BIOMATRIX Specialty Infusion Pharmacy News

Summer 2024
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Dedicated to Making a Difference

"May sunshine surround you each new day.
And may smiles and love never be far away."
— Catherine Pulsifer

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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
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BIOMATRIX
Specialty Infusion Pharmacy

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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.

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Check out our new website!
https://www.biomatrixsprx.com

A Note from the Editor

We at BioMatrix hope you are soaking in the summer sunshine! When my family was young, I really enjoyed the break from the school routine. The kids, their friends, and the ribbon of chaos that weaved through each day were celebrated. However, by the end of summer, I was ready for a little law and order! Summer will be over in the blink of an eye, and it will be time to usher the kids back to class.

This issue addresses going back to school and the need for 504 plans for students with a bleeding disorder, including a list of suggested accommodations to request. You will also find an article about steps you can take to reduce the back-to-school stress for the children in our community.

Speaking of stress, be sure to read up on insurance coverage *Alternative Funding Programs*. Although we understand the need to reduce health care costs, it often seems to be at the expense of the patient. Learn to see if and how your insurance coverage may be affected.

Whatever floats your boat this summer, enjoy it all!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
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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

The *New Bully* on the Insurance Playground: *Alternative Funding Programs*

BY SHELBY SMOAK, Ph.D.

In the ever-changing health insurance landscape, policies do as they always have – they change. The 'new kids on the block' in 2024 are *Alternative Funding Programs*, or AFPs. While AFPs staked out their street corner a few years' back, their adoption by Pharmacy Benefit Managers (PBMs) has them moving into the blocks and neighborhoods next to you. In 2023, about 14% of employers were utilizing AFP-style programs.[i] Let's take a look at AFPs and see how you might encounter them in your own health insurance plan.

What are AFPs?

AFPs are ***alternative funding programs*** that aim to flip the script on how specialty medications are paid for through your insurance plan. Intended to reduce the cost of expensive specialty medications like factor products, AFPs are sold to employers, especially for self-funded plans, and offers to save those company plans money through their third-party administrative services. The first AFP to enter the market, SaveOnSP, for example, advertises on their website's home page, "SaveOnSP can help reduce the financial burden."[ii] PrudentRx, now a big hitter with the CVS PBM, says plainly on their homepage: "PrudentRx was founded to help health plans of any size manage the rising cost of specialty medications."

How does a typical AFP work?

There are several steps involved in how an AFP operates within a health plan, so let's break it down:

1. An AFP will ask the health plan PBM to remove, or "carve-out," certain high-cost specialty medications

from their formularies. Pointedly, those medications are no longer covered AT ALL by the health plan. These drugs are classified by the PBM as "non-essential" and removed from any health plan coverage. This allows the plan to bypass annual limits on a patient's out-of-pocket cost and leaves the patient either "uninsured" or "under-insured" for those medications, which is a key step in the AFP design.

2. Patients on these high-cost specialty medications are then referred to the AFP by the plan. A key point here is, at this point in the process, the patient is no longer being covered by the plan for those medications. Operating as a third-party to the plan, the AFP has full and total control. The AFP completely manages the patient's access to that specific medication.

3. The AFP will manage access to the medication in the following way:
    a. They will refer the patient to a charitable organization and represent the patient as "uninsured" or "under-insured" in order to access free drugs through a manufacturer patient assistance program.
    b. The charitable organization then refers the patient to a manufacturer copay assistance program and has the patient sign up for a copay card, which is then given to the AFP.
4. The AFP then strips all the money from the copay card and pockets it.
5. The AFP then authorizes for the drug to be dispensed to the patient for zero cost, or a nominal $10 – $25 dispense fee.
6. The AFP then shares a percentage of the transaction with the plan.
7. When a copay card is used, none of the money is applied to a patient's deductible or out-of-pocket expense.

This sounds like a copay-maximizer policy. Is it?

In many ways, an AFP looks like a copay-maximizer policy. In a maximizer, the copay card dollars are used as a way for the patient to access a specialty medication, and then those dollars are not applied to a patient's deductible or out-of-pocket. So an AFP does share that effect with the maximizer. However, the key difference is that a co-pay maximizer operates within the health plan and is still legally bound by maximum out-of-pocket amounts, which in a 2024 ACA plan is $9450 for an individual. An AFP operates completely outside of a health plan and has no limits on how much money they can take from a patient, or by proxy, from a patient's manufacturer copay card.

What are some examples of AFPs?

SaveOnSP was for the longest time the best-known AFP. It primarily works with the Express Scripts PBM. PrudentRx has risen to the top of the pack in 2024, largely as a result of their partnership arrangement with the CVS PBM. Other players include: ImpactRx, Paydhealth, RxFree4Me, SHARx, ScriptSourcing, Matrix Payer*, and Horton Group. (*The AFP Matrix Payer, is, in no way, affiliated with BioMatrix Specialty Infusion Pharmacy.)

Do AFPs help patients?

While health plans and PBMS will claim AFPs help patients access high-cost specialty drugs, the reality is much different.

Here are a few concerns with AFPs:

1. AFPs confuse patients. The messaging is unclear from the health plan who must tell a patient their drug is not covered and then must direct the patient to call the AFP. Often the patient may not fully understand why they are calling the AFP, nor has it been made abundantly clear that their medication is not covered by their health plan.
2. AFPs force patients onto charity care, which the patient may find they are ineligible for due to income limitations or other factors.
3. An AFP may force patients to sign up for manufacturer copay cards, which must be turned over to the AFP to receive medication approval. This adds a layer of complexity to accessing the medication, and often resulting in unnecessary delays in care.
4. The process for accessing medications through an AFP is burdensome to the patient. Call the AFP, call the manufacturer, call the AFP back with the manufacturer copay card information, etc. This leads to non-compliance as patients grow frustrated and sometimes give up, and may delay treatment if out of or running low on medication.

5. If a patient grows upset with an AFP, they have nobody to call for grievances. The health plan is out of the picture and is no longer liable for any delays in care, patient frustrations, or other issues with being able to access the medication.

With all these issues and problems, the only current conclusion is that rather than helping patients, AFPs seem to hinder a patient's ability to access their specialty medications, thus putting their health in jeopardy. But to give the AFP some credit, after a patient jumps through all these hoops, in most situations, even if delayed, the patient does receive their specialty medication.

Are AFPs legal?

The jury is still out on that. A few things raise flags on their legality. For one, they are taking the full extent of the copay dollars on a manufacture card, which in the case of factor products can be $12,000 – $24,000. For another, an AFP is misrepresenting a patient to a charitable organization as "uninsured," despite the patient having insurance.

Some AFPs have even resorted to using imported drugs as a means to obtain free medication, and this could violate US law.[iii] It appears AFPs have found a loophole in the health care system and are exploiting it for their own financial gain.

Are AFPs being challenged?

Yes. Johnson and Johnson filed a lawsuit against SaveOnSP in July 2023. The lawsuit included Accredo, Cigna, and ESI (the PBM for Cigna), and alleges that the three were in a "scheme designed to siphon money" from the Johnson and Johnson assistance program CarePath.[iv] AbbVie has filed a similar lawsuit alleging AFPs are "fraudulent" and "deceptive."

States like Tennessee are working to fold AFP practices into their push for Copay Accumulator legislation, but unfortunately, states that currently have accumulator laws will be immune to AFP policies. AFPs have effectively undermined all current state copay accumulator bans.

Even though an AFP may appear as a maximizer, it is not, and is thus not legally bound to state maximizer law restrictions.

There is not yet a federal or national challenge to AFPs.

What can I do if my plan has an AFP?

Since most of these AFP vendors target self-funded plans, its likely your employer/Human Resources Department selected the AFP based on the savings they were promised without necessarily fully understanding its negative impact. Consider bringing it to their attention and see if they are able to make a change mid-year; if not, your information may encourage them to not select an AFP vendor the following year.

In some cases, your employer might be able to move your factor medication from a pharmacy PBM benefit to a medical benefit. Making this switch will remove you from the AFP which is only triggered on the pharmacy side by the PBM.

For additional questions, feel free to reach out to education@biomatrixsprx.com, or contact your local BioMatrix TAE (Territory Account Executive).

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The 411 on 504s:

SECTION 504 PLANS

BY SHELBY SMOAK, PH.D.

What would the young minds of our community be if their education were derailed by their bleeding disorder? They would be deprived of their right to learn. That unfortunate situation is exactly where a 504 plan comes into play.

With the efforts of our dedicated team members, BioMatrix has been engaged in the work of tailoring 504 plans to individual students. We have benefited many by advocating for necessary classroom and time-essential adjustments.

One particular story comes to mind about an 8th grader with hemophilia who began experiencing a persistent and severe elbow bleed. He struggled to carry his books and sling his backpack over his shoulder due to his compromised arm. We needed to write an accommodation to help this child as it was clear that carrying the books between school and home was painful and likely exacerbating his bleeding.

Every day, the student had to decide whether to endure the pain in his elbow while transporting his textbooks between school and home, or to leave the books at school and deal with incomplete homework and falling behind in class. Felix Jacquez Garcia, a BioMatrix Territory Account Executive, worked with the family to help the student. They advocated for the school to allow the student to have a duplicate set of textbooks: one to keep at his desk in school, and the other for use at home, and the school agreed to this arrangement.

