BIOMATRIX
Specialty Infusion Pharmacy
News

Winter 2025
Volume 20 | Issue 1

Dedicated to Making a Difference

> **Smile in the mirror. Do that every morning and you'll start to see a big difference in your life.**
>
> **— Yoko Ono**

VOLUME 20 | ISSUE 1
WINTER 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 and Justin Lindhorst

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

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All information, content, and material is for informational purposes only and is not intended to serve as a substitute for the consultation, diagnosis, and/or medical treatment of a qualified physician or healthcare provider or as legal advice. Please consult a physician or other health care professional for your specific health care and/or medical needs or concerns and never disregard professional medical advice or delay in seeking it because of something you have read here or on our website.

BIOMATRIX
Specialty Infusion Pharmacy

A Moment in Your Spectacular Life!

Our 2025 *Living a Spectacular Life* Calendar is now available!

Filled with joyous photos of community members, our calendar highlights just how amazing life can be, even with a bleeding disorder!

REQUEST YOUR FREE CALENDAR TODAY!
Contact your Territory Account Executive or email us: info@biomatrixsprx.com

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A Note from the Editor

Happy New Year!

As we kick off another exciting year, everyone at BioMatrix Specialty Infusion Pharmacy wants to extend a heartfelt thank you to our wonderful readers and contributors. Your support means the world to us, and we genuinely appreciate your feedback, comments, and insights.

In the year ahead, we're eager to bring you a wealth of engaging articles and inspiring stories that resonate with your experiences. Whether it's the latest research breakthroughs, personal success stories, tips for living well with a bleeding disorder, or updates from the community, our goal is to provide content that is not only informative but uplifting as well.

As we embark on this journey through 2025, let's focus on building connections, sharing knowledge, and inspiring one another. We are committed to being here for you, ready to support and encourage you in every way we can. Here's to an amazing year ahead, filled with good health, tranquility, joy, and countless opportunities to make a positive impact in our lives and the lives of others.

Wishing you all the very best in 2025!

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

Join our growing team!

BioMatrix Specialty Infusion Pharmacy is seeking experienced professionals dedicated to making a difference in the bleeding disorders community.

Enjoy competitive pay, a robust benefits package, and being part of a nationwide team focused on improving health outcomes.

We are looking for individuals who understand the healthcare landscape, the unique needs of the bleeding disorder community, and have experience with patient-centric pharmacy and support services.

Interested? Send your resume to:
Angie Ferrier, *Senior Human Resource Manager*
angie.ferrier@biomatrixsprx.com

HOW TO AVOID ACCESS-TO-CARE ISSUES WHEN INITIATING NEW COVERAGE

BY JUSTIN LINDHORST

The beginning of the year often signals the start of new health insurance coverage. For those with bleeding disorders, initiating new coverage can sometimes lead to challenges that delay access to prescribed therapy.

Specialty infusion pharmacies can help patients with bleeding disorders navigate access-to-care challenges when beginning new insurance coverage in the new year. This article provides tips and best practices that patients and their loved ones can implement and links to valuable resources.

Work with Your Specialty Infusion Pharmacy to Review Your New Plan Carefully

Anyone who has a bleeding disorder or a loved one with a bleeding disorder can recall an occasion where they spent a significant amount of time on the phone with their health insurance plan. Unfortunately, it's not uncommon for patients to be told one thing by one customer service representative only to be told something entirely different by another.

Specialty infusion pharmacies can help overcome barriers to care and navigate the complexities of the healthcare system. They conduct thorough benefits investigations, facilitate access to financial support programs, and collaborate with your insurance plan and medical team to assist with prior authorizations and appeals.

Specialty infusion pharmacies such as BioMatrix employ staff who are very well versed in promptly identifying and resolving coverage issues specific to those with bleeding disorders. The first tool at their disposal is conducting a comprehensive benefits investigation.

The benefits investigation provides a detailed outline of coverage specific to your therapy, including whether it is covered under the medical or pharmacy benefit, whether the medication requires prior authorization, your financial responsibility, and what specialty infusion pharmacy providers are available under your new plan.

After the benefits investigation is complete, the specialty infusion pharmacy can refer you to available and appropriate patient assistance programs to reduce financial barriers to care. They can also work with your medical provider and health plan to obtain timely prior authorization for service and assist when an appeal is necessary.

Be Proactive

Don't wait until you are critically low on medication to place your first order. Placing your order promptly will give your hematologist and specialty infusion pharmacy enough time to address any issues that may arise, ensuring that your care remains uninterrupted.

It is also crucial to maintain an adequate supply of your medications to bridge any potential gaps during the transition. Be sure to inform your hematologist, Hemophilia Treatment Center (HTC), and specialty infusion pharmacy about your insurance change as soon as possible to ensure continuity of care.

Reach Out to a Social Worker

If you are experiencing or anticipate coverage issues, social workers can be a great source of support. Many medical providers caring for patients with bleeding disorders engage social workers as part of a multidisciplinary care team. Ask your healthcare provider if social workers are available to assist with coverage or other concerns.

Keep Detailed Records

When contacting your insurance provider about any issue or concern, it is essential to document every interaction. Keep notes that include:

- Date and time of call
- Reason for call
- Name of the employee(s) you spoke with
- Reference number for the call (make sure to specifically request the reference number)
- Outcome of the call
- Any impact on your health resulting from the issue or call

Document Medical Necessity

Work with your hematologist to document the medical necessity of your treatment. Having robust documentation on file can speed up the resolution of issues related to prior authorization, denials, step therapy, or appeals. Ask your hematologist to write a letter on official letterhead identifying your diagnosis, why you have been prescribed the particular therapy, any previously failed treatments, and the consequences of not having access to your prescribed therapy.

Include medical records, clinical evaluations, lab tests, or other supplemental documentation supporting your diagnosis and treatment. Keep a copy for your personal records, and request a copy be kept on file with your specialty infusion pharmacy.

Check for Copay Accumulators

If you are using a manufacturer or other third-party copay assistance program, it is essential to determine if your plan uses a copay accumulator. Verify with your specialty infusion pharmacy to ensure payments are being received from the copay assistance program you are enrolled in.

Once you've verified payments are being made, check your Explanation of Benefits (EOB). If the payments from your assistance program are not being applied to your out-of-pocket costs, your plan may be using a copay accumulator program.

Understand the Appeal Process

The process for filing an appeal varies by insurance plan. Check with your insurance provider to determine their specific appeal process. Don't hesitate to involve your medical provider and specialty infusion pharmacy for additional assistance.

To understand the denial of the claim, investigate the EOB. The denial may have a code listed on the EOB. In some cases, a letter may be included with codes and a key to explain the reason for denial. Identifying the code will allow you to see if it was an actual denial or a basic miscoding by the provider or insurance.

Keep all documentation, including referrals, clinician notes, medical history, medications or prescriptions, and notes from all communications with providers and insurance regarding the claim. It is crucial to remember that the burden of proof is in your hands.

Organize Your Paperwork

If you have the necessary documents, you may also need to file a written appeal letter to the insurance company. Keep documentation of your claim number, insurance information, and provider and service information readily available. Request a reference number and the name of the employee you speak with on every phone call to your insurance provider.

Be aware of the appeal timeline (which can be 30/60/90 days in many cases). Make sure to submit all paperwork and make calls within the timeline allowed. If your appeal

is denied a second time, you may be able to file another appeal. In some states, provisions of the Affordable Care Act (ACA) allow an external review process for claims that have been denied.

Follow up on every call, text, email, and mailed document you submit. Be sure you have a record of receipt for every submission.

Navigating new coverage can be challenging for bleeding disorder patients who require specialty medication. Prevent potential disruptions in care by leveraging every resource available to you. Work with your specialty infusion pharmacy and medical providers early to identify, address, and resolve any issues before they escalate into an urgent concern or critical problem.

Adhering to these guidelines when contacting your health plan can make a significant difference in maintaining uninterrupted access to the therapies and services necessary for your health.

BioMatrix Can Help

BioMatrix offers a free, no-obligation benefit investigation that will help you understand your exact coverage — whether or not you're a patient with us. If you are a patient with us, contact your Territory Account Executive to initiate a free benefits investigation. If you're not a patient with us, fill out the form on this web page to get started: www.biomatrixsprx.com/bleeding-disorders/patient-navigation

Useful Links

Centers for Medicare and Medicaid Services (CMS)
Official website for CMS: www.cms.gov/

eHealth Insurance Glossary
eHealth provides a list of common insurance terms on their website: www.ehealthinsurance.com/health-insurance-glossary/terms-c/

Employee Benefits Security Administration
Official website for the U.S. Department of Labor Employee Benefits Security Administration: www.dol.gov/agencies/ebsa

National Association of Insurance Commissioners (NAIC)
NAIC is a standard-setting and regulatory support organization. Their website includes a map that will allow you to determine the insurance commissioner in your state: https://content.naic.org/

Patient Advocate Foundation (PAF)
PAF is dedicated to improving healthcare access. Their website offers education, assistance, and resources related to healthcare coverage: www.patientadvocate.org/

United States Department of Labor
The website includes information on the Employee Retirement Income Security Act (ERISA) and Consolidated Omnibus Budget Reconciliation Act (COBRA) plans: www.dol.gov/general/topic/health-plans

[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

MY DECIDING FACTOR:

Making time for what matters most.

vonvendi
[von Willebrand factor (Recombinant)]

Erica
VONVENDI Use: On-Demand & Surgery

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

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

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

VONVENDI [von Willebrand factor (Recombinant)] Important Information

What is VONVENDI?

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

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

Detailed Important Risk Information

Who should not use VONVENDI?

You should not use VONVENDI if you:

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

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

How should I use VONVENDI?

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

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

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

You should tell your healthcare provider if you:

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

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

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

What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

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

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

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

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

Takeda

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

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

vonvendi
[von Willebrand factor (Recombinant)]

What is VONVENDI?

