

BIOMATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**FALL 2023
VOLUME 18 | ISSUE 4**

**“ Fun is about as good a habit
as there is. — Jimmy Buffett**

”

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

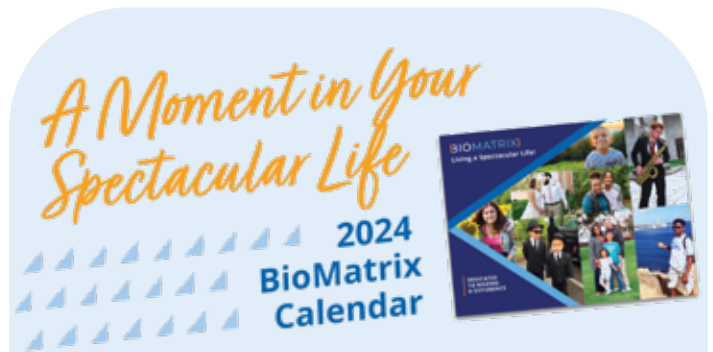
All of us at BioMatrix hope this season finds you doing well! As we settle into fall, let's take a minute to catch our breath. Enjoy the colors of falling leaves and cool evenings with our windows open. The hustle and bustle of the holiday season will soon be upon us, and we will find ourselves busy with those rhythms and rituals, but for now, relish the peacefulness and the change of seasons.

While you're at it, sit outside with *BioMatrix News* and enjoy an article or two! We start by honoring our former co-worker, Johnny de la Fuente, and then go on to a discussion about Pharmacy Benefit Managers and how they may affect our medical care.

Be sure to check out our *BioMatrix on the Move* section. Our Care Coordinators host and attend events all over the country. Our Education Specialists are available to present at local events, large or small. Just give our team a call or send a message to learn about the great variety of topics we offer: Shelby Smoak, 540-660-5179, education@biomatrixsprx.com.

Be well!

Maria Santucci Vetter
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Our 2024 *Living a Spectacular Life* Calendar will soon be available!

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

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

bit.ly/2024SpectacularLife

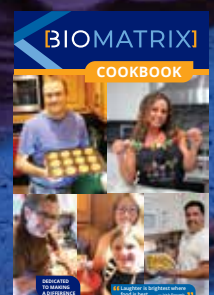
Order Your Calendar Today!

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>





With Heartfelt Remembrance

Juan Bruno "Johnny" de la Fuente

April 30, 1958 – July 18, 2023

Born in Havana, Cuba, Juan Bruno was just two years old when he arrived in Miami. After earning a degree in International Finance and Marketing from the University of Miami, "Johnny" began his career as a care coordinator. Growing up with severe hemophilia gave him a unique view of how to assist individuals and families within the bleeding disorders community. He especially liked working with young parents and youth guiding them toward empowerment and successful self-care so they can better navigate the obstacles they face living with a bleeding disorder. In Miami, Johnny lived in two cultures at the same time. Being bilingual and able to cross language barriers was extremely rewarding for him as he was able to provide great service and support to Spanish-speaking families.

John came to work for BioMatrix (formerly Matrix) in February of 2007, and as his co-worker and sometimes manager, I can attest that Johnny focused on the details. He knew the members of the bleeding disorders community and what they needed.

I relished the day trips across the Florida peninsula to work with Johnny in his home territory of Miami. It was always an adventure! After the workday ended, Johnny would say, "I want to take you somewhere," or "I want to show you something," and off we'd go. Johnny introduced me to places in and around "his city" that I never would have found on my own. He moved around Miami as if he were the mayor. He knew everyone and if there were people he hadn't met, he soon did, often getting complete strangers involved in our shenanigans. In Little Havana or visiting the Versailles for Cuban coffee, I always felt like a local when I traveled with him.

Our friend loved people - he loved attention and, with a broad smile, lit up any room he entered. Johnny often arrived late and didn't much care for meetings, but he'd stay as long as necessary if someone needed a shoulder or a sympathetic ear. He would literally give you the shirt off his back.

As I spoke with co-workers after Johnny's passing, I found that everyone had something different to say about why he was important to them. One friend spoke about Johnny's faith and had long conversations that helped each of them have a deeper appreciation of the importance of their own values. Another co-worker told of how their discussions centered on family. Many of the recollections were in agreement on how he was always having fun, how Johnny made them feel special, and how he went out of his way to be a true friend.

There are so many things about Johnny that I and many others will miss – his generosity, his energy, and his welcoming smile. – *Dave Burgeson*





Thoughts and Memories

"He lived the way he wanted, no one was going to change that... he will be missed." – Rob Carter

"Johnny sure was a character! Always sweet and such a ladies' man. He talked faster than anyone I know but was always so passionate about what he was telling you. He would light up a room and keep you laughing. If you

ever met Johnny, you would remember him with a smile. Rest in peace, dear Johnny." – Cyndy Coors

"I met Johnny when I first joined BioMatrix and attended the 2013 Hemophilia Walk in South Florida. Johnny was so friendly and welcoming, he seemed to know everyone! Through the years, Johnny would stop by the corporate office, and he never showed up empty-handed. He'd bring *pastelitos* for the team from Miami and you could always tell he was in the office by the smell of his cologne! I will miss Johnny tremendously!" – Angie Ferrier

"Johnny was an all-around good guy. After my son was killed, he called every birthday and death day to check on me. He will be missed." – Donna Garner

"Johnny was an exceptional human being. He knew a lot of people and made friends wherever he went. John traveled a lot and going places with him was always an adventure. He is going to be deeply missed." – Hector Heer

"Johnny was a force, larger than life, with a story to share about every part of his incredible journey here on earth. Until we meet again." – Eva Kraemer



"John was a kind, caring man who was extremely dedicated to the bleeding disorders community. His personality brought smiles and laughter to any room he entered. Johnny will be deeply missed. I'm honored to have called him my friend, colleague and blood brother." – Justin Lindhorst

"I met Johnny in 2015. From the start, he made me feel like we had been friends forever. At first, I had been calling him Tony and he never corrected me, saying I could call him whatever I wanted. Johnny definitely knew how to have a good time and live life to the fullest. When I met his girlfriend, Christy, she told me all the wonderful things he had shared with her about our friendship and the good times we shared. It truly warmed my heart! Johnny, you have given me so many wonderful memories and I will truly cherish every one of them. I will miss you greatly, my friend." – Tina McMullen

"Johnny had *The Most Interesting Man in the World* persona and he always made me smile. He had a heart of gold and was always more concerned about everyone else's mental well-being or physical health than his own. Johnny will be missed and never forgotten!" – Lisa Miller

"Johnny was someone fun to be around – he always found something to laugh about. Around him, you just couldn't be mad or sad. One year following a work meeting, my son and I were spending a couple of extra days in Miami. We were first going to make a quick stop to drive Johnny home. Little did we know we were going on a four-hour tour of the city. Johnny had us visit Little Havana and we enjoyed time in an awesome neighborhood park. It's a memory I will cherish, and I am grateful for the happy times spent with Johnny. He will be missed." – Susan Moore

"I worked with Johnny since I started with Matrix. The best words to describe him was that he was a true gentleman! He always looked out for the ladies in our company like a big brother would! He would be the first to reach out to me on every holiday and would even check on my family in Florida during bad storms, even though he was in the path as well. Johnny will be truly missed, such a kind soul!" – Rania Salem



"In 2015 I had the pleasure of meeting Johnny when I joined Matrix Health Group. From the moment we crossed paths, his warm and outgoing nature made an instant impact on me. He had a way of making everyone feel like an old friend, and his friendly demeanor was contagious. Every time Johnny visited our corporate office, he never failed to spread joy in the form of pastries and hugs. During the holiday seasons, Johnny's kindness extended even further. He had a special talent for making delicious homemade coquito, a drink that became synonymous with his name. Whenever I see coquito now it brings back fond memories of Johnny's thoughtfulness and the joy he brought to the workplace. His legacy of kindness and generosity will live on in our hearts and in the stories we share. I'm grateful to have known him." – Diane Schumacher

"Johnny felt like family, like home. He made friends everywhere he went and when he got to know you he made you feel so special. From the day we met, I knew he would be someone who I would hold near and dear to my heart. Losing him is deep and profound. I will always remember our laughs and bear hugs, and getting into trouble together." Love you always. – Michelle Stielper

"Johnny's heart was as big as his spirited personality. Oh, how I will miss his calls before upcoming meetings to say how he couldn't wait to be with us all, his *familia*. I would tell him to not forget his hats, after all, hats were his signature look. My favorite on him was always the Cuban

fedora. A while back I shared a sweet photo of my grandson skipping wearing a fedora. His feet were off the ground as he skipped. I captioned the photo "Just like our Johnny... walking on sunshine with a Fedora on his head and sunshine in his heart." The next time I saw Johnny, he brought an authentic Cuban fedora that matched his for my grandson. It's our newest family treasure. Rest easy, Johnny, rest easy." – Terry Stone



