

BIOMATRIX

NEWS



**DEDICATED
TO MAKING
A DIFFERENCE**

**WINTER 2022
VOLUME 17 | ISSUE 1**

“ Hope smiles from the threshold of the year to come, whispering 'it will be happier.' — Alfred Tennyson ”

ABOUT BIOMATRIX

BioMatrix Specialty Pharmacy is removing burden, improving health, and making life easier for patients with chronic, difficult to treat conditions.

BioMatrix offers accredited, comprehensive specialty pharmacy and support services for a range of chronic health conditions. Our clinicians and support staff offer a tailored approach to every therapeutic category, improving

quality of life for patients and producing positive outcomes along the healthcare continuum.

Our services include the clinical monitoring, tracking, and management tools required by today's healthcare stakeholders while providing individualized patient support leading to better health outcomes.

MISSION + VISION

The **MISSION** of BioMatrix is to improve outcomes through individualized specialty pharmacy services empowering patients to live each day to its fullest potential.

Our **Mission** and **Vision** are realized through the value we place in our five guiding principles. These principles represent our commitment to our employees, patients, and the community – driving our organization to excellence.

INTEGRITY – Our professionalism, strength, and stability come from our resolve to operate honestly, morally, and with a higher purpose to meet and exceed the expectations of all.

DEDICATION – Our dedication is evident in our close attention to detail, personal touch, and resolve to advocate from the heart, giving each relationship a close family feel.

Our **VISION** is to set the standard for exceptional care, maximizing the health and satisfaction for each patient served.

COMPASSION – We are sensitive to each individual's unique situation. Our ability to listen, empathize, and support those we work with distinguishes our business practice.

ENRICHMENT – We understand that in order to perform at our best, we must always seek to learn and grow while using our knowledge to assist and empower others.

ENTHUSIASM – Our confidence in the services we provide is illustrated by the energy, drive, and passion we exhibit in all we do.

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter

Editors: Susan Moore and Justin Lindhorst

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

Health-related topics found in BIOMATRIX NEWS are for informational use only and are not intended to take the place of treatment or medical advice provided by healthcare professionals or hemophilia treatment centers. Please consult with healthcare professionals when medical questions arise.

In Remembrance



Val Bias

We are saddened to hear of the passing of Val Bias, community member and former CEO of the National Hemophilia Foundation. He passed away unexpectedly Thursday, Dec. 30, 2021.

Val served as NHF's CEO for nearly 12 years from 2008 to 2019. Before becoming CEO, Val enjoyed a long history with NHF, dedicating his career to the hemophilia community serving as chairman of the NHF Board of Directors, as an executive director, healthcare advocate, lobbyist and consultant in several volunteer positions.

Our sincere condolences to his wife, Robin, his son Langston, his family and loved ones, and to everyone whose lives he touched.

To read more about Val's legacy, visit:
<https://www.hemophilia.org/news>.

Condolences and communications may be sent to
communications@hemophilia.org

A NOTE FROM THE EDITOR

Dear Readers:

Happy New Year and welcome to the 17th year of *BioMatrix News*! We are pleased to continue our tradition of providing readers with informative and educational articles. We especially like sharing personal success stories from within the bleeding disorders community.

In this issue we introduce to you our 2021 BioMatrix Scholarship Award recipients! These young people in our community are truly inspirational. Even with the difficulties and uncertainty of the past year, these outstanding students continued moving forward in their quest to achieve their educational dreams. We proudly congratulate you!

Last fall, our team of Regional Care Coordinators were busy encouraging folks in the community to participate in our *Living A Spectacular Life 2022* calendar. This is the

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calendar I use at my desk all year long and each time I make a note or set an appointment, I pause on the photos of that month and smile.

Despite the challenges we so often face, the photos remind me how resilient and joyful we are as a community. In those faces, I see joy, pride, humor, strength, surprise, peace, beauty, wonder and love.

In addition to the work I do producing this quarterly publication, I can tell you that collecting and constructing the calendar is a favorite part of my job. A huge thank you to all community members who diligently sent in their photos. If you'd like a free calendar, please refer to page 26 to see how to order one.

Wishing you an awesome year!

Maria Santucci Vetter
Editor-in-Chief, *BioMatrix News*
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BIOMATRIX PROUDLY ANNOUNCES THE 2021 MEMORIAL SCHOLARSHIP RECIPIENTS!

Each year, BioMatrix provides six \$1,000 scholarships for bleeding disorders community members seeking higher education. Since 2013, our scholarships have honored the memory of several individuals who impacted the bleeding disorders community in unique ways. BioMatrix partners with the Hemophilia Federation of America for administrative support and independent, third-party evaluation of applicants.

It is with great pleasure we announce the 2021 recipients of our Memorial Scholarship Program. Thank you to everyone who applied — we wish you great success in your bright future! Without further ado, we introduce you to our scholarship recipients!



LUKE CASTALDO

Junior at Moody Bible Institute: Music-Worship and Media Arts
BioMatrix Ron Niederman Memorial Scholarship

At an early age Luke learned that having hemophilia can present a host of obstacles, such as the pain that comes with bleeding episodes, infusing, and being teased by other kids. Luke accepted these challenges and grew resilient. His life lessons taught him to communicate about his bleeding disorder and advocate for himself, to be creatively adaptable, and to appreciate the sacrifices of his mentors in the community. “These obstacles, hard as they were, prepared me for life, which has been influenced by hemophilia in three major ways: resilience, leadership, and hope for the future.” Congratulations, Luke!



JARETT GUILLOW

Doctoral Degree at University of California Riverside School of Medicine
BioMatrix Joe Holibaugh Memorial Scholarship

Jarett embraces his hemophilia wholeheartedly – looking past the negative and strictly focusing on the positive influences of his bleeding disorder. He has a deep appreciation for the community friendships he’s made, the lessons he’s learned and the experiences he’s had that have all influenced his life goals. “I aspire to be a pediatric hematologist because of my experiences with hemophilia. From being my guiding force towards studying to being physically active and to finally being accepted into medical school, hemophilia has made a beneficial impact on my life.” Congratulations, Jarett!



LUKE LUCKEY

Junior at University of Michigan-Ann Arbor: Biopsychology, Cognition, and Neuroscience
BioMatrix Mark Coats Memorial Scholarship

Circumstances were not easy early in Luke’s life when he was diagnosed with severe hemophilia. Born in China, he was placed for adoption and spent 9 years at an orphanage experiencing severe pain and subpar medical treatment. Adopted at age 10 and coming to the US, life became much better as did his health. “Hemophilia has greatly influenced my life in various ways. I’ve developed empathy, compassion, and care for others. I am also optimistic for the future, as I believe that I am capable of achieving anything if I work very hard. Having hemophilia gives me a sense of purpose to do good things in the world.” Congratulations, Luke!



STEVEN SCLAFANI

Sophomore at Utica College: Physical Therapy
BioMatrix Tim Kennedy Memorial Scholarship

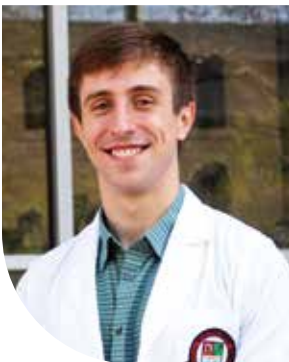
Steven makes no bones about the challenges of living with severe hemophilia; however, he has a confidence that does not allow him to be defined or limited by its so-called "disadvantage." He's a fighter and has a healthy sense of humbleness! "Living with a bleeding disorder doesn't make me special. I have never wanted to be looked at as the kid who will die from a papercut or the kid who has to walk around with bubble wrap on. Everybody has their struggles. Luckily, mine pushed me to be successful in life. So, in a weird way, I am very thankful for hemophilia." Congratulations, Steven!



Laikyn Dae Tyson

Freshman at North Carolina State: Criminology
BioMatrix Millie Gonzalez Memorial Scholarship

Born into an energetic family, Laikyn was just as physically active and athletic as her brothers. However, her diagnosis of hemophilia and anemia had her parents, doctors and even her friends worrying over her and encouraging her to be more careful. Laikyn initially pushed back and rebelled against the notion of having to be more cautious. However, after a significant health scare, she came to understand the importance, "I realized I did need to be more careful. I could not ignore my disease any longer. I came to the conclusion that just because I have to "be careful" does not mean I have to give up my life." Congratulations, Laikyn!



TIMOTHY WOHL

Clinical Doctorate at Ohio State University: Physical Therapy
BioMatrix Mike Hylton Memorial Scholarship

When Timothy was diagnosed with von Willebrand disease at age 5, fearing an injury, his parents were protective and limited his physical activities. This caused him to be fearful of participating in typical childhood activities such as playtime and recess at school. Through years of interacting with doctors and physical therapists, Timothy gained an understanding of his bleeding disorder and became a competitive swimmer in high school and college. This inspired him to become a physical therapist, "My long-term career goal is to work with children who face barriers to exercise like I did, so I can help them regain a sense of autonomy in their lives." Congratulations, Timothy!

