?

We're putting together a new edition of our famous community cookbook!

Join us in celebrating the joy of culinary creativity by sharing your favorite recipe with the community!

Submit your recipe at:
<https://bit.ly/bmx-recipes-2024>



BIOMATRIX





UNDERSTANDING SPECIALTY DRUG COVERAGE: MEDICAL AND PHARMACY BENEFIT

BY JUSTIN LINDHORST AND REGINA VALENZUELA

Have you ever felt confused or unsure about your healthcare coverage? If you answered yes, you're not alone. In fact, a recent survey found 56% of Americans report feeling "completely lost" when it comes to understanding their health insurance.ⁱ For patients taking specialty medications, understanding coverage can be even more challenging. This article provides an overview of specialty drug coverage under the medical and pharmacy benefit and includes links to additional resources to help you understand your health insurance.

In the past, health services were all covered under the insurance plan's major medical benefits – the pharmacy benefit did not exist. Starting in the 1960s, insurance companies began providing coverage for prescription medication. The first Pharmacy Benefit Managers (PBMs) were created during this time to act as an intermediary, to help health insurance companies control cost, set prescription drug formularies, and process a large volume of prescription drug claims.

PBM management of prescription drugs helped create a separate administrative structure outside of major medical benefits for prescription drugs – the pharmacy benefit. In today's healthcare landscape, the three biggest PBMs control pharmacy benefits for nearly 270 million Americans.ⁱⁱ

According to the Kaiser Family Foundation, 48.5% of the population in the United States have health coverage through their employer, 6.1% have individual non-group

coverage, 21.1% have Medicaid, 14.3% have Medicare, and 1.3% have military health coverage.ⁱⁱⁱ Coverage for prescription medication varies across each of these different health plans.

For employer based, non-group individual coverage, Medicaid, and TRICARE – coverage for health services are managed under a pharmacy benefit and medical benefit. Health insurance companies typically manage their own medical benefit package, but some choose to outsource management of their pharmacy benefit to a separate PBM. This is why some patients have a medical benefits card, and a separate pharmacy benefit prescription drug card.

For patients on Medicare – Part A covers in-patient services/hospitalization, Part B is the "medical benefit," providing coverage for out-patient services, home-health care, and most infused specialty medications and Medicare Part D covers pharmacy benefits.

PHARMACY BENEFIT

Many patients who are prescribed specialty medication receive training from a medical provider so they can take their medicine at home. This includes patients on oral, topical, intravenous, or subcutaneous therapies. Specialty medication is typically covered under the pharmacy benefit when the *patient or caregiver self-administers the prescribed medication at home*.

When a specialty medication is covered under the pharmacy benefit, the insurance company's PBM has a lot of control over how and when a patient can access their prescribed medicine. Patients may be subject to formulary restrictions, step-therapy, specialty pharmacy mandates, and copay accumulators.

Under the pharmacy benefit, drugs are placed into a classification system of different tiers. Lower cost or generic drugs are typically tier I, and specialty medications mostly fall into tier IV – the highest tier. Drug tiers impact patient out-of-pocket costs such as copay and coinsurance. The higher the tier, the greater the out-of-pocket expense for the patient.

Coverage under the pharmacy benefit may also be subject to a deductible or maximum out-of-pocket separate from the medical benefit. Tier IV medications are also subject to more PBM utilization management techniques such as prior authorization. Patients may need to work with their specialty pharmacy and medical provider to demonstrate “medical necessity” for their prescribed medication before they can receive it.

MEDICAL BENEFIT

Coverage for specialty medication under the medical benefit typically occurs when the *drug is administered by a health care professional in a hospital, physician office, or infusion center*. Providers often use the “Buy and Bill” method where the drug is purchased and kept by the provider and then the claim is billed to the insurance company after the medication is administered to the patient. The insurance company reviews the claim, and the provider is paid at a later date. Out of pocket expenses for specialty drugs processed under the medical benefit often include deductible, co-pay, and/or coinsurance.

For patients who have Medicare, 80% of the office-administered drug is covered by Medicare Part B, with the remaining 20% picked up by a supplemental plan purchased by the patient.^{iv} Coverage under the medical benefit occurs independent of the plan's PBMs, which means patients may avoid some of the formulary restrictions, step-therapy, or pharmacy mandates imposed under the pharmacy benefit.

BUT WAIT! THERE'S MORE

In the world of health insurance, “It depends” is a common answer to many coverage questions. As previously mentioned, specialty medication is typically covered under the pharmacy benefit if self-injected/self-administered and under the medical benefit when administered by a healthcare provider. But there are cases where coverage is offered for self-injected medication under the medical benefit – typically under employer-based or non-group commercial health plans.

Coverage provided for self-injected medication under the medical benefit may be an attractive option for patients who do not wish to have their pharmacy mandated to them by a PBM, when the pharmacy benefit includes step-therapy, a copay accumulator, or the prescribed drug is not included on the pharmacy benefit formulary.

For patients on Medicare – it's important to know that most infused specialty medications such as factor products for patients with a bleeding disorder are covered under Medicare Part B, not Medicare Part D. This has a significant impact on out-of-pocket costs because under Part B, 80% of the drug is covered by Medicare, and the remaining 20% is picked up by the patient's supplemental plan. Under Medicare Part D, there is currently no maximum out-of-pocket for prescription drugs – though there is legislation that will begin to address this issue in 2024.

Another important consideration is how claims billed to the pharmacy or medical benefit impact a patient's deductible and maximum out-of-pocket. Many patients with a chronic, expensive, lifelong condition become accustomed to meeting their deductible or max out-of-pocket with their first shipment of medication in the new year. This is because when covered under the pharmacy benefit, associated out-of-pocket costs are immediately applied toward the deductible and max out-of-pocket.

Under the medical benefit, the claim submitted by the provider's office who administered the drug undergoes review before it is approved. This can take time, and associated out-of-pocket expenses take longer to be applied toward a patient's deductible and maximum out-of-pocket.





STILL CONFUSED? YOUR SPECIALTY PHARMACY CAN HELP.

Health insurance *is* confusing. The healthcare landscape in the United States is complex and fragmented, and it's often a good idea to tap an expert to better understand your health coverage. Reputable specialty pharmacies employ teams of experts in insurance billing and reimbursement. These teams understand how to properly secure authorization for prescribed specialty therapies, how to correctly bill insurance plans for services, and how to connect patients with appropriate resources and programs focused on reducing financial burden.

They can also help patients better understand their coverage for specialty medication by conducting a benefits investigation. A thorough benefits investigation completed by an expert can help patients gain a solid understanding of their coverage options and associated out-of-pocket expenses for specialty medication under their insurance plan – without the jargon and red tape.

BioMatrix is an infusion-focused specialty pharmacy supporting patients with bleeding disorders, autoimmune disorders, neurological disorders, and other rare health conditions. If you'd like assistance understanding how your specialty medication is covered, we can help. Use the link to the form below and we'll conduct a no obligation benefit investigation to help you understand coverage for your prescribed specialty infusion therapy.

bit.ly/bd-patientnavigation

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- iv. Specialty Drug Resource. (N.D.). Medical vs Pharmacy benefits. <https://www.specialtydrugresource.com/coverage-landscape-overview/medical-vs-pharmacy-benefit>

READ MORE ABOUT HEALTH INSURANCE:

Health Insurance Basics

<https://www.biomatrixsprx.com/news/health-insurance-basics>

The Right to the Right Coverage – Patient Rights and Health Insurance Policies

<https://www.biomatrixsprx.com/news/the-right-to-the-right-coveragepatient-rights-and-health-insurance-policies>

Understanding Medicare Coverage

<https://www.biomatrixsprx.com/news/understanding-medicare-coverage>

Understanding Medicare Coverage Gaps

<https://www.biomatrixsprx.com/news/understanding-medicare-coverage-gaps>

Understanding Medicare Eligibility

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Understanding Step Therapy Mandates

<https://www.biomatrixsprx.com/news/understanding-step-therapy-mandates>

Understanding Redetermination for Medicaid and CHIP Beneficiaries

<https://www.biomatrixsprx.com/news/understanding-redetermination-for-medicaid-and-chip-beneficiaries>

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.



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.