"Juan Bruno de la Fuente - that name echoed many times whenever we gathered for a meeting or event. It was as if royalty had entered the room, and when his name was yelled out, a huge smile cast across Johnny's face. He was a kind soul many of us will never forget. I have so many fond memories of Johnny over the years. He had a positive energy and greeted you with tremendous love and affection. If I felt down, he would lift my spirits. If I needed a boost in self-confidence, he would let me know I made a difference. Johnny was an all-around cool dude, blood brother, and someone I could talk to about anything, and he was always ready to offer an opinion. I had great respect for Johnny. It makes me sad I will not get to physically see him to talk with him, but I know I can still spiritually speak to him, and that brings me comfort. John, you will be greatly missed by many, but the impressions you made on everyone will carry on."
 - David Tignor



"Johnny was all personality! From the moment we met, we shared a special bond. I don't think he ever missed sending me a message on my birthday or holidays - even Father's Day. I will miss his very late-night calls and the laughter we shared. RIP, Johnny. I will always remember you with love and affection."
 - Maria Santucci Vetter



"Johnny was family, he was always cheerful with a heart full of kindness. We'll forever remember the joy of seeing him walk in with his thoughtful treats and loud laughter, because he was not shy. He made sure his presence was known! Johnny, you will be deeply missed."
 - Adis Velasquez

"Let's face it, Johnny was never on time. Whether it was a team call, a team meeting or going to dinner, he was always late. At one of our meetings in Ft. Lauderdale, everyone was checked into the hotel and we were waiting to go to dinner. Johnny was supposed to rent a car to help bring people to the office and to dinner. He comes racing up in a 2-seat GTO convertible, yells out, 'Sorry, this was all they had left!' and says, 'Hop in, Rich!' and off we went laughing and speeding to the restaurant. 'Rich, watch how fast this goes!' That was Johnny. He and I were instant friends the first time we met. We were very close in age and had experienced the same things growing up. I will miss him. Ride on, brother, ride on."
 - Richard Vogel



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-2023>



Supporting our community is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!



Scan to connect



PHARMACY BENEFIT MANAGERS: THE SQUEEZE IS ON THE HEALTH CARE MIDDLEMEN

BY SHELBY SMOAK, PhD

If you've been watching the news, you have likely heard some chatter about Congress investigating Pharmacy Benefit Managers (PBMs) and creating legislative bills to address concerns with PBMs. You may have also seen a frequent anti-PBM commercial where a patient tries to pick up her doctor-approved medication at a pharmacy. A man jumps in and takes it away, saying she can't have that particular medication; that she will have to use another one. She then replies, "But you're not my doctor." But, he is her PBM...

What are PBMs? What do they do? And why is Congress investigating them? Let's get started.

What is a PBM?

A pharmacy benefit manager, or PBM for short, is a third-party partner with a health insurance plan that provides prescription drug benefits to the plan members. PBMs function as an intermediary between the entities involved in getting prescription drugs from the manufacturer to the patient's individual insurance plans.

PBMs create drug formularies, establish drug inclusions and exclusions, and institute specialty drug-cost tiers; they negotiate drug rebates, create pharmacy networks, and handle the claim billing, processing, and payment for drug benefits.

When did PBMs start?

PBMs began operating in the 1960s when they helped insurers control drug spending by using formularies and administering drug claims. Their role expanded slightly in the 1970s and 1980s. It wasn't until the 1990s that PBMs began to change and expand more broadly. Initially, they were acquired by pharmaceutical companies, but the Federal Trade Commission (FTC) ended the practice, citing concerns over conflicts of interest.

Today, there are over 66 PBMs; however, the top three control almost 89% of the market. Many PBMs are also owned by an insurance provider, a position that echoes the FTC's concerns expressed several decades ago.¹



What does a PBM do?

PBMs work in the background on prescription drugs. They play no role in the physical distribution of drugs, but handle payment and rebate negotiations between the manufacturers, wholesalers, pharmacies, and insurance plans.ⁱ

Do I have a PBM?

Yes. If you have a health insurance plan, you have a PBM. In commercial plans, the PBM may be more controlling and restrictive, but even government plans like Medicare use a third-party PBM to help manage prescription drugs for their members.

Is my bleeding disorder medication impacted by a PBM?

Maybe. Historically, PBMs have not been involved in injectables like bleeding disorder medications because these drugs fell almost exclusively on the medical benefit side of insurance benefits and were thus immune from pharmacy claims. But recently, coverage for products to treat bleeding disorders has fallen under prescription drugs, and thus PBMs.

With that, PBMs have made inclusions and exclusions of certain hemophilia and VWD products on their drug formulary. If a VWD, hemophilia A or hemophilia B product is excluded by your PBM, they may not pay for that particular product and will likely intend for you to use another medication.

This means if you are a patient subscriber and your PBM does not support the bleeding disorder medication you are currently using or intend to start using, it may not be covered. Check with your health insurance plan and PBM for more information.

What about copay accumulator adjusters and copay maximizers? Are those part of PBMs?

Yes! Copay accumulator adjusters and copay maximizers are operated by PBMs. When the PBM institutes a copay accumulator, the money paid by manufacturer copay cards for your infusion brand product does not count towards your deductible and out-of-pocket but is instead absorbed by the PBM. You are still responsible for those out-of-pocket cost-sharing amounts.

PBM INVESTIGATION AND THE LAW

Why is Congress investigating PBMs?

To answer that question, you must first understand how PBMs make their money.

How do PBMs make their money?

PBMs earn their money in three primary ways:ⁱ

1. Through an administrative fee for their services
2. Through “spread pricing,” which is the difference between what is paid to pharmacies and the negotiated payment to health plans.
3. Through shared savings, which is the amount a PBM keeps from a discounted or rebated price from drug manufacturers.

PBMs also earn income by driving patients to in-house pharmacies or PBM-owned specialty pharmacies.

So then, why is Congress investigating PBMs?

According to testimony by a senior economics fellow, Karen Van Nuys, PhD, provided to the Senate Finance Committee this year, evidence shows that PBMs “leverage their position to extract profits in ways that are detrimental to patients, payers, and the drug innovation system more broadly.”

In other words, PBMs negotiate drug prices that are often more favorable (profitable) to themselves than more affordable for patients, and PBMs take money from the healthcare ecosystem that might be better served in drug development. Van Nuys also claims that PBMs increase drug costs and, as example, states that Medicare pays almost 21% more for the same drugs that can be purchased at Costco.ⁱⁱ

Going back to how PBMs earn money, some economists argue that the structure inherently favors PBMs seeking a higher drug price from a manufacturer because they could then increase the rebate amount and thus increase the PBM’s earnings. Furthermore, as another testifier to Congress put it, “PBMs force manufacturers to raise their list price, in exchange for formulary placement.”ⁱⁱⁱ

Remember, PBMs include and exclude drugs from their formularies. If a PBM excludes a manufacturer's drug, not only will patients lose access to that drug, but manufacturers would, necessarily, lose revenue from those potential drug sales.

Congress is investigating the truth of these matters and trying to answer the question: Do PBMs increase drug costs?

Are there any proposed legislative bills to address the PBM issue?

Yes, there are several proposed bills in Congress and the Senate. Here are a few:

HELP Copays Act (H.R. 830 | S. 1375): **"Help Ensure Lower Patient Copays Act"**

Seeks to require any third-party payment, financial assistance, product discounts or vouchers, copay assistance or other reductions to apply to a patient's out-of-pocket expenses.^{iv, v}

Patients Before Middlemen (PBM) Act: (S. 1967)

Seeks to prohibit PBM compensation based on the price of the drug as a condition of entering into a contract with Medicare Part D plan.^{vi}

Strengthening Pharmacy Access for Seniors Act (S. 2405):

Seeks to increase transparency measures on PBMs and provide seniors with additional options to fill their prescriptions. The bill would end limitations or restrictions that PBMs often place on certain medications without the PBM clarifying its reasoning.^{vii}