This is exactly the purpose of a 504 plan: to address issues stemming from a physical impairment and guarantee that students with such impairments do not lag behind in their education. Every child should be afforded the same opportunities for learning – a chronic diagnosis like a bleeding disorder should not put any child at a disadvantage. Let's look more specifically at 504 plans to gain a clearer understanding of their intended function.

What is a 504 plan?

The 504 plan was created to ensure that a child with a disability (broadly defined) as identified under the law will have accommodations provided to support their access to learning successfully. Named after Section 504 of the Rehabilitation Act of 1973, the 504 plan is a federal civil rights law that protects against discrimination.

Who is entitled to a 504 plan?

A 504 plan is available to students attending a federally funded school and are impacted by a qualifying health impairment that affects one or more "major life activities." To qualify, a child must meet one of the following criteria:

- Have a physical or mental impairment that substantially limits one or more life activity
- Have a record of such impairment
- Be regarded as having such an impairment

Students with a bleeding disorder will qualify for a 504 plan due to the documented evidence of limitations caused by bleeding episodes. The 504 plan specifies the limitations should be assessed based on the child without medication. In other words, would the child experience limitations if the bleeding disorder were untreated?

What are examples of "major life activities" that would qualify a child for a 504 plan?

These criteria can seem a bit loose, but when we talk with families about 504 plans, we encourage them to imagine their son or daughter without medication. The available therapies and treatments today allow most persons with a bleeding disorder to experience a full and almost "normal" life (whatever that is!). With a 504 plan, consideration must be given to what the child's life would be without medication. Would they be ambulatory? Would they be on crutches or in a wheelchair? Would they have full use of their arms? What "major life activities" would then be impacted? The list below offers a few of the more common issues for students with bleeding disorders:

- Caring for oneself - bathing, brushing teeth, getting dressed, managing bodily functions
- Walking - accessing the classroom and seating
- Bending - being able to pick things up from the floor, tying your shoes
- Performing manual tasks - lifting items, carrying books or backpack
- Academic challenges such as learning, reading, study skills or sustaining attention/concentration
- Communication skills
- Mental health conditions such as anxiety, depression or self-esteem issues

Why should I establish a 504 plan for my child?

- It can protect the student's educational integrity given their medical condition
- It helps prevent their bleeding disorder from negatively impacting their educational performance
- It protects the student's educational interest under similar protections from the Office of Civil Rights
- It does not categorize your child as a special education student and does not alter the standards or expectations of the educational goals

How does a 504 plan differ from IEP (Individualized Education Program) goals?

504 plans enable adjustments to be made in school settings to remove barriers for individuals with physical and/or mental impairments. On the other hand, IEP goals are specifically targeted at addressing learning disabilities and eliminating barriers in those cases by providing specialized instruction and services.

How can I set up a 504 plan?

A 504 plan referral can be initiated by a parent, a family member, a guardian, or a member of the school staff. The referral then goes to a school counselor, nurse, teacher, or 504 coordinator. Sometimes a physician may be required to submit documentation.

How can I prepare for a 504 meeting?

Have the following information ready:

- Diagnosis
- School attendance issues for the past year
- Planned absences for medical appointments or procedures
- A list of potential or foreseeable issues
- A list of requested accommodations (see page 9 for suggestions)

Parents should consider and obtain 504 plans for their children affected by a bleeding disorder or other conditions. Implementing a 504 plan is a wise decision, but it's important to note that it doesn't give a child an advantage in their studies or provide a free pass on tests or assignments. They will still have to do the work. They will still need to complete assignments, study for tests, and pass educational goals like any other student. A 504 plan assures that when their condition raises complications, the student will not be negatively impacted and will have an equal opportunity to achieve academic success.

For assistance in starting the process for your student, email us at education@biomatrixsprx.com.

504 PLANS:

SUGGESTED ACCOMMODATIONS

BY SHELBY SMOAK, PH.D.
FELIX JACQUEZ GARCIA
JEANETTE JONES, MA Ed

Following is a list of the accommodations typically applied within 504 plans. Each plan should be tailored to meet the specific needs of the student. It's important to note that in a 504 plan, the student's condition should be considered without medication. Even if not currently needed, accommodations should be requested based on the potential impact of any health issue or physical mobility impairment.

In 504 plans for middle school and above, we often see language regarding a student's ability to "self-diagnose" and/or "self-limit." To empower a student to make decisions about their abilities and limitations, they should be considered "self-diagnosing" and/or "self-limiting."

ABSENCES

- All medical-related absences, including doctor visits and medical conferences, should be considered excused
- Grading during medical absences will be based on pre-agreed-upon completed make-up work
- Rushed assignments due to absences will not be marked as "0" nor held against the student's grade
- Teachers should promptly provide class notes to the student or assign a designated note-taker during absences
- If an absence extends beyond two consecutive school days, peer or teacher-supported tutoring will be offered to help the student catch up, typically at a rate of 1 hour of tutoring for every 8 hours of classroom time missed
- After returning to school, the student should be allowed 1–1.5 days per missed day to make up work
- Alternative condensed assignments should be considered for extensive absences
- The student will be offered an extended deadline for missed tests upon their return

CLASSROOM

- Student with mobility issues may need to leave early and/or arrive late
- Students with heavy menstruation issues will require additional time between classes and extra bathroom breaks
- Based on mobility, the student will be provided access to an elevator for multi-floor class changes
- Copies of textbooks should be provided to the student to keep at home for use during absences and to students with mobility issues to prevent problems with transporting them; copies of textbooks should be provided at the start of the year in anticipation of their future need
- Students should have immediate access to a private location such as the nurse's office to infuse or evaluate a bleed

CLASSROOM SEATING

- Proper accommodations for desks and chairs should be considered for students with mobility issues or walking aids such as crutches, for example, with more surrounding space or higher seats for ease of access
- Seating with easier access to doors will be offered during times when use of mobility devices is required or the student needs immediate access to the nurse's office or a bathroom
- Space will be provided for lower limb elevation or upper body resting when needed

PHYSICAL EDUCATION AND PLAYGROUND

- The student should be considered "self-limiting" and be allowed to opt out of activities that extend beyond their physical abilities
- When an activity is deemed unsafe or unsuitable, alternative activities should be considered
- Young children, especially elementary school-age, may require additional monitoring during recess or recreation time

REDUCING *Stress* AT SCHOOL: What You Can Do To Be Prepared

BY JEANETTE JONES, MA Ed

Didn't summer break just begin? Time flies, and the 'back to school' buzz is about to begin. Soon our lives will be filled with checklists, enrollments, school supplies, final plans, and STRESS. As caregivers, we feel the anxiety of our young loved ones returning to school, but our children feel nervous, too.

Even when we equally feel excited for the new school year, fear and worry can still creep in. Add a bleeding disorder to the mix, and it is understandable why so many families just like ours struggle with the transition back into school after an enjoyable summer safe at home.

When my son with a bleeding disorder began pre-kindergarten, I was nervous for him, and I'm quite sure it did not help. Perhaps my anxiety rubbed off on him - he really struggled throughout his first year of school. Hard lessons were learned, but now, we know how to be better prepared. This year, we are ready to send our daughter to school for the first time. She is also a bleeder like my son and me. To make the transition easier, I have collected some helpful suggestions to support everyone involved, and we're happy to share them with you.

TALK ABOUT IT

Daniel Tiger's mom (of the PBS KIDS television series *Daniel Tiger's Neighborhood*) says it best. "When we do something new, let's talk about what we do." Transitions are difficult for many, and discussing changes and what to expect can make things less scary. Additionally, by initiating conversation, you are creating a safe space for your child to express any fears and feel welcome to ask questions.

PRACTICE YOUR NEW ROUTINE EARLY

Reach out to the school and ask for a mock schedule for a typical day or week in their class. Review this schedule with your child, and if you can, try spending a few days or a week mimicking or marking each time an expected school day activity will take place. For example, wake up at the time you would for a typical school day, go through your morning checklist, mimic the school day schedule including classes, meals, play (etc.), coming home, and after school activities. Of course, this is not expected to be done perfectly, but even setting alarms and mentioning what to expect at certain times of the day can help children acclimate to a new schedule.

SEE BEFORE YOU START

So much fear revolves around being unfamiliar with a new location. It would have been incredibly helpful for my child to have visited the school ahead of the standard 'meet the teacher' in order to walk through the halls and imitate his various routes; from drop off to the classroom, from the classroom to the playground, from the classroom to the cafeteria, etc. Children also need to know where important rooms are such as the nurse's office, main office, library (my son's favorite), and others.

EDUCATE THE STAFF

When your child is at school, the adults responsible need to know about their bleeding disorder, what to expect, what YOU expect, and what to do in any bleeding situation. An in-service with the school staff should be set up before school starts to help them understand your child's condition. Our community's national and local organizations have resources to make this task easier for families. You can also ask your local industry representatives as well. They can often join your education meetings to help you teach the school staff.

MAKE A PLAN (504/IEP)

At the very least, create a 504 plan to provide your child with protection and access to resources and accommodations if needed including more time to move between classes, excused absences for doctor visits or education conferences, the ability to reschedule exams if needed, or extra bathroom breaks and access to period products for menstruators. There are times when an IEP is also needed. Work with the school to determine which is best for your child's care.

