# BIOMATRIX Specialty Infusion Pharmacy News

Fall 2025
Volume 20 | Issue 4

## Dedicated to Making a Difference

"How wonderful life is while you're in the world."

— Elton John, "Your Song"

VOLUME 20 | ISSUE 4
FALL 2025

## About BIOMATRIX

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

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

## Our Promise

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

## Fine Print

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

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

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BIOMATRIX
Specialty Infusion Pharmacy

**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.**

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

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BIOMATRIX
Specialty Infusion Pharmacy

**A Moment in Your Spectacular Life!**

**It's calendar time!**
Our ***2026 Living a Spectacular Life*** calendar will highlight just how amazing life can be with a bleeding disorder! To have your photo included, send us your joyful photo by November 15th!
*(Only first names will be included with photos.)*

- Happy Moments
- Family Fun
- Proud Achievements
- Your Favorite Activities
- Travel Snapshots
- Smiles, Smiles, Smiles!

» bit.ly/CalendarPhotoRelease

**Don't Wait!**
**Submit a Photo Today!**

# A Note from the Editor

As the air turns crisp and the leaves shift from green to warm, golden hues, fall reminds us to slow down, savor cozy moments, and celebrate the beauty of change.

In this issue, we've gathered heartfelt stories that reflect the spirit of this wonderful season. Read on about two remarkable individuals: a compassionate social worker who shares his insights from a rewarding career dedicated to the bleeding disorders community, and an exceptionally talented artist who captivates our imagination with his creativity.

We're also excited to shine a spotlight on a national organization that plays a vital role within our community: The Coalition for Hemophilia B! This organization works tirelessly to support individuals and families affected by hemophilia B, and we're excited to share their mission and accomplishments with you.

Just like the autumn season, we hope these pages offer you warmth, inspiration, and new perspectives. Whether it's finding joy in small comforts, exploring new ideas, or preparing for the festive celebrations that come with this time of year, we encourage you to take a moment to savor the cool weather, embrace the beauty around you, and enjoy the upcoming holidays!


**Maria Santucci Vetter**
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# A JOURNEY THROUGH CHALLENGES AND CREATIVITY

**BY TERRY STONE**

**Have you ever seen something so intriguing and wondered who created it? If you have a Series 1999 $5 bill tucked away in your wallet, take it out and give it a closer look. It features a stunning engraving of President Lincoln, with each line, dot, and dash carefully crafted as part of the original artwork. Someone had to engrave this image onto a steel plate for the reproduction of the currency, and that person is none other than the incredible Picture Engraver Artist, William Fleishell.**

A true Renaissance man in every way, William has risen above life's challenges to accomplish greatness. Being diagnosed with hemophilia B as a child did not keep him from his dreams; it fueled his desire to follow his heart and live his passion.

As a master engraver whose extraordinary talent has left an indelible mark on the artwork of our nation's currency, William worked for the Department of the Treasury Bureau of Engraving and Printing. Regarding that $5 bill, William poured over 500 hours into sculpting and cutting this image into a master die. He also engraved the image of Philadelphia's Independence Hall and the intricate border on the Series 1996 $100 bill, among numerous other engravings. William is one of only about 40 banknote portrait engravers in the world. A skilled journeyman in this most prestigious group of engravers, William served the Bureau for 34 years. He fulfilled a vital role in the Bureau's mission, which continues to be responsible for creating security documents, paper money, and passports.

William's artistry transcends the confines of time, allowing viewers a glimpse into the moments captured in his work. Some of his creations are so detailed that you might need to look twice to determine if they are photographic illusions. However, they are exquisite, meticulously crafted drawings and engravings, rich with brilliant lines and tonalities. It's an experience akin to time travel – his art effortlessly transports you back to the very period the artwork depicts. It's not just magical; it's a true experience of transformation.

Having the chance to meet William and visit his studio nestled in the vibrant heart of our nation's capital is truly an unforgettable experience. His enthusiasm for his craft shines through, making even the journey to his studio feel like a fascinating heritage walking tour led by a savvy local guide.

An eighth-generation Washingtonian, William lives in the Capitol Hill/Navy Yard neighborhood where his family has resided since the 1750s. When he shares stories about D.C., it's clear that nobody knows this city better than he does. His roots run deep in the fabric of Washington, and his pride in being a native Washtonian is profound. Visiting William is not just about admiring his work; it's an immersion into a rich history intertwined with art, culture, and the vibrant life of our nation's capital.

To know the man is to revel in his impressive accomplishments and artful legacy. And yet there is so much more to William, many who have met him may not even know. William was born with hemophilia B, a rare bleeding disorder whose origin started in his family back in Scotland, the ancestral home of his mother's family, and where other members of his family still live today.

Drawing submitted with William's application to the Dept. of the Treasury's Bureau of Printing and Engraving

Although William was not 'formally' diagnosed with hemophilia until age 10, he was always treated and cared for as having the disorder because of his family history and his bleeding tendencies. At the tender age of two, he had an accident with a sharpened pencil that landed in his nostril, 1/8 inch away from his brain. He experienced lingering issues with terrible, gushing nose bleeds and insomnia, as well as other bleeds that plagued him throughout his school years, where, as a shy boy, he often became the target of bullies.

It took the old saying "kids can be cruel" to a whole new level. William said they wanted to hurt him to see if he would bleed. The constant worry about potential injuries loomed over him, but his father's words rang in his ears: "Don't shy away, face them head-on." Gathering courage, William stood up to his bullies despite the risks. At the age of 17, he experienced a significant growth spurt, growing a foot taller! From that point on, no one bothered him.

William's mother felt guilty about his diagnosis, while his father, who had a strong, tough-guy demeanor, wished for William to embody the same qualities. However, he understood the risks involved. Aware that his son faced greater risks due to his bleeding disorder, he kept William away from sports and took extra precautions in caring for him. He was a nurturing and devoted father.

William's parents never told him that his life expectancy during his childhood was drastically shorter compared to today's standards. He only learned about this recently while watching "On the Shoulders of Giants," a film produced by Believe Limited, and he was not pleased to discover it. In the documentary, a senior community leader shares his life story and discusses the reduced life expectancy for hemophiliacs in the past. This affected William deeply. He believes that having this knowledge earlier might have altered his actions throughout his life. Nevertheless, William has navigated his journey and has much to show for it. The bumps and bruises he experienced over the years have turned into valuable life lessons.

Since childhood, William has always known he wanted to pursue a career in the arts. His family's lineage on his father's side is steeped in creativity, boasting a German heritage of professional printers. His father was a skilled artist and master calligrapher. Even his great-great-grandfather, James Fleishell, left his mark as a stone carver at the U.S. Capitol.

While art came naturally to William, he was not one to rely solely on talent. He committed himself to countless hours of training, immersing himself in the rich tapestry of fine arts education at some of the nation's most prestigious institutions. At the Pennsylvania Academy of Fine Arts, he earned a certificate and received multiple awards for excellence. Later while working at the Bureau, he earned a bachelor's degree in printmaking at George Washington University. He also studied anatomy and considered a career in medical illustration.

At age 27, William's dedication and talent led him to a remarkable opportunity. A stunning crow quill pen drawing he had painstakingly crafted over 18 months – a whimsical arrangement of relics one might find in an attic – caught the attention of the Bureau of Engraving and Printing in Washington, D.C. What followed was a momentous 10-year apprenticeship, the longest of its kind in North America. He was hired on the spot, stepping into a world where art and precision meet. There, he perfected the intricate skill of vignette portrait engraving, a craft that transforms delicate artistry into a solid steel engraving.

William soon graduated to journeyman picture engraver in 1998, and in addition to the work on currency, found himself with the unique honor of crafting the official engraved portraits of former President George W. Bush,

late Supreme Court Justice William Rehnquist, current Chief Supreme Court Justice John Roberts, and various Secretaries of the Treasury over the years. Perhaps most notably, he was responsible for the engraved portrait of George Washington commemorated on a 1997 stamp, issued to celebrate the 150th anniversary of the first U.S. postage stamp. With each piece he produced, William transformed his passion into tangible works of art—masterpieces destined for paper money, postage stamps, and various official U.S. documents. As his career flourished, so did his sense of pride in contributing to the legacy of American artistry and history. His last official portraits with the Bureau were of Eleanor Roosevelt and Frederick Douglass.

After William's impressive 34 years of service, he bid farewell to the Bureau in October 2021, a direct result of pain and joint issues. The job was creative, yes, but it was also physically demanding, particularly when working with machinery, and the process of his work started to take a toll on him. Although he persevered through the pain for many years, he ultimately decided it was time for a change.

Taking his leave from the Bureau with a catalog of brilliant work over the years, William embarked on a vibrant new chapter brimming with creativity. His days are now a delightful canvas of teaching art classes, where he passionately shares his love for all forms of artistic expression. A proud descendant of veterans, William finds deep fulfillment in giving back to military families through the Armed Services Art Partnership. On Capitol Hill, he hosts free painting and drawing classes specifically for veterans and their families. He also teaches at the Washington Studio School and the Capitol Hill Arts Workshop, where he inspires ambitious students with engaging workshops.

William's artistic journey is as dynamic as the pieces he creates. He is busy with commissioned work for prestigious clients, including The New York Historical Society, Oprah Winfrey, the Bugatti family, and the Cooper Hewitt Museum, to name a few. His diverse portfolio of commissioned work features everything from stunning artworks to elegant wine labels, personalized stationery, and bookplate designs. His talent has garnered significant attention over the years, showcased in various articles and television features, including a captivating segment on the Discovery Channel called "Inside the World's Mightiest Bank" (https://www.youtube.com/watch?v=o1LG5WObgts).

In the early 1990s, William was introduced to The Coalition for Hemophilia B. He is proud to be one of the early members of this organization. He recently attended his very first Annual Symposium in 2022 and has cultivated numerous friendships within the community, discovering a sense of belonging and shared purpose. He plans to continue the growing friendships and connect with new friends soon at upcoming events with the Coalition, as well as his local chapter, The Hemophilia Association of the Capital Area.