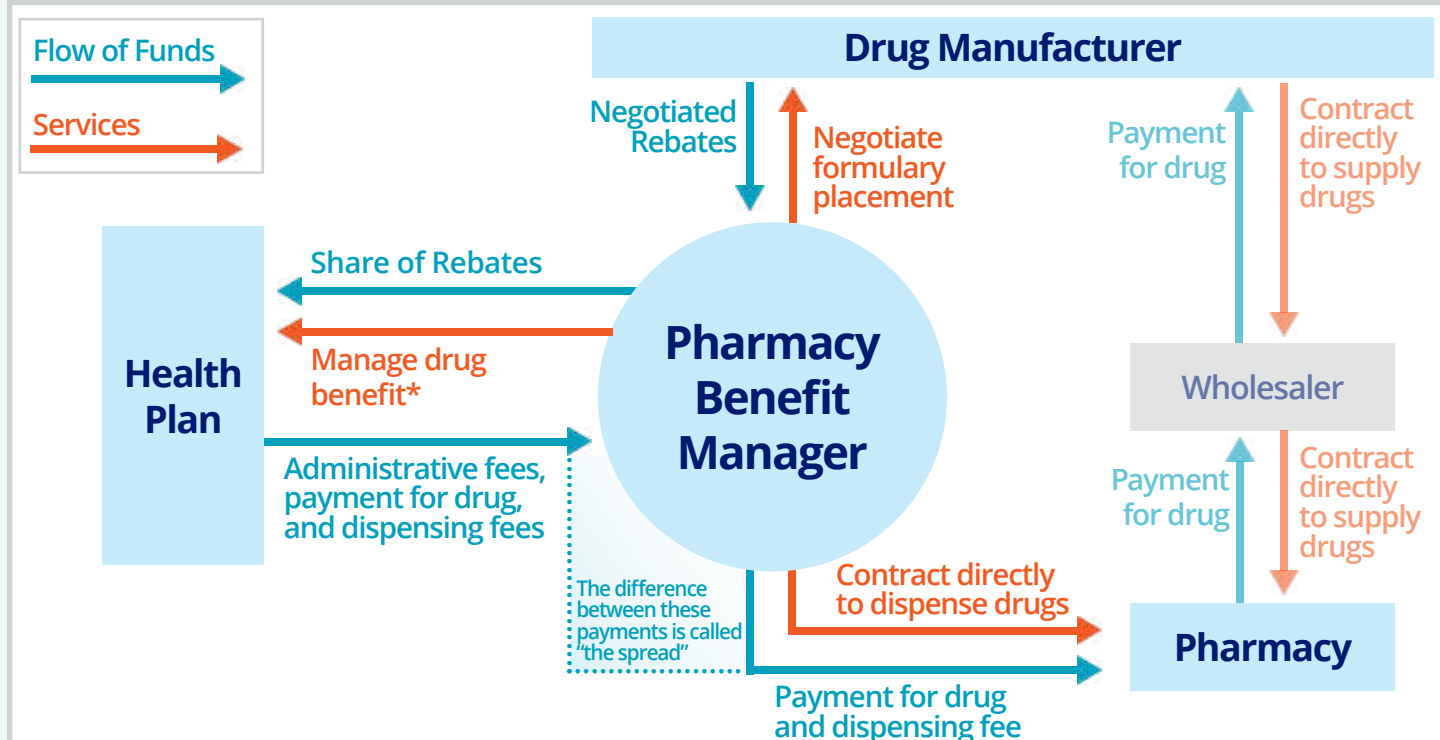
Pharmacy Benefit Manager Transparency Act of 2023 (H.R. 2816 | S.127):

These bills would make "spread pricing" (charging the plan a different amount than the PBM reimburses the pharmacy) illegal and would end "clawbacking" reimbursement payments made to pharmacies.^{viii, ix} Pharmacies do not "pay" the PBM, the PBM "clawback" or deducts paid claim funds directly from the pharmacy's bank account often without notice and/or with questionable reasoning, often weeks or months later.

Health Care Price Transparency Act (H.R. 4822 | S. 1130):

Aims to give transparency and access to pricing information on prescription drugs. Insurance plans must publish the in- and out-of-network charges for covered items and services and the negotiated prices for covered prescription drugs. Plans must provide a tool for consumers to search for this cost information.^{x, xi}

ROLE OF A PHARMACY BENEFIT MANAGER IN PROVIDING SERVICES AND FLOW OF FUNDS FOR PRESCRIPTION DRUGS



* Includes establishing formulary and patient adherence programs and implementing utilization management tools - such as prior authorization, step therapy, and tiering - to steer patients toward certain drugs on formulary.

Source: Elizabeth Seeley and Aaron S. Kesselheim, *Pharmacy Benefit Managers: Practices, Controversies, and What Lies Ahead* (Commonwealth Fund, Mar. 2019). <http://doi.org/10.26099/n60j-0886>

Hidden Fee Disclosure Act (H.R. 4508):

Requires that providers give patients transparent cost data from price comparisons before providing treatment. Aims to bolster requirements for PBMs to disclose compensation to plan sponsors and other fiduciaries.^{xii}

What's going on in Florida regarding PBMs?

So glad you asked! Florida is the first state to pass legislation restricting PBM operations within the state. The bill increases oversight of PBM operations and stops a PBM from requiring patients to use an in-house or mail-order pharmacy also owned by the PBM. Its intent is to return business to local pharmacies.^{xiii}

How is this going to affect me and my medication?

For the time being, nothing will change. Florida residents on state plans may see some differences next year through fewer restrictions and increased pharmacy choices for their prescriptions. The Congressional bills are yet in the future but can result in positive outcomes for patients should they gain support and become law.

What about the Federal Trade Commission (FTC)?

The Federal Trade Commission is also investigating PBMs for anti-competitive practices, the same issue that caused them to intervene in the 1990s with pharmaceutical manufacturers and their own PBMs. The six largest PBMs have been issued "compulsory orders." These require those PBMs to provide information and records of their business practices.

The FTC has indicated it is seeking information on leveraging fees and clawbacks to non-affiliated

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pharmacies; steering patients to affiliated pharmacies; using opaque reimbursement methods; and negotiating rebates with pharma manufacturers that impact patient drug cost.

The FTC has also withdrawn its past letters of advocacy for PBMs and has deemed their past conclusions unreliable at this point. Basically, the FTC is saying that what they determined ten or more years ago about PBMs is no longer valid; they want to re-investigate PBMs and draw a more current conclusion regarding anti-competitive behavior.^{xiv}

What can I do?

If you want to learn more about PBMs, reach out to the BioMatrix Education Team at education@biomatrixsprx.com. You can also contact your Congressional representatives in support.

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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.

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.

BEYOND THE *Swagger*

BY FELIX "SWAGGER" JACQUEZ GARCIA

Back in the day (pre-2000s), most adult community members with severe hemophilia had joint damage from lack of prompt treatment, perhaps an inhibitor, or the infamous hardheaded noncompliance from which some of us suffered. Though plenty of damage happened in wrists, elbows, and shoulders, it seems most of it was in weight bearing joints – hips, knees and ankles. This resulted in many of us having an obvious limp. We accepted that limp and among our blood brothers found humor in it (call it a coping mechanism). We referred to it as the *Hemo Swagger*.



In high school and before my first total knee replacement, I used a cane to get around. I owned that *look* like I bought it with a Visa card! I even had a couple of fancy tweed and felt hats to complete the haughty look. After healing from knee replacement surgery, it was hard for me to stop carrying the cane. The swagger was gone (at least for a while), and I didn't need the help to walk, but my cane had been a part of me for such a long time, I struggled to leave it behind.

After high school, I got involved in the bleeding disorders community and quickly realized I wasn't alone. The *Hemo Swagger* was a trademark look at every bleeding disorders event I attended! Hemophilia Federation of America even had T-shirts printed with the phrase "*It's not a Limp, it's a Swagger!*" You knew exactly who the blood brothers were by watching them walk from one meeting session to another.

Some of you with young children may feel the urge to feel sad for us about this, but please don't. The sight literally would bring a smile to my face. I fit in like nowhere else, and that feeling brought me joy. I like to think most of us felt comfort seeing us together like that. Not that we wished pain and discomfort on anyone else – we certainly didn't, but it brought us a sense of comfort and belonging to know we were not alone in the diagnosis and effects of having a rare bleeding disorder.





In the early 2000s, I began attending advisory board meetings for pharmaceutical companies. I had the opportunity to help influence manufacturers' educational and marketing materials, the types of programs they sponsored, and even where they focused their research. I remember participating in a meeting and being asked what we saw for the future of hemophilia treatment.

The two biggest hopes most participants had were treatment in pill form and treatment via subcutaneous injection. At the time, we were told by the experts that neither was realistic. However, the company thought a long-acting product might be the next big thing. For the sake of preserving veins and ensuring prophylactic routines, each of us agreed the improvement would be beneficial for our community.

Fast forward a few more years, and the first long-acting product hit the market. Soon after, multiple products became available for both hemophilia A and B; treatment options have expanded to allow prophylaxis to become easier for most, and especially for the younger generations. This was the beginning of the decline of the swagger, which for all sorts of reasons, was not a bad thing.

The evolution of treatment has brought more convenience, efficacy, and less intrusion into the lives of those with a bleeding disorder. This has resulted in increasing adherence to treatment plans and decreasing Annual Bleed Rates (ABR), making it harder to identify a person with a bleeding disorder just by their gait!

Older guys like me have had surgeries and joint replacements, and many of us now walk with no or barely noticeable limps. The younger generation is faring even better with improved access to health care, new and improved factor products, and prophylactic care. A patient must no longer wait for a joint or muscle bleed to be out of control before receiving treatment.

I still smile when I look at our community gathering at meetings, but now it's not the Hemo Swagger that makes me smile. It's the fact we still come together as a community, we still find a commonality, and we still find joy and comradery in one another's company. I hope future generations never have to experience life with a permanent hitch in their gait, but I am proud to have

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lived through the days when it was almost impossible to avoid. For those of you who may still have one or if you remember those days, we are family. May we 'swagger' together for years to come!

If you are young and healthy enough to have hopefully avoided serious knee or ankle issues, be sure to thank a "veteran" blood brother or sister for paving the path. Our community fought hard for access to care, demanded better treatments, and pushed for all these new treatment technologies we enjoy today, and more coming in the future (I'm still pushing for a factor pill!).

And about my cane? Since my surgery and treatment have been successful, my cane is now used to shift the AC vent up and down. Don't worry bleeding disorders family, our bond - whether visible or not - still runs deep through our veins. **#HemoStrong**



MOVING FORWARD

BY JULIAN MACDONALD

When I was young, I lacked a dream to chase. My head was always in the clouds, without a goal on the horizon to pursue. My days were filled with school, television, and sleep. There weren't a lot of things that piqued my interest.