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

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

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

Who should not use VONVENDI?

You should not use VONVENDI if you:

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

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

What should I tell my doctor before I use VONVENDI?

You should tell your healthcare provider if you:

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

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

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

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

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

What are the possible side effects of VONVENDI?

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

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

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

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

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

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

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

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

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

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US-VON-0657v2.0 05/24

Takeda

NO COMMERCIALS HERE...

BY FELIX JACQUEZ GARCIA

Sitting on my couch with the coffee table in front of me, I began laying out my clotting factor and supplies. I turned on the television, and as the familiar blue glow washed over the room, I prepared to infuse.

With my clotting factor mixed, I started looking for a suitable vein. Just then, a commercial for *Wounded Warriors* caught my attention. I paused to watch, my heart swelling with admiration. "Now, this is something I can support," I thought.

As I watched, I couldn't help but reflect on the many individuals I know who resemble those soldiers – those who walk with a limp, rely on crutches or a wheelchair, or need a little extra help navigating the world, much like the brave veterans showcased in the commercial. Yet, there won't be a campaign for those with hemophilia, a bittersweet realization.

Let me pause here to express my deepest gratitude for all who have served in the Armed Forces, protecting the values and freedoms I hold dear. Their sacrifices deserve every bit of recognition and support we can offer. I urge you to please reach out to a veteran or a local veteran service organization. It's disheartening that they must spend money on commercials to garner our support.

Many of us with bleeding disorders, myself included, once dreamed of serving our country. I remember attending recruiting meetings when I was young and filled with hope – until I had to disclose my hemophilia. I would have proudly paid my dues as an American, just as countless others with bleeding disorders would have. In my heart, I believe that the injuries and pain endured in service to our nation would have been a badge of honor.

Yet, the pain that fills our days carries no such honor. We do not earn our scars on distant battlefields; rather, our battles manifest within us in ways often unseen. We face daily struggles involving bleeds, arthritis, synovial inflammation, and joint deterioration. For some of us, there are the added challenges of dealing with HIV/AIDS and hepatitis.

When my fellow blood warriors and I walk – or sometimes limp – down a hallway, there are no salutes or approving nods, no decorations of valor to acknowledge our silent

struggles. But even in this, our fight holds its own kind of honor. Our battle is about becoming productive, contributing members of society – supporting ourselves, our loved ones, and our communities.

To my blood brothers and sisters, I honor you deeply – those who came before us and bravely ventured into new treatments, not out of convenience, but for the sake of progress in science. You were the courageous pioneers when our medications needed to be more effective and safe.

I salute those who remember whole blood, fresh frozen plasma, and cryoprecipitate – the trailblazers who lived "on demand," with no prophylactic treatment offered, sometimes forced to prove their struggles before receiving the care they needed. You are not forgotten.

Many mentors from our bleeding disorders community have left us, but some have defied the odds and continue to inspire through their strength and tenacity. Many have emerged as leaders, lighting the way for others. Some may have stepped back but returned to fill crucial roles in our organizations.

I am profoundly grateful for the sacrifices made under circumstances that many in our community, thankfully and hopefully, may never have to face. Your examples of resilience are a treasure, and I appreciate everything done for us by our fore-brothers and sisters.

Though there may not be commercials or television ads highlighting our struggles, and the broader public might not fully grasp what we endure, I do. I see you. Let's continue to strive to serve the greater good, even when our efforts go unnoticed.

As for my infusion, it took a while, but eventually the process was completed, ready to keep fighting the good fight.

BIOMATRIX
Specialty Infusion Pharmacy

A Moment in Your Spectacular Life!

Our 2025 *Living a Spectacular Life* Calendar is now available!

Filled with joyous photos of community members, our calendar highlights just how amazing life can be, even with a bleeding disorder!

REQUEST YOUR FREE CALENDAR TODAY!
Contact your Territory Account Executive or email us: info@biomatrixsprx.com

CELEBRATING *70 YEARS!*

Hemophilia Foundation of Southern California
FOR ALL BLEEDING DISORDERS

"Improving the quality of life and building community for those living with inherited bleeding disorders in Southern California."

BY RIGOBERTO GARCIA, ED

We at BioMatrix extend our heartfelt support to everyone affected by the tragic fires in Los Angeles. The profound loss and destruction are truly heartbreaking, and our thoughts and prayers are with all impacted during this challenging time. HFSC is collaborating with national organizations to provide emergency support for the bleeding disorders community. If you or someone you know needs assistance, please contact HFSC: Office: 626-765-6656, Rigo's Cell: 626-485-5689, Email: rigo@hemosocal.org or info@hemosocal.org.

As we celebrate the 70th Anniversary of the Hemophilia Foundation of Southern California, we take a moment to reflect on the fantastic journey we've embarked on together since our humble beginnings. Founded in 1954, our Foundation has always been dedicated to providing our community with the education, resources, and support that help individuals and families thrive.

The Hemophilia Foundation of Southern California (HFSC) is the premier resource for individuals affected by bleeding disorders in Southern California. Our mission is to improve the quality of life and cultivate a sense of community for those living with inherited bleeding disorders in the region.

We take pride in our rich history, which began when a group of parents united in desperation and frustration, both financially and medically, decided to organize a network of support for their children and others living with hemophilia. These families, faced with limited resources and a lack of understanding of the condition, decided to take action. They referred to themselves and their children as "sufferers" and founded the Southern California Society for Hemophilia, the first hemophilia foundation west of the Mississippi River and one of only a few in the entire nation.

Today, HFSC proudly serves over 3,800 community members affected by hemophilia, von Willebrand Disease, and other rare bleeding disorders across nine counties. Our reach and impact have grown tremendously over the decades. We offer comprehensive support services, passionately advocate for policies that enhance the lives of those with bleeding disorders, and deliver valuable education to families. Thanks to advancements in medication and treatment, managing bleeding disorders has become more hopeful and promising, turning distant dreams into reality.

Copley News Service Photo
BRAVE LAD --- Dr. Shelby Dietrich, pediatrician at Orthopedic Hospital in Los Angeles, examines swollen and bruised leg of 11-year-old Casey, who suffers from hemophilia. Casey just completed therapy in hot swimming pool.

We empower individuals and families to live fuller lives through vital programs such as support groups, educational seminars, emergency financial assistance, and advocacy. One of our standout initiatives is our *Family Information Day*, an educational event that provides essential resources and knowledge to families impacted by bleeding disorders.

This special event supports critical services and fosters a warm sense of community among families, healthcare professionals, and industry partners. With all three of

With the Red Cross

First concentrated factor

Hatmaking fundraiser

Kenneth Ketchum, ED

our Hemophilia Treatment Centers (HTCs) in attendance, our community members have the opportunity to connect directly with their hematologists, gaining access to expert guidance and personalized care. *Family Information Day* is truly a cornerstone of our mission to educate, connect, and uplift our community.

Working in southern California presents unique challenges, and we approach these with compassion and determination. Our region is vast, with communities ranging from vibrant urban centers to more rural areas, making it challenging to ensure everyone has equal access to care and resources. Additionally, California's high cost of living often adds an extra layer of stress for families already grappling with significant healthcare costs.

We strive to educate the general public—and even some healthcare professionals—about bleeding disorders, as these conditions are often misunderstood. Through our ongoing education and advocacy efforts, we aim to break down barriers and ensure every member of our community receives the care they truly deserve.

Alongside our *Family Information Day*, we take immense pride in our *Familia de Sangre Conference*, the largest all-Spanish conference for the bleeding disorders community in the nation, held in partnership with the three other California bleeding disorders organizations.

This important event provides a crucial platform for Spanish-speaking families, offering access to education, resources, and support while fostering lasting connections within the community. It's a beautiful time to celebrate our shared experiences and uplift the individuals and families shaping our Foundation's bright future.

Throughout the year, we organize a range of engaging events, including back-to-school symposiums, new family meetings, retreats, empowerment workshops, industry forums, and various social gatherings. We participate in fundraising activities, such as walks, and awareness campaigns like legislative days in Sacramento and Washington D.C. Additionally, we offer educational scholarships, free medical alert IDs, and our *Hemophilia in Action* newsletter.

We deeply value our collaboration with national partners like the Hemophilia Federation of America (HFA), which is vital to our success. HFA amplifies the voices of local organizations by advocating for healthcare policies and treatment access at the national level. They provide essential resources, leadership training, and education that enhance our ability to serve the community. By continuing to work closely with HFA, we can tackle shared challenges, expand our reach, and ensure that the needs of the bleeding disorders community are addressed both locally and nationally.

Want to learn more about HFSC? Visit our website at www.hemosocal.org or email us at info@hemosocal.org.

Together, we can continue to make a meaningful difference!

HFSC Staff
(left to right) Laura Desai, Dir of Operations, Omar Torres, Outreach Coord., Michele Warner, Dir of Development, Casey O'Brien, Senior Events Mgr, and Rigoberto Garcia, Executive Director

Hemophilia Foundation of Southern California
FOR ALL BLEEDING DISORDERS

A MOMENT IN HISTORY

I Get By With A Little Help From My Friends

It's 1964, Beatlemania had swept the nation, and the Beatles were in Los Angeles to play a sold-out show at the Hollywood Bowl. Elsewhere in Los Angeles, the then-named Hemophilia Society was speaking with Alan Livingston, president of Capitol Records and father to a son with hemophilia, about hosting a fundraiser. Livingston enlisted the help of his wife, actress Nancy Olson of Sunset Boulevard fame, to help with an idea for an event, and the Beatles Garden Party was born.

Olson worked with her mother, who had a large garden at her Brentwood home, to put together the perfect fundraiser. They would host a garden party, charging $25 for adults and children, and attendees would, in turn, meet and take a photo with The Beatles. The pair worked with Warren Cowan, co-founder of publicity firm Rogers & Cowen, who represented the band, to lean on their roster of famous clients to make up the guest list.

