

BIO MATRIX

NEWS



DEDICATED
TO MAKING
A DIFFERENCE

FALL 2021
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“ Never regret anything that
made you smile. — Mark Twain ”

ABOUT BIOMATRIX

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

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

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

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

MISSION + VISION

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

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

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

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

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

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

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

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

FINE PRINT

Editor-in-Chief: Maria Santucci Vetter

Editors: Susan Moore and Justin Lindhorst

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

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

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A NOTE FROM THE EDITOR

Dear Readers:

It's been an interesting summer, but with 90-degree high humidity days, the approaching cool weather is certainly welcome. Let's be realistic though – in the next month or two of Illinois temperatures, I'll be longing for summer again!

At BioMatrix, we remain careful with social distancing and masking as we navigate the world of in-person gatherings. Our bleeding disorders team is committed to following regional and local mandates. Let's continue to be vigilant, get vaccinated if you are able, and work together to gain more control over COVID-19. We are hopeful to one day soon be able to *freely* interact with everyone at community events.

In the meantime, this issue of *BioMatrix News* offers a special *Music Playlist* featuring artists from our bleeding disorders community. And boy, are we a talented bunch – it must be in the genes! We are also compiling a playlist of our readers' favorite songs when dealing with a bleeding disorder. Please submit your meaningful song (see page

11 for submission directions). Once we've gathered plenty, we will share the playlist with our community friends and families.

This edition's featured chapter is the Northern Ohio Hemophilia Foundation – we hope you'll enjoy learning more about this fantastic organization. You'll also find great information on long/short-term insurance, an introduction to Regional Care Coordinator Jeff Johnson, and much more!

Lastly, our famous *Living a Spectacular Life 2022 Calendar* will soon be available. Contact your Regional Care Coordinator to receive a calendar at no cost!

Take a breather before the holidays hit and, as always, we wish you happiness and good health!

Maria Santucci Vetter
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DISABILITY INSURANCE

DISABILITY HAPPENS SHORT- AND LONG-TERM DISABILITY

BY SHELBY SMOAK, Ph.D.

In the last *BioMatrix News* issue, we focused on Social Security Disability, a government-supported program available to you if you have worked and paid into the disability program and are dealing with a disability/injury that will prevent you from working for a year or more.

This article focuses on short- and long-term disability plans that are protective financial coverage for persons who become unable to work for, typically, a shorter length of time. While there are many differences between Social Security Disability and short- and long-term disability coverage, a glaring contrast is that SSDI in addition to financial support will also offer you healthcare coverage via Medicare should you qualify; short- and long-term disability policies, however, are intended for financial security only.

Can a Disability Happen to You?

Certainly, members of the bleeding disorders community may likely answer a resounding “YES!” but too often those same persons may lack the financial protection of a short- and long-term disability policy.

In America, 51.2 million people, over 15% of our population, have at least one disability.ⁱ Automobile accidents account for 2.8 million disabilities per year while home accidents contributes a disabling injury every 3 seconds. Every year 5.6% of Americans experience a short-term disability.ⁱⁱ

A bleeding disorder does not exclude a person from being subject to the possibility of another kind of disability. In fact, having a bleeding disorder may likely compound a disabling injury or illness, lending the need for short- and long-term disability insurance more imperative. Remember, a bleeding disorder does not make you immune to other health complications.

In addition, many caregivers of persons with bleeding disorders may have become so focused on their loved one(s) that they overlook protecting themselves from the same disability potential. A survey done by the Council for

Disability Awareness revealed that over half of American families did not have enough money in savings to cover three months of living expenses (the average length for a short-term disability).ⁱⁱⁱ

So, if you are injured and unable to work, whether this is bleeding disorder-related or not, what is your plan for earning income and paying bills? If you need surgery for a joint replacement or any other bleeding disorder-induced complication, how will you pay bills during your recovery period? Having a short- and long-term disability policy will provide income for any unforeseen injury or illness, inside or outside of your bleeding disorder.

What is Short-Term Disability Insurance?

- Short-Term Disability is a type of insurance benefit that provides some compensation or income replacement for non-work-related injury or illness that renders you unable to work for a limited time.
- “Non-work related” is important because injuries that happen on the clock will normally fall under workers’ compensation policies.
- Common reasons for short-term disability are pregnancy complications, herniated discs, cancer, accidental injury, surgery, and mental health challenges.

What are Typical Short-Term Disability Policy Coverage and Rules?

- While benefit payment is plan-specific, on average a short-term policy pays 50-60% of your earned income when you are unable to do your job for a short amount of time.
- Premiums are based on age and annual gross income but are typically 1-3% of your earned income. A person earning \$50,000 a year can expect to pay \$500-\$1500 annually for a plan.
- Many employers offer plans, or you can self-purchase a plan at, usually, a higher cost.
- These 5 states require employers

to offer short-term disability policies: California, Hawaii, New Jersey, New York, and Rhode Island.

- The definition of “disability” is plan-specific and can sometimes be ambiguous, so please read the fine print when signing up for a policy.
- Policies can be valid for 30 days to a year but are typically intended for 6 months or less of use.
- Benefits will end when your policy coverage period concludes, when your predetermined time period is over, or when you return to work.
- If you are unable to return to work when a short-term policy terminates, a transition to a long-term disability policy or Social Security disability may be necessary.

What is Long-Term Disability Insurance?

- Long-Term Disability provides insurance if you are out of work for a long period of time: usually years.
- While benefit payment is plan-specific, on average a long-term policy also pays 50-60% of your earned income when you are unable to do your job.
- Premiums are based on age, occupation, and annual gross income, but are again typically 1-3% of your earned income.
- Many employers do not offer plans, so you may need to self-purchase a plan. If an employer does offer a plan, it may not give the coverage you need, so acquiring a supplemental policy like AFLAC may provide more adequate financial coverage.
- Policies are usually valid for 2-5 years, or until age 65.
- Benefits will end when your policy coverage period concludes, when your predetermined time period is over, or when you return to work.
- If you are unable to return to work when a long-term policy terminates, a transition to Social Security Disability may be necessary.

EXAMPLE OF SHORT-TERM, LONG-TERM & SSDI

Joe is a salaried employee earning \$60,000 a year, approx. \$1150 weekly.
He is paid 100% of premiums for his 7-day elimination 13-week 60% benefit Short-Term disability with after tax dollars.
Joe’s employer pays 100% for Long-Term disability with a 90-day elimination period 5-year policy, 60% of income.

SICK DAYS: June 1-7
Joe suffers a sudden illness on June 1st and uses 7 sick days. He receives \$1150, his standard salary for the week.

SHORT-TERM DISABILITY: June 8-September 8
Joe is not able to return to work and must utilize his Short-Term disability. He receives \$690 weekly for 13 weeks (60% of \$1150). No taxes are deducted.

LONG-TERM DISABILITY: Sept 9-March 7 of next year
Joe is still disabled. His Short-Term disability is exhausted. His 90-day elimination period is completed.
Joe’s Long-Term disability kicks in. He receives a net weekly benefit of \$586 a week (60% of income minus 15% taxes). His disability persists and finally SSDI is approved.

LONG TERM DISABILITY & SSDI: March 8 for 3.75 years.
Joe’s Long-Term disability integrates and reduces benefits \$1 for \$1 with \$290 weekly SSDI benefits. Long-Term disability reduces to \$400. Total taxable is \$690. Net \$586 a week.

SSDI BENEFITS ONLY: September 9, 5 years later
Long-Term disability benefit ends. SSDI pays \$290 a week taxable. Likely no taxes due to low income.