My parents recognized my dilemma and tried to get me involved with any hobby or sport possible. As a result, I wore many hats as a child, painter, potter, and even a boy scout. However, it was a trip to the nearby local theatre that filled me with dread. I asked my dad to please call off the meeting with the director, but he wouldn't. He was certain that he had found it for me: the spark. It brings me no joy to admit he was, in fact, right.

No matter how hard I tried not to enjoy performing, it intrigued me. I had found my home... my passion. Nothing makes me so excited or fulfilled as when I am singing on a stage. My first audition became the catalyst of many to come.

I didn't have many problems pursuing theater as my life's work - not stage fright, not passion, not even hemophilia. When it came to my bleeding disorder, I was fortunate. Although I have severe hemophilia A, I had not experienced a joint bleed or any extreme complication until I was in middle school. I did have an inhibitor at an early age, but after almost three years of immune tolerance therapy, my inhibitor was eradicated with no long-lasting effects.

I started becoming aware of how my condition might change how I am perceived by others. I learned it was common *not* to disclose one's diagnosis of hemophilia to some people for fear of discrimination. It was important to keep that information confidential unless disclosure was necessary. Unfortunately, I did a remarkably terrible job of keeping it secret. As a kid, I experimented with the idea of making it a part of my social identity.

As I grew older, I was desperate to find somewhere I belonged. Hemophilia camp was that place for me. I didn't know it at the time, but being around other people who dealt with the same condition I have was a critical part of finding myself. It helped me



build confidence and understand how my body functioned on a practical level. At camp, I learned to self-infuse, thereby becoming entrusted with my own treatments. Three times a week on my own, I maintained my regular infusion schedule.

My teenage years were complicated. I became tired of the prophylactic treatments, and since I had not experienced any serious bleeds, I did not see the point in continuing to infuse nearly every other day since nothing bad ever happened. It became a battle every few days for me to even acknowledge my own disorder.

I enjoyed forgetting about it, but I was always reminded that I was not cured, just fortunate. I got to where I was learning my limits. I would neglect treatment and infuse when I felt a symptom begin to appear. I knew how long I could go without infusing and could sense when a bleed was about to happen. Playing this game, I thought I could do whatever I wanted and that I would never have any consequences. When something had been a part of my life for so long, it was hard to realize that it could complicate my future. Hemophilia was always there; why would it get worse?

I never thought about what a bleeding disorder might mean for my career or what might happen when I moved out on my own. It only takes one terrible bleed to change

how active you can be, and in my line of work, mobility was the name of the game. It was just another thing I had not considered. In theatre, anything can go wrong. From mishaps on stage and demanding schedules to long hours of repetitive physical activity, my bleeding disorder could become problematic.

Moving out of my parent's house and pursuing the last years of college led to a great deal of change, including a change of blood clotting product. The limits I had tested for myself became irrelevant. I had been on the same product for nearly twenty years, and I was still having issues maintaining a treatment schedule. New medication was uncharted territory. Initially it was not as effective and there were a great deal of mishaps, bleeds, and medical scares that I hadn't experienced before.

Toward the end of my college career, I started to achieve meaningful growth as a person and a performer. I was offered my first professional opportunity in the theatre. I struggled for years trying to force myself out of mistreating my old medical routine and I knew my lack-of routine was unsustainable. If I was going to pursue my future, I had to confront what I had been running from: my own bleeding disorder. Pretending it did not exist was never going to secure my physical health, but regular medication would.

I still had issues keeping my hemophilia under control, but I was having more success with the new medication. It turned out being compliant with a treatment plan kept the

symptoms at bay pretty effectively.

Having graduated college, I feel there are a great deal of possibilities open to me that were not before. As a full-time performer, I now find myself in a constant rehearsal cycle, and it is exhilarating. Through intense dance routines, long hours of movement, and still having the energy to be with friends, my disorder does not get in the way.

I spend every day among accomplished professionals with the same devotion to their art the way that I have come to appreciate. In achieving compliance with my medication, I have found confidence I didn't know I could have.

My disorder hadn't been getting in my way; it was me. The liberating part about actively confronting my diagnosis was that I could free myself of the obstacles that kept me subdued. Having a medical diagnosis was never something I could control, and I spent a long time running from it. However, I can take charge of my own future. It turns out a big part of that was as simple as a little discomfort and inconvenience in exchange for a world of possibilities.



Let's get together to talk about IXINITY®

“

My own diagnosis keeps me very attached to this community as a family. I love seeing someone with a bleeding disorder accomplish something they thought they couldn't, and I live for helping them to get there.

Myles Ganley,
Community Experience Manager



▶ Scan me
or visit
IXINITY.com
today!

▶ Contact Myles at 208-602-0780 or myles.ganley@medexus.com

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IXINITY®
coagulation factor IX
(recombinant)

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.

NEW MEXICO

Felix Jacquez Garcia

BioMatrix enjoys working with our pharmaceutical partners to host educational gatherings, so, when Sanofi CoRe Manager Alexandra Abreu asked if we would like to host a **Community Dinner** together to discuss their new Factor VIII product, we jumped at the opportunity. We gathered May 18th with our guests at Albuquerque's Andaluz Hotel where UC Davis HTC's co-director and Sanofi speaker Dr. Adam Giermasz presented information on Altuviiiio™ sparking questions and dialog about the product and treatment in general.



Sean and Reylene enjoy dinner

After dinner, we raffled two summer yard games. One of the winners gave their prize to a child in the group – such a sweet thing to do! Thank you to Sanofi for partnering with us to bring information and a reason for the community to gather!



Lakeia, Dave, Rodney and Gary



Gina, little Xavier and Vanessa

FLORIDA

Peggy Klingmann and Marcy Foertsch

Sanofi and BioMatrix came together June 23rd for an **Educational Dinner** to provide information and an opportunity to bond with bleeding disorders community members. We met our guests at Tampa's Maggiano's Little Italy where appetizers were served as pediatric hematologist Dr. Guillermo DeAngelo gave an engaging overview of the new Sanofi factor product, Altuviiiio™. Following his presentation, we led our BioMatrix game of *JeoParody* based on bleeding disorder-related topics. Did you know concentrated factor products were invented in 1967, or that the first human gene therapy trials were done in 1990? Our audience learned this and so much more. The competitive spirit was high in each team with everyone coming out a winner!

We concluded the enjoyable evening and look forward to our time together in the future. Thanks so much to Eric Burgeson of Sanofi for helping us bring our *JeoParody Challenge* to the Tampa community.



Thumbs up! Gale, Michael, Crystal, Christina, Sonny and Sarah

TENNESSEE

LeAnn Wilson and Cyndy Coors

The theme for Tennessee Hemophilia Bleeding Disorder Foundation's (THBDF) **53rd Annual Meeting** was *Better Together - One Blood • One Family*. Gathering at the Embassy Suites in Murfreesboro the weekend of June 2nd-4th. The event began with casual time to meet up with friends and visit industry representatives staffing the booths. The evening gave way to a reception dinner and welcome, followed by a variety of rap sessions covering topics such as *Women's Initiative* and *Dad's in Action*.



And the gift basket goes to Shelby!

Saturday was packed with presentations and breakout sessions. Topics included titles such as *Being Prepared for a Hemophilia Emergency* and *Bleeds: How to Recognize and Respond*. BioMatrix Director of Advocacy and Education Terry Rice presented *Financing with a Chronic Illness*, which garnered lots of interest and fostered participation.

We wrapped up the weekend at Grove Williamson Family Farm, a local party venue where we enjoyed live music by talented blood brothers and sisters, tasty barbecue, door prizes and visits to the Black Box ice cream truck for dessert. Thank you to THBDF staff and volunteers for putting together this memorable weekend!

FLORIDA

Hector Heer and John Martinez

Hemophilia Foundation of Greater Florida celebrated the **23rd Annual Family Program** at SeaWorld Orlando June 3rd with a fabulous day of education and fun in the sun! Technically though, it was cloudy, but families brightened the occasion with big smiles and delight as they arrived to participate in this highlight event.

As families approached the main conference room, they had the opportunity to visit the row of sponsors providing information on new therapies and products. Once inside, breakfast was served to start the day energetically. Executive Director Fran Hayes welcomed everyone and joyfully celebrated the attendance of over 500 at this





Who has the answer?

Jose collects his prize!

long-standing and coveted event.

BioMatrix was then introduced as the primary content provider of the event, and we brought our bleeding disorders *Jeopardy* game! The room was divided into large teams, who then recruited a volunteer to represent them. Each team was tasked with coming up with a name. This simple task ruptured into jubilant rounds of laughter and communal support. Beginning the game, each team volunteer chose a category and monetary value in sequence and used the knowledge of their teammates to try to provide the correct answers. As the game progressed, each team became more competitive while the volunteers ran table to table to obtain potential answers. Even the most knowledgeable and experienced people were challenged with some of the questions providing opportunities for energetic interactions.

Once the game was over, there was a clear winning team, but the participants wanted to keep playing, so a second *Jeopardy* board was introduced with quicker play participation rules enacted, and the invigorating competition continued! When the game ended and prizes were raffled, the guests made their way to enjoy time at SeaWorld.

Thank you to the Hemophilia Foundation of Greater Florida, and to the staff and volunteers who help make this program such a wonderful success!

OHIO

Shelia Biljes

Life is sweet! So, sugar was the theme at b.a. Sweetie Candy Company in Cleveland as BioMatrix partnered with



Brandon flashes his gorgeous smile!