The 2022-2023 school-year application will open in March 2022 and be accepted through August 1, 2022.
Beginning March 2022, apply online: scholarship@biomatrixsprx.com



Joe Holibaugh (1971-2006)
\$1000 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor



Ron Niederman (1950-1999)
\$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members



Tim Kennedy (1962-2011)
\$1000 Scholarship
For MEN with hemophilia



Mike Hylton (1945-1998)
\$1000 Scholarship
For MEN with hemophilia or VWD and their immediate family members



Millie Gonzalez (1953-2001)
\$1000 Scholarship
For WOMEN with hemophilia or von Willebrand Disease



Mark Coats (1956-1963)
\$1000 Scholarship
For MEN and WOMEN with hemophilia



MENTAL HEALTH *Transparency*

BY KELLY GONZALEZ, EDUCATION SPECIALIST

People don't "fake" depression – they fake being okay.

As an educational speaker in the bleeding disorders community, anyone who has heard me present knows my family has had more than its fair share of health crises and stressful situations. It's not surprising I have suffered and occasionally still suffer from bouts of *situational depression*. It took many years of enduring anxiety and internal struggles to discover what I experienced is a normal, often expected, response to high levels of stress.

After years of fighting to pretend I was okay in situations where no typical person should expect to be okay, I learned that mental health transparency was a myth. Although it's getting better, there are not very many places or resources where people can openly speak about mental health without fear of being labeled or ignored. This revelation happened after what I refer to as my "Breakdown of 2016."

That year several traumatic incidences took place and accumulated, causing me to experience what I believe was a breakdown. The series of taxing situations left me feeling shaken and psychologically out of sorts. Fortunately, a very compassionate friend and Hemophilia Treatment Center Nevada provider, Amber Federizo, sat me down and did not allow me to brush things aside. She explained she thought I had *Situational Depression* or

Post Traumatic Stress Disorder (PTSD) and encouraged me to see a mental health professional. She validated to me that the emotional highs and lows, along with the anxiety and frustration, was totally normal for anyone who had been through what I had, and who faced the same issues. She let me know I had NOTHING of which to be ashamed. Amber immediately called in a referral for me to see a professional mental health provider.

Especially with overlapping medical conditions, a health crisis can cause a person to feel much more stressed and intensely worn out. I was suffering from a significant bout of what my doctor confirmed as *Situational Depression*, also referred to as *Adjustment Disorder*.

**If you are not okay, speak up;
do not feel embarrassed or
too unimportant to seek help.**

Situational Depression happens when a person feels a more exaggerated emotional response within a few months of a particularly stressful situation. As an example, many people in the bleeding disorder community have related to me they have felt especially down or despondent following the diagnosis of a bleeding disorder in their baby, an especially difficult or traumatic bleeding episode, or of learning of a health deterioration or additional condition.

The symptoms are similar to standard depression but are specifically related to a stressful incident or cause of

stress. As I did more research, I realized this was exactly what I was going through.

The following from www.verywellmind.com provides a list of situational depression symptoms:

- Feelings of low mood and sadness
- Frequent bouts of crying
- Hopelessness
- Poor concentration
- Lack of motivation
- Loss of pleasure
- Withdrawing from normal activities
- Loneliness or social isolation
- Thoughts of suicide

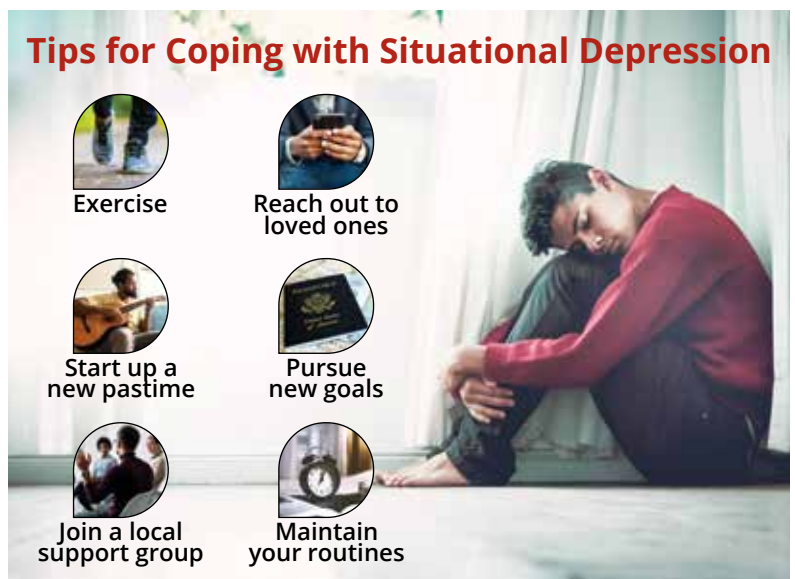
Situational depression affects men and women equally and will last until either what is causing the stress no longer exists, or you've learned to adjust to it, typically about 6 months.

Unfortunately it is not something many people know about or discuss openly. They may find themselves struggling to identify their emotional response or might be embarrassed or worried about the stigma attached to their feelings.

In the year 2022, I am surprised people still feel embarrassed when experiencing bouts of depression. People we know, care about, and see daily may be suffering, but they put on a brave face and keep it to themselves. How many of those closest to us have turned to us for guidance, support, or acceptance? Whether it can be contributed to social, cultural, or individual family values, many are convinced that it is not okay to show you're struggling. We have convinced ourselves that opening up and conversing about negative emotions or depression is taboo and should be kept to ourselves.

There are not many things I can say with total and complete confidence, but I will say this - depression is NOT a dirty word. You are NOT alone. It is okay to not be okay, but it is not okay to stay silent (for long).

To those who think mental health struggles are something to be ashamed of, YOU ARE WRONG. Taking charge of your mental health by speaking up, pursuing healthy outlets, seeking professional help, or even medical intervention



is beyond brave – it's a strong step toward remedying the emotional challenges one may face.

If you are intimidated by the judgment of others for seeking mental health help, please know, undoubtedly, those people are wrong. You are strong enough to confront your mental health challenge and intelligent enough to find reinforcements and get help.

This conversation NEEDS to happen. So, let's have it – mental health transparency. If you are not okay, speak up; do not feel embarrassed or too unimportant to seek help. Honor yourself for bravely facing the scary. Be pleased with yourself for setting an example of self-love and mental health awareness. Be proud of yourself because you are courageous!

Wishing you much love and light!

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ABOUT THE AUTHOR:

Kelly Lynn Gonzalez, BioMatrix Senior Education Specialist and Regional Care Coordinator

Kelly is a patient, parent of patients and spouse in the rare disease community. Having personal experience with bleeding disorders, autoimmune disease, primary immunodeficiency disease, epilepsy and cancer, Kelly's extensive experience is colored by three decades of managing chronic health conditions. She draws on both her personal journey and professional expertise to educate, inspire, and empower those she serves. She channels a sincere passion for helping others facing chronic illness with previous experience as a teacher to lead and serve the bleeding disorders community. Kelly holds an MBA and MA in Education.



PEER-BASED SUPPORT: WHAT WE DO AND WHY WE DO IT

BY SHELBY SMOAK, Ph.D.



2018 data suggests most U.S. physicians spend 12-28 minutes with patients with 1 in 4 spending less than 12 minutes.ⁱ In many cases these few minutes will be the only direct physician contact with that patient for the year. Patients and doctors agree that too often, more time with patients is wanted by both parties. One survey noted that only 14% of physicians felt their visits with patients “offered all the time needed to provide the highest standards of care.”ⁱⁱ

Peer support can help fill this gap, reinforcing physician recommendations while providing ongoing support around education, access to care, adherence, psychosocial challenges, and assistance with general daily maintenance. This type of support can be especially beneficial for patients with bleeding disorders.

As an editorial in *The Annals of Family Medicine* states, “Social support is a powerful force in human behavior and health,”ⁱⁱⁱ and indeed, substantial research documents the advantages of peer support in promoting positive patient outcomes. Peer support programs leverage peers as resources to motivate constructive health behaviors and provide necessary patient education.

Peer support can offer meaningful contact and provide the needed lift to promote positive patient health outcomes.

What is Peer Support?

The simplest understanding of peer support in healthcare is when peers – “people sharing similar experiences or backgrounds” – become “great sources of support for one another” in navigating a chronic illness.^{iv} For people living with a chronic illness, peer support links them with persons who have knowledge and experience that others, including many professionals, do not.

What are the goals of a peer support program?

To put a fine point on it, the goal of a peer support program is to provide a more positive patient health outcome. These outcomes are gained by interventions that rely upon community peers rather than trained professionals to address the daily challenges of a chronic illness.

Who are peer supporters?

Peer supporters are typically one of two types: (1) a person who has knowledge of the condition from their own experiences, or (2) a person who is trained to be empathic and understanding of a particular condition. Their role is to extend the work of healthcare professionals by providing practical, educational, social, and emotional support. They can help with many simple healthcare services (paperwork, medication ordering) and participate in community events as advocates for themselves (if applicable) and their patients. Their role enhances other healthcare professionals’ jobs, but yet remains distinct from the healthcare provided by others within the field.

How does peer support assist in daily patient maintenance?

Care for a chronic illness does not end with the physician. That is simply where it begins. Set upon the path of chronic illness and given diagnosis and treatment protocols, a patient must navigate the disruptions and adaptations now forced upon them. These are many and are as diverging trails extending out from the crossroads of their illness.

Chief among these adaptations is perhaps medication adherence, the thing that, not solely, but may most promote disease management and a positive health outcome. Adherence promotes a more proactive behavior and indicates the patient buying into their care and disease maintenance. It is a lifestyle change, and one that peer support can motivate. One study with HIV patients found improvements in adherence to medication when peer supporters who were also HIV-positive and who had high levels of adherence were utilized.^v Another study which polled several peer supported antiretroviral (ART) therapy trials concluded, “Peer support plus telephone [intervention] was superior in improving adherence than standard of care.”^{vi} Peer support from those taking ART therapy immediately evidences to new patients an ability to live with HIV and, furthermore, encourages an investment into the daily medication adherence necessary for survival.