UTILIZE MEDICAL ALERT TOOLS

In my opinion, not wearing a medical ID of some kind can be dangerous. When we cannot speak for ourselves, we need our data to speak for us. Anything could happen, and it's best to be prepared. My kids love their medical alert bracelets, especially my daughter because hers is pink! Letting them choose their favorite color or style can incentivize their willingness to keep it on. Discuss the importance of wearing them before they start. Some Hemophilia Treatment Centers provide medical alert jewelry for their patients at little or no cost (e.g. examples: MyID Shop, Medical Alert Foundation®, American Medical ID®)

PACK A 'BLEED' BAG

Just like your emergency 'go–bag,' a similar collection of bleed support items can help alleviate stress and anxiety for children, caregivers, and school staff. Depending on the needs of your child, the bag can stay at school or come home as often as necessary. Here is a list of what's in our bag along with a few ideas from our fellow community members. (Examples of brand products can be found at pharmacies, big box retailers or Amazon.)

- **Medication and infusion supplies** such as infusion needles, tourniquet, gloves, alcohol wipes, gauze pads, tape, etc. Depending on the medication your child uses, oral spray or infusible, it can be kept in the bleed bag or stored in a secure refrigerator at their school.
- **Emergency Care Plan** – Steps that should be taken for minor injuries such as scrapes, bumps and nose bleeds. Should also include information to give to EMT or emergency room.
- **Emergency contact list**
- **Travel Letter** – a letter from the child's physician (on letterhead) outlining the child's diagnosis, severity, medications and dosage, treatment regimen for various levels of injury, and physician contact information. This information is highly helpful in an emergency where the parent is unreachable.
- **Copy of the 504/IEP** outlining the provided services.

- **First aid powder packs and bandages** featuring bleeding control technology to help control bleeding from minor cuts (powder examples: BleedStop™, BleedCease®, WoundSeal®; bandage examples: QuickClot® dressing/bandages (QuickClot® Clotting Gauze, Curad® Quickstop)
- **Hydrocolloid bandages** for faster healing of surface wounds (e.g. Band-Aid Hydro Seal®, CVS Health Advanced Healing Hydrocolloid Bandages™, DynaDerm Hydrocolloid Dressing, Walgreens Hydrocolloid Gel Bandages)
- **Adhesive bandage strips** for small cuts and scrapes (favorite styles/colors)
- **Bandage wrap** (e.g. Ace™, Coban™)
- **Saline gel** for dry noses to help prevent a nosebleed (e.g. AYR® Saline Nasal Gel, Boogie® Saline Nasal Gel, NeilMed® NasoGel®)
- **Nosebleed tools -** clamp, plug or stopper (e.g. RhinoPinch Nasal Clips®, Nosebleed Stopper, Quick Seal® Nose Bleed Plugs, Mueller® Nasal Plugs, Nampons™ for Nosebleeds, Nose It All™)

- **Instant icepacks**
- **Menstruation products** (if applicable)
- **Antiseptic first aid wipes** to clean off wounds (e.g. Dermoplast®, Hart Wound Wipes, PhysiciansCare Antiseptic Towelettes, Medi-FIRST Antiseptic First Aid Wipes)
- **Change of clothes** in case clothing is soiled with blood. Many schools cannot allow a child in class with visible blood on clothing for concern of exposure to another person.
- **Comfort item** (my son loves his stuffed turtle, Lucky)

CONNECT WITH YOUR COMMUNITY

Our bleeding disorders family is the best resource out there. They have lived it and have experienced what you are going through, or you may be dealing with the same issues at the same time. Their guidance and comforting support can ease your stress and alleviate anxiety. You might even get lucky if another community family has gone through the same school system as you and the school is already aware of bleeding disorders. If you have not already, I highly encourage you to get involved with your local chapter and national organizations, join a social media group, and take advantage of every community connection opportunity available. We can lean on each other and can learn from those who have already walked in our shoes.

While every story is unique, we hope some these helpful ideas will ensure your school year will be a great triumph. If you have any success stories, or you might have more ideas to share with your community, we would love to hear from you. Wishing you all a safe, successful school year!

THE JOURNEY SIBLINGS SHARE

BY PAISLEY H.

Brothers and sisters can share many things, love and hate, war and peace, and maybe even a few secrets from mom and dad. This bond can be enriching, and competitive, and sometimes just be the best medicine to get you through anything. We have seven kids in my family. Two of my brothers, James and Lane, have severe hemophilia. James was adopted from Bulgaria as a teenager. Lane is 17 and two years older than me. Since most of my experience with hemophilia is with Lane, I will talk about him.

For some hemophilia can get complicated, and it did for Lane. He has an inhibitor which means clotting factor doesn't work the way it's supposed to in stopping his bleeding episodes. Our family became regulars at the emergency room. For as long as I can remember I accompanied my brother and was at his bedside during many, many ER visits and long hospital stays. My parents had me tested for carrier status when I was a toddler. I feel relieved to know I am not a carrier and that my future children won't have to go through what Lane has.

Regardless of my awesome sister status, Lane was pretty impatient with me when we were younger. I'm sure I was as nice as can be, but he always wanted to get his own way - what brother doesn't. I still find him only semi-tolerable, but truth be known we are very close and get along well, but why admit such things.

Especially when we were younger, he and I loved to wrestle any time he didn't have a bleed, but that wasn't very often. I could pin him and claim victory almost every time. Part of winning, though, was because of his hemophilia. He often had a tender joint or two which I felt bad about, but I still didn't mind the WIN! Sure, it was an unfair advantage, but all is fair in love and wrestling.

He started a new medicine a few years ago and ever since, he rarely has a bleed. He's grown bigger, stronger and takes no mercy. Now I can no longer win a wrestling match, but it's okay, I think it's his turn to be the victor. I'm all about being a supportive sister and I am his biggest fan! Now, we can do so many more things together that used to be considered extremely dangerous for him, like riding dirt bikes. It's a lot to worry about when your older brother has a bleeding disorder. Even with the new medicine, I still worry about it, but not as much as I used to.

Having brothers with hemophilia can be hard sometimes, especially where we live. Getting help for any kind of an emergency is at least an hour away. For appointments with specialists, we have to travel 9 to 10 hours each way. If you have not already guessed, we live in a very rural area.

When I am on a break from sibling quality time, I enjoy painting, swimming, athletics, riding horses, and working on our ranch. One of my favorite things is baking and decorating cakes. I started baking when I was much younger. I donate cakes to folks from our church and birthday cakes to relatives. I have made many cakes for my siblings, cousins, and an aunt and uncle. I even recreated a 50th anniversary cake for my grandparents from an old photo! The most cupcakes I have ever made at once was 270 for my cousin's graduation party.

This summer I will be creating a wedding cake for a dear family friend! I never would have thought I would get this far or skilled at making cakes let alone have the opportunity to decorate a wedding cake!

Lane loves being my taste tester. He is not afraid to tell me if something tastes bad. After he started his new medicine, I made a "100" cake for him to celebrate the first time he went 100 days without a bleed. One of my next cakes will be for his high school graduation. I can't wait to smash it in his face, and then steal his bedroom when he moves out! The bond is strong between siblings, and we wouldn't have it any other way.

Spectacular cake designs created by Paisley!

HEMOPHILIA FEDERATION OF AMERICA IN REVIEW

ANNUAL SYMPOSIUM, CELEBRATING 30 YEARS!

OUR JOURNEY, OUR COMMUNITY

BY EVA KRAEMER, RANIA SALEM AND AUSTIN CALDWELL

The Hemophilia Federation of America held its *Annual Symposium, Our Journey, Our Community* at the JW Marriott hotel in Indianapolis, Indiana, April 8–14th. The event's theme celebrated both the organization's 30th anniversary and the community's history. Attendees gathered to learn about the latest bleeding disorder therapies and treatment options.

Siblings Madilyn and Lukas share a special handshake

The event kicked-off with CEO Dan Kelsey sharing his insights on the future of HFA and the vision for bleeding disorder treatments. At the awards ceremony, many individuals were celebrated for their outstanding contributions to the community. The weekend was filled with sessions on new and emerging therapies, mental health, and bridging the intergenerational gap. The film, *On the Shoulders of Giants*, produced by Believe Limited and directed by Drama Del Rosario, also premiered at the event. The movie explores the lives of older generations with hemophilia and follows blood brother Wayne Cook's journey as he reconnects with others who share similar experiences. The film can be viewed at *On The Shoulders of Giants* (https://www.ontheshouldersfilm.com/).

Murali and Rocky take a selfie

Regly (center) stops for a photo with Rania and Eva

Austin Caldwell, a new member of the BioMatrix team Hemophilia Division based in North Carolina, shared his perspective on the event.

"This was my first large event as a BioMatrix Territory Account Executive. The exhibit hall was bustling with excitement, and it was awesome reconnecting with members of the community. Being at the booth filled me with lots of emotion and I am excited to embark on my new adventures. Having a bleeding disorder myself, I was able to connect with others who share commonalities. Growing up in the bleeding disorders community and now being able to serve is very heart-warming to me.