Stephanie and dad, Chris

HEMA Biologics and Northern Ohio Hemophilia Foundation June 8th to present a family fun-filled **Educational Dinner**. Justin Lively of HEMA Biologics began the event with an overview of SEVENFACT[®] as dinner was served. Shelby Smoak, PhD, BioMatrix Education Specialist, followed with a new program called *Constructive Communication with Your Healthcare Provider*.

Then we had an entertaining presentation of personality comparisons based on favorite candy choices, which resulted in hearty laughter. Did you know that if your favorite candy bar is an Almond Joy, you're

considered a flirt? Butterfinger lover? You're a smooth talker and articulate, but a little sneaky.

Families were invited to enjoy a refreshing treat from the Soda Shoppe and a round of mini golf on the Candyland course in Sweetie Golfland Park. The kids were full of vim and vigor as they left Sweetie Soda Shoppe. What a way to celebrate the end of the school year as we kicked off the summer season!



Big smiles, full bellies!
Brylin and Brook

NEW MEXICO

Felix Jacquez Garcia

BioMatrix was pleased to partner with Novo Nordisk June 8th for a Fireside Chat and Dinner at Albuquerque's M'tucci's Italian Restaurant. The featured speaker of the evening was Novo Nordisk Patient Ambassador Bradley Odac. Bradley spoke of his origins in Kenya and testified on the contrast between hemophilia treatment in Kenya and that of the care he receives in the US. His presentation was eye-opening and inspiring. We hope the youth in the audience heard his message and appreciate the access to care they have and realize how much they can accomplish in their lives.



Bradley and Stacey



Hiram and Felix Garcia



Isabel, Tice, Lakeia, Dave, Gary and Carla



(Right) Jennie, Jessica, Hailey, Annmarie and Haylee; (left) Stacey, Bernadette, Sean, Reylene, Felicia and Vanessa



Tanya, Zach, Carlitos and Rodney

Closing out the evening was an overview of the BioMatrix *Patient Navigation Program*. Open to all members of the bleeding disorders community regardless of specialty pharmacy affiliation, this program is for those who may be facing challenges related to insurance, financial hardship, or other nonclinical issues impacting coverage or access to treatment. BioMatrix has designated patient navigators available to help patients work through obstacles in securing and understanding health insurance and applying for or maintaining Medicare or Medicaid. To apply or for more information, patients may contact their BioMatrix Regional Care Coordinator or visit: bit.ly/bd-patientnavigation. Many thanks to Novo Nordisk for their continued support!

PENNSYLVANIA

Tina McMullen

King of Prussia's Sheraton Valley Forge Hotel was the place to be June 21st for Eastern Pennsylvania Bleeding Disorder Foundation's (EPBDF) **Annual Meeting**. The large gathering of about 165 attendees had the opportunity to visit industry personnel at the specialty pharmacy and manufacturers' booths and to reunite with other attendees in the expansive exhibit area.



Mom and Son!
Vicky and Tommy

The event kicked off with opening remarks by Executive Director Sarah Ross Pilacik who spoke of the Foundation's 50 Advocacy Ambassadors and the important work they do with state legislators. Guest speaker, Regina Butler, RN-BC, Clinical Manager for the Division of Hematology at Children's Hospital of Philadelphia, led us through the HTC's history and its growth over the past 50 years. Her presentation walked us through the treatments in 1973 to all our current treatment options. For many of us in the Philadelphia bleeding disorders community, Regina has a special place in our hearts. We have been blessed to have her on our children's medical team.

The evening concluded with Board President Leonard Azzarano giving remarks on the EPBDF's history and how it is moving forward. Sarah Pilacik and Lisa Lee, you both knocked it out of the park! The Annual Meeting was a huge success. I, along with the entire bleeding disorders community, look forward to future events with the Eastern Pennsylvania Bleeding Disorder Foundation!

NEW JERSEY

Richard Vogel and Carolina Luna

On a mild June 21st evening in Newark more than 30 community members arrived at Don Pepe's Restaurant for an informative **Educational Dinner** sponsored by Sanofi and BioMatrix. Community Relations and Education Manager Manny Lopez-Serrano spoke about Sanofi's once-a-week factor VIII replacement therapy, Altuviio™. He provided a detailed understanding of the importance of factor activity levels and why they are more than just peaks and troughs. Manny was engaging and community members responded with lots of questions.



Spreading brightness!
Milinda and Milybet

BioMatrix Educator and RCC John Martinez presented an interactive program *Camera On: Photography and the Art of Healing*, which discussed art, the brain, and healing through photography. He explained terminology and techniques that enhance picture-taking ability while finding relaxation in the process. John had the group run through various exercises using the techniques he explained. At the end of the evening, we shared our photos, and the results were amazing. Many thanks to Sanofi for partnering with us on this enjoyable and enlightening event.

NEW JERSEY

Carolina Luna and Rich Vogel

¡No hay nada mejor que compartir buena comida con buenos amigos! (There's nothing better than sharing good food with good friends!) And that was the case at the **Spanish Educational Dinner** at Don Pepe Restaurant June 22nd. Spanish-speaking community members were happy and enthused to participate in the program sponsored by Sanofi and BioMatrix. Education Manager Manny Lopez-Serrano and via Zoom from Puerto Rico, Dr. Leslie Soto discussed Sanofi's once-weekly Factor VIII replacement therapy, Altuviio™. An extensive Q and A followed about factor levels and why they matter.

BioMatrix Educator/RCC John Martinez presented *Encienda Su Cámara: Sanación y el arte de la fotografía (Camera On: Photography and the Art of Healing)*. John discussed the art of photography and the healing, stress-relieving powers available right at your fingertips using your cell phone camera. John gave us techniques and tips to improve our photography skills and relax through the lens of the camera. Everyone had fun with the exercise, especially when John shared our pics on the big screen! The evening ended with all declaring, "¡Gran presentación!" (Great presentation!) Thank you to Sanofi for partnering with us!

VIRTUAL EVENT

John Martinez

BioMatrix understands the need for all patients to understand the complicated world of insurance. To this end, we hosted a virtual event in Spanish on **Insurance Basics (Información Básica de Seguros Médicos)** June 24th. Folks gathered in a high-energy virtual environment eager to connect and learn in a comfortable setting, and in a language they could understand. The program is an overview of the terminology necessary to navigate the basics of insurance and working with insurance providers. Participants were engaged and asked pertinent questions that contributed to a greater understanding of an often-complex topic.



BioMatrix RCCs, John Martinez, Felix Jacquez Garcia, Gaby Griffin, and Eva Kraemer with Blanca, Manuel, Anna and Isaias, Lucia and Monica

Everyone then joined in a fun-filled Spanish version of BioMatrix *JeoParody*. Most had a familiarity with the game and soon engaged in this family-friendly competition during rounds of questions and answers. Though the final scores were close and there was a clear winner, everyone still felt like a champion!

Closing out the evening was an overview of the BioMatrix *Patient Navigation Program*. Open to all members of the bleeding disorders community regardless of specialty pharmacy affiliation, this program is for those who may be facing challenges related to insurance, financial hardship, or other nonclinical issues impacting coverage or access to treatment. If you or your organization are interested in one of our programs offered in Spanish, please reach out to us at education@biomatrixsprx.com.

TENNESSEE

LeAnn Wilson

BioMatrix has several educational programs that stand out and our **Sewing to Heal** program takes the cake! With an overwhelming amount of interest, Nashville community members arrived June 30th at Home2 Suite in Nashville ready to sew. After a quick meal and short introductions by sponsors, Medexus and HEMA Biologics, BioMatrix Regional Care Coordinator Shelia Biljes took the floor, explained the project, and reviewed the tote bag materials for each person to complete.

Seasoned and novice sewing machine operators prepared to begin. A couple of older children decided to try their hand at sewing as well, including an 8-year-old boy. From that moment on, it was pedal to the metal for some; for others, more of a nervous start, but nonetheless everyone was sewing!

At times it seemed as if the worries of the day-to-day stress lifted from the shoulders of each person. Soon, laughter filled the room with many expressing surprise at not having sewn a finger or two! (Note: No one suffered any injuries while sewing!)

By the end of the event, everyone was proud to display their completed tote bag and happily gathered to take pictures with the group. Some were filled with so much pride they mentioned they could see themselves working for Vera Bradley! Thank you to our sponsors and to Shelia for showing us just how fun and relaxing sewing can be!



Haylee & Matthew



Shelia & Willa



Sewing Champs!



Almost done!



Millie, Ollie & Jen



Shelia & Dr. Domm



Ollie & LeAnn



Morgan & Tara



Hamming for the camera



LeAnn & Shelia helping



Rich, Joe & Alexa



Lily & Milly



Flor & Leslie



Rich



Chris

NEW JERSEY

Richard Vogel

On the warm, summer evening of July 12th, guests arrived to experience a new community event that combined education, great food and sewing as a stress-relieving technique. Sheila Biljes, assisted by LeeAnn Wilson, both BioMatrix Regional Care Coordinators, arrived early at Bella Napoli in Bloomfield to set up 20 full-sized sewing machines to present **Sewing to Heal**.

The evening began with dinner and a presentation by Takeda's Jan Martin MSN, RN-BC, CPN who led an interactive discussion on why *Women Matter in Bleeding Disorders*, covering different types of bleeding and the difficulties of women obtaining a proper diagnosis.