**[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.

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World Hemophilia Day 2023



Anthony Llanes

AND THE ASOCIACIÓN PUERTORRIQUEÑA DE HEMOFILIA Y CONDICIONES DE SANGRADO

(PUERTO RICAN ASSOCIATION OF HEMOPHILIA AND BLEEDING CONDITIONS)

BY JUSTIN LINDHORST

As a child, Anthony was begrudgingly accustomed to being told “No.” No sports, no bike riding, no skating, no horseplay. Though his family had nothing but good intentions, he was frequently reminded that stepping outside the bubble his family had wrapped him in was a recipe for disaster. “You won’t live to celebrate your 18th birthday if you do that,” his Abuelita would chastise when he was too rambunctious. Having severe hemophilia was hard enough, but being treated like fragile porcelain made things more challenging. Even gym class felt like a punishment. As his classmates played games in the warm Puerto Rican sun, teachers required Anthony to spend the time in the library doing book reports.

Anthony does not hold any ill-will toward his teachers and family who only wanted to keep him safe. There was no prior history of hemophilia in his family, and growing up in Puerto Rico presented its own challenges. To this day the island has a single pediatric Hemophilia Treatment Center staffed by one doctor and one nurse. Hospitals outside of the HTC, government agencies and school systems lacked awareness for protocols and best practices for people living with a bleeding disorder.



Board of Directors
Anthony Llanes, Mariel Laureano, Anabelle Quiles,
Fabiola Danastorg, Keyshla Ortiz and Eduardo Rodríguez

Camp



One thing that helped make life with hemophilia easier for Anthony and his family was getting involved with the local chapter, the Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado. Founded in 1999 by a couple with a son impacted with hemophilia, the chapter served primarily as a social network for families on the island. Meeting with others in the community helped Anthony and his family feel less isolated and better connected to those who understood the challenges life with hemophilia can present.

Reaching adolescence, Anthony began to rebel. "I became reckless. I disconnected from the community. I had been told for so long not to do so many things, I was determined I would do everything I wanted, despite the consequences," he explained. Over time, those consequences began to add up. Frequent bleeding episodes punctuated this time in his life, and as the length and intensity of his bleeds increased, Anthony realized it was time to make a change. He began taking more proactive steps to manage his bleeding disorder and overall well-being. As his health improved, he became compelled to help other youth in the community avoid some of the bad decisions he made during that rebellious time.

In summer of 2014, Anthony was asked by chapter leadership to speak to a group of children at the annual bleeding disorder summer camp program. Arriving to camp in a wheelchair following surgery on a target knee joint, Anthony could have never anticipated how deeply that day would impact him.

Not having the opportunity to attend camp as a child, speaking that day was his first chance to experience the magic of camp. "I knew right away I wanted to be more involved," Anthony said. "The kids were so happy to be there and so attentive. Before I left that day, I told the camp director she could count on me as a volunteer the following year, and I've been involved ever since." After volunteering as a counselor for several years and attending conferences such as the National Hemophilia Foundation and NACCHO (North American Camping Conference of Hemophilia Organizations), in 2016, Anthony and another community member were asked to assume the position of Camp Co-Directors.

In 2018, a disaster struck the island in the form of devastating Hurricane Maria. As the intensity and scope of the natural disaster shocked the world, Anthony was volunteering with the chapter to help connect bleeding disorder community members with much needed aid and emergency support. Operating directly alongside HFA, the team worked long, tedious hours in the wake of the hurricane. "We did not have an electronic database with patient contact information, we were using paper records to locate and provide support for families," he shared. "I'll never forget riding alongside HFA personnel trying to navigate impassable roads, attempting to find alternate routes, and coordinating with local emergency employees to reach families in need." It was during this time that Anthony's guidance solidified him as a leader in the community and the face of the chapter. The resilience shown by members of the bleeding disorder community and all Puerto Ricans during that difficult time along with the outpour of support from HFA, NBDF and all corners of the world left a lasting mark on Anthony.

As the island grappled with the aftermath of the storm, a significant change within the chapter occurred. After many years of leadership and support, the couple who had been running the chapter since 1999 informed the community they were resigning. HFA stepped in and organized community members to hold an open election

Advocacy

for a new chapter board chair. The votes were tallied, and Anthony emerged as the clear nominee. "I remember feeling shocked, and initially very unsure whether I was ready or in a position in my life to assume that responsibility," Anthony recalled. "Though I was uncertain, I realized for so many people to put their faith in me meant something, and I decided to take the position."

As Board Chair, there was much to be done. "I had to learn a lot about nonprofit administration, finances and operations on the fly," Anthony explained. "Our biggest initial challenge was that we did not have 501-C3 status, so we were not formally recognized as a charitable foundation. We also spent a lot of time moving everything from a mostly paper format to electronic records." Anthony received a lot of assistance from NBDF, HFA and other executive directors stateside, and credits their ongoing support as instrumental in the growth of the chapter.

During this time Anthony also conducted extensive outreach to better understand the needs and wants of the community. In 2019 he hosted a total of 25 programs that allowed him to interface at a deeper level with the community and align the chapter priorities with the needs of Puerto Ricans living with a bleeding disorder. Anthony, the board, and many volunteers worked very hard and within two years, Anthony transitioned from his role as Board Chair and assumed the position of Executive Director.

Today the Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado continues to thrive. Working extensively with the HTC, volunteers, NBDF, HFA, and community members on the island, the chapter has significantly expanded its educational, financial, and legislative activities. Their advocacy efforts have led to the introduction of four new bills addressing needs such as establishing a patient registration system to determine the number of people impacted with a bleeding disorder on the island; providing emergency protocols to first responders and health systems outside of the HTC; and expanding research initiatives. Programming for men, women, teens, mental health issues, and an emergency financial assistance program have helped to bridge gaps and address specific needs in the community. The Chapter also now hosts two primary fundraisers, a UNITE Walk and a T-shirt fundraiser for World Hemophilia Day.

Much is on the horizon for the chapter. From May 3-5, 2024, the organization will host their first "Moin Conference." The weekend program will welcome Spanish-speaking patients and families from chapters across United States along with the local population for a weekend of education and community building. Outreach efforts to engage with patients across the island and establish a registry continues to be a priority so no patient or family is left behind. The chapter is also hard at work advocating for the creation of an adult HTC. Day after day, the chapter is helping to raise awareness and improve quality of life for their members.

As the Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado approaches 25 years of service to the community, Anthony and his team are looking forward to celebrating achievements and continuing the mission of the chapter. For Anthony, the future very much is connected to his past. "My experiences living with hemophilia on the island stays at the forefront as we develop new programs and services," Anthony shared. "My childhood, rebellious teenage period, all the wonderful people I have met, and everything I have learned along the way will continue to influence the story of our chapter."



Events



Celebrating SUCCESS AND GROWTH

BY OMAR AND MILYBET CEPEDA, EdD

“You cannot dream of becoming something you do not know about. You have to learn to dream big. Education exposes you to what the world has to offer, to the possibilities open to you.”

— Sonia Sotomayor



Before the days of modern medicine, a child with hemophilia spent a lot of time in hospitals and at home healing from bleeding episodes. As a result, many children living with a bleeding disorder experienced prolonged school absences and other challenges in academic settings. With accessibility of medication, prophylactic regimens, longer-acting clotting factors, Individualized Education Programs (IEP) and 504 Education Plans outlining educational modifications and accommodations for students with a health condition such as hemophilia, a bleeding disorder is no longer a barrier to education. This is the story of one family's journey where success is intentional, not accidental, as told by mother and son.

Milybet:

In 2002, I married my high school sweetheart, Harry. My father had hemophilia - my husband knew I was a carrier and that I had a 50% chance of passing it on to our future child. Harry was familiar with hemophilia and assured me he was in for the long haul. In 2004, our son, Omar, was born and, as we almost expected, was diagnosed with severe hemophilia. A week later, I lamented to my husband, “He is going to grow up so fast; he will be in college soon.” Harry laughed and replied, “You’re so silly!” Well, that was a fast 19 years ago!



When Omar was first born, I wanted to bubble wrap myself around him. As a special education teacher, I contemplated leaving my job to stay home with him. However, when Omar was about a year old, Harry was injured and no longer able to work. He became a full-time Mr. Mom to our son.

While we adore our Omar to pieces, we worried. At times, I felt hopeless and lost in a world that revolved around navigating his health concerns. I often struggled to manage the chaos of an infusion and was consumed with apprehension when my son faced medical challenges. Sometimes my husband and I lost sleep, and sometimes

our hearts skipped a beat—sometimes several beats—yet our son has always brought us such joy and makes us smile every single day.