What Are the Basic Types of Long-Term Policies?

There are 2 basic types of long-term disability policies: *Own-Occupation* insurance and *Any-Occupation* insurance.

1. **Own-Occupation** disability insurance defines a disability as an inability to work at your present occupation, even if you can work at another. For example, consider you are a truck driver but experience an illness that results in vertigo and partial blindness. You are no longer able to drive due to these issues. An own occupation disability would provide coverage for your inability to work in your present job—truck driver.
2. **Any-Occupation** disability insurance covers you if you are unable to work at any occupation. In the example of the truck driver, an any-occupation policy would unlikely offer payment for job loss. While you may no longer be able to perform your normal daily work of driving, an any-occupation policy would consider you still employable as perhaps a dispatcher or some other non-driving position.

Ultimately, the own-occupation policy is more desirable since if you were to become disabled in any way, you would only need to show an inability to work in your present job, which can be easier to prove. These policies, however, are more expensive, or they just may not be offered through your plan.



An any-occupation policy is more common, is more affordable, but is sometimes harder to prove. If you were to become disabled, you would need to show that with your skillset and (lack of) ability you are unable to do any other kind of job, regardless of what your employment was at the time of your injury or illness. For the above example, it may be difficult to prove the truck driver is unable to do any other kind of work.

Should I Pay Premiums Using Pre-Tax or Post-Tax Dollars?

Deciding whether you should pay short- and long-term disability policies with pre- or post-tax dollars is a complicated equation. Basically, if you pay for a disability with pre-tax dollars, the taxes would be saved by you immediately, but would be taken out when you receive payouts from the policy; likewise, if you pay for a disability policy with post-tax dollars, you will see less realized income now, but your income would be greater upon the policy payout. Ultimately, you have to assess whether it is more important that you have additional money now by paying for the policy with pre-tax dollars, or later, by paying for the policy with post-tax dollars.

How Does Short- and Long-Term Disability Integrate?

A short-term disability policy typically offers coverage for 90-180 days, 3-6 months; the policy may have an elimination period of 0-14 days, in which case you would need to rely upon your employee benefits for financial stability. If you are unable to return to work when the short-term policy terminates, the long-term policy takes over at that 3- or 6-month mark, depending on the long-term policy rules. Long-term policies usually have an exclusion period of 90-180 days, about the length of the typical short-term policy. Once the long-term policy is active, the benefit duration is 2-5 years, or until age 65.

Will a Short- and/or Long-Term Disability Policy Provide Enough Income to Maintain My Current Standard of Living?

The hard answer to this question is *no*. Short- and long-term policies only provide up to 50-60% of your current income, so unless you are not using almost half of your income each year, the financial change will be felt.

Consider if a person (let's call him Joe) is currently employed, earning \$60,000/yr. but then becomes injured and must apply for his short-term disability policy benefits because he is unable to return to work. Before, Joe received \$1150 weekly; with a short-term policy paying 60% of his salary, Joe will be reduced to \$690 a week.

Luckily, Joe paid his premiums with post-tax dollars and will receive the full \$690. Unfortunately, Joe does not recover, is unable to return to work, and his short-term disability is terminating. He must apply for his long-term disability benefits, which also pay 60%. However, Joe used pre-tax dollars to pay for his long-term policy, and thus taxes will be taken out of his payment. Joe is paid \$690 weekly by his policy but 15% taxes are taken out, so Joe instead receives \$586 a week.

Effectively, Joe's disability and his inability to return to work have, in a matter of months, reduced his realized income from \$1150 to \$586 a week. Unless Joe has considerable savings or another form of unearned income (stock, for example), Joe would unlikely be able to maintain the lifestyle he enjoyed before the disability. This is the hard, grim truth. However, consider if Joe failed to secure short- or long-term disability policies, and instead of \$586 would receive \$0. Joe would likely be seeking government assistance via Medicaid or considering Social Security Disability, which would pay even less than a short- or long-term policy, but, moreover, may take a year or more for approval (see "Disability Happens" BioMatrix News Summer 2021 – [https://www.biomatrixsprx.com/bleeding-](https://www.biomatrixsprx.com/bleeding-disorders-publications)

[disorders-publications](https://www.biomatrixsprx.com/bleeding-disorders-publications)). Without the support of a short- or long-term policy, Joe would be without any income or financial support.

Ultimately, BioMatrix nor myself propret to be financial advisors regarding the economics of a disability. BioMatrix, however, is deeply vested in the sustained care of persons with chronic illness, and I, as a person with a chronic illness, am deeply vested in the sustained support for myself and others as we navigate the twists and turns of chronic illness and as we plan for the unexpected. So while on one hand it is heartbreaking to hear about persons confronting a disability, on the other hand, it is even more devastating when we hear about the dire financial straits the disability precipitated. Short- and long-term disability policies are support mechanisms to soften those financial losses.

Hopefully, this piece has you looking into those policies, reaching out to your employer about policy options, or picking up the phone to speak to a disability policy expert. While these policies may leave your financial glass only half full in the case of a temporary or long-term disability, that, I think, is a much better prospect than an empty glass.

References:

- i. Council for Disability Awareness. "Chances of Disability." [Disabilitycanhappen.org](https://www.disabilitycanhappen.org). 15% figure gained by 51.2 disabilities out of 328.9 million Americans, 2019 Census stat.
- ii. Council for Disability Awareness. "Statistics." [Disabilitycanhappen.org](https://www.disabilitycanhappen.org).
- iii. Ibid.

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Northern Ohio Hemophilia Foundation "Rockin' Cleveland!"

BY SHELIA BILJES

Every city has a story, its very own history that locals take pride in and visitors come to marvel. So, what is Cleveland's story? Well, it's home of the Rock & Roll Hall of Fame and of the Cleveland Clinic Medical Center. That's pretty cool!

It also boasts beautiful beaches on Lake Erie, the Terminal Tower, the Christmas Story House, and its cherished major league sports teams, the beloved Browns, champion Cavaliers and the former Indians, now Guardians.

All of that is a tourism bureau's dream, but what about an organization less known to the masses, but oh, so very important to families with bleeding disorders? You would have to look over the Hall of Fame, past the Tower and beyond the stadiums to glimpse inside an ordinary building and find the Northern Ohio Hemophilia Foundation (NOHF), whose history is philanthropic, its place in the community it serves is treasured, and there is no admission charge!

NOHF has served the needs of the bleeding disorders community for over 66 years. Founded in 1954, it was just a social group of parents gathering in local venues such as a library, a library, or someone's kitchen table, to offer support as they struggled to raise children with hemophilia. From its humble beginnings to a quaint office, the chapter now serves 24 counties with over 300 members.

As a newly established organization, NOHF was funded by The Health Fund of Greater Cleveland, a non-profit that ran from 1959-1977 and covered 75% of the chapter's operating costs. United Torch Services, later renamed United Way, took over the Health Fund in support of the

chapter. The remaining costs needed to be covered by member fundraising and the chapter rose to the occasion. The Rehab-Attic Shop was created as a way to meet the need. The shop sold second-hand items donated by chapter members and friends to raise funds.

The annual *Hearts for Hemophilia* event morphed into *The Black and Blue Ball* and is currently the largest fundraising event for the chapter. Organized yearly by Special Events Manager Dawn Evans, the event did not lose momentum even when due to COVID-19, it was held as a Zoom dinner and auction in 2020.

The *Annual Meeting and Clambake* occurred every fall throughout the 50's and 60's, evolving from park gatherings to meeting in hotel banquet rooms, eventually growing into an overnight stay to encompass enough time for education and socialization.