The girls meet up at HFA! Eva, Janet, Rania, Natalie and Kayla

Happy Symposium attendee, Evelyn

As a consumer, I attended many of the sessions; one of the most touching was *Celebration of Life: Lest We Forget: Honor the Past. Celebrate the Present. Embrace the Future.* I found this session to be deeply moving. Honoring those who have passed made me very emotional as I sit here today living a healthy life. I am grateful for the difficult path they paved for us all. To me, Lest We Forget means not taking for granted the sacrifices of those who came before us. WE WILL NEVER FORGET!"

Sherri (far right) visits with good friends at the BioMatrix booth, Austin, Rania and Eva

Congratulations to HFA for 30 years of dedicated service to the community, and many thanks to their team for hosting this important event!

We look forward to seeing everyone again for the 2025 HFA Symposium, March 27–30, 2025, in San Diego!

18TH ANNUAL SYMPOSIUM!

BY MICHELLE STIELPER, TINA MCMULLEN AND FELIX JACQUEZ GARCIA

There is never a better time to "B" together than for The Coalition for Hemophilia B's *18th Annual Symposium*! Usually hosted in Florida, this year the event was held at the Renaissance Dallas Hotel April 25th-28th. It was still plenty warm!

The Coalition always seems to exceed every expectation of educational programming. This year was absolute proof. The sessions spanned all possible topics and age groups - something for everyone. There were sessions for new families, individuals over 50, Spanish speaking, inhibitors, specifically for women, for men, industry updates, insurance navigation, career development, and self- infusion.

Keynote speaker Mina Nguyen-Driver, Psy.D., shared a harrowing story of how her Vietnamese Air Force pilot father gathered his wife and three small children and escaped Vietnam during the Fall of Saigon. She also spoke about her family's subsequent journey with hemophilia following her brother's diagnosis.

The children's programming is always remarkable, to the extent that the kids hardly want their parents to collect them at the end of the day. It is hard to leave when there is so much fun buzzing around with your friends!

The BioMatrix booth was humming with energy over our Texas-themed JeoParody game. Friendly competition rang strong between the guys and gals, with the guys pulling off a narrow victory. We also had many busy Bs flying by every day to make sure they got another entry into our gift basket drawing. It was stocked with summertime grilling goodies. Congrats to our lucky winner, Courtney!

Everyone leaves the Coalition with more knowledge than they came with, and even deeper friendships. We always say that the B community feels like family, and the Symposium feels like our family reunion. We eagerly anticipate it every year, and now that it is over, we look forward to it again next year. BioMatrix is proud to be a part of this annual event, and we love having the chance to reconnect with our special community. Many kudos to Kim Phelan and her hardworking, devoted team for organizing another fantastic Symposium. Just when you think it can't be any better, they somehow make it so!

A Rather 'B'eautiful Family Reunion!

BY FELIX JACQUEZ GARCIA

I get a little nervous before a family reunion – meeting up with relatives I haven't seen in a while, wondering how I'm going to spend my time, and worried about that one talkative cousin cornering me and keeping me from chatting with the rest of the family. It's enough to make anyone a little concerned. My anticipation of attending The Coalition for Hemophilia B Annual Symposium makes me feel that same way.

This was my first year attending without my best friend and blood brother, Alfonso "Fonzie" by my side, who passed away earlier this year. The thought of him not being at the Symposium made it harder to look forward to it. That said, what happens naturally at a reunion did, in fact, happen. Family came together and made me feel welcomed and less alone.

We all hugged and embraced as we walked through the halls or met in sessions. The love is real and pronounced. We shared meals, experiences, and oh so many laughs, and yes, we raised a glass to my brother Fonzie, and to the others we've lost over the years.

The Coalition took great time and effort to cover as many bases as possible and provide an expansive variety of sessions. You had to choose one over another since you couldn't be at them all – the weekend is only so long! I missed half the sessions I wanted to attend, but I appreciated all the sessions that I was able to take in.

One that stood out to me was a screening of *On the Shoulders of Giants*, a documentary produced by Believe Limited in partnership with Entertainment 2 Affect Change that features Wayne Cook as he travels across the United States visiting with older generations of people with hemophilia and speaks about their impact on our community today. If you're interested, the film can be viewed on YouTube at: https://www.ontheshouldersfilm.com/

In addition to attending sessions, my time at the Symposium included representing BioMatrix Specialty Infusion Pharmacy as I helped staff our booth in the exhibit hall. I love the action and energy in the hall! So many families and individuals visited to hear about our pharmacy's services and see what promo items we were offering. And then there's our JeoParody game. We tailored our hemophilia education game by adding a little Texas flavor. Portraying the game show role is always a treat for me! If you stopped by our booth or caught a moment with me throughout the event, thank you! I guarantee I didn't spend as much time with you as I wanted. I hope to see my "family" soon at one of the Coalition's 2024 "On the Road" meetings or at the 2025 Coalition for Hemophilia B Symposium April 10–13 in Orlando, Florida!

Bloodbrothers, Jesus, Felix and Sebastian

Karla and Felix soak in the education

Relaxing after a wonderful weekend at CHB Symposium!
Ryan, Felix and Jeannette

Upcoming Coalition for Hemophilia B
Meetings on the Road
To register, visit
https://www.hemob.org/meetings-on-the-road

October 12: San Antonio, TX, and Columbus, OH
October 19: Denver, CO, and St. Louis, MO
October 26: Richmond, VA, and Chicago, IL
November 9: Birmingham, AL, and Anaheim, CA

Networking and snacking go hand-in-hand at CHB!
Chris and Felix

Men's Retreat: *The Best of Times*

BY SHELBY SMOAK, PH.D.

When I write an essay, I like to open it with a good quote, and for this one, I'm going to lean into Dickens and go with his oft-quoted phrase, "It was the best of times" because it was. For a hemophilia ***Men's Retreat***, one cannot imagine a better event than the one hosted May 31st–June 2nd at Rehoboth Beach, DE. This is the third year of this annual event, and each one improves from the one before. Sponsored by HEMA Biologics, Medexus, Octapharma and BioMatrix, and hosted by Country Boy Fishing, this event provided meaningful connections, valuable education, and, more than anything, a respite from the daily labors of life with a chronic condition.

From our meeting space, I watched as the summer sun descended across the Delaware boardwalk and the sea beyond it: a swirl of purple punctuated with blazes of orange clouds. We all gazed at it here and there while we spent opening night getting reacquainted with past friends and embracing new ones. The convivial atmosphere was almost palpable as we laughed and shared our past experiences over a summer-inspired meal. Medexus speaker Christian Harris then led us through the history of fashion, including stops in Tsarist Russia and engaging Queen Victoria, a key historical figure for Hemophilia B history.

Medexus' Christian Harris presents

Royal Men, Reid, Angel, and John

The next day, Hema Biologics representative Justin Lively introduced the group to their inhibitor therapy. This was followed by my own informal BioMatrix insurance program *Can You Stump Shelby* where the audience lobbied coverage questions about Medicare, copay accumulators, and step therapy, I attempted to answer them, referring to the appropriate slides where warranted. The group took away strategies for navigating PBM policies, even if my evident omniscience failed me a time or two.

BioMatrix's Rich Vogel and Shelby Smoak

Carl practices his golf swing

Octapharma's Paul Brayshaw takes aim

Bonding continued with an excursion to throw axes and play digital Top Golf. Rap sessions continued inside, outside, poolside, beachside, boardwalk side, and just on the side throughout the day.

In the evening session, Octapharma speaker Dr. Claudio Sandoval spoke on pain management. He introduced the pros/cons of various interventions and provoked discussion around a topic that deeply interests those, like me, who are pressing 50+ years on worn ankles, replaced knees, and eroded elbows. Fun fact: the iron in blood and its acidic quality causes our joints to become malformed with excessive bleeding! Also: less iron intake is not an apparent solution. Thank you for that, Dr. Sandoval!

We carried the night forward with more sharing, laughing, and enjoying the moment. As the night grew late, the moon rose, and the beach and the town emptied.

Shelby and Chris take time to catch up

The next day, flying home, refreshed, yet tired, in that liminal oxymoronic space, I wondered why these events are so important. Is it the way we learn from one another how to care for our conditions? Is it how we can have conversations about life and jobs without having to always pause and explain hemophilia? Is it because we can make fun of hemophilia and it's okay? Certainly, it's likely all these things and much more. There is very little that is light about living with hemophilia, but an event like this adds levity to it. It tells me it's okay, shows me how to keep moving forward and staying healthy. And that's really why it was, indeed, the *best of times*.

BIOMATRIX ON THE *Move*

The BioMatrix Education Team and Territory Account Executives (formerly known as Regional Care Coordinators) have been busy attending community gatherings and hosting educational events across the 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.

NEVADA

John Martinez

On March 30th, the Nevada Chapter of NBDF organized a ***Spring Education Day*** at the Clark County Wetlands Park Nature Center in Las Vegas to celebrate the beginning of a new season. Despite the overcast sky, the event was attended by many participants and sponsors who came with sunny dispositions and smiles.

Lots of Exhibit Hall activity!