On August 24, 1964 (the day after their Hollywood Bowl performance), the garden was set for the exclusive event with heavy security – a riot squad was holed up in the garage of the home as word spread who was in the garden. Famous faces at the party included Frank Sinatra and his daughters Nancy and Tina, Dean Martin and his five children, Kirk Douglas with sons Michael and Joel, Tony Curtis, and Lloyd Bridges with sons Jeff and Beau.

R.S.V.P. Capitol Records, Inc.
(Reservations & Information)
HOllywood 2-6252, Ext. 270.
Admission by ticket only.
Charitable contribution:
Twenty-five dollars per
person(each child,each adult).
Make checks payable to
The Hemophilia Foundation.
All children will meet and be photographed individually with The Beatles. Children must be accompanied by an adult: adults must be accompanied by children.

Alan W. Livingston
President, Capitol Records, Inc.
cordially invites you
to attend a
"Meet The Beatles"
Charity Garden Party
for the benefit of
The Hemophilia Foundation
of Southern California

Monday, August 24, 1964
4:00-7:00 p.m.
415 Arrendale Avenue
Brentwood Park
Los Angeles 49, California

At the end of the event, Beatles manager Brian Epstein donated $10,000; which coupled with the money raised from attendees, yielded a successful fundraiser for the Hemophilia Society!

CAMP BLOOD BROTHERS AND SISTERS CELEBRATING 45 YEARS!

Hemophilia Foundation of Southern California
FOR ALL BLEEDING DISORDERS

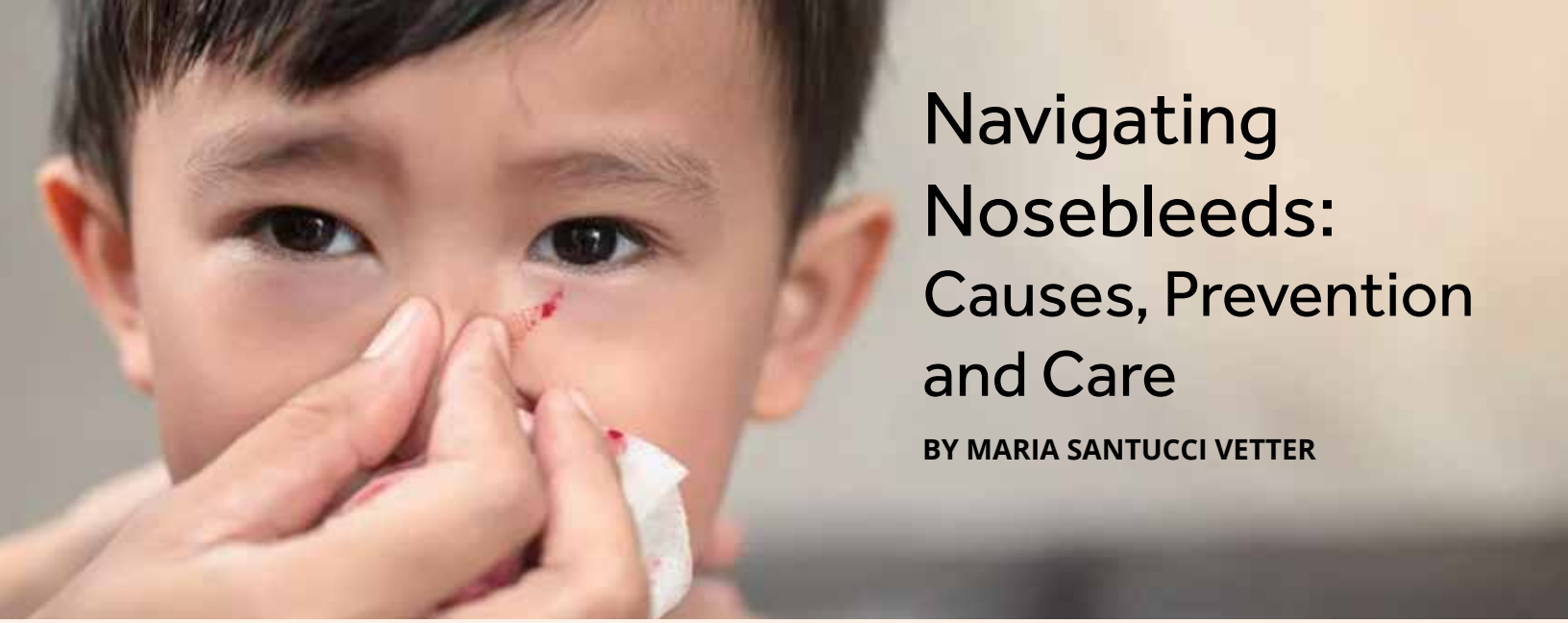
Since 1979, *Camp Blood Brothers and Sisters* has been the ultimate summer adventure for our community youth! For 20 years, we have proudly called The Painted Turtle Camp in scenic Lake Hughes our camp home. It is more than just a getaway; it's a thrilling opportunity for affected kids and their siblings to get to know other kids who face the daily challenges of a bleeding disorder.

Imagine six action-packed summer days filled with everything from archery to arts and crafts, along with boating, horseback riding, a ropes course, woodshop, fishing, music, and swimming! Our campers, aged 7-16, can dive into these traditional camp activities while learning about safety protocols and which activities may require an infusion of medication before participating. Teens aged 17-18 can attend camp as *Leaders-in-Training*, guiding the next generation of campers!

Campers can also take part in awesome bleeding disorder education, where they can learn to self-infuse and earn the coveted *Big Stick* award! Throughout the week, close friendships blossom over exciting bonding activities, creating memories that last a lifetime.

Supported by amazing peers, counselors, and our dedicated on-site medical staff, a sense of self-confidence, exploration, and belonging is fostered. Kids can truly be kids at Camp Blood Brothers and Sisters!

First Camp 1979



Navigating Nosebleeds: Causes, Prevention and Care

BY MARIA SANTUCCI VETTER

For many of us living with a bleeding disorder, nosebleeds are common and typically seen as mild issues. While it may appear that a significant amount of blood is lost, nosebleeds are rarely dangerous. My oldest son, who has severe hemophilia, never experienced a nosebleed, but my youngest went through a challenging period of frequent nosebleeds. Waking up to blood-covered bedding was frustrating and frightening.

What is a Nosebleed?

The medical term for a nosebleed is epistaxis. Bleeding occurs when tiny, fragile blood vessels in the mucous membrane lining the nose rupture. These blood vessels are located close to the surface of the nose and are easily injured. There are two primary types of nosebleeds:

Anterior Nosebleeds - Most common, bleeding comes from the front of the nose where the two nostrils meet, just below the bony bridge of the nose. The delicate blood vessels in this area can easily break. Anterior nosebleeds can usually be treated at home without seeking medical intervention.

Posterior Nosebleeds - This type of nosebleed occurs deeper inside the nose, closer to the throat, where the blood vessels are larger. Posterior nosebleeds may require immediate medical attention.

What Causes Nosebleeds?

Nosebleeds can occur without any trauma. Dry air and scratching in the nose are typical triggers. The membranes in the nose are more prone to bleeding when they are dry, crusty, or itchy. Common causes of nosebleeds include:

- Nose-picking, especially in children
- Trauma to the nose
- Foreign objects placed in the nose
- Colds, sinus infections, nasal congestion, hay fever, allergies
- Forceful nose-blowing or hard sneezing
- Dry air and forced air indoor heating
- Dry, hot, low-humidity, or high-altitude climates
- Medical conditions such as high blood pressure, a nasal tumor or polyp
- Excessive use of inhaled nasal sprays or recreational drugs
- Exposure to smoke, fumes, or chemical irritants
- Taking medications that thin the blood

Who is More Prone to Nosebleeds?

While anyone can experience a nosebleed at some point in their life, certain groups are more susceptible:

- Children aged 2-10 – Young children often stick their fingers or objects in their noses
- Adults over 45 – Atherosclerosis (hardening of the artery walls) and high blood pressure become more common as we age
- Pregnant women – The expansion of blood vessels during pregnancy places additional pressure on the delicate capillaries in the nose
- People on blood-thinning medications such as warfarin, aspirin, or NSAIDS
- Individuals with bleeding disorders like hemophilia, von Willebrand disease, or platelet dysfunction

How to Prevent Nosebleeds

Preventing nosebleeds starts with ensuring the nose stays moist and avoiding situations that can lead to bleeding. Here are some effective strategies:

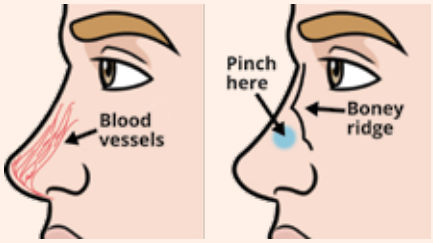
- Teach children to keep fingers and objects out of their noses. Be patient, as this can be a challenging habit to break. At 3-years-old, my son was highly skilled at wedging Legos up his nose.
- Avoid picking, rubbing, or scratching your nose. Keeping children's fingernails short can help minimize injuries.
- Humidify the air in your home with a humidifier or vaporizer, especially at night. Lower the thermostat to prevent excessive dryness.
- Moisten the inside of the nose by using a saline spray or gel a couple times a day, particularly before bed. Products like Bacitracin®, Vaseline®, Ayr Gel®, KY Jelly®,

or an antibiotic ointment can be effective.

- Avoid harsh nose-blowing.
- Sneeze with your mouth open to reduce its force.
- Limit the use of antihistamine and decongestant sprays, which can dry out the nasal passages.
- Wear protective equipment for the head and face during activities that may lead to injury.
- Avoid heavy lifting and strenuous activities for 24 hours following a nosebleed, as these activities can increase pressure on blood vessels, potentially causing another bleed.