The *Annual Meeting* continues to this day with nearly 200 members gathering to learn more about ever-changing topics such as insurance, treatment options, joint health, and chapter and industry business.

NOHF is noted for its famous members: Jesse Schrader, professional baseball player famous for his 92 mph pitch is a current member and uses his talents to work with children in the community. Randi Paltrow, Executive Director in the 90s, is the aunt of Gwyneth Paltrow. In 1997, Gwyneth honored Cleveland with a visit that generated chapter funds.



Arthur S. Hecker
\$29,500 Fund Drive Set by Hemophilia Unit
The Northern Ohio Chapter of the National Hemophilia Foundation last night announced plans for a \$29,500 fund drive to begin here next month.

During the campaign, a booklet, "The Hemophilic and His School," will be distributed. The booklet is one of many projects resulting from last year's campaign, according to Arthur S. Hecker, the group's president. Hecker said money raised would help research projects at area hospitals, provide orthopedic appliances and, when possible, frozen plasma. Hemophilia is a bleeding condition which chiefly affects males. There are about 1,000 hemophiliacs in northern Ohio.

Kenwood Post
May 1965

Northern Ohio Hemophilia Foundation

Remember when...



Bleeding Disorders Camp - 1968



1968



Bleeding Disorders Camp - 1968



Ruth Saylor, ED (right) - 1973



Children's Party



Bleeding Disorders Camp - 1968



Members, Frank Chrencik, Art Hecker, John Bernstein, Don Matchett and Guy Flynn - 1969



1967



Rickey Warchel - 1970



Annual Meeting and Clam Bake - 1968



1967



DOUBLE REWARD. Young hemophilia victims resped double rewards from Higbee's antique toy exhibit. Proceeds went to Hemophilia Foundation, 14820 Detroit Ave., Lakewood. Three East Cleveland boys, from left, Michael, Peter and Paul Shelling, will spend two weeks at camp with 37 other hemophiliacs. With them is grandmother, Mrs. Mary Shelling, and Richard Branaghan, executive director of the foundation.

The Sun Post/Ledger - Aug 1969



HEMOPHILIA FOUNDATION pamphlet is being distributed here to describe the services available for those with this blood condition. Arthur S. Hecker, president of the Health Fund agency, shows the new pamphlet to Mrs. John T. Bernstein, 33700 Cedar Rd., Pepper Pike, and her son, John, 3, who has hemophilia.

Cleveland Press - April 1966



Dr. Ratnoff - 1973



Glenn Pierce (age 12) 1967



Dawn Evans, Tanya Ricchi, La'Chandra Oliver and Randi Clites

Several of the most honored members and friends may not be known to the general public but are greatly regarded in the hemophilia community nationwide. In the 1950s, Dr. Oscar Ratnoff, a hematologist at Case Western Reserve University School of Medicine, identified Factor XII. He also isolated blood proteins and found the blueprint for the clotting cascade. This research led to treatments we still use today. In the early 1970s, he also developed a way to identify carrier status. At the top of his list of accomplishments, he saved many hemophilia patients from contracting AIDS by following the connection between HIV and blood clotting factors, and warning of the risks early in the epidemic.

Another chapter member, Glenn Pierce, is known for his work with NHF and MASAC. Our very first Executive Director Ruth Saylor, 1957 until 1988, forged her way in the arena of advocacy and networking. She made each and every member feel special and valued, and even visited members' homes frequently. She spoke at events across the country raising awareness on the issues most impacting the bleeding disorders community.

Today NOHF's staff includes Executive Director Tanya Ricchi, Special Events Manager Dawn Evans, Program Manager Randi Clites and Administrative Manager La'Chandra Oliver. The team works diligently on behalf of all chapter members ensuring all available resources are accessible to those that need them. Among these resources are scholarships, emergency aid, medic alert bracelets, summer and family camp, educational dinners and events.

Tanya Ricchi shares her thoughts on upcoming objectives, "My goal for the chapter is to support our families through the times of change that are on the horizon and strive to find creative ways to continue providing meaningful and relevant education and support. We want to encourage and assist the members of our bleeding disorders community to reach their full potential."

As a 24-year member, I am proud of my chapter and what it accomplishes on a daily basis. Tanya and her team move the community forward meeting the ever-changing needs of its members through specialized programs, scholarships, emergency assistance and more. The towers, halls and stadiums on Cleveland's shoreline cannot outshine the meaning of strength and hard work of the Northern Ohio Hemophilia Foundation.

NOHF: 216-834-0051, info@nohf.org
<https://nohf.org/>

MISSION THE NORTHERN OHIO HEMOPHILIA FOUNDATION INC.

To enhance the quality of life for people with genetic bleeding disorders and their families, through advocacy, education, research and other constituency services.

Happy NOHF Members Through the Years!





LET'S PLAY IX GOLF OUTING
Oct. 19 In-Person



GEN IX ADVOCACY EXPERIENCE
Oct. 28-31 In-Person



MEN'S EDUCATION & EMPOWERMENT RETREATS
Oct. 28-31 In-Person | Dec. 9-12 In-Person



WOMEN'S EDUCATION & EMPOWERMENT RETREATS
Nov. 12-15 In-Person | Dec. 16-19 Virtual

hemob.org
(212) 520-8272

FOR MORE INFORMATION AND TO REGISTER:
[HEMOB.ORG/PROGRAMS-EVENTS](https://www.hemob.org/programs-events)

Contribute to our **BIOMATRIX** **Community Playlist** project!



Do you have a song that means something 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>

Music, Health and

Feeling Groovy!

BY ELIZABETH VANSANT, MT-BC

The simple act of listening to music can have powerful impacts, but by actively making music, both your physical and mental health can improve tremendously.

When you listen to a song, various parts of your brain start lighting up. Your temporal lobe helps process tone and pitch while your cerebellum aids in processing rhythm and timing. Your amygdala and hippocampus also activate by tugging on your emotions and memories. These different parts of the brain work together to help you make sense of the auditory stimulus that is your favorite summer jam.

If that's already at work when listening to music, think about all the other parts of the brain that light up when you pick up an instrument or start singing. For example, your motor cortex goes crazy to help sweep a bow across a violin or move your fingers on a keyboard. I could get lost down a rabbit hole when thinking about how amazing the brain is when stimulated by music, so let's instead dive into why music makes you feel the way it does.

Music and emotions are intrinsically entwined. Think back to this morning's workout routine: Were you listening to music? Was that music upbeat or slow and contemplative? Chances are, it was "pump up" music that made you want to keep going. Had you put on a sad song you likely may have either a) quickly changed tunes or b) decided working out wasn't in the cards for you today. If just listening to a song can evoke such reactions, pretend you're now actively creating music. Suddenly, you have a new, creative way to express how you are feeling.

You may want to relax and unwind so you play some slow, meditative music. Or perhaps you want to process what you experienced during the day so you create something to evoke those feelings: it might be fast to evoke a hurriedness or anxiety you felt, or it may be incredibly slow to portray a sloth-like mood you experienced.

There is another huge impact for health – having a community! Being part of a band or choir is an easy way to create a network of like-minded individuals. This has been extremely difficult to achieve during the pandemic, but once people are able to safely gather and create music, I encourage everyone to join a group, or even just go see a show. The mutual love for music will likely lift your spirits in just a few minutes.

We've discussed the benefits that music provides for improving mental health, but did you know that listening to or playing music can also aid you physically? Let's do an experiment: I want you to go on a walk and listen to music. Put your favorite playlist or album on and just walk. Now, notice your pace in relation to the music you're hearing.