Sheila then shared her story about how her doctor suggested she start sewing to help with stress after experiencing a period of overwhelming issues. Somewhat skeptical, Sheila tried it and found the doctor was on to something! It worked so well, Sheila was inspired to develop an educational program where women can relax, share stories, and sew a project to take home. On this evening, the women and some men made beautiful tote bags. Sheila had pre-cut the material so all we had to do was sew the pieces together.

Everyone bragged about their newly found sewing talents as the evening wrapped up over coffee and Italian pastries. Many thanks to Takeda for partnering with BioMatrix to bring this unique activity to the community!



Leslie

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix and Bayer partnered July 12th for an **Educational Dinner** at Columbia Restaurant in historic Ybor City. Bayer introduced patient speaker Juan Pablo Lopez, the first in his family to be diagnosed with hemophilia A, who detailed his journey from Mexico to the United States as a young child and spoke of his challenges with a bleeding disorder.



BioMatrix then brought out the fun with our bleeding disorders version of *Loteria*! Much like Bingo, cards were called out, *La Farmacie!* *La Sinovitis!* *La Jeringa!* as players marked their boards. Barbie Arrebola of Bayer helped moderate the game, and after four rounds, winners received candy treats. Thanks to all our community members who came out, and thanks to Bayer for partnering with us and helping make this event happen!

NEW MEXICO

Felix Jacquez Garcia

July 12th in New Mexico was surely a hot day when the Albuquerque bleeding disorders community came together to fill the meeting room at County Line Barbecue for an **Educational Dinner**. It was great to have everyone gather to break bread, take in education and spend quality time. Genentech generously sponsored this event and we were fortunate to have two Clinical Education Managers on hand, Derek Nelson, who has been a staple at events for years, and we were introduced to Terry Gooch, who is transitioning to take Derek's place in New Mexico as he moves on to another role. Though Derek will be missed Terry will be a welcome addition to our community events.



Sponsors/Speakers: Terry Gooch, Olivia Kidd, Dr. Salinas and Derek Nelson

Genentech also brought in two wonderful presenters: Pediatric Hematologist Dr. Vanessa Salinas Luna of CIBD HTC in Orange, CA, and Olivia, Hemlibra ambassador and mom of an affected son. The two teamed up in a presentation giving a clinical and real-life scenario of using the Genentech product. The dialog between the presenters and the audience was lively and it was a great opportunity for patients to ask questions and hear the opinion of other experts.

BioMatrix shared information about their *Patient Navigation* program, open to all members of the bleeding

disorders community regardless of specialty pharmacy affiliation.



Hailey, Haylee and AnneMarie, Sean, Reylene and Xavier (There's always *that* one kid...)

This program is for those who experience challenges related to insurance coverage, difficulties accessing prescribed therapy, financial burdens due to medical care, and more. If you or someone you know needs help with any barrier to care, please visit our website (bit.ly/bd-patientnavigation) and request the completely confidential assistance of our professional Patient Navigators.



Maria, Carmen, Vanessa, Felicia and Monica



Monique, Keith and Carlito

A New Mexico event just isn't complete without a raffle! Congratulations to Reuben Jr. for winning the raffle prize - a cooler packed with summer time necessities. Remember to use the sunblock!



Raffle winner! Reuben Jr. and his dad



Adrian, Angela, Jess, Bernadette and Jennifer



Alyssa, Debbie, Kevin, Michelle, Nathan and Reuben Jr.



Mikayla, Sean, Mikayla, Elias, Pops, Matthew, Daniel & Janisa



Owen, Alex, Reuben, Jr., Paulette and Reuben, Sr.

PENNSYLVANIA

Shelia Biljes

Mother nature had mercy on us July 16th with a sunny but not a terribly hot day in Pittsburgh as over 120 people gathered at the Sheraton Hotel Station Square for Western Pennsylvania Bleeding Disorders Foundation's (WPBDF) **Annual Meeting**.



Shared smiles! Chris and Shelia Biljes

Upon arrival, guests were offered plenty of time to meet up with community friends and visit the event sponsors at their booths in the exhibit hall. As dinner was served, Executive Director Kara Dornish cordially greeted everyone and gave the foundation's state of address, discussing its services and programs, reviewing events over the past year, what to look forward to in the months to come, and honoring its top volunteers.

When the meeting wrapped up, families walked down to the pier just outside the hotel to board a Gateway Clipper for a sunset cruise down the Pittsburgh River. Many thanks to WPBDF for hosting this enjoyable mid-summer event!

OHIO

Shelia Biljes

Do you know that a swarm of ladybugs is called a *loveliness*? The ladies of northern Ohio definitely formed a loveliness as we gathered at Medina's Santosuossos Restaurant for our monthly **Ladies Educational Luncheon** July 20th.



June

While the women were treated to a delicious Italian meal, Bayer Community Educator Wendy Perkins presented *Understanding PK Studies* and led the conversation on their importance. Following, the group enjoyed a round of



Rose



Kristen and Arwyn



Mariana

ladybug trivia and learn things they may never have even wanted to know about the cute little bugs! A ladybug craft ended our session, and eventually, everyone realized it was time to head home. Thank you Bayer for sponsoring another meaningful and delightful luncheon!

NEW JERSEY

Richard Vogel

Like most of the country, New Jersey has been having record hot temperatures this summer. One way to beat the heat is to jump in a cooling swimming pool. Hemophilia Association of New Jersey provided a refreshing opportunity July 23rd with their **3rd Annual Summer Wellness Gathering** at the Eagle's Landing Day Camp in North Brunswick. Eagle's Landing has ALL the fun one camp can offer including a beautiful 20-acre facility with 4 sparkling pools, a spray park, soccer and softball fields, 3 full-size basketball courts, a sand volleyball court, and a 9-hole mini-golf course. CSL Behring sponsored special swim clinic sessions for young children and teens.

After lunch, playfulness ensued. It was great fun just watching as folks of all ages enjoyed the activities from the water slide to the big water bucket. Though it was hot, it was worth seeing the smiles on faces as everybody came away with enough fun memories to last until next summer!



David and Luis

Erder, Maria, Jenifer, Noah and Carlos

OHIO

Shelia Biljes

Take me out to the ball game! Ohio weather did not disappoint July 23rd for Northern Ohio Hemophilia Chapter's (NOHF) **Family Education Day and Cleveland Guardians Baseball Game**. The cheerful group gathered at Cleveland's Garden Hilton for breakfast, time with industry sponsors, and instructions. Massage therapist Mandy Bartolovich presented a demonstration on her techniques with bleeding disorder patients, now being offered at the Cleveland University HTC. The program also included a demonstration on K-taping for joint health and yoga breathing instructions. Something for everyone!

Following the presentations, a short walk to the baseball stadium



All in the family! Shelby & Matthew with Mayson, Kayleigh & Matthew



Guardian Fans! Joe & Kitty



Peanuts or Cracker Jills?

had everyone basking in the sunshine as the Cleveland Guardians took on the Philadelphia Phillies. Though the Guardians lost, a couple of late-game scores brought anticipation and hope, making the eventual loss easier to swallow. Many thanks to NOHF for hosting this exciting summer event!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Sponsored by HEMA Biologics and BioMatrix, an **Educational Dinner** was held July 26th at Tampa's Brio Italian Grille. During dinner, Travis Perry of HEMA Biologics presented information and fielded questions about their SEVENFACT[®] factor replacement product.

Following Travis was BioMatrix Advocate and Education Specialist Dr. Shelby Smoak who gave an engaging presentation titled *No Need to Bleed*. The program focuses on hemophilic arthropathy, microbleeds and the long-term effects of bleeding. Everyone was receptive to listen and eager to participate in the discussion.



Christina, Sonny, Destiny and Mason

Following dinner, our community members shared stories and ideas as they sought out Travis and Shelby for a few final thoughts. We thank our co-sponsor HEMA Biologics and look forward to being together again soon!

OHIO

Shelia Biljes

"Education is the Passport to the Future, for Tomorrow Belongs to Those Who Prepare for it Today," a quote by Malcolm X kicked off the **Annual Back to School Event** hosted by Sanofi and BioMatrix August 7th. North Canton's Twisted Olive Restaurant was the perfect setting to review a few basics as kids headed back to school. Backpack safety and storing clotting factor at school were the main topics.

Community Relations and Education Manager Laith Elkurd presented an overview on Sanofi's product Altuviiiio[™], answering many questions on the new treatment for hemophilia A. Following his presentation, it was time for the school-age children to "earn" school supplies by answering trivia questions.

Many thanks to Sanofi for partnering with us for this engaging evening!

ILLINOIS

Eva Kraemer

Having a bleeding disorder is one facet of a person's life, but not all. Medexus and Octapharma joined BioMatrix to acknowledge this by hosting an **Educational Dinner** August 12th at Brookfield's Pisan's Pizzeria. Axel Freese gave a motivational presentation about the importance

of finding your vocation in life and his journey to find his own. Everyone then headed to a neighboring arcade for some good old-fashioned pinball and video games.



BioMatrix is committed to providing our Illinois bleeding disorders community unique opportunities to network and share. Many thanks to Octapharma and Medexus for collaborating and co-sponsoring this event with us!



Alex Freese: "When you got it, you got it!"