How to Stop a Nosebleed

Many "home remedies" claim to stop nosebleeds – a penny placed under the upper lip, applying a cold pack on the back of the neck or forehead, drinking cayenne pepper or hot sauce mixed with water, gargling or dabbing the inside of the nose with vinegar. However, there is no scientific proof that these methods are effective.



Applying firm, consistent pressure to the septum is *essential* in stopping a nosebleed because it compresses the blood vessels. When a nosebleed occurs, it can be challenging for a clot to form until the bleeding slows down, as freely flowing blood washes away the components needed for clotting.

Follow these steps to manage a nosebleed effectively:

1. ***Stay calm:*** It's normal to feel anxious when you see blood. If a child is experiencing a nosebleed, offer reassurance and encourage them to remain still and quiet. Crying can increase the blood flow.
2. ***Breathe through your mouth.***
3. ***Positioning:*** Sit upright or stand and slightly lean forward so blood drains out of the nose rather than going down the throat. Leaning forward also helps you monitor whether it has stopped. Avoid swallowing any blood, as it can lead to vomiting.
4. ***Clear the Nose:*** Gently blow your nose to remove mucus and soft, jelly-like clots, as these can hinder proper clotting and cause blood to continue oozing.
5. ***Pinch the Nose and Apply Firm Pressure:*** Using your thumb and index finger, pinch the sides of your nose at the soft part just above the nostrils. Apply firm, consistent pressure and hold it for 10 minutes.
6. ***Check the Bleeding:*** After 10 minutes, release the pressure and check if the bleeding has stopped. If it hasn't, repeat the steps, increasing the duration of consistent pressure as needed.
7. ***Consider a topical clotting powder:*** WoundSeal®, NasalCREASE®, or Quick Seal® are over-the-counter powders that, when applied to the inside of the nose, help form a protective clot.

Additional methods as *approved and directed* by your physician:

- Infuse with clotting factor, administer desmopressin (DDAVP), or use aminocaproic acid (Amicar®) or tranexamic acid (Lysteda®) if necessary.
- Apply a spray of phenylephrine, such as Afrin® or Neo-Synephrine® to help constrict the blood vessels. This can also be done between steps #4 and #5 – after clearing the nose and before pinching the nose.
- For recurring nosebleeds, consult your doctor about using an estrogen cream such as Premarin®. During a challenging time with my son's nosebleeds, an ENT surgeon suggested cauterizing his nose. We sought a second opinion from an allergist, who recommended applying a small amount of Premarin® with a Q-tip in his nose twice daily for three days. The estrogen helps thicken the mucosal lining, allowing the blood vessels to heal. The Premarin® treatment was remarkably effective; after the three-day treatment, my son went an entire year without a nosebleed.
- If other options have been exhausted, cauterization may be necessary to seal the bleeding blood vessels.
- Surgery may be required to remove polyps, or correct a broken nose or a deviated septum.

When to Seek Emergency Medical Attention

- If a nosebleed results from a head injury, a fall or blow to the face, or if the nose is possibly broken.
- If an object is stuck in the nose - have a medical professional remove it to prevent further damage.
- If the bleeding does not stop after 20 minutes or if more than an expected amount of blood has been lost.
- If the bleeding causes weakness, dizziness, faintness, nausea, vomiting, shortness of breath, or difficulty breathing.

While nosebleeds can be alarming, they are often manageable with proper care and prevention strategies. Understanding the underlying causes, recognizing who is more at risk, and implementing effective measures can significantly reduce the frequency and severity of nosebleeds. If nosebleeds become persistent or severe, it's important to seek medical advice to rule out any underlying health issues. With awareness and a proactive approach, individuals and families can navigate the challenges of nosebleeds with greater confidence and peace of mind.

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BIOMATRIX ON THE *Move*

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

VIRGINIA

Terry Stone

Barbara is proud of her new cutting board!

Sisterhood: According to the Oxford Dictionary, it is "an association, society, or community of women linked by a common interest." This is exactly what women of the Hemophilia Association of the Capital Area (HACA) embody—a community built on caring and sharing. These resilient women gathered again for a ***Women's Retreat*** September 20-22 at Meadowkirk at Delta Farm in Middleburg on a beautiful fall weekend.

This retreat was filled with familiar faces and empowering experiences. Dr. Anna Bell, LICSW, LCSW-C, LISW, created a special program, *Taking Care of You,* specifically for our group. Dr. Bell provides a safe space for sharing and learning, and her nurturing approach equips us with essential tools for self-care. Later that day, she also led a discussion session for women with bleeding disorders.

The group participated in a session titled *Advocating in the ER*, presented by NBDF speaker Cathy Tiggs. Many shared their emergency room experiences and exchanged ideas on enhancing those visits positively. After such a serious topic, it was perfect to unwind with Vint Hill Yoga, where we focused on quieting our minds and stretching our bodies—an excellent remedy for the soul – no prescription needed!

A highlight of the weekend was the *Art Experience* Saturday evening, led by Michelle Stielper, a BioMatrix art instructor. This year's project involved creating personalized cheese boards. Participants selected from various fabrics to customize their boards, making the project simple and enjoyable.

A heartfelt thank you goes out to Executive Director Brenda Bordelon, Chapter Administrator Robin Monin, and all the sponsors for making this wonderful chapter weekend possible!

FLORIDA

Marcy Foertsch and Peggy Klingmann

BioMatrix partnered with CSL Behring September 27th to host an evening of ***Education and Trivia*** for our local bleeding disorder community at Tampa's Whiskey Cake Restaurant. The event began with Mily, CSL's Patient Advocate Speaker, who shared her journey as a woman living with a bleeding disorder. After dinner, attendees participated in a competitive and enjoyable round of BioMatrix bleeding disorder trivia. Everyone was a winner, and we look forward to engaging and serving our community again soon! A heartfelt thank you to CSL Behring and everyone who joined us!

VIRGINIA

Michelle Stielper and Terry Stone

The landscape of hemophilia care continues to change, and education is more important than ever. With the launch of new generation products and long-awaited gene therapy, the Virginia Hemophilia Foundation gathered its patient community for their annual ***Medical Symposium*** at Great Wolf Lodge, Williamsburg, September 28-29.

After a hearty welcome and remarks from Executive Director Kelly Waters, the keynote presentation offered a moderated panel discussion, Candid Conversations, which included several presenters from NBDF and several "Lived Experience Experts" who shared their journey about the products they are using. The panel offered real stories of a patient's experience with their therapy, and the NBDF team engaged the audience with thoughts about "shared decision-making" for those who may be considering a change of treatment.

The afternoon offered multiple break-out sessions where manufacturer partners presented branded programs on their products and therapies. After a fulfilling day of education, families gathered and enjoyed an evening of free time and adventures with their own pack and den of friends at the indoor waterpark, Great Wolf Lodge.

Thanks to the leadership team of Kelly Waters and Heather Conner for coordinating this informative and fun event for the entire family and to the sponsors who continue to make great events possible.

NEW MEXICO

Felix Jacquez Garcia

Many New Mexico bleeding disorders community members centered their "chi" at Albuquerque's Topgolf October 3rd. For this ***Educational Event***, BioMatrix was thrilled to collaborate with CSL Behring, which featured Patient Advocate Speaker, Rick, who shared his inspiring story and led a table-side Tai Chi session before everyone swung some golf balls.

During the event, Rick recounted his journey through various treatment options, starting with whole blood, moving to fresh frozen plasma, then to factor concentrates, and finally to a long-acting prophylactic product. He proudly shared that, thanks to significant advancements in treatment and a few wise choices, he has been bleed-free for seven years.

An overview of our BioMatrix Patient Navigation program followed. If you have issues accessing treatment, have questions about health insurance, Medicare, Medicaid, or Social Security, or need help accessing other resources, contact us for assistance: https://www.biomatrixsprx.com/bleeding-disorders/patient-navigation.

It was wonderful to see new and familiar faces at this enjoyable event. We look forward to gathering again very soon!

Keira and Robert

Jose and Dave

Mark, Aveann and Jahro

Alex and Julie

Nathan, Monica, John and Rick practice their swings

A cool treat for Sawyer

TENNESSEE

LeAnn Wilson and David Tignor

Start your engines...then wreck 'em! On October 5th BioMatrix and CSL Behring teamed up with the Tennessee Hemophilia and Bleeding Disorder Foundation (THBDF) to host a ***Demolition Derby*** at Bristol Motor Speedway.

Attendees enjoyed a thrilling day as they watched cars crash into each other! This event showcased the excitement of drivers using their vehicles to collide until only one car remained operational, securing the victory. In addition to the action in the grandstands, community members had access to the pits, where they could see the teams working on their cars (or what was left of them), meet some of the drivers, and experience the action up close.

Ride the bull, Tucker!

We appreciate CSL Behring and THBDF for partnering with BioMatrix to provide community members the opportunity to witness this incredible event. It was an unforgettable day of metal-on-metal excitement!

Good friends, Silas and Tucker

Demo driver Scott Drevenak stops to pose with Tucker, Silas and Arlo

NEW JERSEY

Richard Vogel

Jaida, Rich Vogel, Dana, Daija and Jaiden

On this beautiful fall weekend, the Hemophilia Association of New Jersey (HANJ), Sanofi and BioMatrix partnered October 6th to host an enjoyable afternoon of learning while enjoying apple cider donuts at the ***Annual Education and Apple Picking Fall Family Event*** at the picturesque Hill Creek Farms in Mullica Hills.