How does peer support help with social and emotional support?

The emotions a chronic illness like a bleeding disorder can trigger are varied and complex and range from anger to fear to exhaustion to guilt. Depression alone is estimated to impact almost one-third of persons with a serious medical condition.^{vii} A study isolated to members of the bleeding disorders community noted that 37% of men surveyed about their hemophilia reported experiencing depression.^{viii}

These feelings can fluctuate over the course of the illness and are usually beyond the capabilities of any single doctor's office not versed in training patients on how to cope with their illness. In fact, an article in *Social Science & Medicine* studying chronic illness and mental health notes, "Data highlighted the significance of the physician's emotional support as the most sought for yet least attainable resource in alleviating distress"^{ix} Here, peer support has proven itself a great asset.

Since emotional support is difficult to encourage, peer support often begins in answering questions and providing information, but gradually evolves into more meaningful emotional support once trust is built over time.^x In studying the advantages of peer support for mental health, one trial that employed peer supporters for 12 months in primary care facilities demonstrated a 30% decrease in the prevalence of common mental disorders and, more

strikingly, a 36% decrease in suicide attempts.^{xi}

Clearly, peer engagement with patients resulted in a measurable and very positive outcome. However, the ability to reach emotionally struggling patients can be difficult, but as one study uncovered, emotional support can be effectively delivered implicitly via conversation and activities, concluding that explicit and implicit emotional support are varied dimensions of the same thing and are facilitated by the trust developed through extended peer support engagement.^{xii} A key goal of peer support is, indeed, to build relationships through trust and not necessarily expertise.^{xiii}

Peer support can offer meaningful contact and provide the needed lift to promote positive patient health outcomes.

The bleeding disorders community illustrates these multi-faceted degrees of peer support. The integration of persons with bleeding disorders supporting other persons with bleeding disorders is well known in the community. Community members serve as local bleeding disorder chapter directors and are in leadership roles at national organizations like National Hemophilia Foundation, Hemophilia Federation of America, and The Coalition for Hemophilia B.

Additionally, persons with bleeding disorders serve as peer supporters within the specialty pharmacy and drug manufacturing spaces. These persons guide families through the nuances of managing the expensive and demanding disease, and, for many families, their peer support person becomes the touchstone for the varied supports of medicine, healthy behaviors, and emotional stability.

How does peer support provide ongoing support?

Another key marker of a successful peer support program is its ability to provide ongoing, extended support. Peer support programs must remember that bleeding disorders are forever, and reinforcing the care of persons with a bleeding disorder over a lifetime should be the goal.

Much of this is evident in the copious programming provided to the bleeding disorders community through national organizations, local chapters, and industry-sponsored events. The tangible benefits of this are noted when looking at a study conducted with diabetes patients. To address the need for ongoing support, healthcare providers in China in conjunction with the Chinese Diabetes Society developed over thirty community-centered education and outreach programs, much like those within our own bleeding disorders community. In one instance, retired persons with diabetes led peer support groups that emphasized the obstacles to daily self-management, and they formed common interest groups that joined for walking and shopping. Compared to



controls, this one group saw significant benefits in BMI reduction, blood pressure, and blood glucose counts.^{xiv}

What are the economic benefits of peer support?

Studies and research provide ample evidence of the success peer support programs can have on patient adherence, daily maintenance, emotional support, and outreach. Patients and their positive health outcomes are testaments to this approach. But moreover, investigation into the economic advantages of peer support indicates strong gains when comparing peer support programs against control, non-peer supported care.

One study set out to directly measure the return on investment for peer-based support. The study followed almost 600 underserved men, all of whom required uncompensated care. Following their use of primary, specialty, and urgent care services for 9 months before and after peer support, the study concluded that peer support workers prevented \$14,224/mo. in care, or \$95,941/yr. Given that the program cost was \$6229/mo., the study estimated ROI (Return on Investment) at 2.28:1, not an insignificant amount.^{xv}

Another cost-analysis study forecasted quality adjusted life year (QALY) and estimated that, within the Latino diabetic population of their study, peer support interventions gained \$10,995-\$33,319 in savings each year when compared with usual care.^{xvi} A more myopically focused look at cost-effective analysis noted an almost \$300 drop in medication needs (\$1542/mo. vs the average \$1821) for peer-supported diabetes interventions.^{xvii} This metric alone indicates an immediate financial advantage of peer support to the patient who would see their out-of-pocket costs drop as well.

While these numbers alone show economic advantages to providers, the healthcare system and the patient—numbers are not patients, but when positive outcomes exist on both sides of the equation – patients with better healthcare outcomes and a healthcare system with a reduced burden – it's a win for everyone.

Conclusion

For persons with a chronic illness like a bleeding disorder, adherence to care plans is required for an optimum outcome, and peer support leans into actualizing external factors that facilitate better care plan adherence. Peer support offers a holistic, wrap-around care model that provides assistance for a variety of needs: care access information, insurance coverage education, resources for financial issues and emotional distress, coping strategies and so on.

Dating back to a study in the 1950s which showed that “contact comfort” is vital for health and extending into the growing Peers for Progress research^{xviii} – peer support programs have come a long way, but they still have much room to grow.



Peer support is a practical solution for the best possible outcomes, and nothing else is equally substitutable for peer-to-peer communication and support. Therefore, it should become a critical part of proper chronic illness care, including bleeding disorders. By engaging peer support for their patients, centers of excellence that manage chronic illness, including specialty pharmacies and other industry partners, can be part of the solution.

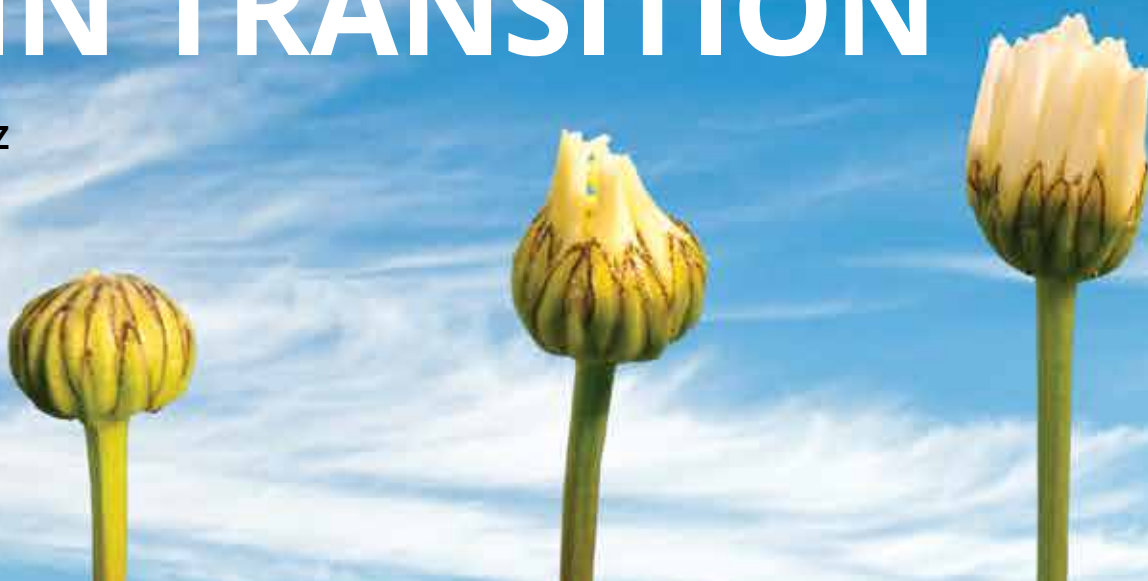
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LIFE IN TRANSITION

BY JACEY GONZALEZ



Transition for some comes easy. Pivoting and taking another path is something they can execute with little to no thought. I am not that person.

Due to various medical conditions that included a cancer diagnosis at young age as well as a bleeding disorder, I was kept somewhat isolated from the rest of the world. My life was kept in a bubble and usually my mother intervened before anything got into our bubble. Stability was key in keeping a sick child as healthy as possible. This is true for many children affected by a bleeding disorder, especially those with an inhibitor or children diagnosed in families with no history of bleeding disorders. Parents are often naturally inclined to protect their child from experiencing bleeding episodes, damaged joints, extra infusions and trips to the emergency room. Not intentional, but parents of kids with bleeding disorders sometimes hold their kids back and hinder them from being able to easily transition to adulthood. They tend to want to do for their child be it due to fear, feelings of guilt, or the need to be in control.

When I started kindergarten, I thought I would be brave, make friends easily, and breeze through school because I was already “advanced” for my age. On the very first day of class, I hopped out of the car in front of school — I didn’t want my mom causing an emotional scene. I walked by myself to the playground where the other kindergartners were gathering; however, as I approached, I started crying silently, wishing I had a hand to hold. Nothing had prepped me in my 5 years of isolation to be able to face new kids and make friends.

If you think I grew out of it by now as an adult, you’re wrong.

Every first day of school has started with tears. Even

in college when I thought I was ready to explore a new place and new experiences with new people, I drove to my mom’s hotel at 5 am the day she was leaving and sat against her door crying until she opened it. No matter what change in life came my way, I resisted – even when I knew it was for the better.