VIRGINIA

Terry Stone and Michelle Stielper

Nothing screams summer fun like an old-fashioned picnic! The Hemophilia Association of the Capital Area hosted its **Annual Family Picnic** at Lake Fairfax Water Mine Park in Reston on a very hot and sunny August 13th. The gathering started late morning with hugs and hellos, followed by a perfect picnic lunch from Willard's Real Pit BBQ. After lunch, families visited and caught up, marveled how much all the kids have grown, and ran back and forth from the picnic pavilion to the water park where everyone spent a fun and fabulous day together.



Mona, baby Felix and RCC Michelle Stielper

BioMatrix was pleased to help sponsor this family event, and thanks to all who donated to the HACA clothing drive for those in need!

OHIO

Shelia Biljes

Threats of storms cannot keep the ladies of northern Ohio from gathering for our monthly **Educational Lunch**. Sponsored by Novo Nordisk, the women met at Bucc'i's J-Bella Italian Restaurant in Strongsville August 23rd. It was the first day of school for most local children, so moms in the group were excited to arrive and relax.



Keiden and mom, Jessica

Before lunch, we painted suncatchers as Judy Doyle, Novo Nordisk Patient Liaison, told the story of the giant suncatcher hanging in the lobby of Akron Children's Hospital. Judy also facilitated *What's Your Infusion Personality?* an interactive game that determines the type of caretaker you are. Finding out I was a rebel was no surprise while others realized they fell into protector, advocate or commander categories. It was very eye-opening to some and no surprise to others! As lunch ended, the skies opened and torrential rain poured down, which gave a reason to stay and visit just a little longer.



Deborah and Edna



CONFERENCE RECAP

Justin Lindhorst

The National Bleeding Disorders Foundation (formerly the National Hemophilia Foundation) hosted its **75th Bleeding Disorders Conference** in National Harbor, Maryland August 17th-19th. Community members gathered from across the country to participate in educational programming, networking, and special events focused on remembering our past while plotting a new course toward a promising future. With an eye on inclusivity, the first major announcement came as the National Hemophilia Foundation announced its renaming to the National Bleeding Disorders Foundation (NBDF). Though the organization has long served individuals with VWD, platelet disorders, and other rare factor deficiencies, the rebranding represents a commitment by the organization to help all people with bleeding disorders feel welcome, served, and seen.

BioMatrix was proud to have our research poster, "Effectiveness of Patient Navigation in Resolving Health-System Related Barriers to Care" selected to be



displayed in the research section of the exhibit hall. The retrospective study presented findings from the first six months of our patient navigation program. The program aims to reduce health system-related barriers to care including insurance, social, and financial challenges associated with having a chronic bleeding disorder. Our sincere thanks to everyone who stopped by and reviewed our research.

With 75 years of experience hosting their annual conference, NBDF continues to provide bleeding disorders community members and professionals a high-quality event. Connecting with new and old friends, learning the latest advancements in treatment and care, and just spending time together does much to keep our community strong. Mark your calendars for next year's meeting September 12-14th in Atlanta, Georgia!

DELAWARE | MAINE

Tina McMullen

The rain in Chesapeake City August 24th held steady most of the day. Luckily, it subsided and gave way for Brandywine Valley Hemophilia Foundation members to attend a beautiful evening **Sunset Cruise** onboard M/V Summer Breeze 45' trident USCG COI. The evening began with a presentation by Mike Zolotnitsky, PT, DPT on Kinesio-taping sponsored by Octapharma. Mike explained the importance of, and demonstrated taping techniques. One can only imagine what people thought when they witnessed people disembarking at the end of the cruise with wrists, elbows, shoulders... pretty much every joint area covered in Kinesio tape!

During the cruise, we enjoyed views of the Elk River,

Chesapeake & Delaware Canal, and wildlife of the Upper Bay, while enjoying snacks of Wawa hoagies, chips, and cookies sponsored by BioMatrix. The ship's captain offered children and adults the opportunity to steer the boat, giving out captain licenses to those who did!

A big shout out to Board President Gail Novak for thinking outside the box on bringing a unique learning experience to the Brandywine Valley community. Many thanks to Octapharma and representative Paul Brayshaw for sponsoring the cruise. It is always a pleasure to offer our community education and have fun while doing so!



Gail Novak was SO excited to get her Captain's License!



The kids had so much fun!



Tina photobombs Mike and Paul



Good friends, Samantha and Matthew



Gail and Robert Novak and RCC Tina McMullen



Clean Up Crew! Tina, Rich, Robert, Gail, Paul and Chris

NEW MEXICO

Felix Jacquez Garcia

Thanks to a collaboration with Medexus, Octapharma, and BioMatrix, the Albuquerque bleeding disorder community got their stretch on as members enjoyed a light dinner followed by a demonstration of the **Stretch Zone** method August 24th.



Elizabeth enjoys her stretch session with Stretch Zone practitioner

After each sponsor rep said a few words of welcome and briefly introduced their product, the floor was handed over to Stretch Zone trained practitioners. They explained the tremendous benefits of the stretching process that uses a patented strapping system to position, stabilize and isolate muscles to allow for the best possible results with little resistance from the body. Then, the 10-minute sample sessions began! Congrats to lucky raffle winner, Alyssa, who came away with a Stretch Zone gift basket filled with goodies!



Congratulations to raffle winner, Alyssa!

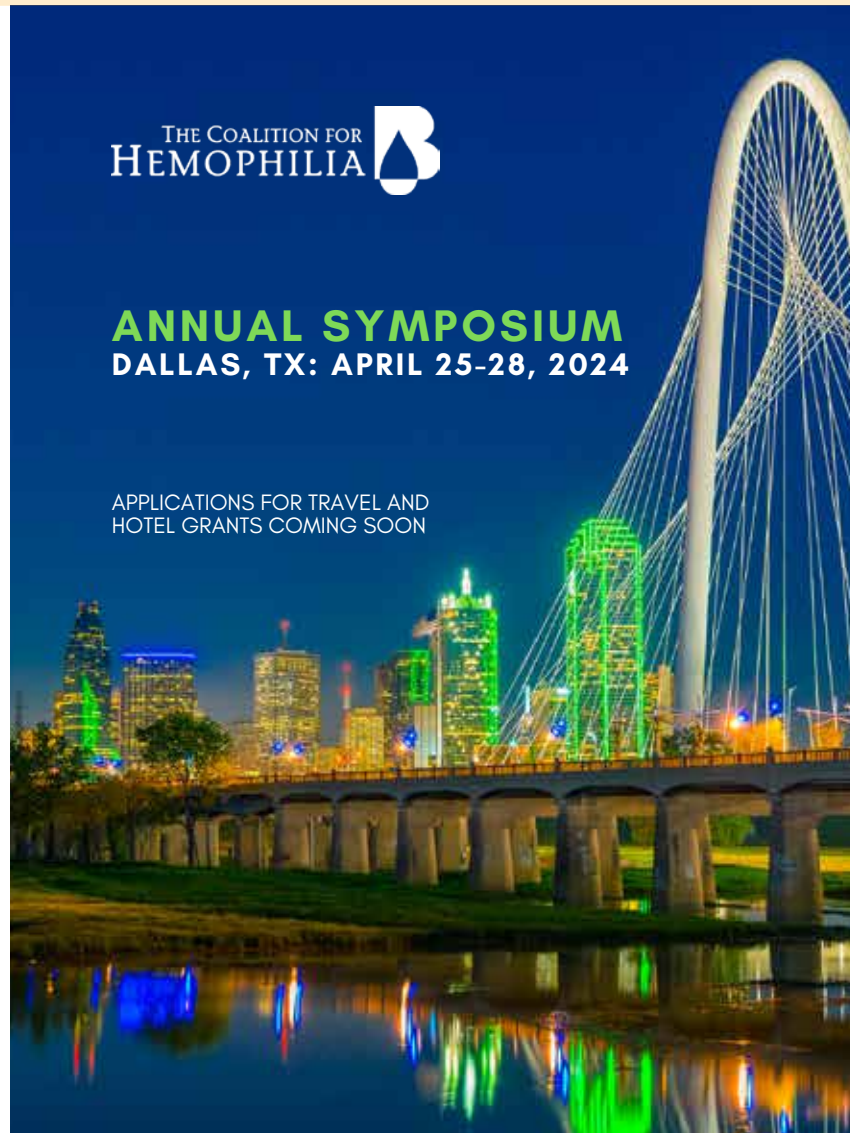
Thanks to Medexus and Octapharma for working with us to bring this unique event to the community!