Chances are, you are matching your gait pattern to the tempo, or speed of the song. If your body can adjust and move itself to the beat, think about what it does on a deeper level. Your breathing and heart rates can also adjust based on the outside, rhythmic stimulus. This can be a game changer when it comes to chronic pain because it allows you to just be present with the music instead of putting focus on slowing your heart and breathing rate.

Now that you've read some of the mental and physical benefits that both listening to and playing music can have, I encourage you to turn up the tunes or pick up an instrument. Enjoy the creative process and move your body to something groovy!



ABOUT ELIZABETH VANSANT, MT-BC

Elizabeth is a board-certified music therapist who primarily works with neurodivergent and disabled people in Seattle, Washington. When not making music, Elizabeth can be found on hiking trails, baking something delicious, or snuggled up on the couch with her cats.

BIOMATRIX] PRESENTS THE COMMUNITY PLAYLIST

BY SHELBY SMOAK, Ph.D.

A lyric from a favorite band of mine, Wilco, has always stuck out to me. When Jeff Tweedy sings, “I was saved by rock n’ roll,” I can’t help but think of all the ways rock ‘n roll has saved me. It began with Billy Joel during my knee synovectomy at age 10. Music became the root for my recovery, and my growth throughout high school and college.

Music distracted me from self-infusion needle sticks and the half hours pushing in 60cc of clotting factor. It saved me from the pain of physical therapy when recovering from a total hip replacement, later a knee replacement, and from a traumatic month-long knee bleed. Music still saves me at 2 am when the pain of a bleed won’t let me sleep, or when I’ve been stuck in an ER for hours. And so, I let music save me, because it can, because no matter what pain I am in, nor what joy I may feel, it is there for me — always. I have come to realize my experience is not

isolated. A plethora of our community members lean into music as their own, unique salvation: a balm to the hurt, a salve for the pain.

Through the BioMatrix Education program “Singing to Heal” which I often lead, I hear the same message about the power of music in other community members’ lives. Moreover, I am awed and impressed by the ways this suffering gets channeled into their musical creations, much like I do in my self-styled project Bleeder where memoir and music-creation blend. While we may not “*write the songs that the whole world sings,*” we may write the words our community can feel.

Without further ado, I invite you to check out this community playlist of original music from people with a bleeding disorder. It’s been a pleasure to hear their songs, to feel their power, and now, to share them with you.

“busting out the darkstar > country trux”

Billy Conde Goldman
(creature-blossom)



Genre: Experimental; Harmolodic Rock ‘n’ Roll

For fans of: Mr. Bungle, Frank Zappa, Mike Patton

Shelby’s take: Atonal saxophone, a vocal cacophony of hypnotic and recurring lines, marching snare rolls, haphazard melodies, and fuzz guitar chords make this song a late-night, coffee-fueled journey into post-modernism.

On having hemophilia A: “Of all the songs I have written since I was a kid, only one mentions hemophilia in word. That said, many songs express pain, loneliness, sadness, fear and anger in the music and the lyrics—all a result of having a bleeding disorder. My sense is such expression would manifest in my songs no matter what, as life can be a struggle independent of wellness. Life can also be joyous and I have experienced much joy from being a part of the bleeding disorders community. This is also reflected in my songs.”

To Find: Search Google “creature-blossom busting out the darkstar”



"That's When I Love Her So"

Dave Colvin



Genre: Country/Folk

For fans of: Beatles, John Prine, George Harrison

Shelby's take: A bouncy acoustic guitar, catchy vocals, and playful lyrics make this upbeat love song a pared down, perfect for your coffee shop, mid-afternoon feel-good moment.

On having hemophilia A:

"Basically since prophylaxis treatment, having hemophilia doesn't impact my music. Back in the day though when giving "as needed" treatment, performances were always problematic. Now I can plan ahead and give factor the day of a performance if needed!"

To Find: Search on Spotify and Apple Music: *Dave Colvin That's When*



"Keeping Up"

Shawn Decker

Co-written with Kyle Wiggins
(Synthetic Division)



Genre: Electronic Dance Music

For fans of: Pet Shop Boys, Depeche Mode, New Order

Shelby's take: Arpeggiated synthesizers, distorted synth-bass rhythms, driving EDM beats, a tasteful application of keyboard melodies, and understated vocals make this track the perfect late-night club companion.

On having hemophilia A:

"Embracing every aspect of my life is important as a songwriter, and my bleeding disorder is certainly part of the equation. Finding peace through adversity has helped me deal with some tough situations medically, and I certainly draw upon that theme quite often in my music."

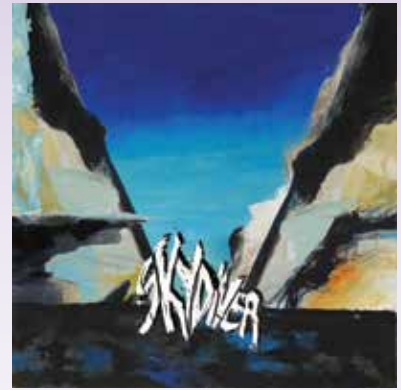
To Find: Search on Spotify and Apple Music: *Synthetic Division Keeping Up*



Photo Credit: Tristan Williams

"Lend Me a Hand"

Spencer Duggan
(Skydiver)



Genre: Alternative Rock

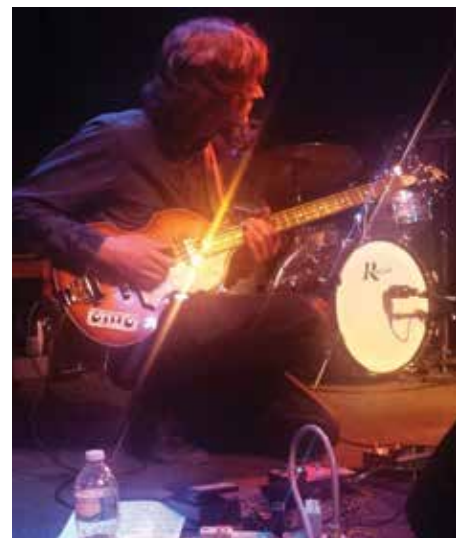
For fans of: Radiohead, Elbow, Doves

Shelby's take: A soft-strummed acoustic guitar, ultra-clean guitar licks, rolling bass lines, jazz-esque drum play; the drift of falsetto vocals carry the song along like the ebb and flow of a quiet city night, lending this song the ideal track for drinks and a rooftop bar.

On having hemophilia B:

"Hemophilia played a large part in discovering my love for music. It is a great way to reset my mind even when things are hard. I consider myself lucky to have it under control so I can keep making music for myself and my local chapter for years to come."

To Find: Search on Spotify and Apple Music: *Skydiver Lend Me a Hand*



"Spratz"

Max Feinstein



Genre: Alternative Rock/Grunge

For fans of: Ween, Fountains of Wayne, Radiohead (Bends-era)

Shelby's take: Infectious distorted guitar riffs, fluid bass lines, a driving chorus, energized vocals, and amazing studio production make this song a pool party instant hit.

On having hemophilia A:

"Joint damage makes it physically difficult to play and has influenced the stylistic aspects of my songwriting. In addition to producing spontaneous bleeds, hemophilia can produce a lot of rage. We don't want that rage to bleed out into the wrong places, much like bleeding into the wrong places. Music was the safest place to channel my aggression and in doing so, it became catharsis."

To Find: Search on Spotify and Apple Music: *Max Feinstein Spratz*



"Remnants"

Trevor Graham
(Organ Dealer)



Genre: Punk/Grindcore

For fans of: Napalm Death, PLF, Death Toll 80K

Shelby's take: Adrenaline fueled angst, thick chugging guitars, propulsive bass lines, snare hits faster than you can clap, and screaming, deep throated vocals thrust this song at you; for half a minute, the song clobbers you with its punk-on-steroids energy.