As the years passed, we became more comfortable with our extra responsibilities as parents of a child with severe hemophilia. We were in this together - counting our blessings, overcoming self-neglect, having the strength to ask for help, reclaiming our lives, sharing our story, and spreading awareness. We want others to know having a child with a bleeding disorder is often challenging but manageable and rewarding.

In addition to his physical health and self-esteem, we were anxious about his education, the challenges he might have in school, his potential, and employment prospects. What would his future hold? Our son made it through pre-school, through grade school, and now, through high school. Next up... college.

When Omar was about ten years old, I decided to pursue a Doctorate in Education with a concentration in Organizational Leadership. It wasn't easy balancing family, a career, and studies, but behind me was a young man rooting for my success, and I had to be a good example for him.

Since we were living it every day, when it came to choosing a dissertation topic, I decided on “Resilience Among Parents of Children with Hemophilia.” The mixed-method study explored the resilient nature of parents and summarized their experiences. The participants addressed diagnoses, severity, nature of the disability, functional limitations, current services and personal experiences of overcoming adversity, with each having a range of emotions on treatments and the prolonged and unpredictable nature of aftercare. The respondents described positive and negative impacts of caregiving, which included a greater appreciation for developing empathy, compassion, patience, inner strength, and new perspectives on life. They revealed their concerns regarding healthcare support, academic support, mental well-being, physical wellness, and economic challenges.

They also shared their experiences on receiving education/ awareness, faith reliance, self-care, and social support network. Their shared experiences offered a context to help better understand what parents go through.

Omar:

Growing up with hemophilia has made my life unpredictable by nature and often affects my well-being. Knowing a mishap can lead to dire health complications or permanent damage is a mental and physical battle. As I grew and matured, I learned to be more receptive to change with an understanding that my condition can lead to unforeseeable consequences. I have been in and out of wheelchairs, crutches, boots, and bandages. Although these issues have some control over my life, I have learned to adapt and become a responsible adult.



I tried to embrace high school and stay active, but it wasn't always easy. I loved playing basketball but had to give it up. I tried cross-country, but my left ankle wasn't having it. I did enjoy golf and I was also a member of the marching band playing the mellophone and French horn all four years. I even joined the American Sign Language Club. I was sometimes lonely but that has to do with being somewhat shy. The pandemic hit and we lost almost two years of face-to-face learning; then due to ankle bleeds and medical appointments I missed a lot of school but was able to keep up with the work, and my grades were good.



Sometimes my health situation would really get me down. Being involved in the bleeding disorders community helped to keep me from spiraling. When I was 10, I began volunteering with my dad as a deejay; DJ Omar, as I am now known – donating my talents on the turntable and bringing

music to a variety of events such as family education symposiums, dinners, and annual walks in Florida, New Jersey and New York.

For me, volunteering is a great stress reducer and distracts me from the pain I experience at times. It fills my soul and leaves me with a warm, fuzzy feeling in my heart. It makes me happy. Through the years, my hemophilia community involvement has been instrumental in my quest for self-exploration and acceptance.

Creating connections and building relationships has allowed me an outlet to combat loneliness. Conversing with individuals in similar situations has taught me that growth and adaptation are critical to overcoming challenges. I genuinely embrace stories and knowledge of community members because our commonality embodies

unity, strength, and resilience. As I progress to the next chapter of my life, I can attest the emotional struggles with my bleeding disorder have significantly declined. I knew once I started college, I would need to be even more mindful, make smart decisions, always be aware of my surroundings, and take more personal care of my hemophilia.

Milybet:

The day arrived when our assignments were marked, final exams taken, and studies completed. The ceremonies were huge, unforgettable moments for us as a family. Our family and friends supported us during our studies and shared in our celebration. Omar and I graduated three days apart, mine in Florida and Omar's in New Jersey. What a fantastic, wonderful milestone to share with my baby boy!



Today I continue to work as a bilingual special education teacher in grades 5–8 in the subjects of English Language Arts and Math. In addition to planning, organizing, and assigning activities specific to each student's abilities, I implement IEPs, assess each student's performance and track their progress. I collaborate with general education teachers, administration, and the Child Study Team. I represent the middle school on the Superintendent's Council of Teachers and am a faculty advisor for the Junior Honor Society and also serve as a part-time professor at Rutgers University.



In my spare time, I am a meditation and mindfulness coach, a motivational speaker and patient advocate presenting at events across the country, and a volunteer and Walk emcee for the Hemophilia Association of New Jersey and the New York City Hemophilia Chapter.

My primary advice to others raising a child with a chronic condition is to learn how to cope, manage your emotions, and keep stress in check when your child is going through a rough patch, hemophilia or not. By managing my own emotions during any difficulty, my son and I can have greater well-being and a healthier state of mind. It is essential to manage your reaction to stress. Many studies have found children whose parents had high stress levels experienced poorer management of their health condition.

Omar:

With hard work, I applied, was accepted and have been attending classes at Rutgers University. College has been my way of starting fresh, motivating me to work as hard as possible. During my first year I was very engaged in my classes and most of my time was focused on my schoolwork. I haven't yet chosen a major, though I am more confident about the direction I want to go in and have it narrowed down between following in my mom's special education footsteps or medicine. My experience has been great. There have been some challenges, but I have been able to navigate each one of them. It's mainly been a matter of getting used to the subjects and materials and managing the workload.



My close friends are aware of my hemophilia. It isn't something that I'm embarrassed by. If it comes

up in conversation, I'll gladly share information if the questions are respectful and considerate. Toward the end of my freshman year, I started to get more involved in school organizations and look forward to being involved in more when classes start back up.

For me, the most significant part of transitioning from high school to adulthood was to be more social. I embraced the opportunity to meet new people during my first year and was welcomed into the new environment. Another major part of this transition was being able to balance everything in my life. I can't always be partying or playing video games. I recommend trying to be productive as soon as you possibly can.

As I progressed through the first year of college, I pursued some goals I've been wanting to achieve for a long time. I started going to the gym regularly and made sure to keep my infusion schedule consistent. This first year has also allowed me to explore other passions of mine that I otherwise wouldn't have explored. I've been greatly interested in the world of filmmaking, and I'd like to learn more about it in the future.

Overall, I feel the key part to a smooth transition, especially if you have a bleeding disorder, is to have a supportive network of people, whether it's family, friends, classmates, coworkers, professors, or advisors. Having trusted people to communicate your problems or concerns is a big part of making this life-changing transition easier.



Also, remember to contact the disability services at your college. Having your potential needs communicated with your professors through disability services, if and before they occur, is imperative.

Milybet and Omar - Our Advice:

- When your graduation day arrives, take a moment to breathe and take it all in. Appreciate how far you've come – you deserve to celebrate. Let it all sync into your memory!
- Remember that no one can ever take away your education. You own your school degree and work experiences.
- Embarking on a new chapter of your life may feel as liberating as it is terrifying. Consider writing down your feelings and speaking with a loved one. Begin preparing for your next steps.
- Work hard. Whether your next step is going to school or getting a job, give it all you've got. Be on time, study for your exams, and complete your work.
- Learn to follow a budget. Understanding how to properly manage your money is a valuable skill that will help you throughout your life.
- Follow a schedule and learn to manage your time. Building this essential habit will increase productivity and punctuality. Whether learned or by nature, managing your time can get you far.
- Don't make excuses - own and learn from your mistakes.
- Be open to change. Continue your education - learn about yourself, take up a new hobby, enroll in college or take a class or two on something you want to explore; pivot your career if you have an interest elsewhere.
- Avoid comparing yourself with others at school or work. You are you. Create your unique path. Your only competition is with yourself. Be the best version of you and don't let anyone dim your light.
- Don't let a bleeding disorder stop you. You have the power to do amazing things!

BIOMATRIX] ON THE *Move*

The BioMatrix Education Team and Regional Care Coordinators have been busy hosting educational events and attending community gatherings. Our team offers a wide and expanding menu of educational topics and fun activities to choose from, including on-line sessions. Interested in scheduling a session for your group of any size either in-person or virtually? Please contact your Regional Care Coordinator or message the Education Team at: education@biomatrixsprx.com.



Allen can still carry son, Austin



Wendy and Kayla pose with Booster the Rooster

TENNESSEE

Cyndy Coors and David Tignor

The Tennessee Hemophilia & Bleeding Disorders Foundation, CSL Behring and BioMatrix partnered together September 5th for **Baseball Night** at First Horizon Park, home of Minor League Nashville Sounds. Community families came out to enjoy food, fellowship, and America's favorite pastime, baseball! Participants even got to visit and take pictures with Booster the Rooster mascot!