Executive Director Stephanie Lapidow welcomed attendees as they chose their lunch, which featured gourmet sandwiches, apple cider, and delicious apple cider donuts, all sourced from the farm. With open enrollment approaching, BioMatrix began the educational segment of the afternoon. Terry Rice, Director of Advocacy and Education, presented an overview of insurance terminology and discussed how the BioMatrix *Patient Navigation* team can assist community members with insurance issues and financial assistance programs.

Sanofi CoRe Manager Alexis Akins shared the benefits of Sanofi's hemophilia B product, Aprolix®. Additionally, Tyshawn Constantine provided an interactive demonstration using balloons to explain how to maintain proper factor levels.

After the presentations, families were invited to explore the farm, enjoy a hayride, and pick apples. It was the perfect way to spend a sunny afternoon in South Jersey.

DELAWARE

Tina McMullen

Wilmington's Columbus Inn was the place to be for the Brandywine Valley Hemophilia Foundation community October 10th. Chapter President Gail Novak recognized a need for education within the community and organized an ***Educational Dinner*** focused on *Insurance Benefits and Patient Navigation*. Bayer and BioMatrix partnered to provide this valuable information.

The evening began with dinner and a presentation by Bayer's Hemophilia Community Relations Manager Margarita Llibre Rogers. Margarita covered essential topics such as Medicaid, Medicare, Medigap, and Medicare Advantage, along with important definitions and the differences between fully insured and self-funded plans.

Following Margarita's presentation, Bill Wilbert, a Patient Resource Specialist from BioMatrix, gave an in-depth overview of the *Patient Navigation* program. He addressed various challenges faced by individuals in the bleeding disorder community, including access to therapy, financial burdens, and insurance issues. Bill highlighted the numerous ways that BioMatrix's Patient Navigation Team offers personalized resources and support to help overcome these barriers.

A heartfelt thank you to Gail and her team for organizing this informative event and to Bayer for their partnership!

TENNESSEE

Cyndy Coors

Takeda's Morgan Cook and Amanda Wilson, ED

October 10th was a beautiful evening for a ***Family Night Out*** in downtown Chattanooga at the iGNiS Glass Studio. Hosted by the Tennessee Hemophilia & Bleeding Disorders Foundation and sponsored by Takeda and BioMatrix, community families gathered for a pizza dinner and a unique opportunity to create beautiful blown glass ornaments. Guided by professional artist instructors, we all had the chance to experience this age-old art form. During the evening, we also heard from Morgan Cook of Takeda, who shared valuable information about their products and available educational programs.

Matt and Joshua watch as an artist showcases his technique

A big thank you goes to THBDF Executive Director Amanda Wilson for bringing everyone together for this wonderful event!

Big smiles from Cyndy Coors, Maria and Scott

Joshua, Ritchel, Julia and Matt

OKLAHOMA

Jeanette Jones

October is the season of haunting, and the bleeding disorders community enjoyed preparing together in Oklahoma. HEMA Biologics and BioMatrix co-hosted ***BOO Bash: Art and Education!*** at HeartLocke Art Studio in Midwest City October 11th.The cheerful evening was filled with fellowship, dinner, and spooky art.

John and Michael

Alyson and Paisley

John, Bella and Elijah

An art teacher guided attendees in creating Halloween or fall-themed paintings. Each canvas featured a unique design created by the teacher, which participants then adapted as they wished. The instructor projected their work onto a big screen, making it easy for everyone to follow along. After outlining our scenes, we chose our preferred colors to complete the pictures. The teacher patiently shared helpful painting techniques to enhance our skills. Members also had the option to work with a blank canvas and draw their own designs.

Michael

Despite the wide range of ages and abilities, everyone participated and created something to be proud of. Like ghosts, the time flew by too quickly, but we look forward to seeing each other again. Until then, happy haunting!

Clayton and Leisa

Brandi

Paisley

Lunch and painting with friends make for a great day!

ARIZONA

Felix Jacquez Garcia

What better way to forget that autumn is approaching than to head to Arizona for some 100˚ weather! On October 13th, we gathered for a ***Men in Blood Group Meeting*** hosted by the Arizona Blood Alliance (ABA) and sponsored by Bayer and BioMatrix. We were grateful the meeting room at Scottsdale Topgolf was fully air-conditioned and the attendees were a great group of "cool" guys.

Bayer Hemophilia Community Consultant Erica Bocanegra discussed how to deal successfully with fear and insecurities. She did an excellent job engaging the group and encouraging interaction. I represented BioMatrix and reminded everyone that Open Enrollment season is here. The BioMatrix Patient Navigation program is available to assist with any barriers to care, insurance issues, accessing treatment, or other necessary resources (https://www.biomatrixsprx.com/bleeding-disorders/patient-navigation).

A special shoutout to volunteer Steven, who did a fantastic job coordinating the meeting and encouraging attendance. We truly appreciate your time and energy. Volunteers are the backbone of many nonprofit organizations, including the ABA, and we value your contributions!

Mike and Steven

Mario

Tony

Felix, Ericka, Giovanny and Steven

Javier

Steven and Tony

DELAWARE

Tina McMullen

Education, lunch, and farm fun all happened at Ramsey Farm in Wilmington October 13th for Brandywine Valley Hemophilia Foundation's ***Educational Lunch***. Sponsored by BioMatrix and Sanofi, this beautiful fall event featured boxed lunches and Sanofi's Alexis Akins, MSN CRNP FNP-C Community Relations and Education Manager presenting a program focused on *Women, Girls, and Hemophilia.* During her presentation, Alexis addressed topics such as the diagnosis of hemophilia, the importance of treatment and support, and advocacy for females living with this condition. She emphasized that education is crucial for helping girls and women with bleeding disorders receive the care they need.

Following the presentation and lunch, attendees enjoyed the rest of the afternoon exploring the delightful Ramsey Farm. Activities included a hayride, a corn maze, pumpkin painting, sunflower picking, and interacting with adorable farm animals. A special thanks goes to Board President Gail Novak for bringing Sanofi and BioMatrix together to provide both education and enjoyment for members of the Brandywine Valley community!

Matt, Blake & Samantha

Tina & Gail

Robert & Tara

Nancy & Jose

Allison, Amelia, Michael & Avery

Walter, Rob & Arthur

NEW YORK

Richard Vogel

On the beautiful fall day of October 20th in upstate New York, community members from the Bleeding Disorders Association of Northeastern New York (BDANENY) enjoyed a day filled with family fun, information, and camaraderie at Dave & Buster's in Albany for the chapter's ***Annual Meeting***.

Manufacturers and specialty pharmacies set up information booths in a designated area where members gathered for lunch and education. This made it easy for attendees to stroll through and collect valuable information. Executive

BDANENY Board Members: Jessica Smith, Cindi Keeler, Patty Marck, Executive Director Beth Maher and Rich Vogel

Director Beth Mahar welcomed everyone and provided an advocacy update along with the BDANENY annual report.

Soon it was time to relax and have some fun in the arcade. The smiles grew wider as it was time to unwind and enjoy the games. Each attendee received tokens to dive into the fun, providing a perfect way to wrap up the day.

Gathering together allowed families in the bleeding disorders community to chat, share stories, and reconnect, and it was a pleasure to see so many familiar faces! It was a wonderful reminder of the strength and warmth found in our community!

OHIO

Shelia Biljes

Hosted by Takeda and BioMatrix, the ***Family Dinner and Trick-or-Treat*** event on October 25th at Tony K's Restaurant in Berea was nothing short of a Halloween blockbuster! Guests included Spider-Man, an alien, a PJ Mask character, and a princess — why not mix superheroes, monsters and royalty under one roof?

Dashawn, Cierra, Emir and Emon

Takeda Nurse Educator Maria Rohan led an eye-opening presentation, *Identifying Joint Bleeds*, explaining what happens when a joint experiences a bleeding episode. Disco, a 6' skeleton, provided a fantastic visual aid, allowing children to point out the joints where they had previously experienced bleeds.

Roy and Brooklyn

The children enjoyed decorating wooden cut-out skeletons and being challenged with skeleton trivia, then all joined in for indoor trick-or-treating. The children paraded through the restaurant as adults handed out candy, pretzels, and popcorn balls to the tune of *Monster Mash*. It was pure pandemonium but nothing short of the best fun ever! Thank you, Takeda, for sponsoring this incredibly entertaining event – it was a fantastic time that left us all grinning from ear to ear!

Tony and Starr

Lila

FLORIDA

Marcy Foertsch and Peggy Klingmann

Members of the bleeding disorders community gathered for an ***Educational Dinner*** October 28th at Terra Gaucha Brazilian Steakhouse Tampa, hosted by Takeda and BioMatrix. The evening began with a presentation by Takeda Community Education Specialist Alexandra Soto, who shared insightful information about the company's long-acting factor VIII product for ADYNOVATE®.

Tony, Paulette and Lynne

As the group enjoyed dinner, BioMatrix Patient Resource Specialist Bill Wilbert offered invaluable insights into our *Patient Navigation* service, which felt especially timely with open enrollment just around the corner. Seeing so many attendees taking notes, scanning the QR code we provided, and asking thoughtful questions was heartening.

We truly cherish these moments of connection and support within our community, and we can't wait to see everyone again soon! A heartfelt thanks to all who joined us and Takeda for their continued partnership.

NEW MEXICO

Felix Jacquez Garcia

As Halloween and Día de los Muertos approached, the New Mexico bleeding disorder community came together October 30th at Albuquerque's Pappadeaux Seafood Kitchen to share a meal, learn, and enjoy quality time together. With BioMatrix and Sanofi co-hosting this ***Educational Dinner***, we had a special request for Sanofi Peer Speaker Chayse to join us. Chayse shared his personal journey of growing up with hemophilia, marrying the love of his life, and being a member of *Chi-Town Transit Authority*, a Chicago Tribute band, as a vocalist and guitar player. He also discussed how his hemophilia treatment helps him manage his daily life more easily. Many of us can relate to his story in one way or another, demonstrating the power of personal experiences to inspire hope.