During 2020, I felt unhappy and anxious. The pandemic had just hit the United States; like many others, I was in a constant state of fluctuation and felt like I couldn’t catch my breath. The immediate mask mandates, adjusting to working alone from home, being isolated from family and friends, and the constant fear I was going to inadvertently do something that would affect my health made me lose all sense of stability. The changes beyond my control were making me feel like I needed to rewrite my dreams and aspirations on a weekly basis.

Finally, to keep from totally crumbling, I leaned into the changes being experienced. Step one was to leave a very negative work environment that had crushed my spirit in my 14 months of employment, with the goal to find a position where I would feel pride working for the organization and feel satisfaction in my role and contributions. I found an incredible opportunity 2700 miles away in Boston, Massachusetts and somehow convinced them to hire me.

The next step was harder. I owned my home in Nevada, which now had to be sold before I would be able to move across the country. My house meant the world to me. It was mine, my pride and joy, that made me feel safe and comforted. But in order to grow, it meant I had to take chances and let go of things – good and bad – that may have been making me feel safe but were getting in the way of moving forward with my life. I’m sure you’ve heard the old adage, “diamonds are made under pressure” and immense pressure is exactly what I was feeling.



To grow, I had to part with “home.” The place that held my secrets, that helped me battle my health conditions, my parents and much younger siblings, loud laughs with close friends, and enough memories to fill a multitude of photo albums. As someone who is a culmination of all her memories, this was a struggle for me, but I needed to keep moving forward.

With a brave face, I sold my home and didn’t shed a tear. I turned in my two weeks’ notice at my job with a sincere smile. I said goodbye to my parents and to my brothers and sister who I knew would be growing up without their older sister within driving distance. I packed up 23 years’ worth of memories, put them in a trailer and drove to Massachusetts. Feeling refreshed and strong, I had finally grown out of the “anxious Jacey” stage of my life. It felt like a cheat code had been unlocked and I was taking full advantage of it. I felt invincible.

For six days this attitude worked until I found myself standing on a train platform on my way to a new job in the middle of a new city where I didn’t know a soul. Underneath it all and with all my newfound bravado, I was still the scared little girl I had always been. Sobbing uncontrollably, I hoped my mom would answer her phone. She did, and told me something that would define my outlook on life from that day forward. “Jacey, you need to let go of the expectations you had for yourself with this transition. The expectations are killing you.”

She was right, I was killing myself for not living up to my own expectations about being fine with transition. Transition isn’t linear. There isn’t a playbook for how

one should make major life decisions. You have to go with it and believe in yourself at least a little to get to the edge of the ledge. Eventually, by digging deep and taking chances, you will find the thing that pushes you to take the proverbial leap.

We need to stop comparing ourselves to what we had hoped to be and to whatever expectations others hold over us. Transition is scary, even without having to manage a health condition or a raging pandemic. Life around us is always changing and we all need to embrace it to have the ability to move forward.

Transition isn’t linear. There isn’t a playbook for how one should make major life decisions.

Take transition at your own pace. Set boundaries and attainable goals. Recognize that parents, loved ones, doctors and others in your life are just working with what they know and with what they are going through at the moment. Don’t bother to regret or blame the situations of your past or your health challenges.

Understand that you’re not alone. Appreciate that others who live with a health condition like hemophilia and von Willebrand may be struggling as well. Reach out to others who may be going through what you are and see how they handle their transitions. Sometimes just sharing your experiences with a like-minded person can be insightful and healing and provide strength. Offer support to one another and let’s learn to pivot and move forward. We’ve got this!

BIOMATRIX

Meet the Team!

BioMatrix is dedicated to making a difference in the bleeding disorders community. Our team of Regional Care Coordinators and Patient Care Specialists provide support that draws on personal experience and a genuine commitment to the bleeding disorders community. Our *Meet the Team* segment invites you to get to know our incredible staff a little better. In this edition we feature Cyndy Coors.



Cyndy Coors
Regional Care Coordinator

There is more to caring for someone than just shipping them medication. Family sticks with you through the hard and the happy. Like family, I am there for it all!

Cyndy Coors has been an active member of the bleeding disorders community for 36 years. She is a unique blend of seasoned professional, talented care coordinator, and gal next door. She's everyone's pal and can make you feel like her best friend even when you have just met her. Having raised a son and daughter with hemophilia while lending support to her grandchildren, Cyndy shares experiences with her patients and anyone who can use a hand. She is a valued member of the BioMatrix family, and we are proud to introduce you to her!

How long have you worked for BioMatrix?

I am proud to be one of the legacy members of the organization. I joined the team in 2003, not long after the company was established. The founding principles resonated with me. Starting with just one patient, their vision was to provide the best possible care and make a difference in the lives of all people with bleeding disorders.

Where did your career path begin, and what brought you to BioMatrix?

My early career was in the medical field. After completing college, I worked for two general surgeons. Later, I transitioned into the specialty pharmacy field. I was caring for my son who has severe hemophilia A and could now help care for others just like him. Coming to BioMatrix offered a place where I could use my experiences and pay it forward to other families while sharing this journey with them.

Tell us a bit about your life and your connection to the bleeding disorders community.

Born in Mobile, Alabama (Go Crimson Tide!), raised in Chattanooga, I now call Soddy Daisy, Tennessee home (Go Trojans!). I am a proud mom of two adult children, Derek and Courtney, and have eight

wonderful grandchildren. Both of my children and 5 of my grandchildren are affected with hemophilia A.

When my son was born, he suffered a traumatic head bleed and thus began our crash course into the world of bleeding disorders. It was so shocking and frightening as we did not have a family history of hemophilia, but as it turned out, I was a carrier. My mom was a carrier too. Despite 'signs' when she was young, it was never investigated. Neither of my siblings are affected.

Derek was an active kid. We became experts at infusions, insurance claims, and managing our day-to-day. We were in a good place; then I found myself going full "momma bear" mode when my daughter began having bleeding issues. I heard a lot of, "Oh, she's just a carrier, she'll be okay." Through experience, I learned *not* to take no for an answer when your gut knows better.

An interesting fact about my life is that I live in a multi-generational home. That's right! Three generations under the same roof. I joined with my son and his family to purchase a home where we all could all live together under one roof. It seems to be a growing trend; there are many benefits to it! Sharing space makes it easier to share your



Cyndy's early days



life, help each other, and be present for so many of life's precious moments.

How do you feel you are *Making a Difference*?

There is no greater teacher than life experiences. Clinical experts can tell you all you need to know from their medical perspective, but there is so much more to living well with a chronic condition. I have been there, survived that! It's been my mission to share my knowledge and support patients so their hemophilia care is a smooth task rolled into their regular week filled with work, school, visits to the zoo, and cheer practice. When you can get to the point where having a bleeding disorder is just part of the routine, that's when you can live your best life. And that's what I help families do. It's what I love!

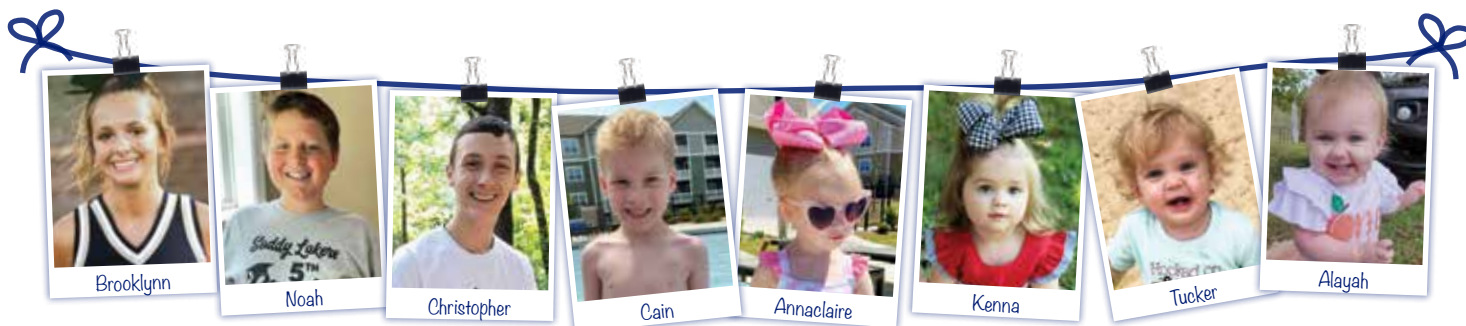


Son, Derek

Daughter, Courtney

Describe your most difficult challenge, and how you overcame it.

Although hemophilia today is a rather manageable disorder, it still can present significant challenges. Some of those early days were chock-full of bleeds, injuries and hospital stays. I wanted to hover over my son and protect him at all costs; however, I didn't want to be a helicopter mom. So how do I protect and defend him while giving him the space and license to just be a kid? A very compassionate HTC nurse offered some of the best guidance when I needed it most. Her words were, "to overcome the worry" and let my kid live. I listened, and it is the most meaningful advice I continue to share with new families. Kids learn by exploring their world. Make their space kid-friendly and then let them be. Don't worry about tomorrow, LIVE for today. If you can redirect your focus from a wide lens, bring in the view, and just concentrate on today, you will be more present. You will lighten the load of worrying while taking the day's highs and lows more easily. It really works!



Brooklynn

Noah

Christopher

Cain

Annaclaire

Kenna

Tucker

Alayah

Cyndy's grandchildren are her special source of great love, pride and joy. Cyndy shares, "I can't explain it, but the love you feel for your grandchildren is even deeper than the love for your children."