Life has not always been easy for William, but he carries the wisdom imparted by his father: "If you learn to draw well, you will always have a way to earn a living. It's what you do with what you are given that makes the difference." In his retirement, William fills his days with creating art and teaching others. His studio, a charming repurposed carriage house, is nestled in a lovely neighborhood where residents share a sense of community. Just steps away from the heart of politics and power, his creativity flourishes.

Though he may have been a bit shy in his younger days, William now loves meeting new people and sharing his passion for art and his personal story. Living and breathing the art culture, William immerses himself in the vibrant community around him. He often says, "If you're into art, you're my friend!" Art is all around us. How could you not love it? If you're new to the art world, William will happily guide you in appreciating it, showing off his hometown. For William, life is nothing short of a beautiful canvas waiting to be painted!

# HEMLIBRA: TRUSTED BY THE COMMUNITY FOR 7 YEARS AND COUNTING

## First approved in 2017.* Over 8,100 patients in the US treated with HEMLIBRA.†

SCAN TO HEAR STORIES FROM THE COMMUNITY

*November 2017: FDA approval for adults and children with hemophilia A with factor VIII inhibitors.

†Number of patients with hemophilia A treated with HEMLIBRA in the US as of March 2024.

### INDICATION & IMPORTANT SAFETY INFORMATION

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

**These serious side effects include:**

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

**Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. If aPCC (Feiba®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (Feiba®) total.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).**

Please see Brief Summary of Medication Guide on following page for Important Safety Information, **including Serious Side Effects**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

# Medication Guide
# HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

## What is the most important information I should know about HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (e.g. increase in bleeds).**

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

## What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

## Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

## How should I use HEMLIBRA?

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

## What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

## How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

## General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

## What are the ingredients in HEMLIBRA?

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
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Genentech
*A Member of the Roche Group*

Annual Symposium 2025

# THE HEART OF A MOVEMENT: A LEGACY OF DETERMINATION, FAMILY, AND LOVE

THE COALITION FOR HEMOPHILIA B

35 ANNIVERSARY

**BY TERRY STONE**

**The Coalition for Hemophilia B is celebrating a remarkable milestone — 35 years of supporting patients and families diagnosed with Factor IX deficiency across the country! In this celebration, we honor the relentless spirit, compassion, and vision that brought the Coalition to fruition. What began as one family's fight quickly transformed into a community triumph.**

Hemophilia is a rare bleeding disorder that affects approximately 33,000 people in the U.S. Even rarer is hemophilia B, also known as Factor IX deficiency or Christmas Disease, which affects about 7,000 individuals. This condition occurs when someone is missing or has low levels of the Factor IX protein. Although there was suspicion of a condition similar to hemophilia A, Factor IX deficiency wasn't identified and named until 1952, when British researchers from Oxford University, Dr. Robert Macfarlane and Dr. Rosemary Biggs diagnosed a young boy living in Canada named Stephen Christmas.

## John Taylor

### IT ALL BEGAN WITH A DIAGNOSIS AND A DETERMINED FATHER

When John and Joyce Taylor's son was diagnosed with severe hemophilia B, they were shocked by the lack of information available. Joyce's father, a pharmacist, had unknowingly lived with mild hemophilia. In his 60s, he was given aspirin in the hospital while suffering from the flu, which resulted in uncontrolled internal bleeding and ultimately led to his death. This tragedy served as a wake-up call for the Taylors, highlighting just how serious and overlooked hemophilia B could be.

Determined to make a difference, John made it his mission to gather as much information as he could. He traveled across the country and around the world, meeting with scientists, hematologists, and researchers in the field of bleeding disorders. He aimed to share the most current and credible information with other families through a patient-focused newsletter, which eventually expanded from a single sheet to a 70-page publication viewed both nationally and globally. This effort culminated in the creation of The Coalition for Hemophilia B.

## Kim Phelan

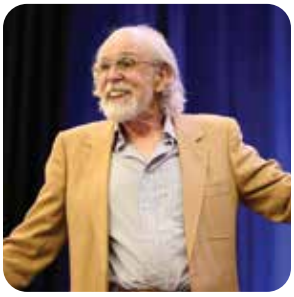
### THE HEART OF THE CHAIN REACTION

Initially on her way to becoming a trader, Kim Phelan took a leap of faith and accepted a job at John's relatively small and quiet upstart financial firm. For someone as outgoing and naturally talkative as Kim, this shift was unexpected, yet it felt like a calling.

When John founded the Coalition in 1990, he invited Kim to join the organization's board. This invitation ultimately led to a full-time role with the Coalition and a lifelong commitment to serving patients and their families, advocating for their needs. Serving as the CEO, Kim often says she didn't choose the Coalition; it chose her.

Raised in a family that valued giving back, Kim began volunteering at a young age. She kept an elderly neighbor company, assisted another neighbor afflicted with multiple sclerosis, and spent time with seniors in nursing homes. As she grew older, she worked with mentally challenged youth, babysat frequently, walked dogs, sold Avon, and even worked at McDonald's. Helping others has always been a significant part of her life.

Kim was profoundly affected by what she witnessed at national events—families devastated by the HIV/Hep C crisis, parents who had to sell their homes to care for their children, and patients who had no support. She approached the Coalition's newsletter with a sense of urgency, knowing that every educational article could be critical and life changing. In the early days, Kim and her family sat around the kitchen table sealing envelopes to send out the newsletter. Today, the Coalition boasts a professional staff, national reach, and robust infrastructure—but the spirit of family remains unchanged.



## Dr. David Clark

### FROM SCIENCE TO SERVICE

Upon the formation of the Coalition, Dr. Clark was brought in as Chairman of the Board, leading the

The family of William Drohan, for whom the CHB Memorial Scholarship is named, with CHB founder, John Taylor, 2008

Coalition into its next chapter with clarity, purpose, and passion. As a senior scientist with a Ph.D. in Chemical Engineering, Dr. David Clark previously collaborated with Dr. William Drohan from the American Red Cross, one of the Coalition's earliest scientific supporters. Although it did not make it to market, together the men worked on a pioneering effort to develop the first Red Cross hemophilia B product.

Dr. Clark possesses a unique talent for conveying clinical knowledge to the community in relatable ways. He became the Coalition's first newsletter contributor, creating content that helps patients and their families navigate their treatment choices with confidence. He welcomes questions and has always been available to Kim and Wayne, as well as to everyone in the community.

## Wayne Cook

### A VOICE BECOMES A LEADER

In 1992, Wayne Cook called Kim and asked, "What can I do? I want to help." A beloved and respected member of the hemophilia B community, Wayne was already well-known; however, this call marked the beginning of a powerful partnership.

As someone with severe hemophilia, Wayne brought lived experience, deep compassion, and fierce dedication to the organization. He connected with patients on a personal level and became a constant presence in their lives. Previously the president of his local hemophilia chapter, he would begin serving as President of the Coalition in 2006, bringing the community's voice to every level of leadership.

John Taylor stepped down in 2006 to pursue a career in the biopharmaceutical industry, leaving the Coalition in capable hands. Together, Kim, Wayne and Dr. Clark formed a trio that became the heart and soul of the Coalition, exemplifying leadership defined by compassion, commitment, and genuine care. Backed by a dedicated staff of professionals and a cast of enthusiastic volunteers,

Annual Symposium 2014

First Men's Retreat 2013

First Meetings-on-the Road 2011

First Women's Retreat 2015

the trio strives to create impactful programs that enrich our community and foster positive change. Together, the organization works tirelessly to achieve its goals and make a difference in the lives of those they serve.

## Power of Progress

### THE FIRST SYMPOSIUM

The first Coalition Symposium in 2007 brought together just over 100 people. Today, it hosts more than 1,000 attendees, including patients, caregivers, medical experts, and industry leaders. This growth is a testament to the Coalition's dedication to serving every patient with hemophilia B, from newborns to veterans. Kim recalls the early days when the exhibit hall was full of adults using crutches, scooters, or wheelchairs, their joints damaged from years of inadequate treatment. "Today, you see people dancing, running, and living full lives," she says. "It's heartwarming to see how treatment advances have truly changed lives."

At the symposiums, it's not just about the science; it's about human connection. Kim shares, "Wayne brings the warmth; he makes you feel like family. Dave brings the knowledge and the patience to answer a million questions. And me? I want people to have the best quality of life, and I am committed to doing everything I can to help."

2023

2013

2014

## The Pandemic Pivot

### RESILIENCE IN ACTION

The COVID-19 shutdown occurred just one week before the 2020 annual symposium. The Coalition had to pivot quickly. The team enrolled in what they now affectionately call "Zoom School" to learn how to move educational programming online. Their first attempt with an outside virtual vendor crashed on opening night, forcing the team to manage the chaos in real time. This experience was eye-opening and inspired the team to build their own online platform.

Today, the Coalition continues to offer both in-person and virtual programming, removing barriers to access and ensuring all patients, whether unable to travel, hospitalized, or homebound, can still connect and learn.

## A Health Scare Hits Home

### WAYNE'S JOURNEY

Year 35 also brought unexpected challenges. Wayne Cook, who contracted hepatitis C during the crisis years of contaminated blood products, experienced life-threatening complications. He needed a liver transplant, but also had a cardiac blockage, making

surgery incredibly high-risk. Wayne underwent back-to-back surgeries in January and miraculously pulled through. He recently walked his daughter down the aisle on her wedding day.

Although his immune system remains fragile and he is not yet able to attend in-person events, he joins programs via FaceTime, bringing his trademark love and strength. "We all miss him deeply," Kim states, "but we know he'll be back with us soon."