It was a beautiful evening for everyone as the Nashville

Sounds played the Memphis Redbirds and came away with a win of 6 to 2! As Babe Ruth once said, "Never let the fear of striking out keep you from playing the game," a statement that can apply in almost anything we do in life, especially when living with a bleeding disorder!

OHIO

Rania Salem

Friends and families gathered at Hyde Park Steakhouse in Dublin for an **Educational Dinner** incorporating learning, comradery and great food, all brought together by Sanofi and BioMatrix. Sanofi's Community Relations and Education Manager Laith Elkurd presented on their breaking edge new factor, Altuviiiio™, and we were honored to have our very own BioMatrix Education Specialist, Shelby Smoak, PhD, present *Effective Communication*. An informative and enjoyable time was had by all thanks to Sanofi, Laith and our guests.

CALIFORNIA

John Martinez, Gaby Griffin and Hector Heer

California's four hemophilia organizations - Hemophilia Foundation of Southern California, Northern California, Central California, and the Hemophilia Association of San Diego County joined to host the 7th annual **"Familia de Sangre"** event September 8-10th at the Anaheim Marriott.



Pedro (right) visits John and Gaby at the BioMatrix booth

Familia de Sangre is the largest Spanish language conference on bleeding disorders in the U.S. and focuses on bringing education and support to Latino families. The arrival of guests was a joyful event where jubilant greetings could be heard throughout the reception area! After dinner and welcome presentations by the sponsors, families toured the exhibit hall where they chatted with the myriad of event sponsors and asked about resources and current programs. During the exhibit hours, the BioMatrix booth ran rounds of our bleeding disorders version of *Jeopardy*. Participating families became quite competitive as they answered questions in their attempts to win. The sheer mass of participants kept the booth extremely busy and hopping with conversations and laughter!

Saturday morning began with a breakfast and a manufacturer-sponsored presentation. Then attendees chose from various presentation options including basics of hemophilia care to the future of new treatment options. Before afternoon sessions began, participants stopped for lunch and more booth visits. We had a great time at the BioMatrix booth especially when a huge crowd gathered for the selection of the raffled gift basket. A resounding cheer was heard as the lucky winner was called! The day ended with time to spend at Disneyland Park.

Sunday morning was bittersweet as families gathered before bidding adiós. The emotions and information shared will continue to have lasting effects. Familia de Sangre grows larger every year - one can only imagine what new experiences and adventures await us in 2024!

TENNESSEE

Cyndy Coors and David Tignor

The Tennessee Hemophilia & Bleeding Disorders Foundation, Sanofi and BioMatrix gathered to support an informative **Educational Dinner** September 12th at Knoxville's Brazeiros Churrascaria Brazilian Steakhouse. During dinner, Sanofi's



Rosa and Laura



Gaby and Marianela



Tyler, Jackson and Madison

CoRe Manager, Cassandra Titus presented a session on *Switch It Up - What Higher Factor Levels Could Mean for Your Treatment Plan*. Following Cassandra was a BioMatrix education session titled *Camera On, Healing and the Art of Photography*. Led by John Martinez, this highly interactive session discusses the benefits of art and photography on one's health. Everyone applied their photo-taking skills in several activities. The night was a huge success with the group enjoying their time together. Many thanks to Sanofi for co-sponsoring this event!



Leah and Kathy



Taylor and Katlyn

NEW MEXICO

Felix Jacquez Garcia

Sanofi held a unique hybrid **Educational Dinner** September 13th. A presentation was aired live via the Sanofi National Broadcast and the only way to attend was to be in person at one of 12 locations all over the country where a Sanofi Community Relations and Education (CoRe) Manager was hosting live. BioMatrix was honored to work with CoRe Manager Alexandra Abreu at Pappadeaux Restaurant in Albuquerque.

The presentation covered information about Sanofi's new Factor VIII product, Altuviio™.

It was great to see our local community members interact and have fun with the Sanofi program. As always, enjoying a meal and spending time with our local bleeding disorders family was awesome, and we learned a few things too. A successful night all around!



Anna, Katalina, Miguel, Serenity and Isaias



Jennifer, Christian, Lakeia, Dave and Jess



Vanessa, Felicia, Angel & Gina



Prespero, Elias, Elizabeth, Carmen and Maria



Joe and Michelle



OHIO

Shelia Biljes

To celebrate the approach of fall, changing leaves and cooler weather in northern Ohio, the women attending our monthly **Educational Lunch** and support meeting gathered



June and Debra

September 13th at Santo Suossos Restaurant in Medina. Takeda Nurse Educator Jan Martin presented "Bleeding Disorders in Women" while the guests enjoyed an amazing Italian buffet. Everyone listened and contributed to the conversation, and we went well into



Katrina and Kelly

the afternoon. We made time at the end of our meeting to paint red trucks and exchangeable seasonal cargo. Everyone's artistic ability seems to be better when they have the support of good friends. Thank you to our co-sponsor Takeda for a wonderful presentation and the opportunity to be together again!

FLORIDA

Hector Heer

Sanofi and BioMatrix sponsored a **Game Night** for community members at Bulla Gastrobar in Doral September 20th. Following a great dinner and presentation by Sanofi, it was time for BioMatrix's bleeding disorder version of *Jeopardy!* The evening proved to be full of education, competition and lots of fun! Thanks to Sanofi for their continued support of our community.



Libia, Mateo, Santiago and Douglas

VIRGINIA

Terry Stone and Michelle Stielper

Empowering YOU! That's what it was all about at the Hemophilia Association of the Capital Area (HACA) **Women's Retreat** in Middleburg. Meadowkirk at Delta Farm was the place to be for a glorious September 22-24th weekend. The farm lends a perfect backdrop for a gathering worthy of these Wonder Women, all of whom run their lives and their family like a BOSS, but need to be reminded that their well-being as the family CEO is equally important.



Making suncatchers!

We were treated to an enriching talk of self-worth as we learned to take better care of ourselves in Dr. Anna Bell's *Taking Care of You* session. The afternoon offered talks on how *Milds Matter* with Bekah Hekathorne, RN/BSN of the Hemophilia Center at OHSU, *The Effects of Chronic Illness on Relationships and Family*, and a presentation on *Self Advocacy* by our very own Michelle Stielper.

The evening found us in the dining hall, where Michelle guided the ladies through making beautiful suncatcher keepsakes for their favorite sunny window. For those who could stay up past 9 pm, the conference room turned into a slumber party where the ladies watched the *Barbie* movie with pillows and blankets on the floor, just like the old days of girlie sleepovers. The laughter that ensued took us back in time...what fun!



Keeping with tradition, we concluded the event with our *Closing Circle*, a safe space where women are surrounded by their tribe as each lady, one by one, shared what they learned from the retreat, along with a goal they want to focus on knowing they have the support and encouragement from their circle of friends. It's a coveted end to a fantastic weekend.

VIRTUAL

Eva Kraemer and John Martinez

On September 23rd, BioMatrix provided a virtual **Feed Mind and Body** opportunity for our Spanish speaking community to connect in an educational and entertaining way. Families were excited for an occasion to continue the ever-important function of lifelong learning within the bleeding disorders community. BioMatrix was proud to offer an overview regarding our *Patient Navigation* program in place to assist families.

Following our educational component, participants were dazzled with the delicious cooking skills of the superb “Chef Mike.” Chef Mike’s interactive demonstration created a tantalizing dish, *Chiles en Nogada*, that had participants lamenting the lack of “smell-o-vision” on their computers. Chef Mike also created a traditional Mexican dessert, *Arroz con Leche*. The demonstration was enhanced by the enthusiastic participation of attendees while sharing their own traditional versions of the recipe. The meeting ended with questions from the participants and many requests for more programming!



NEW YORK

Richard Vogel

On the first weekend of fall, the Bleeding Disorders Association of Northeastern New York (BDANENY) held its **Annual Meeting** at Dave & Buster’s in Albany September 24th. Tropical storm Ophelia could not keep community members from a day of family fun, information and comradery. Manufacturers and specialty pharmacies set up their information booths and community members strolled through gathering information.