Families were welcomed by enthusiastic chapter staff and volunteers, as well as industry representatives who supported the event. Everyone was given access to local resources, such as the American Red Cross and other organizations, to obtain valuable information about the community and available assistance.

The event included morning activities on the 14 miles of paved and unpaved trails, with children and teens taking part while adults attended a presentation on *Equity and Inclusion in Healthcare*. After the presentation, everyone was encouraged to meet with industry representatives. We are appreciative to the Nevada Chapter for the opportunity to participate in this event.

NEW MEXICO

Felix Jacquez Garcia

We jump-started spring with an April 3rd ***Educational Dinner*** event at Albuquerque's M'tucci's. Thanks to the support of Genentech, we had a great dinner and presentation from one of their ambassadors, Harvey. He shared his personal journey with a bleeding disorder and his decision to switch to Hemlibra®. Attendees

Harvey listens intently to Dave

The boys are back in town

appreciated his honesty and candid remarks about not always properly taking care of himself. Harvey did a wonderful job and received rave reviews from the guests.

Lucky raffle winner, Elias

The event concluded with guests catching up with each other and Elias winning the BioMatrix raffle prize which included a car wash and detailing kit, complete with a "supervisor" folding chair. With the weather getting warmer, guests were jokingly offering up their cars for a wash! We thank everyone who joined us and Genentech for sponsoring the gathering!

NEW YORK

Richard Vogel and Carolina Luna

The New York City Hemophilia Chapter (NYCHC) organized an ***In The Know: Treatment Decision Making Summit*** April 6th at the WeWork office located in New York City. The event started with an opportunity for community members to interact and visit with industry and specialty pharmacy representatives before the educational workshops began. The sessions covered various topics for everyone, whether they were parents new to the bleeding disorders community or seasoned members. There is always something new to learn from this community, regardless of the stage of your bleeding disorder journey. One session that stood out for me was the *Understanding the Immune System and Its Relationship to Investigational Gene Therapy,* a topic crucial for advancing our understanding of gene therapy and its interaction with our immune system – essential for the development of safe and effective treatments for hemophilia and vonWillebrand. Much gratitude to NYCHC for hosting this informative event!

Maribel and baby Umut stop to visit Carolina and Rich at the BioMatrix booth

OHIO

Shelia Biljes

With tables decorated in a colorful teapot theme at Brew Garden in Middleburgh Heights, the Greater Ohio Bleeding Disorders Foundation (GOBDF) gathered a special group of women for a unique ***Ladies Event*** April 6th. Takeda and BioMatrix Specialty Infusion Pharmacy were honored to be invited to present programs. Maria Rohan, a Takeda Nurse Educator, presented *Empowering Women* with Bleeding Disorders. After lunch, it was time for a BioMatrix sewing class! What can be more empowering than creating with your own hands? Even those who had never used a sewing machine were able to turn their bright teapot fabric into a beautiful tote bag.

GOBDF did an amazing job organizing this creative opportunity, and we were honored to have been a part of it!

Elfie and Tanya concentrate on the task at hand

Kayleigh is all smiles during her first time sewing!

A sea of colorful and useful totes!

Lisa and Emilie

Lily and Nick enjoy breakfast!

TENNESSEE

David Tignor

With the sound of an air horn, the race was on! The Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) hosted its ***6th Annual Blazin' for Bleeders 5k Run/Fun Walk*** April 6th at Gateway Island in Murfreesboro. Despite the chilly air, the sun was shining brightly as participants gathered for this worthy cause. The event aims to raise funds to support education and advocacy for Tennessee community members. After the race, awards were given to the top runners in their respective age groups. BioMatrix sponsored breakfast and coffee for everyone. We are excited to participate in and support this THBDF fundraising event next year!

Mason and Beckett go for gold!

FLORIDA

Marcy Foertsch and Peggy Klingmann

Sanofi and BioMatrix organized an ***Educational Event*** in Tampa April 9th for bleeding disorder families. The event was held at Terra Gaucha Brazilian Steakhouse and featured great food, learning, and community. The evening began with a presentation by Dr. Erin Cockrell of Tampa's St Joseph's Hospital on ALTUVIIIO®, followed by a presentation on Patient Navigation by BioMatrix Director of Advocacy and Education, Shelby Smoak, Ph.D.

Shelby Smoak and Sanofi's Eric Burgeson

Dr. Smoak highlighted the importance of having a team in place to assist with insurance and benefit challenges and how BioMatrix is well-positioned to be that team. The group was highly engaged, asking questions of both speakers and offering a great deal of positive feedback. Sanofi and BioMatrix are excited to host many more programs like this in the future!

NEVADA

John Martinez

There is more to do in Nevada than the traditional attractions! Round Table Pizza was the place to be April 12th in Reno and April 13th in Las Vegas, where Bayer and BioMatrix co-sponsored evenings of ***Education and Family Game Night***. At each event, Bayer's Hemophilia Community Executive Felipe Greven gave an introduction and brief overview of Bayer's products and services. BioMatrix then presented an educational session on *Family Dynamics* in English and Spanish. The presentation discussed the various family roles in the household of a person with a bleeding disorder. Attendees were invited to share valuable personal examples and experiences, which added an interactive component to the discussion.

After the educational presentations, it was time for our popular bleeding disorders version of *Loteria!* Everyone, regardless of age, joined in this fun game that allowed them to learn bleeding disorders terminology in Spanish while having a great time. As each round of Loteria crowned a winner, players readily reset to begin again and continue to enjoy the camaraderie and competition.

Many attendees expressed interest in future events in their areas. You can bet we will be happy to oblige! We extend our gratitude to Bayer for their continued commitment to the Nevada community, and to the families who shared their time and friendship.

NEW MEXICO

Felix Jacquez Garcia

John Martinez presents *Safer Travels*

Jessica, Bernadette and Stacey

What better day for members of the bleeding disorders community to get together than on World Hemophilia Day! Bayer and BioMatrix hosted an ***Educational Dinner*** April 17th at Main Event in Albuquerque. Bayer Hematology Account Manager Giovanny Pernudi opened the evening by offering information on Bayer's extended factor VIII product, Jivi®. This was followed by BioMatrix Educational Development Specialist John Martinez, who spoke on *Safer Travels*, covering helpful information for vacation planning when traveling with someone with a bleeding disorder.

After dinner, most of the group headed over to the bowling lanes where we knocked down pins, engaged in friendly competition and worked off some of those dinner calories! Many thanks to Bayer for their continued community support and to all our guests for spending their evening with us!

FLORIDA

Hector Heer and Brenda King

Executive Director Ana Calero and Hector Heer

The Foundation Hope & Life USA hosted its ***11th Annual Light of the World*** event at the Oasis Banquet Hall in Miami April 20th. The event brought nearly 150 attendees to recognize the progress made by our bleeding disorders community, commemorate those no longer with us, and celebrate the bright future ahead.

Brenda and Corissa

BioMatrix was proud to sponsor the program and share information about our pharmacy and support services, including our Patient Navigation program. The venue and food contributed to the success of the evening, with many participants staying after the program to continue enjoying each other's company. We are grateful to the Foundation Hope & Light for organizing this annual event and bringing our community together.

VIRGINIA

Terry Stone and Michelle Stielper

Known for its rich history and natural beauty, Virginia is home to the very unique Natural Bridge. Once owned by Thomas Jefferson, the 215-foot-tall limestone arch is listed on the National Register of Historic Landmarks. The structure is a sight to behold. The Virginia Hemophilia Foundation held their ***Annual Meeting and Community Event*** on April 20–21 at this beautiful location.

The keynote presentation was delivered by Dr. Louise Man, Associate Professor, UVA Health Medical Director of the Adult HTC, on *Overview and Management of Mild Bleeding Disorders*. The presentation delved into the science behind why some mild patients' bleeding isn't always mild.

Following was Miriam Goldstein, a lawyer, health advocate, and mother of two sons with hemophilia, who presented *Knowledge is Power: Understanding Health Insurance*. She emphasized the importance of learning and understanding how accumulator adjusters and maximizers can affect out-of-pocket responsibilities. Community advocate Rick Starks presented *The Benefits of Tai Chi, Mindfulness, and Meditation* and shared his personal wellness story.

On the second day, participants explored the beautiful Natural Bridge Park, guided by GutMonkey. It was a weekend full of breathtaking scenery, wonderful people, and unforgettable memories! Thanks to VHF Executive Director Kelly Waters and Assistant Director Heather Conner for planning a perfect weekend of education, networking, and fun. Best event planners EVER!

VERMONT

Richard Vogel

Michael participates in a card trick

The 2nd annual New England Hemophilia Association (NEHA) ***Men's Retreat*** was held May 3–5 at the Stratton Mountain Resort. The event started with a welcome dinner where we were happy to greet many familiar faces as well as new, first-time attendees. Michael Jay Garner returned as the facilitator and continued to share activities that bring us closer to family, friends, and community with everyday objects he calls "smalls." Inspired by Patch Adams, he uses his skills as a medical clown cheering up sick children.

Rich and Tommy bond over aging with hemophilia

On Saturday, we had the opportunity to participate in various programs, including rap sessions about aging with a bleeding disorder and financial presentations. In the afternoon, we had a wire art workshop as a bonding activity. Well-known wire artist Ryan Kelley taught us how to make wire tree sculptures, allowing us to showcase our hidden talents. In the evening, we enjoyed a great meal and a round of music trivia. Free time followed, during which some relaxed in the hot tub/spa while others connected over playoff sports on TV.