## Coalition Programs

### FOR EVERY STAGE OF LIFE

Over the years, the Coalition has expanded its offerings to address the evolving needs of the community, which now include:

- **Patient & Family Support Programs**
  - ☆ Patient Assistance Program
  - ☆ Insurance Navigation Support
  - ☆ Mental Health & Wellness Workshops
  - ☆ College Planning Resources
  - ☆ B Education Hub (including multilingual resources and glossary)
- **Scholarships & Financial Aid**
  - ☆ William N. Drohan Educational Scholarship
  - ☆ Additional Named Scholarships
  - ☆ Travel and Conference Assistance Grants
- **Community Connection & Life Stage Programs**
  - ☆ Annual Symposium
  - ☆ On-the-Road Family Meetings
  - ☆ New Moms Program
  - ☆ Empty-Nester Conversations
  - ☆ Aging with Hemophilia Support Groups
  - ☆ Youth Camps & Leadership Retreats
  - ☆ Men's and Women's Empowerment Retreats
- **Leadership & Advocacy Development**
  - ☆ Teen and Young Adult Leadership Programs
  - ☆ Advocacy Training and Retreats
  - ☆ Patient Advisory Boards and Opportunities

Meetings-on-the Road 2025

Inaugural *The Beats Music Program*

One of the Coalition's most innovative programs is *The Beats Music* Program, which helps community members bond through rhythm and creativity. Kim explains, "Through music, we create a safe, fun space, and the relationships carry over into other programs."

## B Voice

### COALITION'S ADVOCACY IMPACT

Patients need timely, clear information about changes to insurance, Medicaid, Medicare, and other vital healthcare updates. The Coalition has gone above and beyond to stay on top of these developments and ensure that patients are informed and empowered to act.

To support this, the Coalition has created an Advocacy Action Sheet, a very popular and widely shared user-friendly resource filled with timely updates and several proactive steps patients can take. The organization hosts educational sessions that teach individuals the many ways to advocate, whether through storytelling, video, social media, or direct outreach. Everyone can find their voice and their own way to make a difference.

Kim notes, "We even launched a postcard campaign, giving patients the tools to contact their legislators directly. And we've remained active on Capitol Hill, meeting with congressional offices, writing letters, and working alongside over 100 organizations to unify our voices across the rare disease community."

To further support patient empowerment, the Coalition recently invested in a new advocacy platform designed to make it even easier for patients to engage, take action, and stay informed.

Kim shares, "With all the changes happening, it's even hard for us to keep up." That's why it's more important than ever to help patients understand what's going on. It's important to stay informed, be proactive, and gain confidence in the ability to make a difference; and we want them to know, we are here for them every step of the way.

# Mental Health

## OUR SHARED JOURNEY AND COMMITMENT

"Wayne, Dave, and I have all experienced anxiety or depression at different points in our lives. We believe that taking care of your mind is just as essential as taking care of your body, as the two are deeply connected."

The team strongly believes that struggling with any mental health challenge does not define your strength, intelligence, or abilities; it's simply a barrier that deserves attention, healing, and support. When physical health issues challenge a person's body, it is only natural that their mental health can also be affected.

The Coalition is deeply committed to ensuring that every program it offers includes meaningful support for emotional well-being in some way, shape, or form. The Coalition is firm in its mission to break down the stigma and eliminate the barriers that prevent people from accessing the support they need.

# Women Bleed Too

## A CALL FOR RECOGNITION, DIAGNOSIS, AND CARE

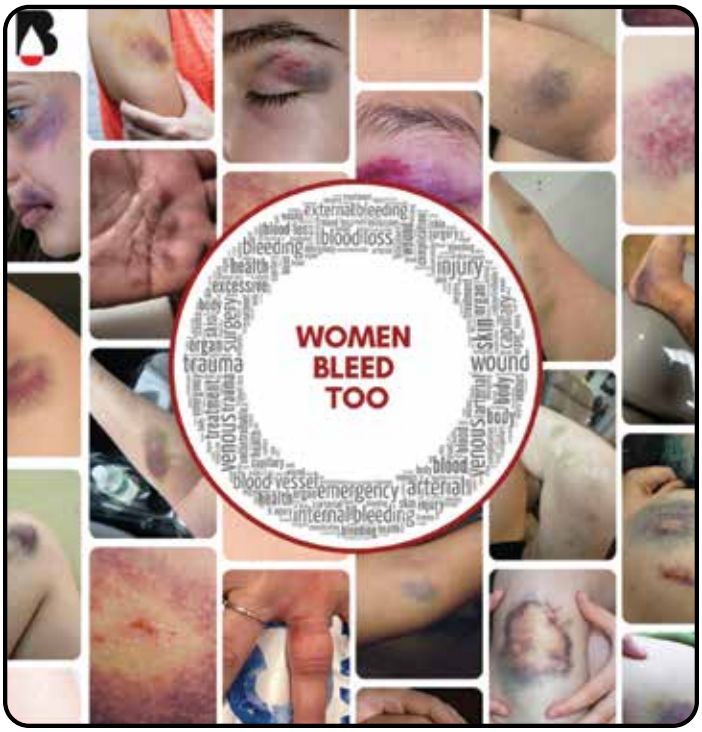
The Coalition is dedicated to ensuring that women and girls with bleeding disorders are correctly diagnosed and treated. For too long, their symptoms have been dismissed, misdiagnosed, or minimized, often leading to devastating physical and emotional consequences. This issue is not just about heavy periods or bruising; undiagnosed bleeding can lead to joint damage, loss of mobility, chronic pain, and mental health struggles. In some instances, such as childbirth or car accidents, a lack of diagnosis can have disastrous results.

Dr. Clark has long advocated for awareness, writing clear and scientifically grounded articles to educate the community and healthcare providers. However, information alone has not been enough. Kim poses a crucial question: "Why, in this day and age, must females wait so long for a proper diagnosis? If words aren't going to change things, then we must show them the truth. We needed to make the invisible visible." This vital question gave rise to the Coalition's campaign: *Women Bleed Too*.

Over the years, the Coalition has quietly gathered countless heartbreaking stories and photos of women in our community, covered in bruises and swollen joints, suffering in silence. The injuries are real, the pain is real, and denial can be deadly.

The Coalition compiled the photos into a striking postcard designed to confront people with the reality of undiagnosed bleeding in women. It was posted on social media, shared at the symposium, and sent in a mailing campaign. Although it may not be easy to look at, its impact is impossible to ignore. While the campaign is titled *Women Bleed Too*, it also applies to young girls and teens who bleed, many of whom grow up believing that their bleeding and pain is normal, or worse, imaginary.

The Coalition is proud to see the bleeding disorders community coming together around this issue, but the work is far from over. Kim emphasizes, "We will keep speaking out, we will keep showing the truth, and we will not stop until every affected woman and girl is diagnosed, treated, and supported with dignity and understanding."



## *Looking Ahead*

### OUR COMMITMENT CONTINUES

As the Coalition looks toward the next chapter, its mission remains clear:

- To be a resource for every person with hemophilia B
- To educate, advocate, and connect
- To evolve as the community evolves, without ever losing the human touch

"We are a family," Kim proclaims, "and we always will be." The heart of The Coalition for Hemophilia B is more than just a nonprofit organization; it's a movement built on determination, education, family, acceptance, and, most importantly, LOVE.

The Coalition has created a beautiful legacy of positively enriching the lives of those living with hemophilia B. They have built a warm and inviting community where everyone is welcome to come, engage, and learn. Their mission statement is not just a phrase; it's a living, breathing testament guiding their monumental efforts to make a difference in the lives of their hemophilia B family each and every day.

If you'd like to learn more or become part of this amazing community, please visit the Coalition's website at https://www.hemob.org/. Email contact@hemob.org or call 212-520-8272.

THE COALITION FOR HEMOPHILIA B

### MISSION

**The Coalition for Hemophilia B, Inc. is a national nonprofit dedicated to making quality of life the centerpiece of care for individuals with hemophilia B and their families. For over 35 years, we have advanced our mission through education, empowerment, advocacy, and outreach — always with a family–centered approach, because hemophilia affects the entire family.**

**Our programs unite patients and caregivers from across the country, creating lasting connections, trusted support systems, and opportunities to gain the knowledge needed to make informed decisions and advocate for themselves and their loved ones.**

**Our dedicated team brings decades of experience and is deeply engaged with the hemophilia B community, both personally and across every communication channel, to ensure no one faces this journey alone.**


# Let's get together to talk about IXINITY®

*After more than 20 years working in the bleeding disorders community, I am still inspired and motivated by the friends and families I meet every day.*

**Dave Todd,**
***Hemophilia Territory Manager***
*MO/KS/NE/IA/IL/WI/ND/SD/MN*

**Contact Dave at 636-542-2355 or dave.todd@medexus.com**

**Scan me or visit IXINITY.com!**

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IXINITY® coagulation factor IX (recombinant)

# BRIDGING GAPS: A SOCIAL WORKER'S EXPERIENCE IN BLEEDING DISORDERS CARE

**BY ROBERT H. JOHNSON MSW, LCSW**

**In 1992, I transitioned directly from graduate school to a newly established position as a hemophilia social worker at a county hospital. This experience was a cultural shock, reminiscent of my college semester in Spain, where I struggled to turn my formal knowledge of Spanish into practical fluency.**

Visiting a Spanish-speaking country required conversing in Spanish, regardless of how limited my skills were. I vividly remember feeling uncertain about what people were saying. At night, I would dream of Spaniards speaking in classrooms and bars, yet I still struggled to understand them. I felt my brain's linguistic centers working overtime, trying to piece everything together. This experience mirrored what would unfold in my first years of professional social work: a journey from disorientation to a sense of competence and connection.

Through my time in Spain and ongoing studies, I developed the necessary skills to apply for a position at a hospital's Hemophilia Treatment Center (HTC), which required proficiency in Spanish. I was the sole applicant and secured the job, despite having limited knowledge about hemophilia. This was also during the AIDS crisis, and I felt a strong desire to make a difference in people's lives through traditional social work.

One advantage of being the first person in a new position is that there is no predecessor to be compared to. Very little is set in stone, allowing for flexibility and improvisation. While this might seem exciting, I rarely felt that way initially. I introduced myself to the patients, offered my assistance, researched hemophilia, and had lengthy conversations with a staff member at the local bleeding disorders chapter. However, the patients did not respond to me as I had anticipated. Frustrated, I retreated into my studies, justifying this as preparation for an upcoming licensure exam for social workers. The HTC had hired me before I passed the exam, but with a clear stipulation: I had to pass the exam or risk being fired.