Paislie and Amy

As lunch was served, attendees were engaged with two presentations, *Dream Big Ideas & Challenge Yourself* and an *Interactive Session on Joint Health*. BDANENY Executive Director Beth Mahar followed with an advocacy update and the annual report. Then it was time to relax and have some fun in the arcade. Armed with tokens, old and young alike enjoyed all that Dave & Buster’s has to offer. It’s hard to beat the thrill of a joystick, smashing some buttons or throwing balls. Arcade games remind us of the delight of being a kid again. It’s always good for families in the bleeding disorders community to get together to talk and share stories – it was a blast catching up with everyone!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Bayer and BioMatrix partnered for an exciting **Educational Dinner** September 26th at Tampa’s Maggiano’s Little Italy Restaurant. Community members gathered and reconnected before the presentations began. On behalf of Bayer, Miami HTC nurse practitioner Maya Bloomberg Smith spoke on medical advances and treatment, and offered information on Jivi®, a longer-acting factor product.

Following Bayer’s presentation, BioMatrix rolled out its new program, *Understanding Patient Navigation*. This interactive program had participants play an escape room-style game with word scrambles, a dice challenge, and hidden-clue puzzles. Along the way, participants learned how patient navigation can be a tool for overcoming non-clinical obstacles to patient care. Terry Rice, BioMatrix’s Director of Education kept things fun and interactive. After the game, Terry gave an interesting PowerPoint presentation demonstrating the value of using patient navigation resources.



Terry Rice discusses Patient Navigation

Thank you to Bayer for co-hosting this event, and thanks to the community members who were able to attend. As always, we look forward to our next event in sunny Florida!

ILLINOIS

Eva Kraemer

On the bright, sunshiny day of September 30th, family and friends came out to Bleeding Disorder Alliance Illinois (BDAl) **Unite Hemophilia Walk** at Brookfield Woods Forest Preserve. BioMatrix, a proud fundraiser for this event, is always enthusiastic to participate. BDAl 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 fundraising event allows everyone an opportunity to get together to support the Illinois bleeding disorder community. This occasion brings so many of us in the community together, making it successful on many levels!



Elliott, Alan, Julian, Brenda, Bella, Hiro and Jessica

VIRGINIA

Terry Stone and Michelle Stielper

The Virginia Hemophilia Foundation hosted its **Annual Medical Symposium** at the Great Wolf Lodge in Williamsburg September 30th. Family wolf packs came out of their habitats and joined with more than 150 strong to learn about the latest products and technologies available, as well as other empowering topics to help navigate care and life with a bleeding disorder.



Michelle Stielper & William

The Keynote presentation was a joint panel of experts who led a talk on *Shared Decision Making and the Shift to Person-Centered Care*. Represented on the panel were various professionals from regional HTC/hospitals as well as two experienced moms from the community. Together, they presented a diverse range of experiences offering tools and talking points to ensure your personal care plan is a combined decision between you and your medical team.

With this skill mastered, you can care for yourself or your loved one with confidence. *Aging Well With Hemophilia* was another enriching presentation by community member Rick Starks. The agenda was complete with a variety of presentations on new products and gene therapy, which is always important to understand and stay informed.

Camp Holiday Trails staff were on hand to engage the teen wolves with their Pop-Up camp activities, while the little wolf pups had fun of their own. The evening was social time at the lodge. After Sunday breakfast, all left to travel back to their den with great knowledge and a full tummy. Many thanks to the Virginia Hemophilia Foundation and their fantastic staff and volunteers!

ARIZONA

Felix Jacquez Garcia

Arizona Blood Alliance brought together the Latino bleeding disorders community for *Herencia Latina*, a special all-Spanish event held in Phoenix October 7th. Hats off to the chapter for thinking outside the box and taking the event to the famous Ponderosa Ranch for visiting with specialty pharmacies and industry reps, education, horseback riding and an authentic cowboy-style dinner!

BioMatrix led several rounds of *100 Latinos Dejeron*, our Spanish Family Feud—bleeding disorders version. We all learned there are no friends in this family friendly competition. The battle was fierce! BioMatrix also shared pertinent information about our *Patient Navigation* program, which is available to anyone affected by a bleeding disorder experiencing challenges with insurance coverage, access to prescribed therapy, and more, (visit: bit.ly/bdpatientnavigation).

The event ended with mariachis singing and folklórico dancers performing for the crowd. It was a magical, musical evening!



Challenge winners! Justin, John and Amy

Participants had the opportunity to compete in our new “breakout room” style patient navigation activity. Divided into teams, attendees were tasked with appealing a fictional insurance denial within 20 minutes through a series of activities and puzzles. One team emerged victorious and claimed the prize! Thanks to Sanofi for partnering on another successful education program!



Chris and Anjelah with Felix Jacquez Garcia



Aturo wins the raffle prize!

FLORIDA

Hector Heer, Justin Lindhorst

Sanofi and BioMatrix co-hosted an *Educational Dinner* October 11th at Morton’s Steakhouse in Fort Lauderdale.

FLORIDA

Justin Lindhorst

The Florida Hemophilia Association hosted its annual *UNITE for Bleeding Disorders Walk* October 14th.

Participants gathered at the Nova Southeastern campus early in the morning to enjoy pre-walk activities including visiting with sponsors, grabbing a quick bite, taking team photos and enjoying a petting zoo. Team BioMatrix was hard to miss in bright neon shirts and bedazzled bucket hats! The UNITE walk is an important opportunity to raise awareness and funds supporting programs and services offered by the Florida Hemophilia Association.



OHIO

Shelia Biljes

The Burntwood Tavern in Cuyahoga Falls was the perfect location for a *Fireside Chat and Dinner* with Genentech October 16th. Large windows gave a perfect view of the flowing Cuyahoga River and gorgeous colors of the fall foliage. Guest speaker from Indianapolis, Tamar, spoke about his life of growing up with hemophilia. A talented musician, he shared some of his songs with the group. Even the youngest in attendance enjoyed the food and music. Thank you to Genentech for your support!



DaShawn, Emir, Eli and Eman

OHIO

Shelia Biljes

Fall in Ohio is a time for scarecrows, pumpkins and the blazing autumn colors of leaves turning to golden yellow, bright orange and dark crimson. This month’s *Ladies Educational Lunch and Craft* was co-hosted by Bayer and BioMatrix October 18th at the Tony K Restaurant in Berea. Bayer Patient Educator Wendy Perkins presented *Understanding Insurance*. The ladies shared their concerns of the ever-changing insurance arena and took notes. A lesson on the MicroHealth App gave the group an option for quickly logging infusions to stay compliant.

After lunch the real fun began with a scarecrow craft made from empty wine bottles. The lunch ended, as always, well into the afternoon with many goodbye hugs. Thank you Bayer and Wendy for another amazing event!



Kaiden and Ben



Connie and Kitty



Evelyn



Jen



Debra



Marie



Michael, Elizabeth and Emma



Matt, Isabelle and Jennifer



Ethan Pins the Spider



Kiven, Elena, Chad and Kyrian



Brynlee



RCCs Shelia Biljes and Rania Salem with Joe Piscitello



Ethan, Garrett and Wyatt with mom, BioMatrix pharmacist, Rebecca Moorman

OHIO

Shelia Biljes and Rania Salem

Little goblins of Central Ohio gathered at Der Dutchman in Plain City October 19th for an evening of Halloween fun! After an amazing dinner sponsored by Bayer, kids participated in games, crafts and decorating cookies. Spider basketball seemed to be a favorite for everyone. Cute spiders made at the craft table were used to pin the spider on the web, a fun game that all the kids enjoyed. A monster mash dance contest had the adults pulling out the cell phones to record the dance moves. Then, it was time to trick-or-treat with a little twist! As kids identified infusion supplies, they received candy to fill their bags.

With kids exhausted and parents done socializing, the evening wrapped up with hugs and goodbyes. Many thanks to everyone that joined us and a special thank you to Bayer for sponsoring our **Halloween Extravaganza!**

CALIFORNIA

Gabriela Griffin

The weather could not have been better on this perfect morning when community members gathered at the Liberty Station NTC Park in San Diego for the Hemophilia Association of San Diego County Unite for **Bleeding Disorders Walk** October 22nd. Everyone was happy to have the opportunity to socialize, visit industry booths, have their face painted or get a soothing massage. Before the walk we also enjoyed a variety of coffee drinks; thanks to Takeda people were alert and on their toes, eager to get to the finish line. Two thumbs up for the upbeat music - it created such a joyful atmosphere! Many thanks to the Hemophilia Association of San Diego County staff for putting together such a memorable walk!