Sunday morning was dedicated to a session with BioMatrix's insurance guru, Terry Rice. After closing remarks from Executive Director Rich Pezzillo, we all bid our goodbyes, leaving behind Stratton Mountain but taking home lasting connections. The men's retreat is special because it is a mix of blood brothers and fathers of affected children. What makes it distinctive is that we share experiences and learn from each other. It's a real bonding experience, and we eagerly look forward to the next men's retreat. Thank you, NEHA!

DELAWARE

Tina McMullen

Wilmington's Daniel S. Frawley Stadium was the place to be May 3rd for Brandywine Valley Hemophilia Foundation's (BVHF) ***Community Event*** for an evening of baseball as the Wilmington Blue Rocks took on Hudson Valley Renegades. Before the game, Octapharma Patient Experience Manager Paul Brayshaw spoke about the company's services, products, and community support services. Paul's 12-year-old son Porter was honored to be chosen to throw out the first pitch. He did great!

Although the Blue Rocks initially fell behind 6–0, they eventually pulled ahead, hitting home run after home run and winning the game 13–8. During the game, guests enjoyed typical baseball comfort food and had the opportunity to take photos with Rocky Bluewinkle, the team mascot. Mr. Celery, another fan favorite, also made an appearance and was especially busy when the Blue Rocks began to surge ahead.

Porter shows off his first-pitch ball, with Graham

The Brandywine Valley community is tight-knit, and the event provided an opportunity for everyone to come together and enjoy America's favorite pastime. Gail Novak, BVHF President, deserves much credit for deciding to combine education and baseball. Many thanks to Octapharma, the BVHF community, and the Blue Rocks for pulling it together and making the event a winning experience for all. Finally, the fireworks display was breathtaking and provided a fitting end to an already exciting evening!

The gang's all here!
Rob, Arthur, Walter & Tara

Family fun!
Phil, Paige, Emily & Wyatt

Brothers Arthur & Walter get in on the fun!

Gail photobombs Wyatt's picture!

Of course, Tina & Gail need a Rocky photo too!

PUERTO RICO

Justin Lindhorst

BioMatrix was thrilled to participate in the Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado's first ***MOIN Conference*** at the Embassy Suites in San Juan May 3-5. The innovative program was a great success and brought together members of the bleeding disorders community from Puerto Rico and the mainland. Participants enjoyed a weekend of networking, education, and chapter community building.

Team BioMatrix: Justin Lindhorst, John Martinez, Gabriella Griffin and Hector Heer with chapter Executive Director, Anthony Llanes (center)

BioMatrix Territory Account Executives Hector Heer and Gaby Griffin, along with educator John Martinez, welcomed attendees at our booth where we provided information on our programs and services and invited community members to participate in our bleeding disorders-themed *JeoParody* game. John Martinez facilitated a competitive and spirited game of *Loteria* for the teenagers who competed for king-sized candy bars.

Teens enjoying *Loteria*!

The event ended with a fantastic final night featuring live music, dancing, and a celebration of Latin culture. The chapter did an amazing job of bringing the community together, and we look forward to future programming with the Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado!

ALABAMA

Cyndy Coors and David Tignor

Sanofi and BioMatrix hosted an ***Educational Dinner*** May 14th at Ruth's Chris Steak House in Birmingham. CoRe Manager Dennis Jones presented *Switch it Up*, which discusses Sanofi's hemophilia A treatment product ALTUVIIIO®, and the difference it can make in a hemophilia management plan. The small, intimate group enjoyed a delicious dinner too! Many thanks to Sanofi for partnering with us!

Sweet smiles from Miranda and Violet!

FLORIDA

Marcy Foerstch and Peggy Klingmann

Kathy, Malachi, Kevin and Josiah

On the evening of May 15th, BioMatrix and Bayer hosted an ***Educational Dinner*** for members of the bleeding disorder community at Whiskey Cake Kitchen in Tampa. The evening kicked off with a brief welcome and introduction, followed by a presentation from Dr. Shveta Gupta, a Pediatric Hematologist at Arnold Palmer Hospital Haley Center in Orlando, on Bayer's hemophilia A treatment, Jivi. After dinner, BioMatrix organized a fun *BBQ and Grillin' Trivia* session led by Shelby Smoak, Ph.D., Education Director, enjoyed by all!

We appreciate Bayer's ongoing support and are grateful to everyone who joined us for the evening. We look forward to the next BioMatrix program!

ILLINOIS

Eva Kraemer

Guests listen intently to the speaker

Getting together always just feels good, especially when coupled with good food and education. That's exactly what we did for an ***Educational Dinner*** May 16th at Seasons 52 in Oakbrook. BioMatrix and Genentech hosted a fantastic evening of discovery and sharing. Presented in English *and* Spanish, BioMatrix Education Specialist John Martinez was on fire as he talked about *Family Dynamics* and how each member plays a vital role in supporting the patient. We rounded out the evening by playing *Loteria* (Mexican BINGO), and let's be honest, who doesn't love BINGO? BioMatrix is delighted to offer the Illinois community unique opportunities to network and share. Many thanks to Genentech for supporting the bleeding disorders community.

NORTH CAROLINA

Austin Caldwell and Justin Lindhorst

BDFNC's Gillian Schultz with Austin Caldwell

On May 18th, BioMatrix participated in the annual ***HOPE Family Day*** hosted by the Bleeding Disorders Foundation of North Carolina (BDFNC) at Marbles Kids Museum in downtown Raleigh. The event provided families with the opportunity to connect while learning about the services offered by the chapter and other industry supporters.

During the event, Lucia Opara, MSW, LCSWA for the UNC Hemophilia and Thrombosis Center, led a helpful presentation and discussion on managing needle phobia in children, offering strategies for managing associated anxiety. While at the BioMatrix booth, we made meaningful connections with many community visitors and provided insight into our services, such as our Patient Navigation program.

Following the program, families received tickets to explore the fun and interactive hands-on exhibits in the museum. We extend our gratitude to BDFNC Executive Director Charlene Cowell and her dedicated staff for hosting this informative and enjoyable event!

TENNESSEE

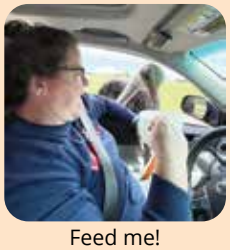
LeAnn Wilson and David Tignor

All aboard!

Members of the bleeding disorders community gathered at the Tennessee Safari Park in Alamo May 18th to experience ***A Day in the Wild***. The Tennessee Hemophilia & Bleeding Disorder Foundation and Bayer partnered with the BioMatrix team to host a unique event for the community. Everyone met at the entrance to collect goody bags and start our adventure together! Although it was drizzling, laughter and excitement buzzed throughout the group.

Oh, hello!

First on the agenda was the walk-through zoo. Being able to get up close to the animals, watch the sloths, feed the giraffes and pet the pygmy goats was amazing! Then it was time to hitch a ride on a guided safari tour bus through the park where camels, llamas, ostriches and many exotic animals freely roam. As we boarded, we were handed slices of bread to feed the animals as they approached the bus. Before we embarked on our journey, BioMatrix's Shelby Smoak gave tips on taking pictures with our phones as a part of BioMatrix's photography program, *Camera On: Healing and the Art of Photography*. With our expedition underway, our tour guide offered details and fun facts on each animal. It was very amusing to watch the kids meet the animals eye-to-eye, feed and pet them as well. Ostriches and emus and gazelles, oh my!



Feed me!

Kodi visits the goats

Camels greet Nikki

Afterward we gathered at the local Olympic Steak House for lunch. Shelby continued his photography presentation by having the kids pose their little animal figurines found in their goody bags to photograph at different angles. The kids took such pride in their photo-taking abilities! The Safari Park allowed us to reenter the park if we wanted to drive through with our own vehicles, which many took advantage of.

This amazing experience was made even better by the folks we shared the day with. Many thanks to Executive Director Amanda Wilson, her team, and Bayer for including us in this unique and special event!

PENNSYLVANIA

Shelia Biljes

BioMatrix and HEMA Biologics partnered with the Western Pennsylvania Bleeding Disorders Foundation (WPBDF) for an ***Insurance Workshop*** May 22nd presenting an enjoyable evening of education, games, and amazing food!

Team BioMatrix
Shelia, Michelle and Shelby

Gathering at Luciano's Italian Brick Oven in Mars, the evening began with a fun ice-breaker game hosted by BioMatrix, which aimed to reveal personality types based on each participant's choice of candy.

During dinner, BioMatrix Director of Advocacy and Education, Shelby Smoak, Ph.D. presented *Insurance Basics: Everything You Didn't Know You Need to Know*. This session covers various insurance challenges and discusses the appeals process. Shelby engaged the audience with an interactive discussion, answering insightful questions.

BioMatrix Territory Account Executive Michelle Stielper led a *Drawing to Heal* art class, where both adults and children learned general artistic principles and how to draw anime figures - unique human-like characters. The talent in the room was truly impressive!