Studying for the exam was just the beginning of my on-the-job learning. Although the hospital had achieved recognition as an HTC, we did not operate like a typical center. For example, there had never been any staff dedicated to following up between hematology clinic visits,

emergency room visits, or inpatient stays. Eventually, I realized that I was responsible for figuring out how to transform our services to resemble those of a traditional Hemophilia Treatment Center.

Feeling overwhelmed, I went through a period of insomnia. My desire to foster warm and supportive relationships—characteristic of social work—clashed with the reality that my patients were not accustomed to such interactions. Despite having the right educational background, language skills, and a certificate in health administration earned alongside my master's in social work, the gap between theory and practice felt insurmountable. A physician offered me this sage advice: "Don't get frustrated about being frustrated. You are getting paid to feel that way."

Passing the licensing exam provided a sense of accomplishment during that first challenging year. However, what truly reinforced my efforts was the Ricky Ray Hemophilia Relief Fund Act of 1998. This landmark legislation offered vital compensatory payments to individuals with bleeding disorders who contracted HIV from contaminated blood used in anti-hemophilic factor products. Helping patients navigate the application process made my work not only fulfilling but also deeply rewarding. To qualify for the compensation, patients had to prove their HIV-positive status and present medical records that documented their use of clotting factor during the era when the use of contaminated blood products was prevalent.

Before I arrived at the HTC, an informal system allowed adults with active bleeds to swing by the hospital's coagulation lab for an immediate clotting factor infusion, and the lab maintained all patient infusion records. However, after several years, this system was discontinued because it disrupted the lab's workflow and lacked the formal safeguards typical of an emergency room.

Patients began contacting me when they realized their official medical records were missing crucial evidence needed to qualify for the Ricky Ray compensation. I found myself stepping into the shoes of a detective, sorting through dusty files stored away in the coagulation lab—searching for what, in some instances, was the only piece of evidence a patient required.

I intensified my efforts to contact every patient for whom I had a phone number, asking them to confirm their HIV status. I distinctly remember a conversation with a middle-aged patient I'll call "Jack." At first, he confidently stated that he was quite sure he had tested negative for HIV. Given that he had mild hemophilia and seldom experienced bleeding, I accepted his answer and encouraged him to keep in touch.

Then, ten days before the Ricky Ray application deadline, Jack called back, urgency in his voice. He revealed he had mistakenly confused the HIV test with another, and that he was, in fact, positive for HIV. We leapt into action, scrambling to meet the impending deadline. In a race against time, we managed to gather and submit the documentation Jack needed to receive his compensation. That was the start of many nail-biting, last-minute collaborations we would share.

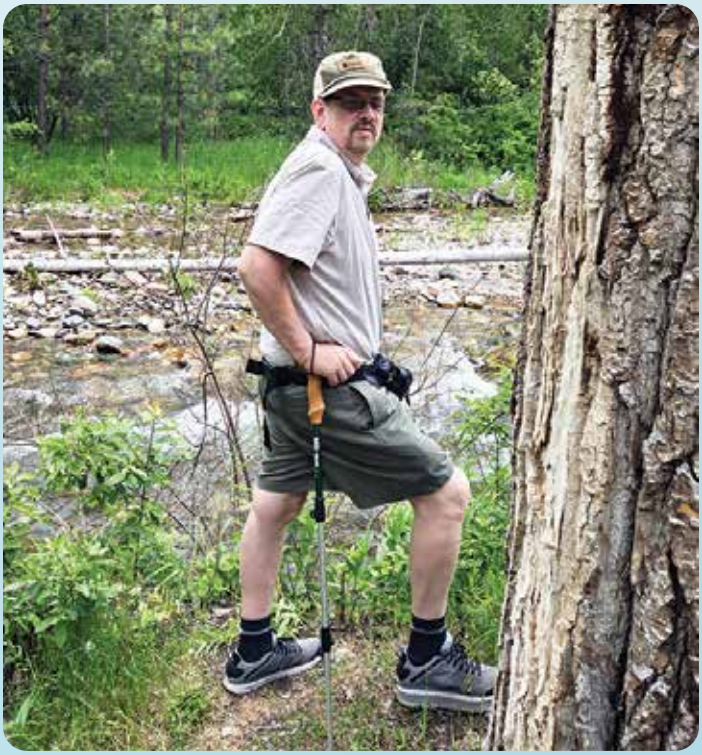
The discontinuation of access to treatment at the coagulation lab had far-reaching consequences. What was once a straightforward hour-long procedure morphed into a grueling four to ten-hour wait in the emergency room for patients needing their infusions. When I began my journey at County, only a handful of pediatric patients were able to self-infuse at home. The mounting complaints about the long wait times motivated me to identify ways for more patients to gain the independence of self-managing their infusions at home.

Creating a robust home care program became my mission as I aimed to transform our treatment center into a more comprehensive resource for our community. I devoted considerable time to understanding how hemophilia care operated beyond the walls of the county hospital, researching ways to adapt home care services to serve our unique patient population, many of whom were economically disadvantaged and often non-English speaking.

We needed home care representatives, nurses, and social workers who were willing to make home visits to patients living in the inner city, often in challenging neighborhoods. I poured my heart into finding passionate personnel with the right skills and attitudes to empower patients and teach them how to manage their infusions at home. In this ongoing journey, every success story brought a renewed sense of purpose—a reminder of the difference we were making, one patient at a time.

One of my key responsibilities while developing a more comprehensive facility was to implement the Universal Data Collection (UDC) program, a mandate from the Centers for Disease Control and Prevention (CDC). This program involved a significant amount of work, but it also helped us become more organized and efficient in our outpatient clinic operations. A key component of UDC involved reporting on joint range of motion, which sparked a deeper collaboration with the physical therapy department, significantly enhancing their involvement with our hemophilia patients.

One day, Jack visited the clinic to discuss his blood



After 29 rewarding years, Social Worker Bob Johnson enjoys his retirement

work with the hematologist. He had decided to begin antiviral treatment for hepatitis C while continuing his HIV treatment. Unfortunately, this combination proved to be dangerous, and his blood counts started to drop significantly due to the toxic effects of both treatments. The hematologist advised him to stop the hepatitis treatment immediately, which he did, just in time to preserve his bone marrow function.

Throughout the years, I had the opportunity to get to know Jack, and my admiration for him deepened. He stood out as a solid guy who managed to keep the same job year after year, maintained a marriage, and raised his children. Jack hoped to work until he turned 62, at which point he could collect Social Security and a pension from the bottling plant where he had dedicated so many years. Jack often expressed his concerns about whether he could reach this goal.

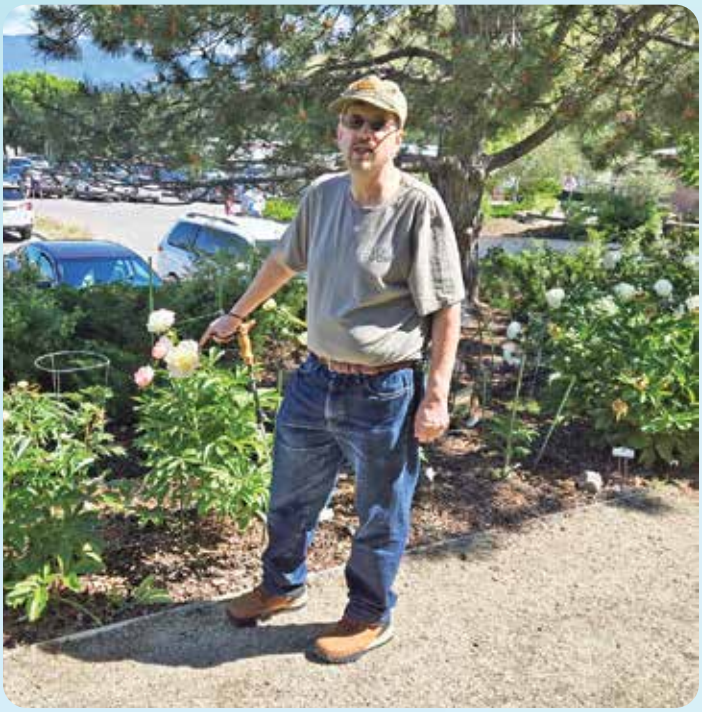
Jack faced the challenge of untreated hepatitis, coupled with new work managers who assigned him tasks far below his capabilities. He found himself contemplating the difficult choice of applying for disability; however, on days when he felt better, his drive to continue working prevailed. I genuinely believed that retiring at 62 would be his best path forward, and I encouraged him to embrace that option. However, I realized that I had become emotionally invested in the idea of witnessing his retirement and the enjoyment of his well-earned pension. I took the time to apologize to him – and to myself – stressing that the final decision was his to make.

From the beginning of my time at the treatment center, I made it a priority to attend the funerals of our patients whenever possible. While some passed away due to trauma, far too many succumbed to AIDS, often complicated by liver failure. It has always been a point of honor for me to represent the HTC at these somber occasions, showing families that their loved ones' lives mattered deeply to us. The devastating impact of the HIV crisis in the hemophilia community is a reality that weighed, and continues to weigh heavily on my heart.

There was always something new to learn about antiviral treatments, advancements in clotting factors, and the ongoing class action lawsuit related to the Ricky Ray Act. In the wake of those turbulent times, I felt a renewed purpose in providing something positive to our patients. By 2009, the death toll among long-established patients had declined, allowing me to shift my focus toward addressing other pressing issues like homelessness and high unemployment. For about two to three years, my work centered around assisting patients and families in need of emergency financial support.

During this time, I had the opportunity to speak with one of Jack's many cousins. As we reminisced about various family members, he mentioned that Jack would be retiring in a few weeks, turning 62. A light bulb went off in my mind—I realized there was a three-year gap between retiring at 62 and becoming eligible for Medicare at 65. I promptly called Jack to explain the COBRA law, outlining how he could maintain his health insurance by paying a monthly fee until he qualified for Medicare. After our conversation, he reached out to his company's human resources department and enrolled in the insurance extension.

Fast forward six months, and I bumped into Jack at a community picnic. He looked remarkable; retirement seemed to suit him both psychologically and physically. His immune system was robust, and his liver continued to function well. I shared my joy at seeing him thrive in this new chapter of his life. He looked at me knowingly and said, "Yeah, I know you were hoping for it."