THE COALITION FOR
HEMOPHILIA



ANNUAL SYMPOSIUM
DALLAS, TX: APRIL 25-28, 2024

APPLICATIONS FOR TRAVEL AND
HOTEL GRANTS COMING SOON



Upcoming Events

OCT 14, 2023 FLORIDA

Unite for Bleeding Disorders Walk
Florida Hemophilia Association
305-235-0717, <https://floridahemophilia.org>
Nova Southeastern University; Davie

Oct 16, 2023 OHIO

Fireside Chat and Dinner
Sponsored by Genentech and BioMatrix
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Burntwood Tavern; Cuyahoga Falls

OCT 18, 2023 OHIO

Ladies Lunch and Craft
Sponsored by Bayer and BioMatrix
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Tony K's Restaurant; Berea

OCT 22, 2023 CALIFORNIA

Unite for Bleeding Disorders Walk
Hemophilia Assoc. of San Diego County
619-325-3570, <https://hasdc.org>
Liberty Station Park; San Diego

OCT 26, 2023 FLORIDA

Educational Dinner
Sponsored by Sanofi and BioMatrix
Contact: Justin Lindhorst, 513-253-8535
justin.lindhorst@biomatrixsprx.com
Flemming's Prime Steakhouse;
Winter Park

OCT 28, 2023 NEW JERSEY

Educational Dinner
Sponsored by Sanofi and BioMatrix
Contact: Rich Vogel, 732-991-7373
richard.vogle@biomatrixsprx.com
Hill Creek Farms; Mullica Hills

NOV 3-4, 2023 OHIO

Annual Meeting
Northern Ohio Hemophilia Foundation
216-834-0051, <https://nohf.org>
Kalahari Resorts; Sandusky

NOV 4, 2023 CALIFORNIA

Unite for Bleeding Disorders Walk
Hemophilia Foundation of So California
626-765-6656, <https://hemosocal.org>
The Meadows at Whittier Narrows;
South El Monte

NOV 4, 2023 MAINE

Fallfest
New England Hemophilia Assn, 781-326-7645
www.newenglandhemophilia.org
Weston Harbourview; Portland

NOV 4-5, 2023 VIRGINIA

Adult Retreat Weekend
Virginia Hemophilia Foundation
804-740-8643, www.vahemophilia.org
Hotel 24 South; Staunton

NOV 15, 2023 NEW MEXICO

Indoor Golf and Education
Sponsored by CSL Behring and BioMatrix
Contact: Felix Garcia, 505-322-0479
felix.garcia@biomatrixsprx.com
ABQ Top Golf; Albuquerque

NOV 18, 2023 OHIO

Dinner and Holiday Wreath Making
Sponsored by Novo Nordisk and BioMatrix
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden; Strongsville

DEC 1-3, 2023 MAINE

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

DEC 2, 2023 OHIO

Cookies with Santa
Hosted by Northern Ohio Hemophilia
Foundation and BioMatrix
Contact: Tanya Ricchi, 216-834-0051
Williams on the Lake, Medina

Dec 2, 2023 VIRGINIA

Holiday Gathering
Hemophilia Assoc. of the Capital Area
703-352-7641, www.HACAcare.org
Oswald Durant Center; Alexandria

DEC 3, 2023 DELAWARE

Year End Meeting
Brandywine Valley Hemophilia Found.
Contact: Kim Hamstead, 302-530-8672
kkhamstead@gmail.com
www.brandywinehemophilia.org
Mendenhall Inn; Mendenhall, PA

DEC 17, 2023 DELAWARE

Education and Holiday Cookie Decorating
Brandywine Valley Hemophilia Found.
Sponsored by Novo Nordisk and BioMatrix
Contact: Gail Novak, gvannicola@verizon.net
www.brandywinehemophilia.org
Mazzella's Italian Restaurant; Wilmington

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!

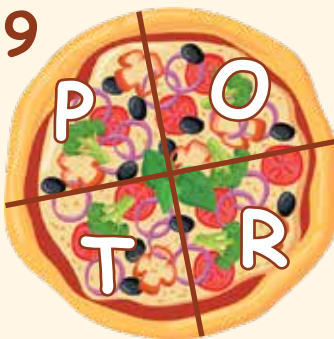
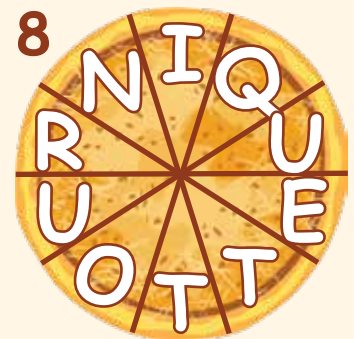
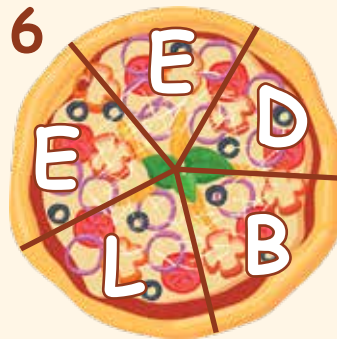
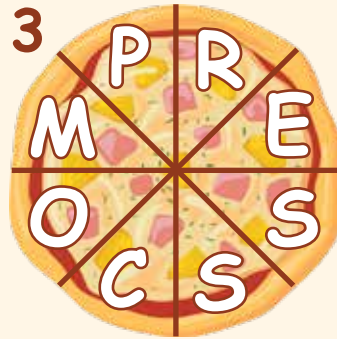
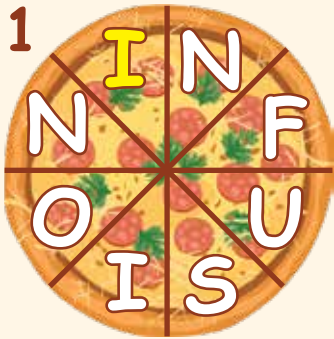
Games on page 27

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



Hi Kids! Time for Fun!

On every slice of each of these delicious pizzas is one letter of a word common to bleeding disorder "vocabulary." Find the first letter of the word and follow around the pizza to read the word. Some of the words read clockwise and some read counterclockwise. Pizza #1 has the first letter highlighted for you. Answers are on page 26. Good Luck!



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

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



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

BIOMATRIX

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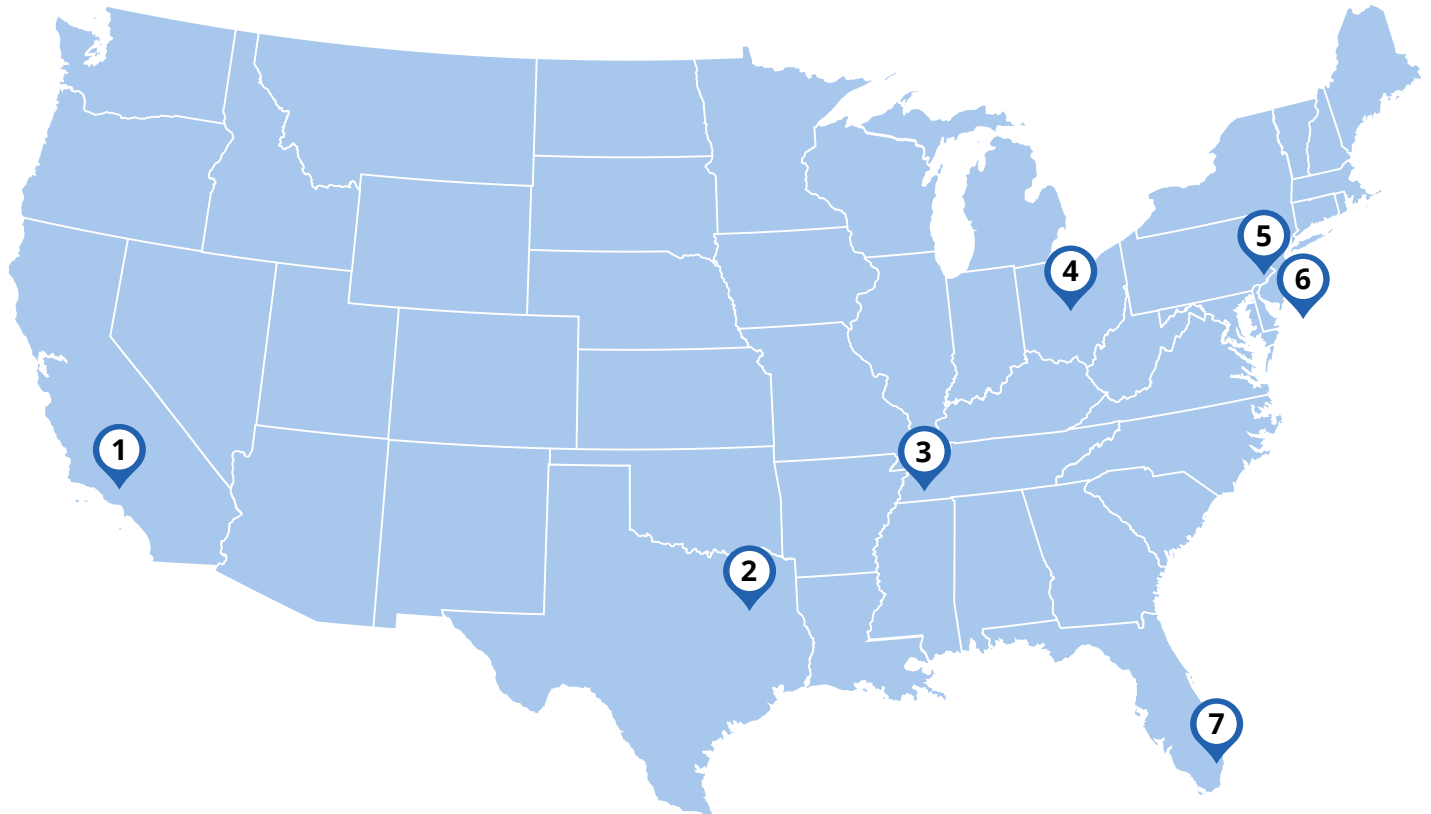
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Pharmacy Locations

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