On having hemophilia A:

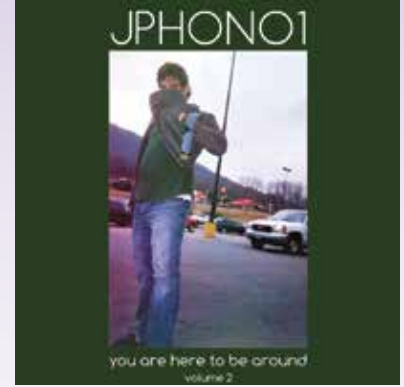
"It makes touring a little difficult sometimes, lots of standing which impacts the joints, then [there is] the trouble of finding a place to infuse."

To Find: Search on Spotify and Apple Music: *Organ Dealer Remnants*



"You are Not Alone"

John Harrison
(Jphono1)



Genre: Alternative/Indie Rock, Jamz

For fans of: Flaming Lips, Pink Floyd, Kurt Vile

Shelby's take: Chill groove, in the pocket bass, 70s-feel guitar lines, fuzzed-out playful organ lines, and Pink Floyd-esque vocal delivery makes this a perfect sunshine, porch-time play.

On having hemophilia B:

"It's not a daily concern but have had internal bleeds that have forced me to cancel live events. Hospital visits and making sure there is factor in my fridge for emergencies. Creatively, it's such a small part of my life it doesn't come into play...but I imagine it's in there in some ways I couldn't identify."

To Find: Search YouTube: *jphono1 You are Not Alone*



“Go-To”

Trevor Martin



Genre: Pop Country

For fans of: Kane Brown, Dan + Shay, Brett Young

Shelby's take: Rolling piano lines, country-telecaster licks; immediate and intimate vocals, the incredibly hooky “Go-To” refrain lands this song somewhere between country ballad and R&B. A supreme listen for driving with your windows down and your hair blowing in the country breeze.

On having hemophilia A:

“Having hemophilia really impacted me earlier on in life. It helped me discover that I really enjoy and have a passion for music. I am not sure I would have discovered that as quickly had I been playing football or another sport.”

To Find: Search on Spotify and Apple Music: *Trevor Martin Go-To*



“No Way José”

Robb McDowell
(Louisville Lip)



Genre: Punk/Alternative Rock

For fans of: Social Distortion, Bad Religion, The Stooges

Shelby's take: Distorted guitars, thudding basslines, locked-in pounding drums; throaty vocals with vitriolic angst drive this song into a high-energy, cathartic vent – ideal for blasting on a warm summer night classic car ride – top down, open and free.

On having hemophilia B: Having a bleeding disorder is probably one of the main reasons I got into writing music among other things. It's a way for me to express my mood and how I'm feeling. I've never been one to talk about “feelings” so this was the best way for me to get things out.

To Find: Search on Spotify and Apple Music: *Louisville Lip No Way Jose*



“Be Mine”

Tamar Mitchel



Genre: R&B/Pop

For fans of: Justin Bieber, Chris Brown, Justin Timberlake

Shelby's take: Hip-hop beats dipping into classic 808 tones, a catchy repetitive guitar line, a head-nod bpm, and tripped out vocals make this song a smooth ride for a late evening city stroll. Mixing soulful R&B with modern electronica carries this tune into sultry perfection.

On having hemophilia A:

“Having hemophilia impacts my music by helping me have the drive to want better for myself and my family. It pushes me to be my best possible self and in doing so, helping others.”

To Find: Search on Spotify and Apple Music: *Tamar Mitchell Be Mine*



"A Collection of British Invasion Hits"

Bobby Murdoch
(The British Invasion Years)



Genre: 1960s Rock

For fans of: The Beatles, The Who, The Zombies

Shelby's take: The nostalgia of jangling guitars, bouncing bass lines, psychedelic keyboards, and familiar lyric sing-alongs make this cover band the ideal live show flashback. Infused with psychedelic hearts, these cover songs nail the 1960s vibe and ooze groovy, mind-bending bliss.

On having hemophilia A:

"Music has always been a way to forget about my bleeding disorder. It also motivates me to continue performing."

To Find: Visit britishinvasionyears.com and click *Videos*



"Glide" Cleaven Pagani



Genre: Alternative

For fans of: Radiohead, Elliott Smith

Shelby's take: Delicate guitar picking, tasteful keyboard subtexts, and whisper-intimate vocals that ponder the burdens of life make this trimmed down song the end-of-night, goodnight, best-friend companion.

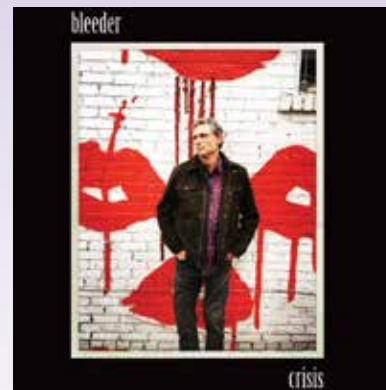
On having hemophilia A:

"I write songs about my life, which includes living with a bleeding disorder. With this song, I attempt to describe how we glide through life encountering many crazy things. It could be a bleeding disorder, psychological illness, divorce, or other situation. We all have burdens to bear that can be unexpected and terrible, but everything is okay when we have someone we love with us."

To Find: Search Bandcamp: *Cleaven Pagani*, Click *Stargazer*, 1st track



"Pain" Shelby Smoak (Bleeder)



Genre: Alternative Rock/Shoegaze

For fans of: Radiohead, The Cure

Guest reviewer's take: A medley of sound with a mixture of new wave alternative, grunge, rock, and indie. Sweet guitar intro with melodic back vocals and smooth bass guitar transitions into a blend of guitar and toe-tapping percussion and fills. The lyrics and message are unmistakable as it not only relates to those with a bleeding disorder but can resonate with anyone living with pain.

On having hemophilia B:

"Music has always been a solace for me. It comforts when nothing else can. Writing music does the same thing. A song like 'Pain' gives voice to something hard to articulate: living with the chronic pain of hemophilia."

To Find: Search on Spotify and Apple Music: *Bleeder Pain*



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 Jeff Johnson.



Jeff Johnson
Regional Care Coordinator

“As a hemophiliac, my role as a Regional Care Coordinator has allowed me to continue a lifelong passion of advocating, educating, and looking out for members of the bleeding disorders community.

Working as a member of the care team has given me joy as I help my community thrive by supporting therapy adherence, minimizing bleeding episodes, navigating insurance and coverage challenges, and working one-on-one to help patients stay bleed free.”

Jeff Johnson is a dedicated, active member of the bleeding disorders community. His commitment to those he serves is evident in the exemplary service and support he provides. Jeff works tirelessly to build community and create a larger voice for a group with unique and essential needs, which has not always been heard.

His extensive leadership experience includes serving as the bleeding disorders camp activities coordinator in Oregon, as a counselor at numerous other camps, as a previous board member for Hemophilia Foundation of Oregon, and working with the Hemophilia Federation of America (HFA) to set up a local Blood Brotherhood program.

Jeff is also a writer whose work has appeared in HFA's newsletter, PEN from LA Kelley Communications, and various chapter and community publications. In whatever capacity he can make a difference, Jeff is passionate about advocating for and serving the interests of the bleeding disorders community at a local and national level.

Tell us about yourself.