Sanofi CoRe Manager Giraldo González collaborated with Dr. Maissaa Janbain from the Louisiana Center for Bleeding and Clotting Disorders to deliver an engaging and informative program about their product, Altuviiio®.

CoRe Manager Giraldo González

Thank you to everyone who attended the event, and a special thanks to Sanofi for bringing such outstanding associates to share with our community!

Arizona

Felix Jacquez Garcia

Event hosts Steven and Yleana

Although Hispanic Heritage Month officially runs from September 15th to October 15th, the Arizona Blood Alliance and its Latino members gathered for another celebration November 2nd for ***Herencia Latina***. After all, the concept of *Tiempo Latino* (Latin time) allows for a bit of flexibility!

Felix Garcia and Steven with the town Sheriff (center)

The event took place at Rawhide Western Town in Chandler, a unique venue that resembles an old western town. It features an expansive dining and entertainment hall, along with an outdoor stage where we watched Wild Bill Hickok engage in a ferocious shootout with the villains of Rawhide. The show was a hit, especially with the kids.

After lunch, BioMatrix led our bleeding disorders *JeoParody* game, conducted entirely in Spanish. There was fierce competition between the teams Sangrones and Juanes, each striving to accumulate the most points. After a tough battle, Team Juanes emerged victorious, showcasing their impressive knowledge of bleeding disorders! Congratulations to both teams for their outstanding effort and enthusiasm! We also congratulate Arizona Blood Alliance for organizing such a successful and enjoyable event!

TENNESSEE

David Tignor and Cyndy Coors

Brynn, Kelly, and Jason

It was a lovely evening spent with BioMatrix and Sanofi for an ***Educational Dinner*** featuring delicious food at Knoxville's Brazeiros Brazilian Steakhouse November 7th. Sanofi CoRe Manager Cassandra Titus presented *Switch It Up! See What Higher Factor Levels Could Mean for You*, focusing on their factor product, Altuviiio®. Sanofi Peer Speaker Courtney Thomas shared her personal journey with hemophilia. Attendees had the opportunity to ask questions, and everyone appreciated the informative session, the great food, and the friendly atmosphere. The night concluded with a selection of amazing dessert options.

Landon enjoys dessert

Thank you to Sanofi for sponsoring our dinner and everyone joining us for this delightful evening.

MASSACHUSETTS

Richard Vogel

The New England Hemophilia Association (NEHA) serves all of New England, rotating its annual events across six states to ensure accessibility for all our members. This year's ***Fallfest*** took place November 8–10 at the Sheraton Monarch Place Hotel in downtown Springfield. Executive Director Rich Pezzillo opened the event by introducing keynote speaker Pat Torrey from Gut Monkey, who engaged attendees with interactive activities.

Tommy, Bernadette, Izzy and Thomas are ready to line dance!

A safe space was provided for discussing concerns about evolving treatment options, facilitated by Dr. Nathan Connell from the Boston Bleeding Disorders Center. Lunch featured various *Lunch and Learn* sessions on bleeding disorder treatment, covering topics such as *Gene Therapy for Hemophilia A* and higher factor levels.

The afternoon included insightful *Panels on Life Transitions*, where local providers, patients, and caregivers shared experiences relevant to different life stages. As the 'old man' of the group, or as some affectionately called me, the 'seasoned' attendee, I participated in the *Adults and Aging* session with Dr. Connell, Joanne Wagner, LICSW, CCM, of the Dartmouth Hemophilia Treatment Center, and my good friend Tommy Russomano, who jokingly teased me about my 'seasoning.'

Matt Delaney from the National Bleeding Disorders Foundation reported on policy issues in Washington, DC, while CEO Phil Gattone attended to connect with the community. After the day's educational sessions, NEHA recognized award recipients during dinner.

After an action-packed day of education, it was time to unwind, don our cowboy boots and hats, and learn to line dance. BioMatrix proudly sponsored the Country Western Dance Party as the evening's main event. An alternative option for the evening was a screening of Believe Limited's film, *On the Shoulders of Giants*. Sunday morning featured breakout sessions where community members engaged in various topic discussions, including a session in Spanish for our Latin community.

Saying goodbye to old and new friends is always bittersweet, but we all look forward to *Fallfest 2025* in Rockport, Maine. Can't wait!

ILLINOIS

Eva Kraemer

Big smiles from Rocky, November and Lily

The Bleeding Disorder Alliance Illinois (BDAI) warmly welcomed everyone to ***Community Connections Weekend*** November 9th, at the Chicago Hilton in Oak Lawn. Chapter Executive Director Liz Burgess and Board President Sammie Valdez greeted attendees with enthusiasm, setting the tone for a wonderful day filled with enriching learning opportunities.

Dr. Jonathan Roberts shared insightful updates on hemophilia research and its profound impact on our community, discussing new therapies currently available and the exciting innovations on the horizon. Senior Vice President of Public Policy & Access of the National Bleeding Disorders Foundation, Nathan Schaefer, led an engaging session on upcoming insurance changes in 2025.

The afternoon breakout sessions were lively and informative, covering topics such as *Advocacy for Youth: Creating Your Elevator Pitch*, *Period Poverty: The Cost of Girls with Bleeding Disorders*, *Salud Mental (Mental Health in Spanish)*, *Steps in Gene Therapy: Treatment for Hemophilia B*, and a heartfelt presentation on *Family Dynamics* by our very own BioMatrix Education Specialist, John Martinez.

As the day came to a close, everyone gathered after dinner to watch the inspiring film *On the Shoulders of Giants*, produced by Believe Ltd. This documentary highlights that with advances in treatment and product safety, current and future generations of individuals with hemophilia can live well into their senior years.

Thank you to BDAI for hosting this enjoyable event

NORTH CAROLINA

Justin Lindhorst

Justin Lindhorst and Shelby Smoak

BioMatrix was proud to support the Bleeding Disorders Foundation of North Carolina's (BDFNC) ***Blood Brotherhood and SOAR Weekend*** held November 15-17 at Wilmington's Embassy Suites.

North Carolina community members gathered for a weekend filled with networking, education, and meaningful connections. The event included engaging sessions for blood brothers and sisters, fostering a sense of camaraderie and support. CHES presented its wonderful *Ladybug* program, and nurses were on hand to teach self-infusion techniques, empowering attendees with vital skills. There were special programs tailored for spouses and partners. Attendees were able to explore the latest treatments and services from various industry vendors, and the weekend culminated in a fantastic magic show that left everyone wide-eyed in awe.

A heartfelt thank you to BDFNC for creating such a memorable, uplifting experience!

NEVADA

John Martinez

BioMatrix partnered with Medexus to host an engaging ***Educational Dinner*** in Las Vegas on November 16th. Families gathered at Round Table Pizza for an evening of delicious pizza, wings, and valuable information, satisfying their hunger for both food and knowledge.

During an interactive presentation on *Open Enrollment*, families were encouraged to ask questions and share their unique circumstances, which led to meaningful discussions. Hemophilia Territory Manager Meredith Paige highlighted the resources offered by Medexus and addressed key questions from attendees.

As the evening came to a close, we looked ahead to our next opportunity to gather and eagerly anticipate that day!

OHIO

Rania Salem

Jennifer, Karen and Reagan with LeAnn Wilson (standing)

LeAnn works with Isaiah and Eli

Stella with Rania Salem

Isaiah and Melissa

On November 16th, guests gathered at the Brio Restaurant in Columbus for an ***Educational Lunch*** highlighting *Sewing for Self-Care,* hosted by Sanofi and BioMatrix.

CoRe Manuel Serrano opened the event with a presentation on Altuviiio®, Sanofi's long-acting product for hemophilia A. We were thrilled to have Sanofi Peer Speaker Jenny and her wonderful son, Paxton, join us! Jenny illustrated how having the right support system has enabled Paxton to flourish and pursue his dreams. They also shared how Paxton's journey with Altuviiio® has empowered him and his family. Paxton emphasized that it is possible to live a normal life with a bleeding disorder while chasing your dreams.

After lunch, BioMatrix's Shelia Biljes shared her personal journey and explained how sewing has helped her cope with anxiety. She highlighted how engaging in

Back row: June, Regan, Jennifer, Rania Salem, Vanessa, Melissa, Stella
Front Row: Karen, Isaiah, Eli and Shelia Biljes

enjoyable activities can relieve some of life's stressors. Shelia came prepared with 16 sewing machines and all the supplies needed for everyone to create beautiful tote bags. Setting up the machines was no small task! Luckily, BioMatrix's LeAnn Wilson traveled from Tennessee to assist with the setup and provide instruction.

Learning a new hobby proved to be a fantastic stress reliever, and some participants expressed interest in purchasing their own sewing machines. Even two young gentlemen who attended left with tote bags, excited to share their finished masterpieces. Everyone had a fantastic time, and we look forward to hosting this event again!

NEW YORK

Richard Vogel

Maria (center) visits with BioMatrix's Carolina and Rich

Kicking off the holiday season with the New York City Hemophilia Chapter's (NYCHC) ***Education Day*** has become my cherished tradition. The Chapter's largest event was held November 17th at the 7th Avenue WeWorks in New York City. In keeping with the holiday spirit, community members mingled with one another and visited industry and specialty pharmacy representatives before the educational workshops began. Whether you were a family new to the bleeding disorders community or someone with years of experience like me, there was a workshop for everyone. No matter how seasoned you are, there is always something new to learn from this community.

This year, I had the honor of being on the panel discussing the *Evolution of Bleeding Disorder-Related Challenges Across the Lifespan*. We had representatives from various age groups, from a teenager to a senior citizen (me!), and we shared our experiences regarding how treatment has evolved for each of us.

The children were excited to create gingerbread houses and, of course, thrilled with the arrival of Santa Claus! Many thanks to NYCHC for hosting this holiday party, and for the help and support of my colleague, Carolina Luna.