Also, we all have that little bit of intuition – that gut feeling that can guide us. Don't ignore it! If you know something doesn't seem right, question it! You know yourself and your loved ones the best. Let that wisdom and that little voice inside of you lead you. Be your own best advocate!

What do you feel is your greatest skill?

I sincerely feel I was put on this earth to be helpful and good to people. Over the years, patients have encountered challenges that I have tried to help them remedy. It doesn't matter whether it's related to hemophilia or not. As a Regional Care Coordinator, I have always cared for my patients with an "all in" approach. There is more to caring for someone than just shipping them medication. Family sticks with you through the hard and the happy. Like family, I am here for it all!

As a Regional Care Coordinator, what is the most cherished part of your job?

I have made friends all over the country who I am so grateful for, and they have entered my life because of living and working in the bleeding disorders community. From clinicians and patients to community members and past and present colleagues, these many friendships have greatly enriched my life. I have learned from many, laughed with most, and have never taken for granted the blessings that have come into my life thanks to these amazing people and the common *factor* we share. I cherish every single friendship, and my life is better because of each one!

Outside of work and family, what is your passion?

My passion is baking. My family loves my baking! Time in the kitchen gives me joy and allows me to quiet my mind. Yes, I know my way around an orange-cranberry bundt cake, and I'm not afraid to share it!

What is your proudest achievement?

I've had so many joyful moments and grateful reflections because my heart is open and finds the good in even the most ordinary things. I will say, however, there is one memory that still makes me smile and feel warm. I was being introduced to someone by the mom of one of my patients; she introduced me as a member of her family. Not just their pharmacy care coordinator, but as their family member! I always treat each patient and their family as part of my own. To be introduced as part of theirs, well, there is no greater honor!



EXTRA, EXTRA READ ALL ABOUT IT!

KEEPING CONNECTIONS STRONG THROUGH THE WINTER MONTHS

2022 VIRTUAL MEETINGS ON THE ROAD

JANUARY 15

AL, LA, MS, TX
2:00 – 6:00 PM CST

JANUARY 22

CT, MA, ME, NH, NJ,
NY, RI, VT
2:00 – 6:00 PM EST

JANUARY 29

FL, GA, PA, WV
2:00 – 6:00 PM EST

FEBRUARY 5

IL, MN, MO, NE, IA
2:00 – 6:00 PM CST

FEBRUARY 19

AZ, CO, ID, MT, ND, NV,
NM, SD, UT, WY
2:00 – 6:00 PM MST

MARCH 5

KY, MI, WI
2:00 – 6:00 PM EST

MARCH 12

DC, DE, MD, NC, SC, TN, VA
2:00 – 6:00 PM EST

MARCH 19

AK, CA, HI, OR, WA
2:00 – 6:00 PM PST

MARCH 26

AR, KS, OH, IN, OK
2:00 – 6:00 PM EST

hemob.org
(212) 520-8272

If unable to attend the designated date, choose another!

LET'S GATHER ON ZOOM! REGISTER NOW AND WE'LL SEE YOU SOON!

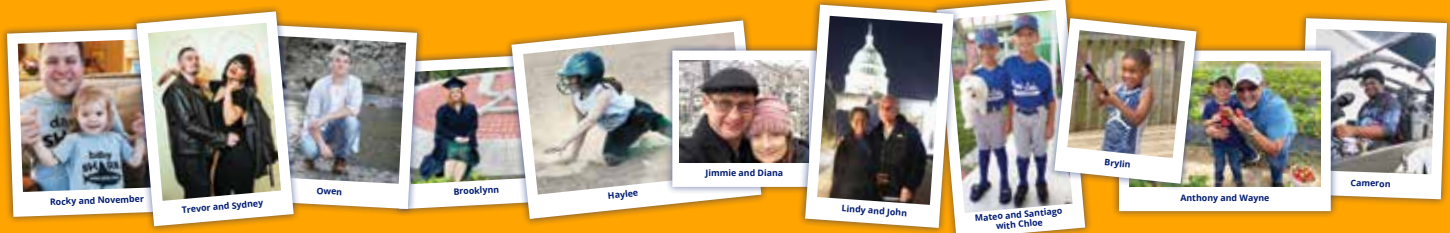
A SPECIAL THANKS
TO OUR SPONSOR:
CSL Behring

Now Available!

2022 CALENDAR "LIVING A SPECTACULAR LIFE"

Our celebration of the bleeding disorders community in a photo calendar began 9 years ago. Our goal has been to show that even with the unexpected twists and turns that come with managing a bleeding disorder, life is nothing short of spectacular!

Get your free copy while they're still available!
Contact your Regional Care Coordinator or email your request to: info@biomatrixsprx.com



BIOMATRIX

ON THE *In-Person* MOVE!

We are happy to report we are beginning to transition back to in-person events! We are making this switch slowly and very carefully with everyone's best interest at the forefront. This past quarter has seen more in-person than virtual events; however, at a moment's notice, our Education Team can quickly set up virtual programs as the need arises. We've even participated in a few hybrid events where a BioMatrix Care Coordinator attended in-person while our Education Team presented online.

Read on to see what we've been up to! If your group (large or small) is interested in scheduling an education session with our team or for a current list of programs available, please contact us at education@biomatrixsprx.com. Looking forward to hearing from you!

OHIO

Shelia Biljes

Spirits were flying high Thursday, September 2nd as BioMatrix partnered with HEMA Biologics for a **Back-to-School Family Dinner** at Maps Air Museum in Canton. The meeting room just above the hanger was full of attendees who were tuned in for a presentation on *Defining Inhibitors* led by Molly McHue, Regional Sales Director, and Alex Lightbourne, HEMA Biologics' Account Manager.

Starting her presentation with fun personal trivia, Molly went on to explain Inhibitors and how they come to be. Meanwhile, kids were busy at tables making paper airplanes and gearing up to visit the museum. An interesting Q & A session proved again the bleeding

disorder community is eager to learn as much as possible and be their own best advocates.

With dinner and education wrapped up, the group headed outside to view the various historical planes and displays. The weather was amazing and the slowly setting sun made a perfect backdrop to stroll and visit each exhibit. Children, and even some of the adults, sat inside fighter jets as the museum tour guides told stories of the past wars and how the planes were used. An authentic MASH unit was one of the displays and some of the medical supplies inside were identified by our youngest patients, impressing the tour guides. Way to show your knowledge, kids!

Thank you, HEMA Biologics, for sponsoring this unique event with us!



Aaron and Ashley



June and Marie



Chantel, Carmelo and Cameron



Conrad and Jessica



Alaina and Carter



Brooklyn, Marshall, Star and Tony



Tegan, Kai and Jace



Tony

OHIO

Shelia Biljes

Sunflowers, turning leaves and thoughts of fall were the themes of this **Ladies Lunch** sponsored by BioMatrix and Grifols September 9th. Hints of cooler weather had begun to settle onto northern Ohio providing a perfect day for friends to gather for a lunch and a fall craft. Utilizing the newly reopened private room at TGI Fridays in Brooklyn, over a dozen women arrived to enjoy lunch, education and companionship. Grifols Educator Virginia Krause, RN presented an interactive session focused on female bleeding disorders.

Afterward it was time to show the group's artistic talent while creating fall centerpieces! Lighted glass blocks boasting the word "thankful" across the front were assembled and decorated, each taking on the personality of its creator. Food, fun, fall crafts and family were definitely the highlight of this gathering!



June



Stephanie, Amber and Cheryl



Kristin and Charlene



Jennifer



Jace contemplates his approach

Kylan shows how it's done

Carter and Kai are off to the races!

OHIO

Shelia Biljes

Summer is fading away quickly but the fun doesn't have to end! BioMatrix partnered with Grifols for a **Fall Family Fun Dinner** September 9th at the Brew Garden Restaurant in Strongsville. With the arrival of over 45 guests, it was destined to be a great time!



Tegan shows how to color within the lines



Marshall and Brooklyn

Carmelo

While the group enjoyed a buffet dinner, Grifols Educator Virginia Krause, RN presented an informational program about **Blood Safety**, tracing the path of the donation and filtering process. Many of us usually have our products delivered each month with no consideration as to the steps that it took to get it there, so insight into part of the process was compelling.

Our usual group welcomed several new families and showed them how it's done! Pumpkin bowling, broomstick races and pumpkin bead crafts were just the start! A variety of fall-flavored coffees and spiced candies completed the evening.

Leaves will fall and Ohio snow will soon roll in, but on this day, we celebrated the joy of friendship and family during harvest.

VIRGINIA

Terry Stone

After 18 months of sheltering in place, perfecting our skills as teachers, working remotely and being all-around commanders in chief of our households, ladies of the Hemophilia Association of the Capital Area (HACA) were ready to break away, get away, escape, flee! Oh, they love their family, but the time was right to reunite with their HACA sisterhood for a **Women's Retreat Weekend** September 10-12th at Meadowkirk at Delta Farm in Middleburg to engage in some girl time, healing and reflection.



Michelle Stielper offers instructions to Anna Belle, who is pleased with her finished work

The tranquility of this spiritual venue and the beautiful weather was the perfect setting for outdoor walks, yoga and meals on the patio. A well-planned docket of topics perfect for post-pandemic healing was enjoyed throughout the weekend. From talking about *Taking Care of You* with our local favorite Anna Bell, LICSW, LCSW-C, LISW, *Guided Meditation* with Satyani McPherson, certified mindfulness instructor, and *Singing to Heal* with our BioMatrix Educator and resident rocker Shelby Smoak who boosted our spirits as we reflected on the science and power of music.