Reflecting on my early experiences after all these years, I've gained a richer understanding of my journey. With my academic background and inherent goodwill, I felt equipped to navigate a world vastly different from my own upbringing. I was confident that I could bridge the gap between my middle-class roots in Montana and the lives of those who depended on the county hospital for their care. I believed I could make swift improvements to the entire system. While my aspirations were founded on a firm belief in progress, the journey took much longer than I ever anticipated. Bringing order to chaos and fostering relationships in the process proved to be a considerable challenge.

It is essential for social workers to cultivate an unwavering belief in positive outcomes for our patients and to actively strive to enhance the chances of these outcomes. Yet, we must approach our aspirations with a gentle grip, ensuring we don't "need" our patients to behave or feel in ways that contradict their own desires or the reality of their situations. Caring leads to hope but having a "need" can cross the line into a betrayal of our role. This boundary is not always easy to maintain, but it is gratifying when one of our cherished hopes comes to fruition.

After 29 fulfilling years, I retired in 2022, a decision tinged with both nostalgia and satisfaction. Many of the patients I worked with now refer to me as an honorary Blood Brother, a title I wear with pride; the bonds formed over years of shared struggles and triumphs. Jack stands out among these "brothers," embodying the spirit of resilience and friendship that defined my journey.

As I reflect on my time at the treatment center, a wave of gratitude washes over me. I remember the exhilarating last-minute collaborations, the barriers we broke down together, the small victories that made the long days worth it, and the heart-wrenching disappointments that tested our resolve. Although this chapter has closed, the connections and cherished memories we created will forever resonate in my heart.

## 🎉 Get Your Free Bleeding Disorders Community T-Shirt!

**We made a T-shirt designed just for the bleeding disorders community — and we're giving it away to our readers for free.**

📦 Limit: One shirt per household
⏳ While supplies last — don't miss out!
📲 Scan the QR code or visit:
https://bit.ly/factorday

# BIOMATRIX ON THE *Move*

**The BioMatrix Education Team, along with our incredible Territory Account Executives, is thrilled to connect with community members and host engaging educational events nationwide! We offer a dynamic range of topics and activities, including online sessions that everyone can enjoy. Are you ready to bring an exciting session to your group – whether it's large or small, in-person or virtual? We're here to help make it happen! Simply reach out to your Territory Account Executive or send us a message at education@biomatrixsprx.com. We look forward to hearing from you!**

## NEW JERSEY

**Richard Vogel**

A cold, rainy spring evening did not deter our Jersey Strong bleeding disorders community from attending the Hemophilia Association of New Jersey (HANJ) ***Annual Meeting*** on May 21st. Upon arrival at Pines Manor in Edison, the meeting commenced with a moment of silence as President Jeff Lynch lit a remembrance candle to honor those we have lost. This tradition began in the 1980s during the AIDS crisis when contaminated blood products impacted many members of our community.

Joe receives Unsung Hero awared from Jeff Lynch, HANJ President

Rich Vogel with scholarship winner Alexa

Legislative Update by Stephanie Lapidow, Executive Director

Executive Director Stephanie Lapidow provided updates on state and federal legislation, announcing that New Jersey passed the *Ensuring Fairness in Cost–Sharing Amounts Act*, which bans the use of copay accumulators in the state. We extend our gratitude to her and the team for their tireless efforts in securing sponsors and co-sponsors, which led to the introduction of the bill in both the Assembly and Senate, and its successful passage.

Keynote speaker Tiffany Smith, DNP, delivered an engaging presentation on *Rebalancing Hemostasis*, explaining how the new subcutaneous therapies work in a way that was easy to understand.

The evening concluded on a high note with awards presented to deserving community members who have contributed to making HANJ a remarkable organization, as well as to the next generation of students who received educational scholarships. Congratulations to all, especially my young friends Alexa and Parvis, for their commitment to furthering their education and brightening the future. I would also like to recognize my "old generation" friends, Joe and Matt, who have played significant roles in shaping our community's future. Please join HANJ in advocating for access to care, regardless of where you live.

## OKLAHOMA

**Jeanette Kiser-Jones**

It was time to enjoy high tea with community members as Novo Nordisk and BioMatrix partnered to host the annual ***Family Tea: Celebrating Mothers and Women with Bleeding Disorders***. We gathered on May 24th at the Red Raspberry Tea Room, a charming venue in Nicoma Park offering a delightful vintage atmosphere for an English-style tea. Attendees had the option to choose from a variety of fancy hats, with many switching them throughout the event for added fun.

Sharon, Sammantha and Hope

Jennifer and Rayne

Jasmine, Baby Jayden, and Stacey

Lori and Jeanette

Sharon and Jeanette

Over the past two years, this event has provided an exceptional opportunity to raise awareness about women with bleeding disorders, foster family support, and offer educational resources. This year, Victoria, a patient ambassador for Novo Nordisk, joined us to share her journey living with hemophilia A. She shared valuable insights on advocacy by discussing her experiences with tracking her bleeding, undergoing testing, finally receiving improved care and treatment, and using her voice to educate legislators about necessary changes.

On behalf of BioMatrix, I presented our session, *Women Bleed, Too!* Attendees learned about the misconceptions surrounding how women can experience bleeding disorders, which have led to delays in diagnosis and treatment. With this knowledge, we can advocate for earlier diagnosis and improved care. Everyone left with a deeper understanding of women's bleeding disorders and how we can work together to improve outcomes for our fellow blood sisters.

Thank you to Novo Nordisk for sponsoring our gathering! We look forward to hosting more events in Oklahoma!

Happy Birthday, Johnny!

## ILLINOIS

**Eva Kraemer**

Whenever we can get together, we do, and that's precisely what we did on Thursday, May 29th, at Maggiano's Little Italy in Oakbrook. BioMatrix and Genentech hosted an inspiring ***Educational Dinner*** filled with discovery, personal stories, and sharing. Julia, a patient advocate from Genentech, shared her son's experiences living with hemophilia A.

We also presented a BioMatrix education program titled *Finding Your Harmony*, which encourages the audience to consider the differences between anxiety and stress, their effects on health and life, and offers tips for managing both. Additionally, we practiced a breathing technique designed to promote relaxation. To conclude the evening, we celebrated the birthday of a remarkable young man!

BioMatrix is honored to provide educational programs to the Illinois bleeding disorder community. A special thanks to Genentech for their partnership!

## FLORIDA

**Marcy Foertsch**

Lego fun! Harold, Leo, Kara and Lilly

Bayer, CSL Behring, Sanofi, and BioMatrix proudly sponsored a fun-filled afternoon with the ***Cruz Fishermen's Building Community*** program. The event featured delicious food, Lego building, and tickets to a special outing.

Malachi's cool Lego creation!

The place to be on May 31st was Buca di Beppo in Orlando, where Cruz Fishermen Director Brandon Young introduced the program's sponsors. Patient Resource Specialist Brenda King and I highlighted BioMatrix's *Patient Navigation* program, discussing the services it provides to individuals with chronic bleeding conditions facing challenges accessing care, such as insurance issues.

Guests engaged in building a creative Lego set, and after lunch and presentations, received tickets to The Crayola Experience. This unique family attraction allows kids and adults to experience color in a whole new way through crayons and marker activities. Everyone was invited to create and name their own color!

We are honored to continue providing educational programs to our Florida bleeding disorder community!

## OHIO

**Shelia Biljes**

June enjoys the craft

The sun peeked through the dark, rainy clouds just long enough for Takeda and BioMatrix to co-sponsor a delightful ***Educational Dinner*** at Papa Joe's Restaurant in Akron on June 5th. Takeda Nurse Educator Maria Rohan presented *Your Body, Your Factor*, providing an overview of how clotting factors function within the body.

Emon loves coloring!

After a delicious dinner, we all joined in on some fun summer-themed games, which brought much laughter as participants tried their luck at winning quirky prizes. The evening wrapped up with a captivating story about one family's summer vacation, leaving us all with smiles and fond memories. We wish everyone a healthy, safe, and joyful summer filled with fun adventures!

Beautiful smile from Chardea!

## FLORIDA

**Marcy Foertsch and Hector Heer**

BioMatrix Specialty Pharmacy was thrilled to be a sponsor at the Bleeding Disorders Foundation of Florida's ***Annual Family Program at SeaWorld*** on June 7th! With over 500 members of the Florida bleeding disorder community in attendance, the atmosphere was brimming with excitement!

Javier and Hector take on SeaWorld!

After breakfast, attendees had the chance to explore the bustling expo area filled with industry representatives eager to share the latest in products and services. At the BioMatrix booth, we connected with visitors about our *Patient Navigation* program, offering guidance for anyone facing insurance or treatment access challenges. We wanted everyone to know that no one is alone on this journey!

The excitement continued as Michael Rosenthal took the stage for a session titled *Smart Adventures: Learn, Laugh and Play*. His engaging presentation left everyone inspired and ready to make the most of the day ahead. Once the program wrapped up, we all made our way to SeaWorld, where the real fun began! With hopes of spotting sea lions, sharks, stingrays, penguins, and maybe even a whale or two, the smiles and laughter were contagious as families roamed the park.

A huge shoutout to Executive Director Fran Hayes and her incredible team for pulling off such a fantastic event! We are proud to support our Florida chapter and the amazing work they do for the bleeding disorders community. We can't wait for next year's adventure!

## SOUTH CAROLINA

**Justin Lindhorst and Brenda King**

The Bleeding Disorders Association of South Carolina energized the community with its vibrant ***HELLO Conference and Annual Meeting*** on June 6th–7th at Embassy Suites Hotel and Conference Center in Greenville. Attendees from all corners of the state came together for an inspiring weekend filled with educational programs, dynamic networking opportunities, exciting chapter updates, and plenty of good old-fashioned family fun!

We were thrilled to participate and share the amazing pharmacy and support services provided by BioMatrix. A great big shoutout to Executive Director Sue Martin and her incredible team of volunteers for orchestrating such an unforgettable event, empowering community members with the vital resources they need to confidently navigate life with a bleeding disorder!