I was born in Denver, Colorado to a couple of teenage sweethearts who were not ready for a kid, especially one with hemophilia. My first few weeks were with a foster family as I was passed over for adoption. My parents came along and were told they could wait three years or take this little hemo-baby right away. They jumped at the chance.

We moved around a bit until my folks put down roots in Vancouver, Washington. Growing up, our home was generational - there were always elders, cousins, nieces and nephews, grandbabies, and a variety of scruffy dogs and cats running around. My family was always bursting with life, love and laughter! The first time I ever lived in a home of fewer than 12 was after high school when I moved out to pursue college, make music, and see the world.

Today I live with my wife of 16 years, Stephanie, and our toddler, Lily. In 2008, we packed up and made the long and arduous trek east from Vancouver to Camas, 10 minutes down the highway, where we currently reside.

Due to hepatitis C contracted from tainted clotting factor, I was unsure of ever having a baby. I did not want to pass the virus to my wife, nor risk not being there for a child. Thanks to a new effective medication, my hep C was cleared in 2017. Soon after, Lily was on her way! We are open to adopting a child in the next couple of years. The gratitude I have for my adoptive family is indescribable and I want to pay that forward.



The most noteworthy things about myself are as follows: I was born in the 1970s with hemophilia and am still alive today. I spent a summer living in a small town just outside Paris and was conversationally fluent in French. I was a jazz musician for many years and served as Master of Ceremonies at the largest high school jazz festival in the Pacific Northwest for two decades.

I once had a life-threatening GI bleed, and nine days after treatment, I was hiking the Great Wall of China after a jazz gig in downtown Beijing. As a writer, I've had several articles about hemophilia and living with a disability published. I am an ordained secular minister and have performed 15 wedding ceremonies. And I love Star Wars, which is neither unique nor remarkable, but I had to put it out there!

What is your connection to the bleeding disorders community?

I have severe hemophilia A and very much consider the community to be my family. I learned my birth uncle had hemophilia and it was suspected I would too, which is partially why I was placed for adoption. Coming of age during the “hemo-caust” of the early 80s, I was a young camper who saw nearly all my early friends and heroes with hemophilia succumb to AIDS and HCV. I have been involved in the community in various capacities most of my life. Wherever and whatever I've been up to, the community has always been as much my family as the wonderful knuckleheads who adopted me.

What brought you to BioMatrix?

I loved the idea of caring for my fellow hemos and participating in more community events. I also wanted to learn about the industry from the inside, hoping it would make me a better advocate. So, I called a friend who had reached out to me previously about coming to the company, and after interviewing, I accepted a position with BioMatrix. Soon after, an opportunity was presented to work closely with the Boise, Idaho Hemophilia Treatment Center – it's been a wonderful experience!

What part of being a Care Coordinator do you cherish the most?

That's a tie between my patients and my peers. Nothing beats chatting daily with other bleeding disorders families. It's sometimes challenging because I have to switch when interacting with my patients from my “Care Coordinator” hat to my “hemo-Yoda” hat that I'd wear if they were just a community friend, but I cherish it all, nonetheless.

Equally important to me are the people I work alongside. I trust my co-workers to take care of my hemophilia family and to do it correctly and compassionately. I am often humbled by the dedication, understanding, and care I see my fellow RCCs direct towards their patients. It makes me immensely grateful to know these are the people who are looking after my people. The people I work with are the best, and the people they care for, I consider my dearest family.

Describe your most difficult challenge?

In the past and still today, having hemophilia has been my most difficult challenge. It was the reason I was orphaned, caused the loss of my childhood camp friends, gave me hep C, and has inflicted daily pain since grade school. I overcame the challenges because of the examples I had to look up to - those who taught me to make hemophilia my strength instead of my weakness.

My health condition has made me stronger, shown me how truly precious life is, armed me with a sense of empathy and humor, and connected me to the most amazing people who walk this Earth. So hemophilia is definitely the highest hurdle I've ever had to jump, which is ironic because it's also the reason my arthritic body is incapable of jumping. I manage to overcome it, again and again, every day because it also drives me, gives me purpose and allows me a way to serve others.

To contact Jeff, call or email: 360-553-6402, jeff.johnson@biomatrixsprx.com



BIOMATRIX] ON THE *Virtual & 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; 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 attends 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

With social distance restrictions easing, we agreed it was time to get in a "flamingling" mood! Ladies gathered June 24th at the Brew Garden in Middleburg Heights for the **3rd Annual Flamingle** sponsored by BioMatrix and Medexus.

Did you know flamingos are very social birds, traveling and living together in large groups? By staying in large groups, flamingos can safely maximize food intake and avoid predators when they are in their vulnerable head-upside-down position. This event represented a gathering of those in a common community who came together for support, just like flamingos!

After introductions and some interesting flamingo trivia, the ladies placed their food orders and settled in as Jill Rowley, Medexus Nurse Educator, and Michelle Stielper, Community Advocate and a woman with hemophilia presented a *Factor in the Family* program.

Lunch was served as the presenters got the conversation going. Following lunch and education, the ladies enjoyed crafting together. Michelle Stielper led a demonstration on making birch branch suncatchers. Now hanging in the home windows of those who attended, the light-catching crystals used in the creations reflect many colors! It was a happy and relaxing way to kick off many more live events hopefully to come soon!



Starr, Shelia Biljes and Brooklyn



Bright smiles from Amber and Stephanie!



Lovely ladies! Kitty, Shelia Biljes and Charlene

OHIO

Shelia Biljes

Nicknamed *Little Switzerland of Ohio*, Sugarcreek is a small, not quite 4 square miles, slice of heaven located between Cleveland and Columbus. The short drive through the town is speckled with farms along the rolling hills. It's the place to go if you are looking for some of the friendliest people and the best home-cooked food in Ohio!

On the picture-perfect day of June 25th, Sugarcreek's Carlisle Inn was the destination for BioMatrix and Medexus representatives to host an **Amish Ladies Brunch and Craft** with a group of lovely women for a few hours of sisterhood.

Medexus Nurse Educator Jill Rowley and Community Advocate speaker Michelle Stielper shared a *Factor in the Family* presentation focused on women with bleeding disorders. After a nourishing brunch, the women continued the conversation while getting in touch with their creative talents and crafted birch branch suncatchers to take home. The cozy gathering was a perfect opportunity to learn and gain support from one another.



BioMatrix's Michelle Stielper, with Nora and Marie (seated)



Chardea, Alayna, and Tiffany with Michelle Stielper



Carter hard at work

OHIO

Shelia Biljes

The exciting fantasy world of anime and its intriguing characters and storylines have become extremely popular with today's youth. With that said, what could be more perfect than bringing together younger members of the Northern Ohio Hemophilia community to master the art! The Brew Garden event room in Middleburg Heights was the perfect place to be on June 24th for *Introduction to Figure Drawing*, a lively and engaging event!

Judy Doyle, Novo Nordisk's Hemophilia Community Liaison presented *8 Tips to Adulting* as everyone enjoyed a delicious taco feast. Her presentation covered everything from the importance of cleaning your room to how to manage finances. This evening was tailored toward young adults, some of whom will soon be stepping out on their own. Great skills to master before heading off to college or jobs.

Following Judy's presentation, Regional Care Coordinator and BioMatrix's artist extraordinaire Michelle Stielper began her program with a focus on learning to draw

anime characters. Inspiring artists were ready, willing and excited to create their masterpieces!

Using the artistic principles of scale and proportion, Michelle led participants through a quick draw exercise. The lesson entailed a focus on tips and tricks to draw an anime character's face in detail and how to add the body in proportion. Michelle discussed and demonstrated how to include shading and blending techniques; details to make their characters look more realistic and pop off the page. Through group and some one-on-one attention throughout the lesson, everyone's simple sketches came to life.