Happy Walkers! Elsa, Gaby and Victoria



Gail and Robert



Emily, Paige, Wyatt & Phil



Amy and Allyson

DELAWARE

Tina McMullen

Brandywine Valley Hemophilia Foundation's community had a gorgeous day for a hayride and apple picking. The beautiful setting at Thousand Acre Farms in Middletown October 22nd did not disappoint! The day started with an educational presentation by Sanofi CoRe Manager Alexis Akins on *Switch It Up*, a program about Sanofi's new product, Altuviiiio™.

After the program, everyone headed out to the apple orchard to pick apples from dwarf trees where some taste-testing *might* have taken place. We then loaded up for a scenic hayride along the waterfront where the spectacular views were awe-inspiring!

Thank you to Foundation President Gail Novak and Alexis Akins of Sanofi for an ideal day to take in beautiful weather, education, conversation and great fun!



FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Sanofi were joined by 30 community members October 25th at Eddie



Christina, Meako and Sarah

V's Prime Seafood Restaurant in Tampa for an **Evening of Education** and light entertainment. The evening began with Sanofi's CoRe Manager, Eric Burgeson, who gave an engaging and informative presentation on Altuviio™, Sanofi's newest factor VIII medication. Attendees were very interested and participated actively in the discussion.

Eric was followed by BioMatrix Advocate and Education Specialist, Shelby Smoak, PhD. Shelby presented *Singing to Heal* which gives insight to how the brain processes and uses music to cope with chronic pain and illnesses. The attendees were keenly absorbed, asking follow-up questions and eager to learn more. After dinner we rounded out our evening with an enthusiastic game of *Music Trivia: Name That Tune!* emceed by Shelby and Eric. As always, it is delightful to bring our bleeding disorders community together, and we look ahead to many future events. Thank you to Sanofi for sponsoring our evening!

FLORIDA

Justin Lindhorst and Hector Heer

Sanofi and BioMatrix hosted an Education Program at Fleming's Steakhouse in Orlando October 26th. Attendees learned how patient navigation can help resolve nonclinical barriers to care such as insurance, financial, and social issues. To illustrate the concept, attendees competed in teams to solve a fictional insurance denial. The "breakout room" style activity includes tabletop puzzles and activities to complete



Sanofi CoRe
Eric Burgeson

within 20 minutes. One team was successful in navigating their appeal before the timer stopped. Following our patient navigation presentation, Sanofi CoRe Manager Eric Burgeson provided a brief presentation on Altuviio™. Thanks to all who attended and to Sanofi for sponsoring!

NEW JERSEY

Richard Vogel

On the scenic fall day of October 28th, Hemophilia Association of New Jersey, Sanofi and BioMatrix partnered to present **Lunch and Learn** - a great afternoon of education, apple cider donuts and apple picking at Hill Creek Farms in Mullica Hills.



Christopher and Allyson

Guests helped themselves to gourmet sandwiches, cider and donuts, all made on the farm, and settled in for a BioMatrix presentation on *Understanding Patient Navigation*. Director of Advocacy and Education Terry Rice explained the concept of patient navigation, starting with a competitive group activity where participants appealed a fictional insurance denial through solving word puzzles. Terry explained how the BioMatrix Patient Navigation team has helped patients across the country solve insurance issues and access financial assistance programs. This service is available to all community members regardless of specialty pharmacy affiliation.

Sanofi CoRE specialists Alexis Akins and Tyshawn Constantine led a discussion on factor level peaks and sustained troughs and how using Altuviio™ can achieve desired levels. Afterward, families explored the farm, went on hayrides and picked apples and pumpkins. It was an ideal activity for a picture-perfect afternoon!



Tyler chooses a prize



Alexandrea and Ben



Carmelo and Shelia



Lila and Kaiden



Shelia and Cameron



Mika and Shelia

OHIO

Shelia Biljes

Cold weather arriving in Ohio doesn't mean the end of bathing suit season! The indoor waterpark at Sandusky's Kalahari Resort extended the fun and was the perfect location for the Northern Ohio Hemophilia Foundation (NOHF) **Annual Meeting** November 3rd.

Industry reps were available Friday in the exhibit area for folks to visit and learn more about their products and services. During dinner, social worker Cathy Tiggs, MSSA, LISW spoke on pain management and was received with remarkable audience participation. Breakout sessions

followed with topics such as *Emotional Health and Well-being* and *Mold the Molecule!*, which explained the science behind von Willebrand Factor. Also on hand was BioMatrix Education Specialist Shelby Smoak, PhD, who held a session on *Singing to Heal - Music, The Brain and Healing*. Soon enough, it was time for wet and wild fun at the water park!

Saturday featured Keynote speaker Rev. Cazandra Campos-MacDonald who spoke on *Taking Back Your Power*. After a few more breakout sessions to attend, and guests were excited to spend more time at the waterpark. Many thanks to NOHF for extending our summer just a little longer!

CALIFORNIA

Gabriela Griffin

Community members gathered November 4th at Whittier Narrows Recreational Park in South El Monte to participate in the Southern California's 15th annual **Unite for Bleeding Disorders Walk**, better

known as the *Super Hemo Walk*; many arrived dressed as their favorite superhero or wore a red cape as a remembrance to the many heroes within our community. Before the walk, we were able to socialize, visit pharmacy and manufactures booths and participate in the Health Fair where everyone could have their glucose, cholesterol, blood pressure, bone density, and more checked. Many thanks to the sponsors and to Hemophilia Foundation of Southern California for organizing this fantastic event!



Laura and Gaby hang out with superheros

MAINE

Richard Vogel

The New England Hemophilia Association (NEHA) held its annual **FallFest** November 4th-5th at the Westin Harborview in beautiful downtown Portland. The community of "Wicked Strong" families reconnected at a welcome reception Friday night.



Tracey wears a purrrfectly happy face

The event officially began with a moving keynote address entitled *Loving the Life You Live* from singer, songwriter and actor, James Ian. Being born with a progressive neuromuscular disease called Spinal Muscular Atrophy, James was constantly told that his goals of becoming a creative artist were unattainable. Despite his physical disability, James has a successful career and has been part of several projects highlighting people with disabilities.

Many NEHA events focus on break-out rap sessions where specific topics are discussed in small, confidential, intimate groups. After a plethora of afternoon sessions, dinner, an awards presentation and a magic show followed. Continuing the festivities, a dance party got the crowd on their feet and movin' to the groove!

Sunday morning sessions included Terry Rice, BioMatrix Director of Advocacy and Education, who spoke about health system challenges faced by members of the community. He discussed the BioMatrix *Patient Navigation* program and how it can help families in navigating the maze of prescribed therapy, resolving insurance issues, and dealing with medically related financial burdens.



Terry Rice talks about Patient Navigation



Rich Vogel staffs the BioMatrix booth

The weekend wrapped up with an update on NEHA's current programs and services, new collaboration and advocacy efforts, and new and exciting programs for next year. Can't wait for 2024!

VIRGINIA

Terry Stone

There was no place better for the Virginia Hemophilia Foundation **Adult Retreat Weekend** than the scenic Blue Ridge Mountains at the quaint historic Hotel 24 in Staunton. Held November 4th-5th, the weekend took a deep dive into topics of wellness and living your best life. In addition to presentations by the professionals, there was plenty of time to share, network and make new friends. The robust agenda included presentations on *The Impact of Factor 8 and Bone Mineralization*, to *Mental Health*, *Reproductive Health*, and a rap on stressors of life with a bleeding disorder.



Art can be fun and useful!

Afternoon was time to relax with a fun *Arts Education Program* led by BioMatrix's own Michelle Stielper. The creative project was a leather sunglass case to hold their new BioMatrix shades. Both guys and gals completed the project and were very proud of their work. Yes, men can sew too!

The day wrapped up with a fabulous dinner at Blue Point Seafood Restaurant, a real treat for all. Great food, great fun, great friends.....what a way to "Retreat!"



Marcos, Angelica and Maria



Chris, Sarah, Aaden, Angelica and Anjelah



Luis and Michelle



Felix and Phil

ARIZONA

Felix Jacquez Garcia

BioMatrix was excited to team up with the Arizona Blood Alliance and Sanofi in Phoenix to host an intimate **Educational Dinner** event November 14th at Bobby-Q BBQ. The discussions centered around Sanofi's extended half-life product, Altuviiiio™, and the BioMatrix *Patient Navigation* program. Our program is open to all members of the community and offers guidance in resolving insurance issues, medical financial burden, and other non-clinical obstacles to patient care.