## TEXAS

**Jeanette Kizer-Jones, Felix Jacques Garcia, and Eva Kraemer**

Levi and Leo

The ***Texas Bleeding Disorders Conference (TBDC)*** brought together families and friends for a wonderful reunion in Plano from June 20th to 22nd. Texas Central Bleeding Disorders and Lonestar Bleeding Disorders Foundation teamed up to create an unforgettable event filled with education, support, and meaningful connections for more than 800 attendees.

Held at the charming Legacy Town Center, the atmosphere was not only beautiful but also warm and welcoming, setting the perfect stage for a fantastic experience. While TBDC provided valuable learning opportunities, the real magic happened in the heartfelt connections made within the community. It was the kind of event that left everyone with tender cheeks from all the smiling and tired arms from the countless hugs shared. Most importantly, participants left feeling inspired and equipped with essential knowledge to help navigate life with a bleeding disorder.

A big thank you to the dedicated staff and volunteers from both chapters who poured their hearts into making this event a true success! Your efforts brought so many people together, and it was a joy to see everyone connect and learn from one another! Every year, more members look forward to the next TBDC, when they can all get together again. We hope to see everyone next year in Austin, June 12–14!

Justin, Dymond, Deanna, Carlos and Baby Hardyn

Daniel, Gareth, Aldrett, Ryett, Everett, and Minnette

Kelly, Ava, Brittany, Zella, and Mila

Wesley, Ryan, Felix, and Rebekah

Mark and Jose

Hosea and Jacqueline

Julia, Juan, Valeria and Raul

Enrique and Nicole

Joshua, Tamara, Tori, John, and Callahan

Lee

Elizabeth, Karla, Daniel and Maria

Annabel, Belen and Nazaret

Saldana, Juan, Julian and Alessandra

Giovani and Lupe

Hailey, Nancy, Jade, and Edgar

Jerome

Felix Garcia with Consuelo and Jesus

Marisol, Juan, Alex, Evelyn, and Dominiqe

James with Jeanette Kiser-Jones

## TENNESSEE

**Cyndy Coors**

Brock, Lindsay and David Tignor

On June 24th, an ***Educational Dinner*** was hosted by the Tennessee Hemophilia and Bleeding Disorders Foundation in collaboration with Octapharma and BioMatrix at Chesapeake's Seafood House in Knoxville. The evening kicked off with a heartfelt welcome from Executive Director Amanda Wilson, who expressed gratitude to the sponsors and attendees for their participation.

ED Amanda Wilson and Moe Hoque with Octapharma

Mohammed Hoque, Patient Experience Manager at Octapharma, took the stage to unveil the innovative products and services his company offers. Following, David Tignor, Territory Account Executive for BioMatrix, delivered a captivating presentation, *Finding Your Harmony*. This interactive session delves into the nuances of anxiety versus stress, offering practical tips for mastering both. Attendees eagerly participated, sharing their personal stories and strategies, creating a supportive community atmosphere.

Katlyn, Addali, Pam and "T-Bone"

The night was filled not just with insightful discussions, but also a delicious meal that brought everyone together. Participants mingled and forged connections, wrapping up a truly enriching evening. A heartfelt thank you to THBDF and Amanda for making this special gathering possible!

## NEW MEXICO

**Felix Jacquez Garcia**

On June 25th, Pfizer and BioMatrix hosted an ***Educational Dinner*** for families from southern New Mexico at the historic La Posta Restaurant in Mesilla, just outside of Las Cruces. While Las Cruces is the second-largest city in New Mexico, families often face a long journey – about three hours – to the New Mexico HTC in Albuquerque or south to El Paso for remote clinic visits held by Gulf States HTC. Because of this, families were especially grateful to have an educational program right in their community.

Felix Garcia with Sandra and Santiago

Aiden and Veronica

Aiden, Veronica, Claudia, Adriana and Jon

Amelia and Kamme

Rosalba and Adolfo

Daniel and Naomi

Isaiah and Diana

Adriana and Jon

Proud raffle winners! Jessica and Isaac

Claudia Zapata LaBry, Pfizer Hemophilia Patient Navigator, gave an interactive presentation on Hympavzi® and emphasized the importance of keeping infusion logs. BioMatrix provided information about our *Patient Navigation* program, explaining how we can support patients navigating insurance or access-to-care challenges, and help connect them with other valuable resources, even if not using our pharmacy services. To learn more, reach out to your nearest BioMatrix Territory Account Executive or visit our website at: https://www.biomatrixsprx.com/bleeding-disorders/patient-navigation.

We look forward to returning to Southern New Mexico soon and hope you can join us for more warm connections and valuable information!

Carl, Tina and Rich

## PENNSYLVANIA

**Tina McMullen**

Over 150 enthusiastic members of the Eastern Pennsylvania Bleeding Disorder Foundation (EPBDF) came together for an unforgettable ***Annual Meeting*** at the Sheraton Valley Forge Hotel on June 25th! Before diving into the main event, attendees explored the busy exhibit hall brimming with display booths and friendly representatives from specialty pharmacies and manufacturers, all ready to answer questions and share valuable information.

The evening kicked off with a dinner as Board President Marisa Ferger welcomed everyone with inspiring opening remarks. The evening also highlighted recent scholarship recipients, introduced by Lisa Lee, Assistant Director. Sarah Pilacik, Executive Director, then took the spotlight to share thrilling updates on EPBDF's recent achievements and what's coming up next!

The highlight of the evening was the keynote address by Corey Parker, Senior Director of Coagulation Sales at CSL Behring, and a former professional baseball player living with hemophilia. Corey, a co-founder of "Getting in the Game," captivated the audience with his heartfelt story, motivating young children with bleeding disorders to embrace sports like baseball and golf. His passion and emotion during the presentation truly showed how dedicated he is to being a positive role model.

Kudos to Sarah Pilacik and Lisa Lee for planning another fantastic event that brought joy and inspiration to the Eastern Pennsylvania bleeding disorders community! We can't wait to see what's next!

## NEW MEXICO

**Felix Jacquez Garcia**

Happy raffle winners! Dave and Lakeia

It was a pleasure to bring another ***Educational Program*** to the Albuquerque bleeding disorder community! This time, BioMatrix partnered with Pfizer for an inspiring gathering on June 26th at El Pinto Restaurant.

Once we settled in, Claudia Zapata LaBry, Pfizer Hemophilia Patient Navigator, gave an enlightening presentation on their new product, Hympavzi®, for the treatment of hemophilia A and B, with and without inhibitors. Following her informative presentation, we dove into an impactful presentation by BioMatrix on *Family Dynamics*. This segment highlighted the essential roles each family member plays in the care and treatment journey, shining a spotlight on their valuable contributions. It was a heartfelt reminder to appreciate the caretakers in our lives, and the audience reacted with enthusiastic nods and thumbs up, a testament to the resonating message.

We wrapped up the evening with an exciting raffle. Congratulations to the winners of our summer-themed gift bundles! A heartfelt thank you to our amazing partner, Pfizer, and everyone who chose to join us for this enjoyable night! Your presence made it all the more special!

## FLORIDA

**Chip Hearn**

The 42nd ***Annual Florida Bleeding Disorders Conference*** took place from June 27–29 at the Palm Beach Gardens Marriott. Hosted by Florida Bleeding Disorders Association (FBDA), the event had the theme "Step by Step," which encouraged participants to take small, steady steps toward growth, health, and success. Classic video game characters Mario and Luigi visually represented the "leveling up" theme. The BioMatrix booth was a popular attraction, featuring a table-sized claw machine. Kids of all ages eagerly tested their skills and dexterity, with many winning miniature stuffed animals and other carnival-style prizes.

With its focus on connection, education, and empowerment, FBDA Executive Director Pepper Adair and staff successfully blended bleeding disorder training with community camaraderie and support. And that's a win for all of us trying to score a personal best in empowerment. Each step forward, every new skill or task we master, helps us achieve a new level of confidence and independence. Sharing these lessons strengthens the entire community, and team victories are often the most rewarding!

Leonardo and Alexandria

## MISSOURI

**Eva Kraemer**

Mike and Kate ham it up!

Exciting developments are underway at the Gateway Hemophilia Association, now rebranded as the Gateway Bleeding Disorders Association (GBDA)! This name change reflects their commitment to serving the diverse bleeding disorders community. Recently, GBDA hosted its annual ***Family Education Weekend***, themed *From Readiness to Resilience,* on July 11–12 at Chesterfield's DoubleTree Hotel, welcoming families from across Missouri and beyond to share knowledge and support.

The weekend began with an enthusiastic welcome from Executive Director Bridget Tyrey and featured an inspiring keynote by life coach Monica Adams-Quentin, who shared her incredible journey of resilience after surviving a massive blood clot at age 19.

Attendees participated in engaging breakout sessions, including *Breaking Barriers, Building Strength* for advocacy tools and *Don't Bleed Dollars* on financial planning. A family session encouraged discussions about the challenges of living with bleeding disorders. Children were not left out of the fun! BioMatrix organized an electrifying game of *Loteria* (Mexican BINGO) for the kids, which quickly became a favorite! The weekend culminated in a delightful dinner, where families gathered by the pool for delicious desserts and a Dive-In Movie featuring *Inside Out*, creating a perfect ending to an unforgettable weekend.

Kudos to the Gateway Bleeding Disorders Association for orchestrating such an enriching and successful event, bringing together families to learn, connect, and thrive!

## OHIO

**Shelia Biljes**

Evelyn and Stephanie

The extreme heat of mid-July couldn't dampen the spirits of the women at our lively ***Ladies Luncheon*** held July 16th at the Avon Lake Cooper's Hawk Winery! What a fantastic place to "Squeeze the Day" in the refreshing comfort of an air-conditioned room surrounded by good friends!

Judy Doyle, Senior Rare Blood Community Liaison with Novo Nordisk, gave a presentation introducing us to Alhemo®, their exciting new prophylactic treatment for hemophilia A and B. It was fascinating to learn about such an innovative advancement in care. Afterward, we dove into a spirited game of "fruit" trivia that sparked plenty of laughter. The energy in the room was contagious as we connected, learned, and supported one another.