FLORIDA

Marcy Foertsch and Peggy Klingmann

Great listeners!

On November 23rd, BioMatrix and Takeda came together to host a delightful ***Educational Brunch*** for local bleeding disorders community members at STK Steakhouse in Lake Buena Vista. Guests were treated to a delicious meal and engaged in a lively discussion about bleeding disorders and advocacy led by Takeda's Community Education Specialist, Alexandra Soto.

Following this conversation, Brenda King, our dedicated Patient Resource Specialist, shared valuable insights into the BioMatrix *Patient Navigation* program, a valued tool

Tony

that helps patients navigate their healthcare journeys.

Afterword, everyone was able to bask in the lovely Florida weather at Disney Springs and venture through the vibrant outdoor shopping and entertainment complex at the Walt Disney World Resort. A heartfelt thank you to Takeda for partnering with us! We're excited to continue engaging with, supporting, and serving our community!

OHIO

Shelia Biljes

Lovely ladies, Marie and Connie

Miya and Deshawn work on handprints

The theme of gratitude took center stage as Novo Nordisk and BioMatrix hosted a ***Family Thanksgiving Dinner*** at Brew Garden in Strongsville November 23rd. We extend our heartfelt thanks to Novo Nordisk for co-sponsoring this special event with us!

The evening began with an insightful presentation by Dr. Jennifer Domm from Nashville Children's Hospital, who spoke about Novo Nordisk's Factor VIII long-acting product, Esperoct®. This event marks her fourth consecutive year joining us from Tennessee! Following Dr. Domm, Novo Nordisk Advocacy Speaker Jalyn shared a touching story of her son, who has hemophilia. Her heartfelt anecdotes brought both laughter and tears to the audience.

As an engaging activity, attendees created memorable pieces of "thankful" art using the handprints of family members. This annual gathering always feels like a family reunion, making it difficult to say goodbye.

TENNESSEE

Cyndy Coors and David Tignor

Cain, Courtney and Annaclaire

Happy girls with Santa! Kenna, Alayah and Annaclaire

Chattanooga was wrapped in a blanket of crisp beauty the evening of December 12th as we gathered for the Tennessee Valley Railroad's ***North Pole*** event, sponsored by CSL Behring and BioMatrix. Train cars shimmered with twinkling lights and were adorned with festive decorations, filling the air with a sense of wonder.

As we embarked on our magical journey to the North Pole, we were captivated by a heartwarming holiday story and sang joyful

carols. We were treated with cookies and hot chocolate and gifted with keepsake ornaments and jingle bells, tokens of a night to remember.

Santa and Anthony

When we arrived at our destination, the excitement was high as Santa Claus joined us onboard! With his warm smile and twinkling eyes, he took the time to pose for photos with the children and listened as they shared their holiday wishes. The event sparkled with the warmth of the holiday spirit, creating cherished memories for all who attended. It indeed was a night filled with joy and togetherness!

FLORIDA

Marcy Foertsch

CoRe Manager, Eric Burgeson

On December 7th, Sanofi and BioMatrix joined forces to host an informative ***Educational Luncheon*** at Fleming's Steakhouse in Tampa. Our event featured a compelling presentation by Eric Burgeson, the CoRe Manager at Sanofi, who shared insights in his talk titled *What's Your Common Factor?* He delved into the evolving insurance landscape affecting those in the bleeding disorders community, illuminating the challenges and changes that many individuals and families face.

Eric took a moment to commend the invaluable BioMatrix Patient Navigation program, emphasizing it as a vital community resource that supports and guides patients. A warm and welcoming atmosphere allowed attendees to engage in meaningful discussions and enjoy a delightful afternoon filled with learning and connection.

NEVADA

John Martinez

The Nevada Chapter of the National Bleeding Disorders Foundation (NBDF) wrapped up a remarkable year with its ***Annual Meeting*** on December 7th at the College of Southern Nevada in Las Vegas. The bright, sunny day was perfect as members of the bleeding disorders community united to celebrate the joy of connection, support, and shared experiences that make our community so unique. BioMatrix was honored to be a sponsor of this event, where attendees received updates on Chapter programs, initiatives, and exciting plans for 2025.

After several informative sessions, families eagerly joined to craft beautiful gingerbread houses, filling the air with laughter and adding to the day's festive spirit.

A sincere thank you to the Nevada Chapter for hosting this special year-end event! We are grateful for the opportunity to gather, reflect on our journey, and strengthen the bonds that united us as a vibrant community

TENNESSEE

LeAnn Wilson and David Tignor

Rachel and Ryan

The Tennessee Hemophilia Bleeding Disorder Foundation, in partnership with CSL Behring and BioMatrix, warmly welcomed community members to ***Holiday Wonders at the Garden*** December 7th at the beautiful Memphis Botanic Garden. The evening was filled with the perfect winter charm, featuring just the right chill in the air.

Rachel and Treleisha

After enjoying a quick meal and sipping on hot chocolate, we took a leisurely stroll along the garden pathways, adorned with festive holiday lights, delightful displays, and joyful music. The atmosphere was magical, making it easy to capture photos and create lasting memories among the twinkling lights.

Haylee and LeAnn

Eri'Ana, Ashley and De'Aria

A heartfelt thank you to THBDF for spreading Christmas cheer and joy throughout the mid-south community! Your efforts brought us closer together during this special time of year.

Haylee and Miracle are Merry & Bright!

TEXAS

Jeanette Jones

Ryan and Julie

'Tis the season to be jolly, and what a wonderful time it was to be with the Texas Central Bleeding Disorders community for their ***Winter Family Education Event***! Over 150 members gathered December 7th at Embassy Suites Grapevine to celebrate the season for Chapter updates and education. The room was beautifully decorated and many sponsors took the opportunity to showcase their festive spirit. The exhibit hall was filled with cheer and Christmas trees, garland, decorative tablescapes, lights, candy, fun giveaways, and more!

As we enjoyed a meal of holiday favorites and delicious desserts, the board of directors and staff reviewed the year's achievements and outlined future goals. Notably,

the TexCen community has experienced a significant increase in personal fundraising, with more Unite Walk teams reaching their fundraising targets and an uptick in advocacy participation. Congratulations to everyone involved!

Ryan, Jerome, Julie and Gina (front)

This time of year TexCen board passes the reins to new leaders. President Ryan Crowe quite literally, passed the elf hat to the newly elected Jerome Bell.

Before stepping down, community leaders honored Ryan with a new Community Impact Award, recognizing his years of dedicated service and commitment to supporting the community. This recognition was truly deserved. Thank you, Ryan!

As the event concluded, families were invited to enjoy an ice sculpture experience at the Gaylord Convention Center. While it was certainly cold inside, it was an experience worth having! Special thanks to the TexCen team for organizing a fantastic event.

PENNSYLVANIA

Tina McMullen

Mendenhall Inn was the place to be December 8th, for the Brandywine Valley Hemophilia Foundation's (BVHF) ***End of the Year Meeting***. The event began with an opportunity to visit with exhibitors and enjoy a buffet lunch.

President Gail Novak gave a warm welcome and a summary of the Foundation's 2024 events. BVHF hosted three fundraising events that sponsored families' attendance at educational seminars, supported two college scholarships, and sent children to one of two summer camps – Hole in the Wall and Dragon Fly. There were seven educational programs, five of which were co-sponsored by our very

Jessica and Deron dress to impress!

Blake, Sam, Matt, Torque with Tina McMullen

Robert and Gail

own BioMatrix, among other initiatives. It is truly remarkable what a completely volunteer foundation can achieve for our community!

Vice President of the board, Jennifer Davis excelled in combining fun and education once again. With help from special elves, attendees were challenged to answer questions about bleeding disorders for a chance to win prizes. With over $900 in prize donations, all the children received rewards, and adult prize winners were given stockings with assorted gift cards. In addition, door prizes were also awarded.

Walter, Tara, Arthur and Rob

BVHF Board Members Jennifer, Kim and Gail

Following the program, everyone headed to Longwood Gardens, a magnificent 1,100-acre public garden, to stroll through the grounds and admire hundreds of thousands of beautiful lights and scenic holiday displays.

A huge thank you goes out to Board member and event Chair Kim Hamstead for organizing such a wonderful day for our community!

OHIO

Shelia Biljes

On December 10th, the wonderful women of the Northern Ohio community came together at Tony K Restaurant in Berea for their final event of the year, the ***Ladies Lunch Holiday Extravaganza.*** With the spirit of the season in the air, Novo Nordisk and BioMatrix partnered to sponsor a delightful gingerbread-themed lunch and cookie exchange. We were honored to have Novo Patient Advocate Speaker Elsie join us from Miami. She shared her powerful journey as a mother of twin sons with hemophilia and her later diagnosis of a bleeding disorder. Elsie's story resonated with many, and she encouraged all of us to embrace self-advocacy and seek the medical support we deserve.

Following her inspiring talk, we dove into the cookie exchange, filling trays with homemade cookies to bring home and share with family and friends.

Thank you, Novo, for hosting this event with us, and we look forward to seeing everyone again in the spring!

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

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

Time for Fun!

Puzzles on page 27

Word Challenge

1) R, 2) O, 3) A,
4) F, 5) C, 6) T

FACTOR

Happy BVHF Holidays!

Happy smiles all around!

Paige, Wyatt, Phil, Gail, Tina, Arthur, Tara, Walter & Rob

DELAWARE

Tina McMullen

The Brandywine Valley Hemophilia Foundation (BVHF) hosted an ***Education and Cookie Decorating Event*** December 15th at Timothy's Riverfront Grill in Wilmington. Members of the bleeding disorders community enjoyed an afternoon filled with education, delicious food, cookie decorating, and socializing.