Thank you to Arizona Blood Alliance and Sanofi for teaming up with us to share this important information and thanks to everyone who took time to join us. We look forward to seeing everyone again soon!



Owen and Alex



Debbie and Reuben



Jessica, Bernadette and Stacey



Isaiah



Dave and Lakeia



Robert

NEW MEXICO

Felix Jacquez Garcia

What to do on a Wednesday evening? Hang out with your friends and BD community at Albuquerque's TopGolf, that's what! CSL Behring and BioMatrix came together November 15th to host an **Educational Event** filled with information, team-building challenges, and of course golf.

Amber Dobbins started us off with a presentation on the multiple products in CSL Behring's tool belt for the bleeding disorders community. She introduced their Gettin' in the Game athlete, Tim, to talk about his hemophilia

journey, his experiences and how prophylaxis has made his life much more accessible and open to adventure. He even led the group through a great team-building activity. Next up was a presentation about BioMatrix's Patient Navigation program. Available to everyone in the community, we assist even those who are not patients of, or don't have the option to be serviced by BioMatrix. We are patient-focused!

Of course, the night would not be complete without hitting a few golf balls! It was a fun and educational evening. Special thanks to CSL Behring and everyone who took time out of their week to join us.



AnnMarie



Robert patiently awaits his turn



Judy, Shelia & Dr. Domm



Noland & Connie



Lila, Jessica and Keiden



Bill visits Grinch



Jessica



Ben & Evelyn

OHIO

Shelia Biljes

Even the Grinch could not be in a bad mood as families of the Northern Ohio Hemophilia Foundation gathered at Strongville's Brew Garden November 18th to kick off the holiday season with a **Family Dinner and Holiday Wreath Making** event. Representing our dinner sponsor, Novo Nordisk,



Dr. Jennifer Domm discussed *Advancements in Hemophilia*. Parents listened as the children worked on creative Grinch pictures for a coloring contest. Mr. Grinch arrived after dinner to take photos with the children and even helped make Grinch-themed crafts. Then it was the adults turn to get creative assembling Christmas wreaths while a Grinch puppet entertained the children. The families enjoyed their time together, and all left in a holiday spirit. Many thanks to Novo for sponsoring our evening!



Zack



Quinton, Gabrielle and Kylan



Selina



Matthew, Mason and Kayleigh



Judy



Samantha, Matt and Nathan

NEW YORK

Richard Vogel and Carolina Luna

One knows the holidays are approaching when the New York City Hemophilia Chapter hosts their annual **Education Day**. Held in the New York City WeWork office building, the event began with time for community members to mix, mingle and visit industry and specialty pharmacy reps before the workshops began.

The workshops had something for everyone, from newly diagnosed families to seasoned veterans.

A highlight of the day was a *Lunch and Learn* panel consisting of HTC treaters who explained the latest therapies and answered questions. A visit from Santa and cookie decorating ended our wonderful day. We look forward to next year!



Milybet, Omar and Harry

VIRTUAL

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

The BioMatrix Spanish Translation Committee hosted their quarterly **Virtual Spanish Education Event** November 30th. After enthusiastic introductions, participants actively engaged in an informative session on *Transition to School and 504 Plans* regarding parental rights and aspects of a 504 program. Everyone shared stories and asked questions about past and current issues with 504 programs and how accommodations continue after high school. Afterward, families enjoyed a fun and competitive round of BioMatrix's bleeding disorders game, *Loteria*.

MAINE

Richard Vogel

The holiday spirit was alive and well December 1st -3rd at the Samoset Resort in Rockport where the New England Hemophilia Association held **Winterfest**.

There was plenty of time to visit and talk with industry and specialty pharmacies before the sessions started. One session featured Sunshine "Sunny" Ben Belkacem, a graphic facilitator and artist, who presented an interactive program using journaling as a de-stressor.

Award-winning hypnotist Roderick Russell demonstrated how hypnosis is no longer considered 'alternative therapy' since there have been many studies and research on its efficacy in dealing with chronic illness. In the evening, Roderick got the festivities going with a comedy hypnosis show that put everyone in a jolly mood as all awaited the arrival of Santa. Adults and kids had a very merry time opening gifts and dancing the night away.

OHIO

Shelia Biljes

Santa is on the move! Northern Ohio Hemophilia Foundation (NOHF) and BioMatrix hosted **Cookies with Santa** December 2nd and were so thrilled that Ole St. Nick stopped for breakfast at Williams on the Lake in Medina to meet the children!

Before the event, chapter members were invited to send in a favorite Christmas cookie recipe. BioMatrix compiled the recipes into a booklet and had them available at the booth. Participants brought two dozen cookies to the event to share, creating a colossal, sweet buffet! Kids and adults also made cute and useful snowman keychains.



Alaina, Carter, Carmelo, Chantel and Chardea visit with Santa and his trusty Elf!



Tyler has a list for Santa



Brothers, Matthew and Maysen

Collin

After breakfast, Santa arrived to share a story and lead a sing-along. Each child was then invited to visit with Santa and have a picture taken. To remember the event, the chapter presented each child with a beautiful teddy bear. It was an amazing morning to kick off the holiday season. Thank you NOHF for this joyful opportunity to kick off the holiday season!

VIRGINIA

Terry Stone and Michelle Stielper

ALL ABOARD THE POLAR EXPRESS!

The *Holiday Season* is a magical time, and the Hemophilia Association of the Capital Area (HACA) created a whimsical journey aboard the Polar Express for their **Holiday Gathering** December 2nd complete with train tickets, whistles, and a conductor's hat and scarf. Oh, and did I say HOT CHOCOLATE too! Conductor Stone was on board to greet all the passengers and keep them on schedule.

Held at Alexandria's Oswald Durrant Center, kids of all ages enjoyed dinner and treats, and of course a special present for each of the good children was given by Mrs. Claus, which means every one of them because all the HACA kids are good!

As tradition would have it, the party ended with an epic snowball fight which was not only fun but has become quite a holiday legend. Yes, the snowballs are soft, it lasted for just 15 minutes, and yes, it was awesome! Happy Holidays!



Good boys, Porter and Graham visit with Mrs. Claus



Jackson gathers snowballs



Brenda Bordelon photobombs Conductor Stone!

PENNSYLVANIA

Tina McMullen

The Mendenhall Inn on Sunday December 3rd was the place to be for the Brandywine Valley Hemophilia Foundation's **2023 Year End Meeting**. Attendees visited with industry reps before a lovely buffet lunch was served.



Gail, Kim and Jennifer

Foundation President Gail Novak gave a recap of the 2023 events, explaining how event sponsorships help provide funds for members to attend camp and educational conventions, college scholarships, and medical research grants to local treatment centers, to name a few. It is truly

amazing what this completely volunteer foundation accomplishes and provides for the community!



Walter, Arthur and Tara Matt and Samantha

Foundation Vice President

Jennifer Davis coordinated an educational game of *Jeopardy*. The room was divided into two teams and contestants had to sing *Jingle Bells* or *Frosty the Snowman* before answering. Of course, this led to plenty of laughter and fun!

Each child received a prize and gift cards were awarded to adults. The group then headed to Longwood Gardens to walk the grounds and marvel at all the holiday lights and displays. Many thanks to Event Chair Kim Hamstead and her team for hosting this holiday event!



Sweet Dallas

FLORIDA

Peggy Klingmann and Marcy Foertsch

Families were in the holiday spirit at an **Educational Dinner** hosted December 5th by Sanofi and BioMatrix at Tampa's Terra Gaucho Brazilian Steakhouse. Sanofi's Eric Burgeson presented information on their new medication ALTUVIIIO™. BioMatrix Education Specialist Shelby Smoak followed leading a discussion on "Insurance Basics." He posed a bold challenge: "Ask me anything you want to know about health insurance," and the questions rolled in. The group learned about the recent rules regarding copay accumulator adjustors, current out-of-pocket and deductible costs, HRAs, HSAs, and much more. This really was a great way to close out the year in good cheer!