Thank you to Novo Nordisk for sponsoring our gathering! It was a remarkable day filled with friendship and fun!

## OHIO

**Shelia Biljes**

Ohio Community members gathered at the Hilton Garden Inn for the Greater Ohio Bleeding Disorders Foundation's (GOBDF) ***Family Education Day*** on July 20th. To kick off the event, Executive Director Tanya Ricchi warmly welcomed everyone and shared an overview of exciting upcoming chapter events. She then handed the microphone to Bill Evert, a paramedic and dedicated father of a child with hemophilia. While everyone enjoyed breakfast, Bill shared valuable insights and important dos and don'ts for calling 911 when a child needs emergency assistance.

Shelia Biljes with Kaeden and Lila Mai

Ryan and Lisa

Afterward, everyone walked across the street to Progressive Field. There, we cheered the Guardians as they faced the California Athletics in a thrilling baseball game. To everyone's delight, the Guardians clinched victory with a resounding score of 8–2! It was a great day of learning, laughter, and lasting memories. Many thanks to GOBDF for hosting this wonderful gathering!

## TENNESSEE

**Cyndy Coors**

The Tennessee Hemophilia & Bleeding Disorders Foundation's ***55th Annual Meetin***g was held from July 25–27 at Dollywood's HeartSong Lodge & Resort in Pigeon Forge, with the theme *Rhinestones and Resilience: Shining Bright, Standing Strong, and Making a Difference*. Participants embraced the theme with fun decorations and outfits inspired by Dolly Parton.

Janet and Jeannetta

David and William

The meeting offered valuable networking opportunities, including three engaging breakout sessions. One standout presentation was led by David Tignor, Senior Territory Account Executive for BioMatrix, titled *Finding Your Harmony*, which provided insights on managing stress and anxiety. Personal stories and coping strategies were shared by participants fostering a rich dialogue that united community members.

Kids and teens enjoyed a Glow-in-the-Dark party and a day at LazerPort Fun Center, while young adults participated in GutMonkey's program and an exciting challenge at Escapology. Saturday evening included raffle drawings, award announcements, and a memorable group photo. Sunday wrapped with special access to Dollywood, where attendees enjoyed the thrilling rides and attractions. It was a perfect conclusion to the weekend!

Thank you to THBDF for fostering such a supportive environment for community members. We can't wait for next year's annual meeting!

## VERMONT

**Richard Vogel**

Place your bets… Shooters shooting… 10 is the number… Blackjack! The atmosphere was electric during casino night — sponsored by BioMatrix — at New England Hemophilia Association's (NEHA) ***3rd Annual Men's Retreat*** July 25–27 at the Mount Snow Resort in West Dover. This event was the perfect way to socialize, laugh, and unwind after a day packed with workshops, engaging educational seminars, and lively discussions. The weekend's theme addressed building bonds, active listening, and being fully present to savor life's moments.

Mark Zatyrka places his bet

Rich wins big!

Our incredible facilitator, Tony Silbert, co-founder of Spartina Consulting, guided us through a dynamic series of workshops. We kicked off Friday night with *Connecting through Conversations* and carried the momentum into Saturday morning with *Reframing Challenges*. One of the standout moments for everyone was taking the exhilarating gondola ski lift to the top of Mount Snow, where we soaked in stunning views and participated in refreshing mindfulness activities.

Back at the lodge, we had the choice of breakout sessions, including *Move with Purpose*, *Beyond Bleeding Disorders*, *Balancing Emotional Wellness*, and *Fuel and Flow*. I was both honored and somewhat surprised when Rich Pezzillo, Executive Director of NEHA, asked me to facilitate a rap session on *Aging with a Bleeding Disorder.* Nevertheless, it turned out to be a fantastic conversation, with participants eagerly sharing their concerns about growing older. We tackled topics from joint limitations and replacement therapies to managing high blood pressure and cholesterol.

As we gathered for the Sunday morning send-off, everyone was talking about the renewed energy we felt, like our "batteries were recharged!" Although the NEHA community spans across New England, it remains a close-knit family that is truly *Wicked Strong*!

## OHIO

**Shelia Biljes**

It's time to start planning for the upcoming school year, and what better way to kick things off than with a lively ***Back to School Dinner and Silent Disco***! The Northwest Ohio Hemophilia Foundation teamed up with Novo Nordisk and BioMatrix on August 6th for this exciting event at Maumee Bay Winery in Toledo.

During dinner, Judy Doyle, Senior Rare Blood Community Liaison with Novo Nordisk, gave an insightful presentation on back-to-school safety. While the children danced in the lively atmosphere of the disco, Judy engaged with parents one-on-one, discussing their personalized back-to-school plans and addressing any concerns they might have.

A huge thank you to the Northwest Ohio Hemophilia Foundation for organizing such a wonderful opportunity for families to connect and celebrate! Let's make this school year safe and successful!

## FLORIDA

**Hector Heer and Chip Hearn**

Anthony and and Michelle

BioMatrix was pleased to partner with Pfizer on August 7th for an ***Educational Dinner*** at Bulla Gastrobar in Doral. Pfizer shared details about Hympavzi®, their newest product for hemophilia A and B. BioMatrix Patient Resource Specialist Brenda Montgomery King spoke about our patient navigation program and how we're helping community members resolve insurance issues and other non-clinical barriers to care. Thanks to all who came out!

## OHIO

**Shelia Biljes**

Emon is ready for Silent Disco!

School days, school days! Good old Golden Rule days! Summer has flown by, and now it's time to dive into the school year with renewed focus and enthusiasm! On August 7th, Novo Nordisk and BioMatrix threw an unforgettable ***Back to School Bash*** at Brew Garden in Strongsville for the families of the Greater Ohio Bleeding Disorder Foundation. The atmosphere buzzed with excitement as families gathered for a night of fun!

Over dinner, Judy Doyle, Senior Rare Blood Community Liaison at Novo Nordisk, inspired everyone with her insights on how to team up with school staff to create safety plans for children with a bleeding disorder. Then came the highlight – *Silent Disco*! The energy in the room was electric, with laughter filling the air. It was just as much fun to watch the dancing as it was to join in!

A huge thank you to the Greater Ohio Bleeding Disorder Foundation for hosting such an exciting event! Let's make this school year one for the books!

## FLORIDA

**Hector Heer and Chip Hearn**

Hector Heer with Fran Hayes

The Island of Adventure event was made possible thanks to the Bleeding Disorders Foundation of Florida. Participants had the opportunity to gather, share a meal, and play games! BioMatrix Territory Account Executive Hector Heer engaged participants with a fun bleeding disorder focused game of *Lotería*. After the event, participants enjoyed the summer sun in the park. It was truly a day full of energy and excitement!

## NEVADA

**John Martinez**

Jace, Tony and Nikki

Dustin and Neaveh

Reno's local bleeding disorders community came together August 16th for a ***Community Connections*** evening of valuable educational content, sponsored by Sanofi and BioMatrix. Families gathered at the Washoe Public House, creating an atmosphere of unity and support while they savored a delicious dinner.

Jean Paul and Olga

The evening began with BioMatrix presenting an insightful program centered on managing stress and anxiety, in both English and Spanish. Participants actively engaged sharing their experiences and unique challenges faced, how they learned effective techniques to cope with stress and anxiety, and empowered them to take control of their mental well-being.

Jesus, Janet and Valeria

Julianna, Diego, Jessica, Isaías, and Fresh

The educational journey continued with an exciting presentation and hands-on painting activity facilitated by Sanofi. Participants dove into an artistic project that allowed them to express gratitude for the support of family and friends. The room was filled with laughter, colorful creations, and heartfelt connections as individuals bonded over shared experiences.

Christina, Kalina and Kevitt

Yadira and Amy

As the evening ended, everyone exchanged warm farewells and heartfelt gratitude for one another. The gathering not only provided invaluable information and support but also fostered a sense of camaraderie that would linger long after the night ended. It truly was a memorable event in "The Biggest Little City in Nevada!"

# Upcoming Events

## OCT 11, 2025 OHIO
***Family Education Day***
NW Ohio Hemophilia Foundation
419–291–5882, nwohemophilia.org
RSVP: Carla Wells, 734-497-5944
carla@nwohemophilia.org
Hilton Garden; Perrysburg

## OCT 16, 2025 FLORIDA
***Educational Dinner***
Hosts: Foundation Hope and Life, Sanofi and BioMatrix
RSVP: Ana Calero, 786-374-6143
anacalero@fhlusa.org
Mondongo's; Miami

## OCT 18, 2025 DELAWARE
***Education, Lunch, and Fall Fun***
Hosts: Brandywine Valley Hemophilia Foundation and BioMatrix
RSVP: Gail Novak, gvannicola@verizon.net
Ramsey's Farm; Talleyville

## OCT 23, 2025 NEW MEXICO
***Fall Education Event***
Sangre de Oro, Inc., 505-341-9321
www.sangredeoro.org
RSVP: sdo@sangredeoro.org
Embassy Suites; Albuquerque

## OCT 23, 2025 PENNSYLVANIA
***Educational Dinner***
Hosts: Pfizer and BioMatrix
RSPV: Tina McMullen, 484-942-4457
tina.mcmullen@biomatrixsprx.com
Shady Maple Smorgasbord; East Earl

## OCT 24, 2025 OKLAHOMA
***Community Dinner***
Hosts: Takeda and BioMatrix
RSVP: Jeanette Kizer-Jones, 405-229-0855
jeanette.jones@biomatrixsprx.com
Charleston's; Tulsa

## OCT 25, 2025 NEVADA
***Annual Meeting & Industry Symposium***
Nevada Chapter, NBDF
702-564-4368, nv.bleeding.org
Sunset Station Hotel & Casino; Henderson

## OCT 25, 2025 OKLAHOMA
***Community Dinner***
Hosts: Takeda and BioMatrix
RSVP: Jeanette Kizer-Jones, 405-229-0855
jeanette.jones@biomatrixsprx.com
Choctaw Nation Community Center; Spiro