Thank you to Executive Director Kara Dornish for inviting us to partner on this event and to HEMA Biologics for their support!

NEW MEXICO

Felix Jacquez Garcia

Thirty years ago when I first began organizing groups for our bleeding disorders community, I learned a very important lesson from my mentors: the goal isn't just to bring the community together, but to bring them together with purpose.

Thanks to our friends at Sanofi, we were able to do just that May 23rd with an ***Educational Dinner*** at Pappadeaux Seafood Kitchen in Albuquerque. The purpose of our gathering was to learn about new pediatric data regarding Sanofi's treatment product, ALTUVIIIO®.

Sanofi Hemophilia Peer Christopher Ingram joined us to share his experiences with having a bleeding disorder. I've known Chris since his teen years. His story includes having made bad decisions in his youth, growing more mature and realizing that he needed to take responsibility and control of his condition. He led us down his path of becoming treatment-adherent and being as "bleed-free" as he's ever been.

What's a pre-summer educational meeting without a raffle? How about two raffles to spread the joy? The prizes included an electric ice shaver ice kit and an electric ice cream-making kit. Congratulations to both families. Enjoy!

Time for Fun!

Games on page 27

8	F	I	N	F	U	S	E		
7	B	P	O	R	T				
6	H	S	Y	R	I	N	G	E	
5	C	B	L	E	E	D			
4	A	F	A	C	T	O	R		
3	G	V	E	I	N				
2	D	P	R	O	P	H	Y		
1	E	N	E	D	L	E			

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

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

Take me out to the ballgame! Nikki, Blessing, Cliff, Harmonee', Milena, and LaReina

Baseball fans, Eva and Eleanor

TENNESSEE

Cyndy Coors, LeAnn Wilson and David Tignor

Let's play ball! On May 23rd, the Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF), CSL Behring, and BioMatrix partnered to gather members of the bleeding disorders community for an ***Evening of Baseball*** at First Horizon Park, home of the Nashville Sounds. Due to bad storms, the game the night before was canceled, so we were treated to a doubleheader, allowing us to watch two 7–inning games between the Nashville Sounds and the Charlotte Knights.

Future baseball star, Matthew

At the gate, the park gave away Sounds jigsaw puzzles and our guests also received a baseball-themed goody bag provided by BioMatrix and CSL Behring. The bags were brimming with baseball-related goodies.

Rebecca, Gianna, and Richard

Mild weather made for a perfect evening of fellowship while watching the action. As the first game ended, we experienced a beautiful sunset. For some, the only distraction of the evening was the cicadas flying around due to the periodical cicada brood in middle Tennessee.

Kerry, Sadie & Chad

The Nashville Sounds won both games over the Charlotte Knights, making this event even more enjoyable! We are thankful and look forward to being part of future events and activities with THBDF and CSL Behring!

Baseball dreams

Nick and Lily

OKLAHOMA

Jeanette Jones

Cathy Tiggs presents

To celebrate the mothers in our bleeding disorders community, BioMatrix hosted an inaugural ***Mother's Celebration Tea*** with the help of our friends at Novo Nordisk. Family members gathered at a lovely and unique French bistro and bakery in Norman May 25th for an afternoon luncheon where they enjoyed yummy sandwiches, delicious desserts, and of course, lots of tea.

Surrounded by flowers and friends, families learned about how females are affected by bleeding disorders and what the community can do to support them in impactful ways. A special thanks goes to our engaging speaker and social worker, Cathy Tiggs. Time was also taken to name motherly figures who are dearly missed by attendees. Additionally, children who attended (young and old) spent time crafting special gifts, picture frames and flowerpots for their mothers to take home and enjoy.

While crafting continued, families connected through supportive conversation. Topics were focused on balancing caregiving and personal needs, the ways in which attendees appreciated their mothers, and celebrating success stories advocating for testing and better care.

Our time concluded with lots of hugs, hands full of goodies to take home and fond memories.

NORTH CAROLINA

Austin Caldwell

Austin and Zack

On May 29th, BioMatrix partnered with Bayer for an ***Educational Dinner*** taking place at Maggiano's Little Italy in Durham where the family-style menu matched the family-like atmosphere of the attendees. Conversation flowed as easily as the marinara sauce!

Two programs were on the agenda. First, Bayer Product Advocate Zach Castillo shared details of his journey with a bleeding disorder and how he overcame obstacles to create a successful and fruitful life for himself. BioMatrix's Director of Advocacy and Education Shelby Smoak, Ph.D, offered a very interesting *Hillbeat on the Road* presentation. His informal talk focused on the landscape of insurance, co-pay accumulators, and barriers to care. He especially messaged about the rise of *Alternative Funding Programs* (AFPs) like SaveOnSP and PrudentRx, and advised about ways to continue accessing medications in these disruptions. Both presentations evoked interaction and questions from the group.

Stay tuned for more programs with Bayer in the states of North Carolina, South Carolina and Georgia soon!

TENNESSEE

David Tignor and LeAnn Wilson

Amanda and Holly

Zoe and Wayne

LeAnn and Haylee

A good word to sum up this year's Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) ***Annual Meeting*** would be Groovy! Held at the Westin Chattanooga May 31–June 2, the theme was Battle of the Decades, highlighting the 1950s through the 2000s. Attendees wore colors that identified the decade they were born, and their name tags featured the same colors. The BioMatrix booth embraced the theme with disco ball balloons and giveaways including mood rings, tie-dye cool cloths, slap bands, flower headbands, 60s-style sunglasses, and provided a 'Decades' gift basket containing items from the decades.

Industry partners sponsored several breakout sessions on Saturday including a BioMatrix-sponsored Financing with a Chronic Illness presented by Director, National Bleeding Disorder Sales Terry Rice. While adults attended breakout sessions, youth had their own fun to tend to: children aged 5–12 visited the Tennessee Aquarium, 13–17-year-olds went on a rock-climbing excursion at Highpoint Climbing, and young adults aged 18–26 participated in a team-building activity at a thrilling escape room. Awards were presented and raffle prizes were drawn Saturday evening followed by a *Chattanooga Selfie Scavenger Hunt* that followed. A lively jam session performed by some attendees who brought their musical instruments along concluded the evening.

The meeting provided an opportunity for community members to connect, attend educational sessions, and have fun! Thanks to THBDF for organizing a stimulating and enjoyable event for the community!

FLORIDA

Hector Heer, Marcy Foerstch and Justin Lindhorst

Hector, Marcy and Justin staff the BioMatrix booth

BioMatrix was delighted to take part in the Bleeding Disorders Foundation of Florida ***Annual Family Program*** at SeaWorld Orlando June 1st. The meeting was well-attended with over 500 community members from across the state. We are grateful to everyone who visited the BioMatrix booth to learn about our pharmacy and the services we offer. We gave away stylish BioMatrix ball caps, which were appreciated on the hot summer day. Breakfast and a light snack were provided, and after an engaging presentation, attendees were free to enjoy the rest of the day at the park. We are excited about future events and are committed to continuing our support for the Foundation's great work!

OKLAHOMA

Jeanette Jones

Michael, Jeanette and Sharon

Leisa and Jayden

Isabella, Elijah and John

Who doesn't love a meal shared in the presence of your bleeding disorders community? It was such a treat to get out for an ***Educational Dinner*** and meet with an intimate group of committed community members while all around the nation, other groups were doing the same. Led by a national broadcast hosted by Sanofi on June 12th, local community hubs in most states united to connect and gain education together.

In Oklahoma, we gathered early at a local eatery in the famous Paseo Arts District to catch up with friends and make new friends. Just as dinner was served, the broadcast began and we all learned more about one of the latest medications to make waves in the bleeding disorders community. The session was presented by Dr. Erin M. Cockrell, a Florida hematologist, and included a personal story from a fellow bleeding disorders community member, Ashley Hall. Their collective expertise and real-life experience were greatly appreciated. Through this hybrid opportunity, attendees were able to interact with the national community by digitally asking questions.

Everyone stayed after the broadcast to continue talking and enjoy each other's company, and of course, to eat dessert. We bid farewell until we meet again!

PENNSYLVANIA

Tina McMullen

Tommy and Vickie

The Eastern Pennsylvania Bleeding Disorders Foundation (EPBDF) held its ***Annual Meeting*** June 12th at the Sheraton Valley Forge Hotel. Before the meeting, the attendees had the chance to meet with specialty pharmacy and manufacturer reps, and other community members in the large exhibit area.

The program began with Marisa Ferger, EPBDF Board Vice President, welcoming the group and honoring Joey Smiles, a community member and recently appointed board member who recently passed away unexpectedly. Executive Director Sarah Pilacik and Assistant Director Lisa Lee highlighted recent scholarship recipients and provided updates on recent and upcoming chapter events.

Keynote speaker Dr. M. Elaine Eyster MD, FACP, who has a long history working in hemophilia, spoke about the advancements in treatments over the years in a presentation titled *Our Journey Together: Where We've Been and Where We're Headed*. The evening ended with closing remarks from Board President Leonard Azzarano.

Congrats to EPBDF for hosting another awesome event!