Tony and Keisha



Crystal and Meako



Maggie and Patsie

Upcoming Events

FEB 8, 2024 OHIO

Couple's Night Out

Sponsored by Octapharma and BioMatrix
Contact Rania Salem, 513-470-5500
rania.salem@biomatrixsprx.com
Cooper's Hawk; Columbus

FEB 9, 2024 OHIO

Couple's Night Out

Sponsored by Northern Ohio Hemophilia Foundation and BioMatrix
216-834-0051, <https://nohf.org>
J Bella Restaurant; Strongsville

FEB 18, 2024 PENNSYLVANIA

Educational Dinner

Sponsored by Novo Nordisk and BioMatrix
Contact: Tina McMullen, 484-942-4457
tina.mcmullen@biomatrixsprx.com
Dutch Lanes, Ephrata

MAR 3, 2024 MISSOURI

Membership Meeting

Gateway Hemophilia Foundation
314-482-5973, gatewayhemophilia.org
Chicken N Pickle, St. Charles

APR 11-14, 2024 INDIANA

2024 Symposium, HFA, 202-675-6984

<https://www.hfasymposium.org/>
JW Marriott; Indianapolis

NATIONAL EVENT!

APR 25-28, 2024 TEXAS

Annual Hybrid Symposium

The Coalition for Hemophilia B
212-520-8272, www.hemob.org/
Renaissance Dallas Hotel; Dallas

NATIONAL EVENT!

MAY 3-5, 2024 PUERTO RICO

Moin Conference

Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado
787-647-7985, <https://hemofiliapr.org/>
Embassy Suites; San Juan

BIOMATRIX

Insurance Issues? We can help!

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

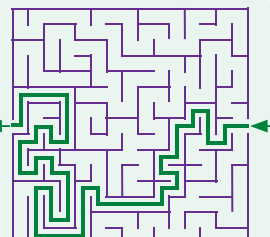
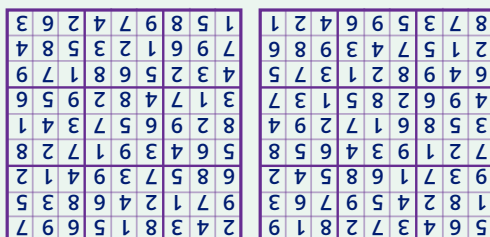
Our Bleeding Disorders Patient Navigation program is here to help.



bit.ly/bd-patientnavigation

Time for Fun!

Games on page 27



Time for Fun!

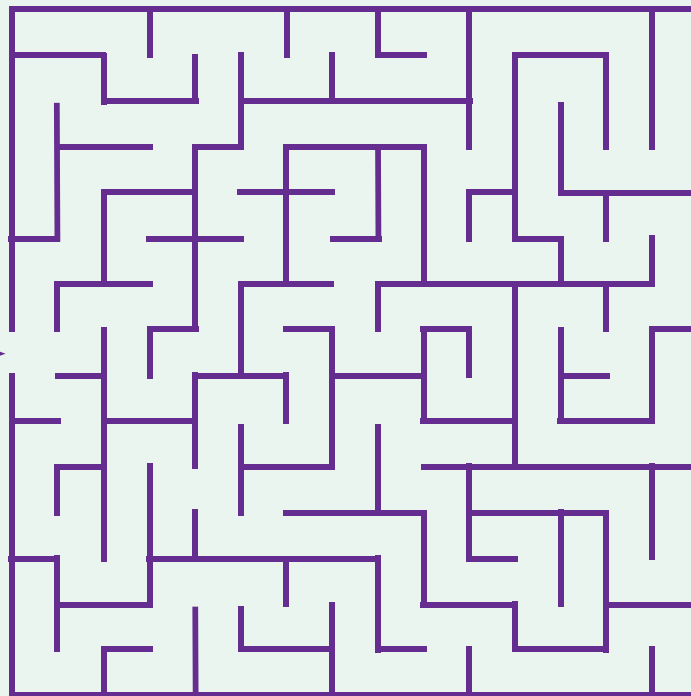
Hi Kids!

OH NO! OUCH!

Johnny took a big spill off his bike. He knows he should infuse with clotting factor right away since he hit and scraped his knees and elbows. This may have caused a bleeding episode to start in his joints. He needs to let his parents know that he needs a factor infusion as soon as possible! Can you help him make his way home? The answer to the maze is on page 26.



START →



What is something very smart that Johnny did before he got on his bike?

He protected his head by wearing a helmet! It is smart to be safe!

What is something Johnny could have done to ride his bike more safely?

Put on elbow and knee pads!



→ END

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

Sudoku!

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



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

BIOMATRIX

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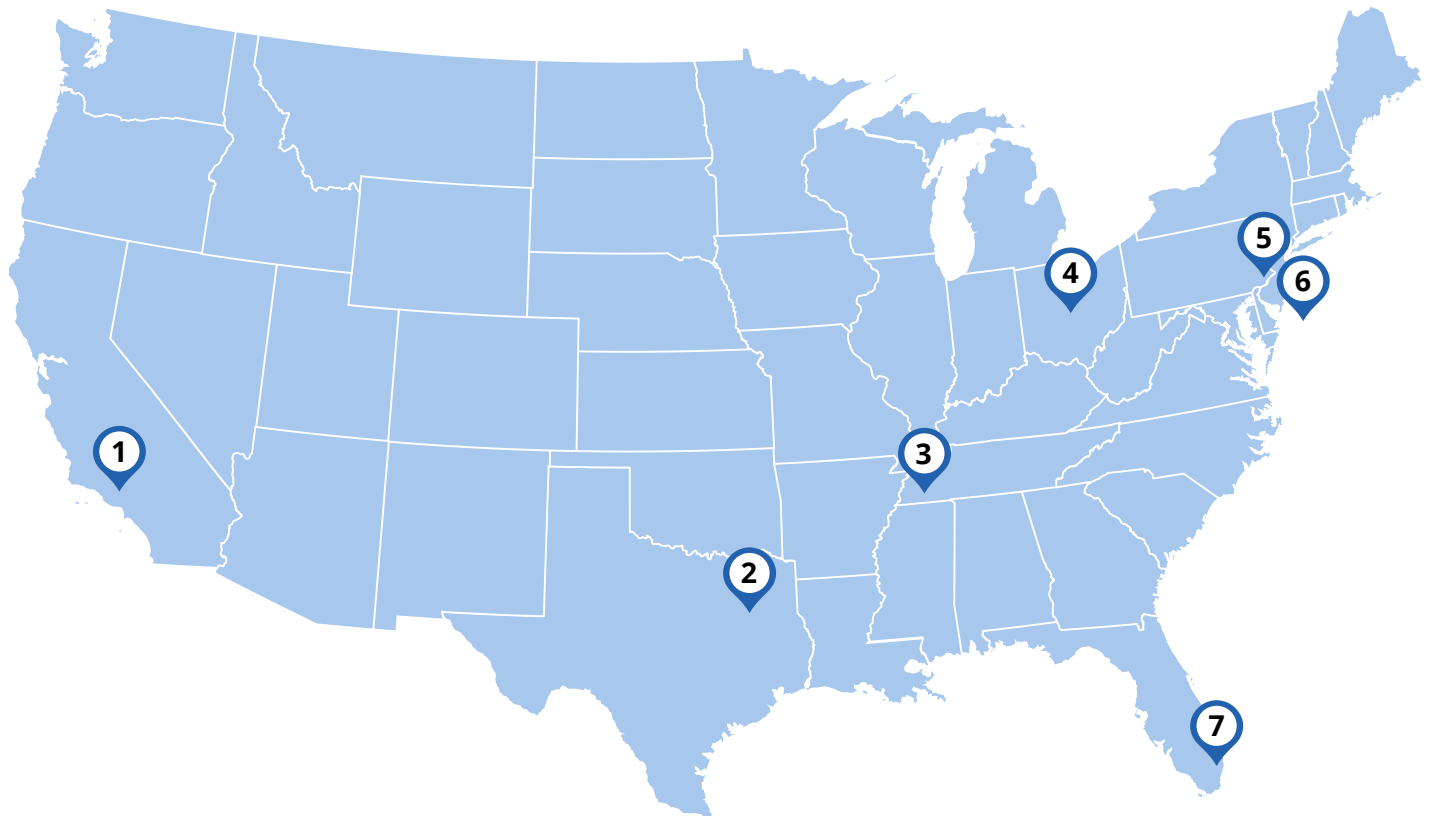
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Pharmacy Locations

1. Canoga Park, California
2. Tyler, Texas
3. Bartlett, Tennessee
4. Dublin, Ohio

5. Garnet Valley, Pennsylvania
6. Totowa, New Jersey
7. Plantation, Florida



**BEST AND
BRIGHTEST**
COMPANIES
TO WORK FOR
IN THE NATION
2019, 2020, 2021,
2022, 2023