Kids and adults alike did an amazing job. A program initially intended for teens and young adults, quickly turned into a family affair as the adults didn't want to miss out on the fun! Those who initially did not think they could draw were impressed by the end of the program! As Michelle says, "In art, there are no mistakes, just happy accidents." At the close of the evening, we had a room full of budding artists and many refrigerator-worthy masterpieces!



So sweet! Quinton and Kylan



Smiles! Ashley and Aaron



Chantel fully concentrates



Carmello and Cameron

SOUTH CAROLINA

March Foertsch and Peggy Klingmann

BioMatrix was pleased to partner with Medexus and Hemophilia of South Carolina for their first in-person program of the year June 26th. We enjoyed a lovely brunch in a cozy meeting room at Coffee Underground in Greenville, a local breakfast and lunch destination.

BioMatrix Education Specialist Kelly Gonzalez gave a virtual presentation of *It's OK to Not Be OK*, followed with a Q&A session. Kelly's presentation centers on how to open a dialogue with healthcare providers regarding pain control, depression management and anxiety.

Attendees were well engaged, gave positive feedback and expressed interest in attending future programs. We look forward to our next visit with the South Carolina bleeding disorders community soon!



Ashley, Lisa and McKenzie listen to the presentation intently



Diana and Brenda converse with Peggy Klingmann



Marcy Foertsch welcomed all



Cristal, Martha, Autumn and Ainsley

OHIO

Shelia Biljes

They say that “music heals the soul,” and it creates a lot of smiles too! Sponsored by BioMatrix and Novo Nordisk, a **Musical Event** was held July 15th at Bucci J-Bella Restaurant in Strongsville.

During a pre-concert Italian dinner, Novo’s Community Liaison Judy Doyle shared her company information and went to each table to introduce Vaughn Ripley, Advocate Speaker, who joined the event virtually.

BioMatrix Education Specialist Shelby Smoak appeared live and in-person to share his music and special presentation, *Singing to Heal*. Brought about by Shelby’s enthusiasm and good humor much fun ensued!

Shelby introduced the group to the healing powers of music, getting the beat going as everyone joined in. Provided with egg shakers, everyone acted as backup band members and the hilarity began. Shaking, singing and merriment filled the room – even restaurant staff joined in! Smiles were on every face as the activities for the evening closed. For me, the energy of the event lasted for days later and is proof that music really does have the ability to heal the soul.



An entertainer on the job



Happy! Kylan and Allyson



DaShawn and Sierra have hands full with Emir and Emon!



Shelby stops for a photo fans, Benjamin and Stephanie

OHIO

Shelia Biljes

After two weeks of rain skies cleared and Mother Nature delivered a beautiful summer day for the **Schwager Family Inaugural Golf Outing**. July 19th proved to be the perfect day for golfers of the Northern Ohio Chapter to take part in a special fundraiser hosted by one of its member families.

The Schwager family has been a vital part of the chapter for many years and this year they grabbed the reins to organize the outing and did a fabulous job. Pine Hills Golf Club in Hinckley, with its rolling hills and deep green lush landscape, provided a spectacular setting for golfers and spectators alike.

For those supporting the fundraiser, opportunities were many. Hole 4 was designed for golfers in a gambling mood, along with a 50/50 raffle. Breakfast and lunch were provided while carts of ice-cold drinks made frequent rounds.

Edna Stone proudly sponsored a hole in honor of her son, Forrest. Many thanks to the Schwager family for their time in organizing this remarkable event, to all the sponsors, and to the golfers who came out to support a wonderful cause! Rumor has it all participants are eager to attend this event again in 2022!



Edna and Forrest looking stylish!



Jerry and Nolan pleased as punch to spend the day on the beautiful course supporting a fantastic event

OHIO

Shelia Biljes

You've heard the old saying, "there are plenty of fish in the sea," and that is certainly the case at Wallace Lake in Berea. On a bright and sunny July 20th, BioMatrix sponsored a highly anticipated **Fishing Derby** – a fun family day for local bleeding disorders community members. Everyone gathered for an appetizing lunch as the kiddos eagerly anticipated the arrival of skillful fisherman, Doug Stewart.

Ready for some action, the children radiated with excitement as they carried their poles to the pier. Safety was number one on the agenda followed closely by fun, fun, and more fun as Doug taught each child to bait their hook with a worm!

Every fish that took a bite was measured and tallied to award winners of the biggest catch and most fish caught. Benjamin caught the largest while his sister Evelyn caught the most. Everyone did a wonderful job and enjoyed helping each other.

Following our fishing adventure, some families jumped in their cars for places unknown while others drove to the other side of Wallace Lake to enjoy the beautiful beach and take a refreshing swim. It was our first fishing derby but definitely not the last! There's more fun to be had!



Trophy winners! Evelyn and Benjamin



Doug Stewart teaches the kids about worm baiting



Looks like Brylin has a big one on his line!



Maddie shows Selena how to reel them in



Selena relaxes after a hard day of fishing



Jace prefers gummy worms



Kai shows off his catch



Evelyn is a fishing pro!



Brayden baits his hook

OKLAHOMA

Felix Garcia and LeAnn Wilson

BioMatrix was proud to be a Silver Sponsor at Oklahoma Hemophilia Foundation's **Annual Meeting** July 24th-25th – the first live and very exciting event of the year! It was dubbed a "Family Reunion" early on and the event proved that true. Families from all over Oklahoma and even some from southern Missouri and western Arkansas gathered for the event at Embassy Suites by Hilton Oklahoma City Northwest. Everyone was happy to see one another and to hear live presentations again. It's safe to say no one forgot to unmute!

To add to the excitement, we sponsored a raffle for the coolest S'mores Gift Basket at the BioMatrix booth. Everyone who signed up for our award-winning newsletter or updated their contact information was entered to win. The lucky name drawn was Iyezack of Oklahoma City. Congratulations to Iyezack and his family because we're sure mom will have him share the sweet treats with the whole family! We look forward to the next opportunity to reunited with our Oklahoma bleeding disorders families!



Emily, Layla, Shannon, Bentley and Lillian enjoyed the family weekend



Meet S'mores basket winner, lucky Iyezack!

BIOMATRIX ON THE *In-Person* MOVE!



Caleb takes great aim

TENNESSEE

David Tignor

Bragging rights were the goal at the **15th Annual "Pitchin' for Caleb" Cornhole Tournament** August 14th at Centennial Park in Crossville. Led by Kelley and Shane Wood in honor of their son who lives with von Willebrand Disease, this distinctive event raises funds to benefit Tennessee Hemophilia and Bleeding Disorders Foundation's Camp Freedom, a summer camp program for children living with bleeding disorders.

After checking in, time was allowed for practice and participants drew the names of their randomly assigned partners. The morning competition started strong with 16 teams each aspiring to be the winners. Following a short break for lunch provided by community members Ronnie and Scotty Webb, the friendly but formidable competition continued into the afternoon. The engaging day wrapped up with door prizes, raffle drawings, and tournament winners announced.

BioMatrix was one of several proud sponsors of this unique fundraising tournament – we look forward to participating again next year!

WASHINGTON DC

Terry Stone

Love was in the air as the Hemophilia Association of the Capital Area (HACA) gathered outside to enjoy lunch and games with family and friends. Everyone was excited to welcome back the **Annual Picnic** at Occoquan Regional Park in Lorton, Virginia on a warm, sunny August 22nd. Wide open spaces offered a great green landscape for games and chasing your best pals that you haven't seen in a while. Chapter leadership were on hand to serve lunch to keep contact at a minimum, and we have it on good authority that seconds or thirds will be kept confidential!