After dinner, Michelle Stielper, BioMatrix RCC and skilled artist guided the ladies to create a beautiful necklace with pressed flowers. Just like these dried flowers that were sealed and pressed into resin to create a beautiful statement piece, it's a reminder that every time we wear it, even when we are under pressure, our beauty shines through! Many thanks to HACA for this relaxing retreat!

OHIO

Shelia Biljes

The combination of fascinating zoo animals, perfect sunshine and fabulous friends is about as good as it gets! Northern Ohio Hemophilia Foundation celebrated its yearly **NHF Unite for Bleeding Disorders Walk** at the Akron Zoo September 11th. A quick stop at the sponsor booths and the teams were off! The Akron Zoo offers paths along



Tyler and Miya

Kim, Shelby, Scott, Theo & Karinne

beautiful rolling hills leading to habitats of animals who entertain and educate onlookers. Bears and lions seem to be everyone's favorite.

Walking with pride and showing off their matching shirts, the group shared their story with other zoo visitors who asked. New teams joined the scene and united with our seasoned walkers. With over 200 attendees, all goals were exceeded! But most of all, spending the day with chapter family and friends while raising funds for a worthwhile cause is the BEST!

OHIO

Shelia Biljes

We have all become experts in finding creative ways to conquer stress and anxiety over the past year and a half. Several years ago, I was attending a sewing class at Pins and Needles Quilt Shop in Middleburg Heights with a friend. My day had begun very stressfully and by the time class was starting I was having a full-blown anxiety attack. Doing my best to ignore my feelings by concentrating on the task at hand – sewing strips of fabric into blocks – I felt the tension begin to ease away.

As my blocks were pieced into a beautiful quilt top, I was feeling joy, pride and peace, and the stress I had been feeling seemed to magically melt away. I bought a sewing machine and set it up in my basement, and soon found myself sewing and breathing my way right out of panic attacks. It was like a cure that would result in a beautiful piece of fabric art. Every quilt, tote bag and table runner I've created finds a home to someone dear to me.

At this same shop September 16th, BioMatrix joined with Medexus for **Sewing B for Hemophilia B – Sewing to Relieve Anxiety**. A beautiful group of moms from the factor IX community gathered to learn a novel technique in battling stress in the hemophilia world. We shared coffee and doughnuts as we waited for everyone to arrive - some traveling hours for this unique event. The next hour of sewing seemed like minutes – so much joy and laughter!

Panera delivered lunch and we settled in to hear the amazing story of Christian Harris, known for his clothing designs, a member of the hemophilia B community and advocate speaker for Medexus. Christian shared how he wrote a 90-page thesis in college on the clothing during the Elizabethan period in Russia during the reign of the Romanovs.



Joanne and Tanya



Smiles from Mary & Marie



Sandy shows her skills



Fantastic work and beautiful totes!

He fully incorporates the story of Prince Alexi, the Russian prince who had hemophilia, and has educated many fellow designers on the effects of hemophilia on the joints and body. He has designed clothing using curves and angles seen in joint bleeds. I don't have words to adequately describe Christian's amazing integration of hemophilia and clothing design. He is currently working on programs for 3D patterns and recreating costumes from movie designs. I felt like we were in the midst of a celebrity fashion show with each new piece of clothing he displayed. Visit his website to view his work, <https://www.christianlharris.com>.



Fashion designer Christian Harris shares his story

The final hour of our time was spent sewing the inner lining of our totes, then it was time to show them off and take some fun pictures. Several of the ladies had never used a sewing machine and I must say each bag was beautiful and looked like professionally quilted bags! Vera Bradley has nothing on us!

SOUTH CAROLINA

Peggy Klingmann and Marcy Foertsch

Bleeding Disorders Association of South Carolina held their **Annual State Educational Family and Adult Retreat** the weekend of September 24-26th. As families arrived in Myrtle Beach at the Marina Inn at Grande Dunes Friday



Janice and Felicia



Keith and Marilyn

evening, they registered and joined the welcoming and opening session, *Do What Moves You: Staying Active*. Fun ice breakers were followed by dinner.

Saturday was full of educational sessions with topics covering advocacy, empowerment and nutrition. An opportunity to learn self-infusion was offered by appointment Sunday morning and round table sessions were offered throughout the day covering a range of topics with something for everyone. These sessions had wonderful speakers who presented helpful information on bleeding disorder topics throughout the day. The exhibit hall was open periodically and attendees were encouraged to visit the sponsors and learn more about their products and services. The event ended with hearty and warm good-byes until we all gather again!

VIRGINIA

Terry Stone and Michelle Stielper

The weather was picture perfect for Hemophilia Association of the Capital Area's (HACA) **Fall Festival & Walk** on a sunny and warm Saturday, October 2nd at Lake Accotink in Springfield. Last year's event was virtual due to the pandemic, so walkers were happy to be together by the lake with fresh air, food and friends!

The initial goal was to raise \$65k, a respectable amount following a gap year. However, supporters blew right through that amount, so the goal was raised, only to have it be blown through again and again. Thanks to many generous friends of HACA, the chapter raised about \$80k!

New this year was a 50/50 raffle and a chance to win the opportunity to throw a pie at HACA staffers, Executive Director Brenda Bordelon and Program Manager Robin Monin. These ladies work hard and were real troopers for taking those pies, especially when Brenda's pie thrower was her husband and Robin's was her mom! Family supporting family - it's how HACA rolls!

Congratulations to all the fundraisers. BioMatrix was happy to receive a 3rd place honor for our team fundraising efforts. We are thrilled to support such a great organization!



Pie in the face!
Robin Monin and Brenda Bordelon

OHIO

Shelia Biljes

A bright, crisp morning set the stage for an **Educational Session** sponsored by BioMatrix and Novo Nordisk October 15th. Formerly an old boathouse, Pick's Restaurant located on the shore of the West Reservoir in Portage Lakes provided a warm atmosphere, fantastic buffet and incredible lake views.



Novo Nordisk Community Liaison Judy Doyle presented *Don't Wait to Thrive* followed by BioMatrix Education Specialist Kelly Gonzalez who spoke on *Communicating Through Stress*, sharing helpful hints for improving family communication during times of stress.

Following the lunch and featured speakers, families took a delightful drive around Portage Lake taking in the beauty of the magnificent fall colors. Thank you to everyone who attended!

OHIO

Shelia Biljes

Spooky sights were on the agenda the evening of October 15th as over 60 people came together for a **Halloween Education and Picnic** event at Lorain County Metro Parks in LaGrange. The group gathered to hear BioMatrix Education Specialist Kelly Gonzalez speak about how communication during times of stress doesn't have to be so SCARY! This fall event included a picnic and craft-making session, enjoyed by everyone!



Parents Corey and Sarah with Bennett and Aubre



Tegan, Kai and Jace decorate Halloween cookies

The evening culminated with a spooky Halloween Boo-Thru, a family-friendly drive-through event traveling down the park's Halloween trail!



Carmelo, Alayna and Carter creating artistic cookies



One of the spooky scenes along the Boo-Thru

CALIFORNIA

John Martinez

BioMatrix and Genentech co-sponsored a fun-filled evening October 16th for families of the Latino Hemophilia Foundation in the Bakersfield



area. The **Dinner Event** was held at Sundale's exclusive Edmonton Petroleum Golf and County Club. Participants were excited to attend an in-person event after such a long time of social isolation, appreciating the opportunity to visit with community members again.

This interactive bilingual English/Spanish event covered tips on how to reformulate our mindset as the landscape of our communities and nation continue to change. The presentation offered opportunities to actively examine the manner in which each individual copes with stressful events in their lives. The sessions included activities nurturing positive thinking and problem resolution. The presenter actively engaged with and encouraged attendee participation helping to make the event a positive experience with real-world applications.

BioMatrix hosted a fun-filled version of *Loteria*, a traditional Mexican game much like bingo but tailored with images common in the bleeding disorders world. Conducted bilingually, everyone, adults and children alike, were able to play along and many learned new Spanish vocabulary words! Families expressed their enjoyment and are looking forward to another in-person event!

NEW YORK

Rich Vogel

On a beautiful fall day in upstate New York, Bleeding Disorders Association of Northeastern New York (BDANENY) held their **Annual Meeting** at Liberty Ridge Farms in Schaghticoke October 24th. With the smell of a wood fire and the sight of leaves starting to change colors, community members turned out for a day of facts and fun.

After gathering the latest information on new products and services from manufacturers and specialty pharmacies in the open air, members gathered under the big top for community updates, education and a meal. Lunch included BBQ brisket and chicken, smoked right there on the farm. Presentations followed on *Color Therapy to Lessen Stress* and *Navigating School with a Bleeding Disorder*.

It's always good for families in the bleeding disorders community to get together to talk, share stories and relax, and there is no better place on a crisp fall day than Liberty Ridge Farms. The children and adults enjoyed an afternoon of pumpkin picking, hayrides, getting lost in a corn maize, and of course, operating the pumpkin cannon. But no fall farm event is complete until they breakout the fresh baked, still warm, apple cider donuts! Thanks to BDANENY employees Beth, Trish and Melissa for a great afternoon of camaraderie, education and fun.