Upcoming Events

AUG 11, 2024 MARYLAND
HACA Chapter Picnic
Host: Hemophilia Assocociation of the Capital Area
703-352-7641, https://hacacares.org/
Watkins Regional Park; Upper Marlboro

AUG 12, 2024 OHIO
Ladies Lunch - Fireside Chat
Hosts: Genentec and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Farmstead Restaurant; Millersburg

AUG 20, 2024 NEVADA
Educational Dinner
Hosts: Octapharma and BioMatrix
RSVP: John Martinez, 559-593-2306
john.martinez@biomatrixsprx.com
Roundtable Pizza; Reno

AUG 21, 2024 ARIZONA
Educational Dinner
Host: Arizona Hemophilia Foundation
Sponsors: Sanofi and BioMatrix
RSVP: azbloodalliance@gmail.com
602-955-3947, www.azbloodalliance.org
Flemming's Prime Steakhouse; Peoria

AUG 22, 2024 NORTH CAROLINA
Educational Dinner
Host: Bleeding Disorders Foundation of South Carolina
Sponsors: Octapharma and BioMatrix
RSVP: Charlene Cowell, 919-319-0014
https://bleedingdisordersnc.org/
BRIO Italian Grill; Raleigh

AUG 24, 2024 NEVADA
Educational Dinner
Hosts: CSL Behring and BioMatrix
RSVP: John Martinez, 559-593-2306
john.martinez@biomatrixsprx.com
Dave and Busters; Sumerlin

SEPT 6–8, 2024 CALIFORNIA
Familia de Sangre
The Largest Spanish-Speaking Bleeding Disorders Conference in the US!
Hosts: Hemophilia Foundations of Northern, Southern and Central California, and Hemophilia Association of San Diego County, 714-750-8000
To Register: www.familiadesangre.org
Anaheim Marriott: Anaheim

SEPT 7, 2024 FLORIDA
Family Fishing Day–Youth Fishing Derby
Host: Country Boy Fishing
Sponsors: Bayer and BioMatrix
RSVP: Marcy Foertsch, 941-518-7063
marcy.foertsch@biomatrixsprx.com
Hillsboro River State Park; Thonotosassa

SEPT 7, 2024 TENNESSEE
18th Annual Pitchin' for Caleb
Host: Tennessee Hemophilia & Bleeding Disorders Foundation
RSVP: Amanda Wilson, 615-900-1486
www.thbdf.org
Centennial Park; Crossville

NATIONAL EVENT! SEPT 12–14, 2024 GEORGIA
76th Bleeding Disorders Conference
National Bleeding Disorders Foundation
212-328-3700 x728
bdc@hemophilia.org
Georgia World Congress Center; Atlanta

SEPT 20–22, 2024 VIRGINIA
HACA's Women's Retreat
Host: Hemophilia Assoc. of the Capital Area
RSVP: 703-352-7641, hacacares.org
Meadowkirk at Delta Farms; Middleburg

SEPT 27–29, 2024 VIRGINIA
Medical Symposium
Host: Virginia Hemophilia Foundation
RSVP: 804-740-8643, vahemophilia.org
Great Wolf Lodge; Williamsburg

OCT 10, 2024 DELAWARE
Educational Dinner
Host: Brandywine Valley Hemophilia Foundation
Sponsors: Bayer and BioMatrix
RSVP: Gail Novak, 302-598-4632
gvannicola@verizon.net
www.brandywinehemophilia.org
Columbus Inn; Wilmington

OCT 19, 2024 VIRGINIA
Fall Festival and Walk
Host: Hemophilia Assocociation of the Capital Area
RSVP: 703-352-7641, hacacares.org
Lake Accotink Park; Springfield

OCT 24, 2024 OHIO
Educational Dinner
Hosts: Takeda and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Bravo Restaurant; Lennox

OCT 25, 2024 OHIO
Educational Dinner
Hosts: Takeda and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Tony K's Restaurant; Berea

NOV 1–3, 2024 VIRGINIA
Adult Retreat
Host: Virginia Hemophilia Foundation
RSVP: 804-740-8643, vahemophilia.org
Hyatt House Richmond; Henrico

NOV 2, 2024 WASHINGTON DC
Educational Event for Spanish-Speaking Community Members
Host: Hemophilia Assocociation of the Capital Area
RSVP: 703-352-7641, hacacares.org
Hilton; Fairfax

NOV 8-10, 2024 MASSACHUSETTS
Fallfest
Host: Newark England Hemophilia Association
RSVP: 781-326-7645
info@newenglandhemophilia.org
Monarch Place Hotel; Springfield

NOV 22, 2024 OHIO
Family Thanksgiving Dinner
Hosts: Novo Nordisk and BioMatrix
RSVP: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com
Brew Garden; Strongsville

Hi Kids! Time for Fun!

In Column 1, there are hidden words that have something to do with bleeding disorders. To get the answers, match the rows in Column 1 with the correct Window Box in Column 2. The first one has been done for you. Then, try solving the SuDoku puzzles!

The solutions to these games can be found on page 23.

	Column 1		Column 2	
1	B L K S U E E H F D	E	A	
2	F W A D V C T O R E	___	B	
3	P X O S R T T O G S	___	C	
4	D N E B N E D X L E	___	D	
5	M V R E L I P N A Y	___	E	B L E E D
6	Q I N K F U J W S E	___	F	
7	B P R N F O P H B Y	___	G	
8	S Y R V I N K L G E	___	H	

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

Sudoku!

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

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

[BIOMATRIX]
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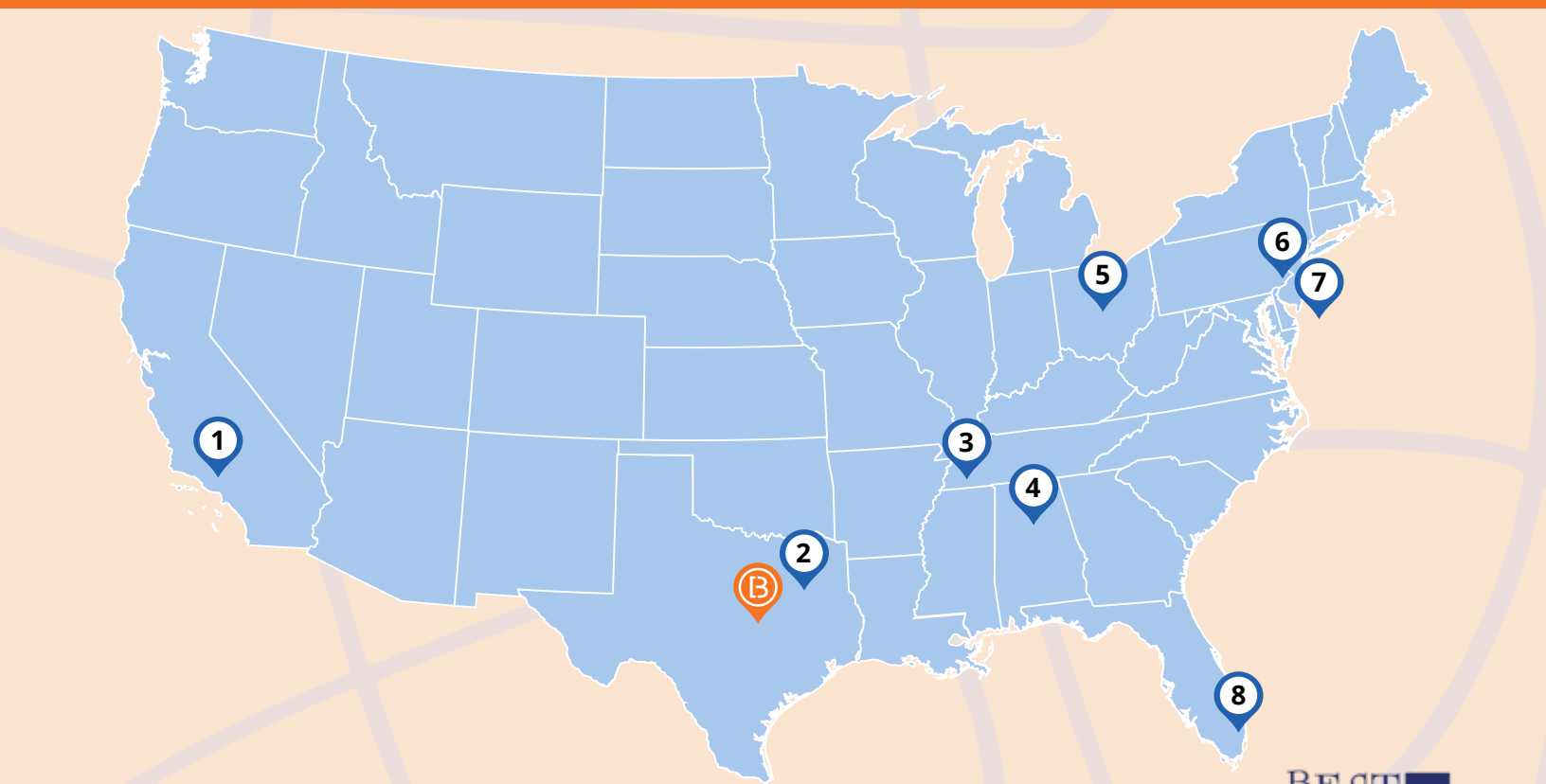

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