## OCT 26, 2025 NEW JERSEY
***Fall Education and Apple Picking***
HANJ Hemophilia Association of NJ
732-249-6000, hanj.org
RSVP: Cindy Hansen, chansen@HANJ.org
Johnson Locust Hill Farm, Jobstown

## OCT 28, 2025 OHIO
***Bone Health Family Dinner***
Hosts: Greater Ohio Bleeding Disorder Foundation, Takeda and BioMatrix
RSVP: Tonya Stewart, 216-834-0051
tanya@gobdf.com
TBA, Akron

## NOV 1, 2025 OHIO
***Annual Meeting***
Greater Ohio Bleeding Disorder Foundation
216-834-0051, gobdf.com
RSVP: Tonya Stewart, tanya@gobdf.com
Pro Football Hall of Fame; Canton

## NATIONAL EVENT!
## NOV 6–8, 2025 FLORIDA
***HOPE Conference***
HOPE Charities, 888-529-8023
www.hopeforhemophilia.org
RSVP: www.hopeforhemophilia.org/hope-conference-2025.html
Hilton Orlando; Lake Buena Vista

## NOV 8-9, 2025 MAINE
***Fallfest***
New England Hemophilia Association
781-326-7645, newenglandhemophilia.org
RSVP: Jodi Weeks
jweeks@nehemophilia.org
Samoset Resort; Rockport

## NOV 8–9, 2025 VIRGINIA
***Weekend Retreat for Spanish Speaking Members***
Hemophilia Association of the Capital Area
703-352-7641, hacacares.org
RSVP: Brenda Bordelon, 703-352-7641
director@hacacares.org
Fairfax

## NOV 13, 2025 OHIO
***Ladies Educational Lunch***
Hosts: Octapharma and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Bonefish Grill; Westlake

## NOV 19, 2025 FLORIDA
***Educational Dinner***
Hosts: CSL Behring and BioMatrix
RSVP: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Oystercatchers; Tampa

## DEC 2, 2025 NEW JERSEY
***Blood Brother/Blood Sister Night***
Hemophilia Association of New Jersey
732-249-6000, hanj.org
RSVP: Cindy Hansen, chansen@HANJ.org
George St. Playhouse; New Brunswick

## DEC 6, 2025 OHIO
***Holiday Dinner***
Greater Ohio Bleeding Disorder Foundation
216-834-0051, gobdf.com
RSVP: Tonya Stewart, tanya@gobdf.com
Stan Hewitt Hall; Akron

## DEC 7, 2025 PENNSYLVANIA
***End of Year Meeting***
Brandywine Valley Hemophilia Foundation
brandywinehemophilia.org
RSVP: Gail Novak, gvannicola@verizon.net
info@brandywinehemophilia.org
Mendenhall Inn; Mendenhall

## DEC 7, 2025 VIRGINIA
***Holiday Gathering***
Hemophilia Association of the Capital Area
703-352-7641, hacacares.org
RSVP: Brenda Bordelon, 703-352-7641
director@hacacares.org
Sherry Sherwood Center; Fairfax

## DEC 9, 2025 FLORIDA
***Educational Dinner***
Hosts: Pfizer and BioMatrix
RSVP: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Maggiano's; Tampa

## DEC 12, 2025 FLORIDA
***Educational Dinner***
Hosts: Takeda and BioMatrix
RSVP: Hector Heer, 954-940-1248
hector.heer@biomatrixsprx.com
Pisco y Nasca, Doral

## DEC 13, 2025 TEXAS
***Winter Chapter Education Day***
Texas Central Bleeding Disorders
972-386-3865, www.texcen.org
RSVP: gina@texcen.org
The Beeman Hotel; Dallas

## NATIONAL EVENT!
## APR 9-12, 2026 NEVADA
***Symposium 2026***
The Coalition for Hemophilia B
212-520-8272, www.hemob.org
Las Vegas

### Time for Fun!

Games on page 31

# Time for Fun!

## Hi Kids!

**Have you ever heard some wild stories about bleeding disorders that just couldn't be true? Sometimes, these myths can be pretty silly! Let's play a fun game and see if you can spot which of these statements are true and which ones are totally made up. Get ready to uncover the real facts and have a laugh while we're at it! Check the T box for True and the F box for False. Answers are on page 26.**

T or F

☐ ☐ 1. Researchers are studying snake venom as a way to stop bleeding in people with hemophilia.

☐ ☐ 2. Most people born with hemophilia are boys, but girls can have hemophilia too.

☐ ☐ 3. People with a bleeding disorder can bleed into joints or muscles inside their body.

☐ ☐ 4. Kids with hemophilia *always* have an uncle or grandpa with hemophilia too.

☐ ☐ 5. Having von Willebrand Disease will make your hairy super curly!

☐ ☐ 6. A "spontaneous bleed" is when a person with hemophilia starts bleeding inside their body for no apparent reason.

☐ ☐ 7. When you turn 35, your bleeding disorder will magically vanish!

T or F

☐ ☐ 8. With proper treatment, kids with a bleeding disorder can play most sports safely

☐ ☐ 9. Bleeding disorders can be cured by eating peanut butter sandwiches.

☐ ☐ 10. Having hemophilia means you are a descendant of royalty.

☐ ☐ 11. Bleeding disorders affect people from every race, ethnicity, and religion.

☐ ☐ 12. Drinking cold tomato juice will help reduce joint bleeds.

☐ ☐ 13. The best way to self-infuse is in a dark room wearing sunglasses

☐ ☐ 14. With today's advances in medical care, people with a bleeding disorder can live happy, long, healthy lives!

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

## Sudoku!

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

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

# [BIOMATRIX]
## Specialty Infusion Pharmacy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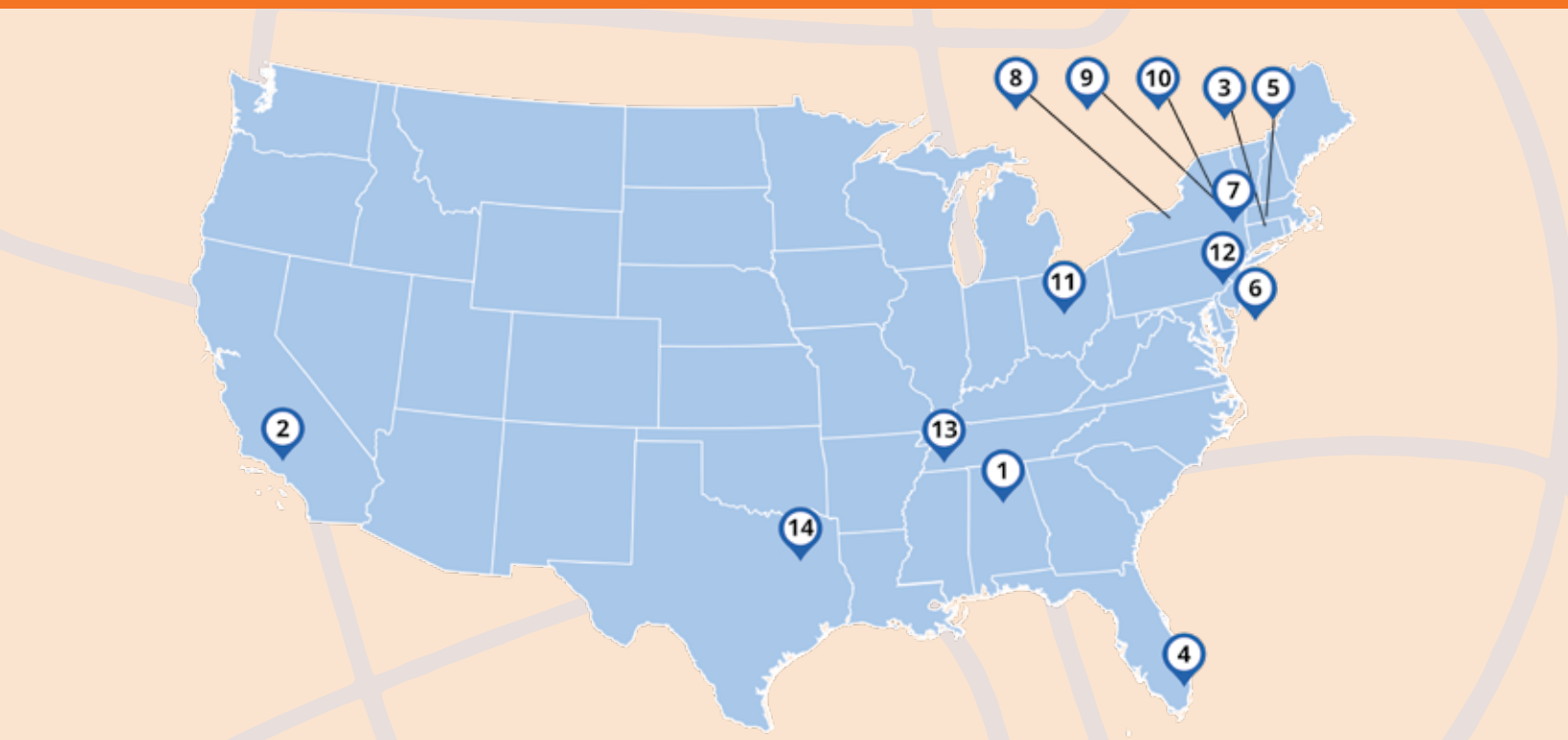
## Dedicated to Making a Difference

BioMatrix values your privacy. We are committed to keeping your information secure and confidential. We take your privacy very seriously by complying fully with HIPAA regulations and employing a team of IT experts whose job is to keep our data safe and secure. Our mailing list is private and will never be sold or shared with a third party. If you have any questions or would like to review our Privacy Policy, please contact our corporate office at 877-337-3002.




### Specialty Infusion Pharmacy Locations

1. Birmingham, Alabama
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5. West Springfield, Massachusetts
6. Totowa, New Jersey
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9. Syracuse, New York
10. Syracuse, New York
11. Dublin, Ohio
12. Garnet Valley, Pennsylvania
13. Bartlett, Tennessee
14. Tyler, Texas

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