Education under the tent



Pumpkin Cannon



Assisting Educating Advocating For The Bleeding Disorders Community.



NEW MEXICO

Felix Garcia

Sangre de Oro (SDO) teamed up with Sanofi Genzyme to host a **November of Thanks** event at El Pinto Restaurant in Albuquerque November 10th. Over 60 SDO community members came out for this joyful event which began with a presentation from Sanofi focused on gratitude. Adding to the excitement, BioMatrix jumped in to help support the event and held a raffle for a popcorn-themed gift basket.

Although we had many visitors and great conversations catching up with folks at the BioMatrix booth, I wasn't the biggest attraction... enter *Pudgy the Turkey*. Everyone lined up to take pictures with our gobbling inflatable friend!

From the venue to the sponsors, the raffles to Pudgy, SDO did a fantastic job hosting this delightful event. We at BioMatrix can't wait to be involved with this event again next year!



Felix Garcia presents the raffle gift to the winners Reuben, Debbie, Reuben Jr. and Alyssa



Alfonso, Jennifer and Clara with Felix Garcia



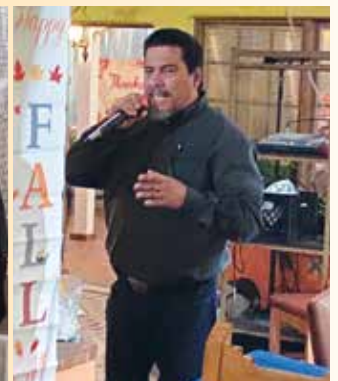
Miguel, Maribel, Michelle and Miguel



Christian, Jennifer, Shilynn and Felix Garcia



Carla and Gary



Felix Garcia



Snoopy fan,
Camden

OHIO

Shelia Biljes

The changing color of leaves, the aroma of pumpkin spice, football cheers and Charlie Brown – all proof that summer is officially gone. What better way to celebrate the fall season than to gather friends for a **Charlie Brown Thanksgiving Dinner & Movie**. BioMatrix teamed with Novo Nordisk November 11th to bring together community families at Brew Garden Restaurant in Strongsville. Novo’s Community Liaison Judy Doyle opened the evening by introducing Advocate Speaker Vaughn Ripley who shared his life story as a full house listened intently while enjoying dinner. Vaughn’s story is both compelling and inspiring. He has a way of taking you deep into the darkest part of his life, then bringing you back to beautiful days with his family and a life full of happiness and purpose.

Dessert was served as *A Charlie Brown Thanksgiving* movie began; a flashback for some, a new experience for others, and enjoyed by all. The evening’s finale was a special visit by Snoopy! The kids squealed with joy as he danced his way into the room. Each family had the opportunity to visit with Snoopy and pose for photos. What a fun way to spend time with friends and build up excitement for the holidays!



Max, Ariella and Alex



Aaron and Ashley



Tegan, Kai and Jace visit with a favorite character



Charlene goes in for a hug!



Judy Doyle, Shelia Biljes and Vaughn Ripley



Cuteness overload! Amir and Amon



June, Madison, Selina and Carter

FLORIDA

Justin Lindhorst

The Florida Hemophilia Association hosted their **11th Annual Unite for Bleeding Disorders Walk** Sunday, November 14th. This year the walk was held at the beautiful Okeehetee Park in West Palm Beach. Participants from across the state enjoyed a fantastic opportunity to lift up, connect with, and learn about the bleeding disorders community while raising critical funds for the chapter. BioMatrix was proud to support the walk as a Bronze Sponsor. Our South Florida employees also engaged in enthusiastic fundraising activities leading up to the walk, including some exciting rounds of bingo held virtually and



Team BioMatrix was all smiles at the Unite for Bleeding Disorders Walk! Darin, Doug, Diane, Marquita, Anthony, Jennifer, Julian, Landon, Justin and Dave

at the BioMatrix corporate office. After the walk, there were refreshments, a deejay and fun activities for all. It was a beautiful, balmy Florida day for a walk, benefiting a great cause!

TENNESSEE

David Tignor

The best place to be November 6th was the Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF) **21st Royal Gala!** Held at City Winery in Nashville, the gala began with a social hour, followed by dinner and Janet Patterson sharing her story about her *Family of Bleeders*. After dinner, the coveted Victoria’s Cup Award was presented to THBDF Board Secretary Amanda Wilson for her years of dedicated service.

Community member Chris Harris then took the stage and gave his testimony of how important bleeding disorders camp was to him, how it affected him personally, and its effect on campers as a whole.

Donated items and gift baskets were part of a silent auction that took place throughout the evening. Once



Janet Patterson:
Family of Bleeders



Chris Harris:
Importance of Camp

BIOMATRIX ON THE *In-Person* MOVE!

it closed, it was time for the event's highlight – a live auction featuring items such as a Middle Tennessee Adventure Package, fine jewelry, and most coveted, a Camp Freedom *Big Stick*.

This highly anticipated annual event helps raise funding for one of THBDF's most important programs, Camp Freedom.



David Tignor and Robby Bond visiting after the gala



CALIFORNIA John Martinez

As we enter the holiday season, many people, especially in our bleeding disorders community, are eager to reconnect with old friends and family. After a nearly two-year hiatus, folks in the San Jose and coastal area finally had the opportunity. BioMatrix participated in a community building in-person event hosted by the Hemophilia Foundation of Northern California (HFNC) and sponsored by Novo Nordisk November 18th. Held at the delicious Maggiano's Italian Restaurant in San Jose, the atmosphere was joyful and warm. Even though some had never met in person, conversations around the table demonstrated the closeness of our community. In the relaxed atmosphere, Heater Barton of Novo Nordisk stimulated conversations among the families.

HFNC's Education and Advocacy Director Ashley Gregory invited each person to introduce and share something about themselves to the group. Conversations ensued and family members opened their hearts to share their challenges and victories. Being able to share with others who truly understand can be very powerful and healing experience.

BioMatrix then led rounds of Loteria! We've put a bleeding disorders spin on this traditional Spanish game, very similar to Bingo. From young children to adults, everyone joined in this lively family game. Children especially enjoyed winning the rounds as HFNC provided large chocolate prizes to the winners.

The bonding and enthusiasm for future events was a heartwarming scene to witness. Thank you to HFNC for bringing us all together!

CONNECTICUT Richard Vogel

The Connecticut Hemophilia Society (CHS) held its **Annual Meeting and Holiday Party** December 4th at the Wyndham in Southbury. After nearly 2 years of a worldwide pandemic that kept most inside and isolated,



Anay shares his gift list

it was a Christmas miracle to be able to come to an in-person event for education, comradery and fun! To help keep everyone safe, CHS had sanitation stations set up throughout the venue and all were asked to wear a mask regardless of vaccination status. After all, hemophilia and northeast weather have a lot in common, you must be prepared and be tough because things can change hour to hour. The theme of the day was resilience and was appropriate for what we all have gone through these last 2 years.

The morning started with a breakfast buffet and time for members to reacquaint with other attendees and to gather information from industry exhibitors. The first presentation of the day was on *Preparing for an Emergency*. While you never know when an emergency will pop up, there are some simple tips to be prepared when they do. Echoing the theme of resilience, a panel of 3 generations of men with hemophilia was next, sharing their personal experiences of living with hemophilia.



Having holiday fun! Eric, Stacie, Jeff, Terri and Mark

After lunch, Rick Starks demonstrated how to stay strong by developing a relationship with your body through Tai Chi. For those not familiar, it involves a series of movements performed in a slow, focused manner and accompanied by deep breathing. It is a self-paced system of gentle physical exercise and stretching with each posture flowing into the next without pause, ensuring your body is in constant motion. The education sessions wrapped up with a conversation on *Adversity, Strength and Resilience*.

Dinner and the holiday party soon followed, with anticipation building as Santa's arrival approached! The festivities in Connecticut continued as gifts and hearty "ho-ho-hos" were given to the excited children!



Connecticut children meet with Santa and his trusty elves!

OHIO

Shelia Biljes

A perfect mixture of rainforest animals and tiny gnomes added to the magic of Northern Ohio Hemophilia Foundation's (NOHF) **Holiday Event**. The Rainforest at Cleveland Metroparks Zoo was the setting for this festive event December 4th with over 150 in attendance! With all safety precautions in order, each family posed for a photo upon check-in and headed over to the sponsor exhibit booths where kids were thrilled to visit as each hosted a craft or game. Letters to Santa, ornaments to paint, pinecone gnomes to dress, string art, a coloring contest and more... everyone had a ball! At the final booth, each family picked up their portrait and made a candy cane frame to display at home throughout the season.

The main rainforest doors opened allowing entrance into the dining area where tables decorated in holiday style were ready for dinner with exotic rainforest animals. A tour of the food stations, including an ice cream bar, was the perfect way to see every animal exhibit. Ice cream in December, you may ask. Don't forget it's super warm and humid in the tropical rainforest. Those of us wearing our favorite holiday sweaters were feeling the heat!

After dinner, the upper floors of the rain forest were opened for the guests. Everything from snakes and bats to monkeys and crocodiles, there was plenty to see and educate oneself about the complexities of the rainforest. By 10:00 pm, kids and animals alike were thinking about bedtime while parents thought about the drive home. With super exhausted kids, hopefully the drive was quiet, but for those with extra energy, the evening provided plenty to talk about!



Looking holiday ready!
Christian, Camden, Calissa, Kaylin and Colin



Kelly and MacKenzie spot an alligator!