Following a warm welcome, Novo guest speaker Vaughn shared his personal story titled *My Life with Hemophilia A*. Vaughn discussed being the first person in his family to be diagnosed with hemophilia and highlighted the importance of maintaining a healthy lifestyle to manage the health challenges associated with bleeding disorders.

Before diving into the fun activities, attendees were treated to a lovely buffet lunch. BioMatrix provided each family with a goody bag with everything needed to decorate holiday cookies. Both children and adults showcased their imagination, talent, and creativity in the decorating festivity.

More happy smiles!
Cole, Vince, Sharon and Kim

A special thank you goes to BVHF President Gail Novak for organizing such a wonderful day and to Novo Nordisk for their educational support and lunch. We appreciate the BVHF community coming out to spend the afternoon with us!

Upcoming Events

FEB 22, 2025 OKLAHOMA
Bleeding Disorders Community Event
Hosts: BioMatrix and Bayer
RSVP: Jeanette Jones, 405-229-0855
jeanette.jones@biomatrixsprx.com
Chicken & Pickle; Oklahoma City

FEB 26, 2025 FLORIDA
Educational Dinner
Hosts: CSL Behring and BioMatrix
RSVP: Marcy Foertsch, 941-518-7063
marcy.foesrtsch@biomatrixsprx.com
Ruth's Chris Steakhouse; Tampa

MARCH 14–16, 2025 CONNECTICUT
Consumer Medical Symposium
Host: New England Hemophilia Association
www.newenglandhemophilia.org
RSVP: Jodi Weeks, 781-326-7645
jweeks@nehemophilia.org
Mystic Marriott Hotel & Spa; Groton

MARCH 22, 2025 NEW JERSEY
Community Connections
Host: Hemophilia Association of New Jersey
RSVP: Cindy Hanson, 732-249-6000
chansen@hanj.org, https://hanj.org/
Pinstripes Bistro; Paramus

NATIONAL EVENT!
MARCH 27–30, 2025 CALIFORNIA
Symposium, Navigating the Future, Together
Host: Hemophilia Federation of America
202-675-6984, www.hfasymposium.org
Sheraton San Diego Hotel & Marina

NATIONAL EVENT!
APRIL 10–13, 2025 FLORIDA
Annual Hybrid Symposium
Host: The Coalition for Hemophilia B
212-520-8272, www.hemob.org
Renaissance Orlando at Seaworld

APRIL 27, 2025 TEXAS
Community Education Meeting
Host: Texas Central Bleeding Disorders
https://texcen.org, 972-386-3865
Sponsors: Bayer and BioMatrix
RSVP: Gina Hundza, gina@texcen.org
Venue: TBD; Dallas

MAY 2–4, 2025 DELAWARE
Men's 4th Annual Retreat
Host: Brandywine Valley Hemophilia
www.brandywinehemophilia.org
RSVP: Gail Novak, 302-598-4632
gvannicola@verizon.net
Sponsors: Octapharma, HEMA Biologics, Medexus, and BioMatrix
Atlantic Sands Hotel; Rehoboth Beach

MAY 16, 2025 DELAWARE
Blue Rocks Baseball
Host: Brandywine Valley Hemophilia
www.brandywinehemophilia.org
RSVP: Gail Novak, 302-598-4632
gvannicola@verizon.net
Daniel S. Frawley Stadium; Wilmington

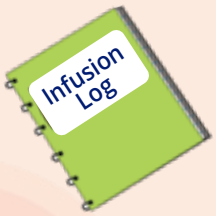
MAY 16–18, 2025 PENNSYLVANIA
Bleeding Disorders Conference
Host: Eastern and Western PA Bleeding Disorders Foundations
RSVP: Kara Dornish, 724-741-6160
kara@wpbdf.org
Hershey Lodge; Hershey

JUNE 14, 2025 FLORIDA
Educational Luncheon
Host: Bayer and BioMatrix
RSVP: Marcy Foertsch, 941-518-7063
marcy.foesrtsch@biomatrixsprx.com
Coopers Hawk Winery; Orlando

JUNE 25, 2025 PENNSYLVANIA
Annual Meeting
Eastern Pennsylvania Bleeding Disorder Foundation, epbdf.org
RSVP: Sarah Ross Pilacik, 610-770-5215
sarah@epbdf.org
Sheraton Valley Forge; King of Prussia

JULY 25–27, 2025 VERMONT
Men's Retreat
Host: New England Hemophilia Association, 781-326-7645
www.newenglandhemophilia.org
Mount Snow Resort; West Dover

Hi Kids! Time for Fun!



Here's a WORD challenge puzzle for you! Follow the clues in each line to find the right letter answer. Then, unscramble the answer letters to find out what someone with a bleeding disorder may need if they are having a bleed. Good Luck! Answers are on page 25.

1) I am in PORT and in SYRINGE, but not in MUSCLE. What letter am I? _____

2) I am in infusion LOG and in JOINT, but not in VEIN. What letter am I? _____

3) I am in SAFETY and in ELEVATE, but not in BRUISE. What letter am I? _____

4) I am in BUTTERFLY and in INFUSE, but not in GAUZE. What letter am I? _____

5) I am in COMPRESS and in ICE, but not in NEEDLE. What letter am I? _____

6) I am in TAPE and in TOURNIQUET, but not in BLEED. What letter am I? _____

1) _____ 2) _____ 3) _____ 4)_____ 5)_____ 6) _____

Unscramble the letters to fill in the word below:

For many kids with a bleeding disorder, clotting ___ ___ ___ ___ ___ ___ is a key part of stopping a bleed or preventing one from happening.

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

Sudoku!

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

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

[BIOMATRIX]
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Dedicated to Making a Difference

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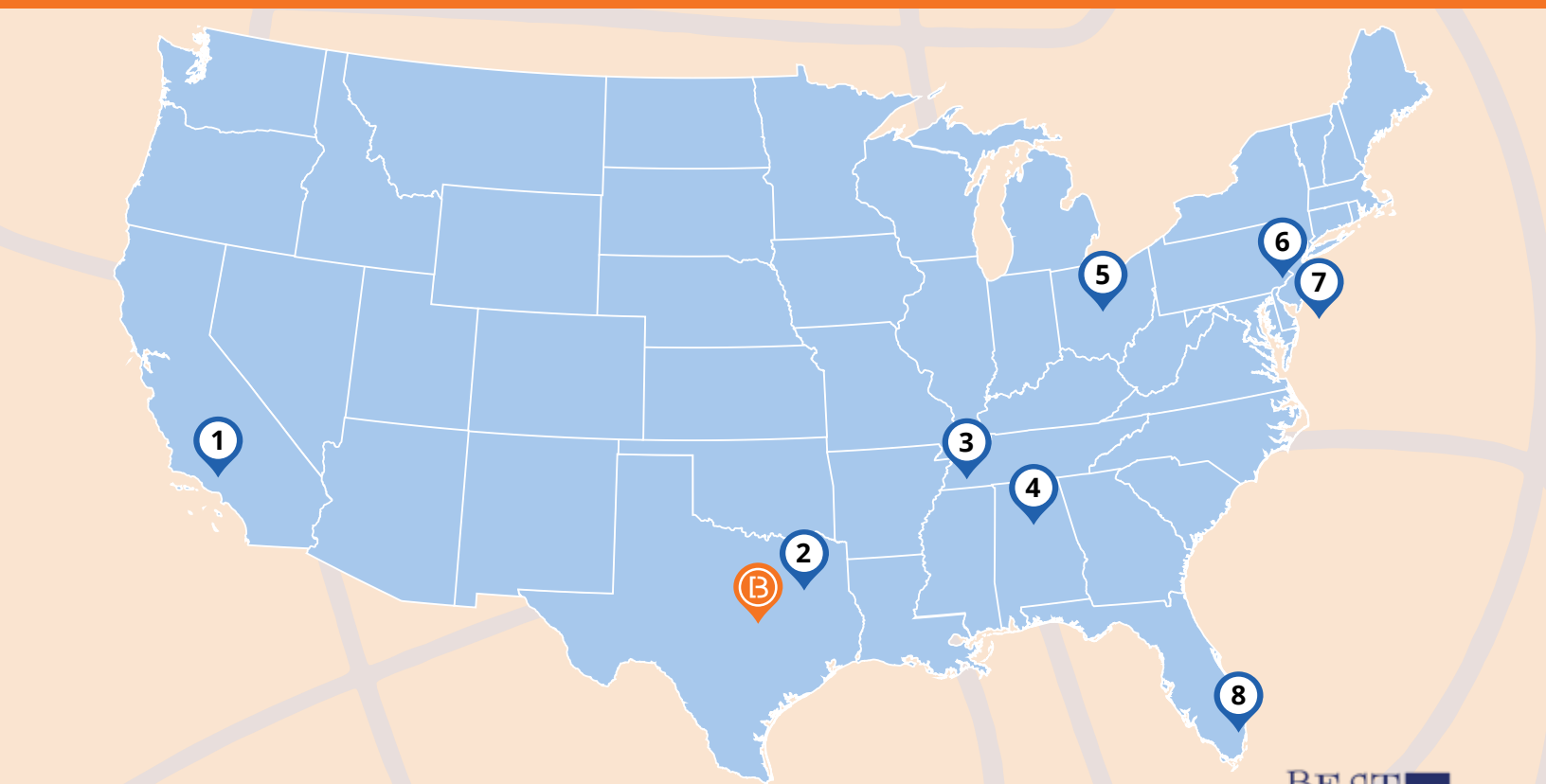

Specialty Infusion Pharmacy Locations

1. Van Nuys, California
2. Tyler, Texas
3. Bartlett, Tennessee
4. Birmingham, Alabama
5. Dublin, Ohio
6. Garnet Valley, Pennsylvania
7. Totowa, New Jersey
8. Plantation, Florida

Infusion Suite

Waco, Texas

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