Mika and Miya looking cozy in holiday sweaters



Debra and Emerie enjoying the event



Big smiles from Kelly and Jenna



Holiday Crafts!



Brandywine Valley Hemophilia Foundation Board Members: Tara Bolinski, Gail Novak, Tom Wallace, Kim Hamstead, and Jennifer Davis



Patrick and Delanie stop for a visit and photo at the BioMatrix booth

PENNSYLVANIA

Tina McMullen

Mendendall Inn Restaurant in Mendendall was the hot spot Sunday, December 5th for Brandywine Valley Hemophilia Foundation's **Year End Event**. Following a lovely lunch buffet, Foundation Board Vice President Jennifer Davis got everyone involved in an educational game – she sure knows how to make education fun for every age!

In the holiday spirit, each child received a gift, and game and door prizes were awarded. With the luncheon wrapping up, Foundation Board President Gail Novak gave an update on events and funding for the year. The gathering concluded with attendees heading over to Longwood Gardens where we found ourselves mesmerized as we strolled amid dramatic holiday lights and displays.

For such a small, volunteer-only foundation, the commitment to the local bleeding disorders community is truly amazing! A special thanks to Board Member and Event Chair Kim Hamstead for planning such a fun event!



Upcoming Events

Many organizations are still deciding whether to hold in-person events given the recent uptick in COVID-19 cases. Check with your BioMatrix Regional Care Coordinator or with your chapter to find out about activities scheduled near you!

JANUARY 29, 2022 VIRTUAL
Hemophilia Association of the Capital Area
Virginia Hemophilia Foundation
703-352-7641, hacacares.org
Virtual Teen Advocacy Program

MARCH 27, 2022 NEW JERSEY
Hemophilia Association of New Jersey
732-249-6000, <https://hanj.org/>
Community Connections
iPlay America; Freehold

APRIL 20-22, 2022 Texas
Hemophilia Federation of America
202-675-6984, www.hfasymposium.org
Annual Symposium
San Antonio

FEBRUARY 10, 2022 VIRTUAL
Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Virtual Education & Craft Night

MARCH 11-13, 2022 MASSACHUSETTS
Connecticut Hemophilia Society
860-495-0006, cthemophilia.org/
17th Annual Alpine Walk
Jiminy Peak Mountain Resort; Hancock

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

Time for Fun!

Puzzles on page 27

- (1) HALL (8) HOPE (15) MALE (22) PALM
- (2) HALE (9) LAME (16) MEAL (23) PEAL
- (3) HEAL (10) LAMP (17) MILE (24) PILE
- (4) HEAP (11) LEAP (18) MOLE (25) PLEA
- (5) HELP (12) LIME (19) MOPE (26) POEM
- (6) HOME (13) LIMP (20) PAIL (27) POLE
- (7) HOLE (14) MAIL (21) PALE

BIOMATRIX

Our cookbook brings together recipes from our family to yours!

Our team of Regional Care Coordinators has provided their very best recipes – from appetizers to entrees and desserts.

To get your free cookbook, contact your Regional Care Coordinator or request online:

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



Contribute to our BIOMATRIX Community Playlist project!



Do you have a song that is meaningful to you?

Our **Community Playlist** will be featured in an upcoming newsletter and will include a Spotify link to listen to submissions.

Contribute to our Playlist here:

<https://www.surveymonkey.com/r/SongPlaylist>

Time for Fun!



Hi Kids!

Would you believe there are 65 4-letter words in HEMOPHILIA based on the Scrabble game dictionary? Are you able to come up with a few of the more 'common' words? We've added a letter to each answer to help! Clue: the answers are in alphabetical order. Answers are on page 26.

Find 2-5 words = ★

Find 11-15 words = ★★☆☆

Find 21+ words = ★★★★★★

Find 6-10 words = ★★☆☆

Find 16-20 words = ★★☆☆☆☆

HEMOPHILIA

- | | | |
|--|--------------------------------|--------------------------------|
| 1) <u>H</u> <u>A</u> <u>I</u> <u>L</u> | 10) _____ <u>P</u> | 19) _____ <u>P</u> _____ |
| 2) _____ <u>E</u> | 11) _____ <u>A</u> _____ | 20) <u>P</u> _____ _____ |
| 3) _____ <u>E</u> _____ | 12) _____ <u>M</u> _____ | 21) _____ <u>L</u> _____ |
| 4) <u>H</u> _____ _____ | 13) <u>L</u> _____ _____ | 22) _____ _____ <u>M</u> |
| 5) _____ _____ <u>P</u> | 14) <u>M</u> _____ _____ | 23) _____ _____ <u>A</u> _____ |
| 6) _____ _____ <u>M</u> _____ | 15) _____ <u>A</u> _____ _____ | 24) _____ <u>I</u> _____ _____ |
| 7) _____ <u>O</u> _____ _____ | 16) _____ <u>E</u> _____ _____ | 25) _____ _____ <u>A</u> |
| 8) <u>H</u> _____ _____ _____ | 17) _____ _____ <u>L</u> _____ | 26) _____ <u>O</u> _____ _____ |
| 9) <u>L</u> _____ _____ _____ | 18) _____ <u>O</u> _____ _____ | 27) <u>P</u> _____ _____ _____ |

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

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



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

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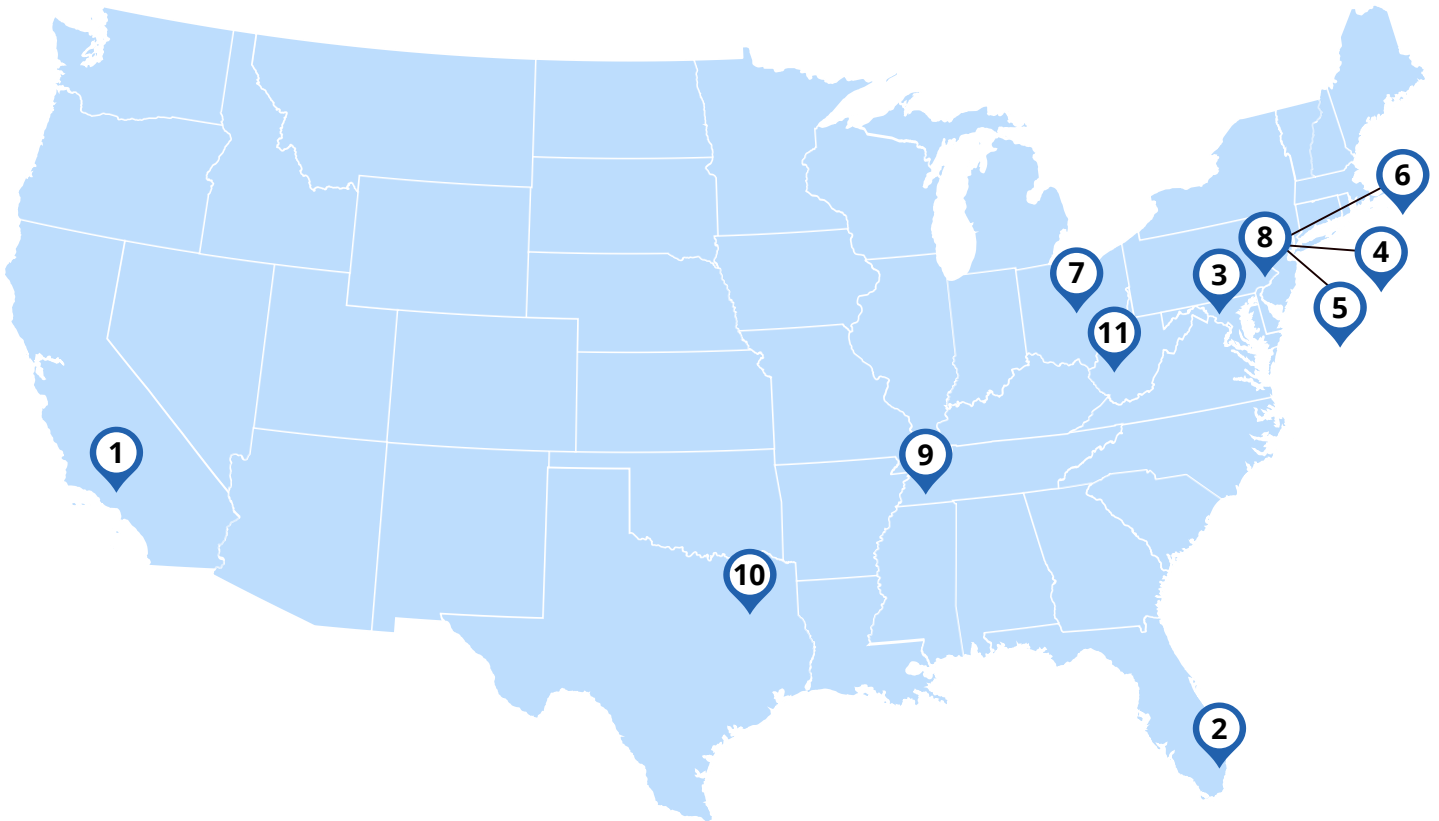
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Specialty Pharmacies



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2. Plantation, Florida
3. Columbia, Maryland
4. Glen Rock, New Jersey

5. Totowa, New Jersey
6. New York, New York
7. Dublin, Ohio
8. Garnet Valley, Pennsylvania

9. Bartlett, Tennessee
10. Tyler, Texas
11. Charleston, West Virginia

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2019, 2020 & 2021