Terry Stone and Medexus' Kelechi catching up on everything!

Safety was a top priority as local guidance was observed. Creativity took center stage as everyone had their own way to say hello based on their contact comfort levels. Some with fist bumps, others with elbow rubs, while others sent air kisses flying from afar, six feet to be exact! Of course, there were some that just couldn't stay away from each other and opted for the long and heartfelt hug that had been building up inside them for 18 months! Whatever their fancy, it was obvious this was an afternoon that was needed by most, enjoyed by all!

OHIO

Shelia Biljes

Humid, 95-degree temperatures did not keep lovely women of Northern Ohio from leaving their air-conditioned homes August 24th and gathering at Bonefish Grill in Westlake where BioMatrix and Genentech hosted a **Ladies Lunch**. Over a delicious lunch, Genentech Clinical Education Manager, Ami Seligman, RN, MHA conveyed the facts and answered questions about their therapy, Hemlibra. Joining Ami was Patient Ambassador Miranda from Indiana. She shared her story of adopting amazing twin boys and facing not only hemophilia but also inhibitors. Her message of hope and faith was an inspiration to all. Everyone received a coveted BioMatrix Cookbook, wrapping up the delightful afternoon of education, good food and social time together.



Stephanie jotting down an important fact

TENNESSEE

David Tignor and LeAnn Wilson

In consideration of the needs and wants of their membership, the Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) held its Annual Meeting as a hybrid event on August 27-29th. The in-person part of the meeting took place at the Embassy Suites in Murfreesboro. The theme of the meeting was very fitting, "One Blood-One Family."

There were a variety of educational sessions for the adults to choose from, along with time to socialize and meet with exhibitors. The kids/teens program was located off-site at Deer Run Retreat Center in Franklin where they enjoyed outdoor activities including a giant swing, swimming and ziplining into the refreshing lake!

After dinner and awards on Saturday, singer/songwriter and community member, Trevor Martin, entertained everyone with his skill on the guitar and singing several of his original songs.



David Tignor shares a moment with old friend Justin



Trevor Martin with music fan, Haylee

One might not realize how much effort it takes to put together a hybrid meeting. It was truly a group effort of the THBDF staff, volunteers and financial supporters. This remarkable event was successful because of the united bleeding disorders community working as "One Blood-One Family." BioMatrix was happy to be part of this event and we are especially appreciative of everyone who stopped by our booth to visit!



Along for the ride, Sarah and Ann



NEW JERSEY

Richard Vogel

Not many chapters or associations can yet celebrate a 50th anniversary but on August 28th, Hemophilia Association of New Jersey (HANJ) did just that with a **Summer Camp Wellness Gathering!** Families gathered at Eagle's Landing Day Camp in North Brunswick. With COVID-19 protocols in place

– families were even given the option of a colored wrist band to reflect their level of comfort – the day was filled with fun, food and games for the HANJ bleeding disorders community.

The day began with educational programs which included topics about joint health, making healthy eating decisions, empowerment and dreaming big. Included was a program that I led on behalf of BioMatrix called, *Camera On-Healing and the Art of Photography*. Reviewing data on art and photography and the effects they have on one's health and brain function, I went over a few concepts of photography and had participants go out and put them into practice. Those who did not have a camera put the concepts to paper, literally. By using photo-sensitive paper and using objects found on the campground, everyone was able to participate.

Following a tasty picnic-style lunch, the fun began. Many enjoyed water activities with a water slide and a big water bucket. For those who wanted to stay dry, BioMatrix sponsored a big slide and carnival games in a separate tent.

It was quite fitting to celebrate HACA's 50th anniversary. The chapter was founded in August 1971 by 10 concerned families. It's has been a long and sometimes difficult journey from those first meetings held in living rooms and at kitchen tables, but worth it to see the smiles on faces, old and young alike!



Assisting Educating Advocating For The Bleeding Disorders Community.



www.hemophiliamed.org

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

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

“The table is a meeting place, a gathering ground, the source of sustenance and nourishment, festivity, safety, and satisfaction. A person cooking is a person giving; Even the simplest food is a gift.” — Laurie Colwin



Upcoming Events

OCTOBER 9, 2021 VIRGINIA

Hosted by BioMatrix and CSL Behring
Bead Your Journey
Surf Club Ocean Grille; Virginia Beach
Contact: Michelle Stielper 703-795-6268
michelle.stielper@biomatrixsprx.com
or Terry Stone, 703 795-6269
terry.stone@biomatrixsprx.com

OCTOBER 13, 2021 OHIO

Hosted by HEMA Biologics and BioMatrix
Family Inhibitors Dinner
Juniper Grill; Cranberry Twp
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com

OCTOBER 15, 2021 OHIO

Hosted by BioMatrix
Family Chili Cookoff and Boo Ride
Lorain Metroparks; Lagrange
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com

OCT. 16, 2021 NEW HAMPSHIRE

New England Hemophilia Association
781-326-7645, newenglandhemophilia.org
FallFest
Sherman Farms; Conway

OCTOBER 17, 2021 TENNESSEE

Tennessee Hemophilia and Bleeding Disorders Foundation
615-900-1486
www.thbdf.org/thbdf-walk-5k
3rd Annual Blazin' for Bleeders
The Park at Harlinsdale Farm; Franklin

OCTOBER 17, 2021 VIRGINIA

Virginia Hemophilia Foundation
804-740-8643, vahemophilia.org
Unite for Bleeding Disorders Walk
Robious Landing Park; Richmond

OCTOBER 20, 2021 OHIO

Hosted by Takeda and BioMatrix
Family Dinner and Fall Craft
Bravo Cucina Italiana; Beachwood
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com

OCTOBER 24, 2021 NEW YORK

Bleeding Disorders Association of Northeastern New York
518-729-3577, www.bdaneny.org
Annual Meeting
Liberty Ridge Farm
Schaghticoke

NOVEMBER 11, 2021 OHIO

Hosted by Novo Nordisk and BioMatrix
Family Dinner
Bucci J Bella Restaurant; Strongsville
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com

NOVEMBER 14, 2021 FLORIDA

Florida Hemophilia Association
305-235-0717, floridahemophilia.org
Unite for Bleeding Disorders Walk
Okeethee Park; West Palm Beach

DECEMBER 4, 2021 OHIO

Hosted by Northern Ohio Hemophilia Foundation and BioMatrix
216-834-0051, <https://nohf.org/>
Holiday Event
Cleveland Zoo Rainforest
Contact: Shelia Biljes, 440-813-1626
shelia.biljes@biomatrixsprx.com

DEC. 5, 2021 PENNSYLVANIA

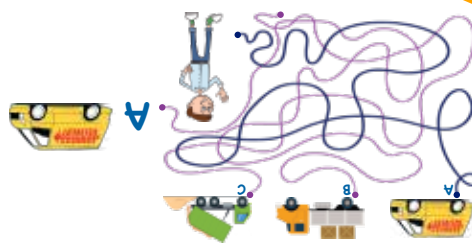
Brandywine Valley Foundation
info@brandywinehemophilia.org
brandywinehemophilia.org
Year End Event
Mendenhall Inn; Mendenhall

Time for Fun!

Puzzles on page 27

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

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



Time for Fun!

Hi Kids! Robert has just one dose of clotting factor left at home. He placed an order and it is supposed to deliver today. Which truck do you think his order of factor is on? Follow the trail to the right truck! Answer is on page 25.



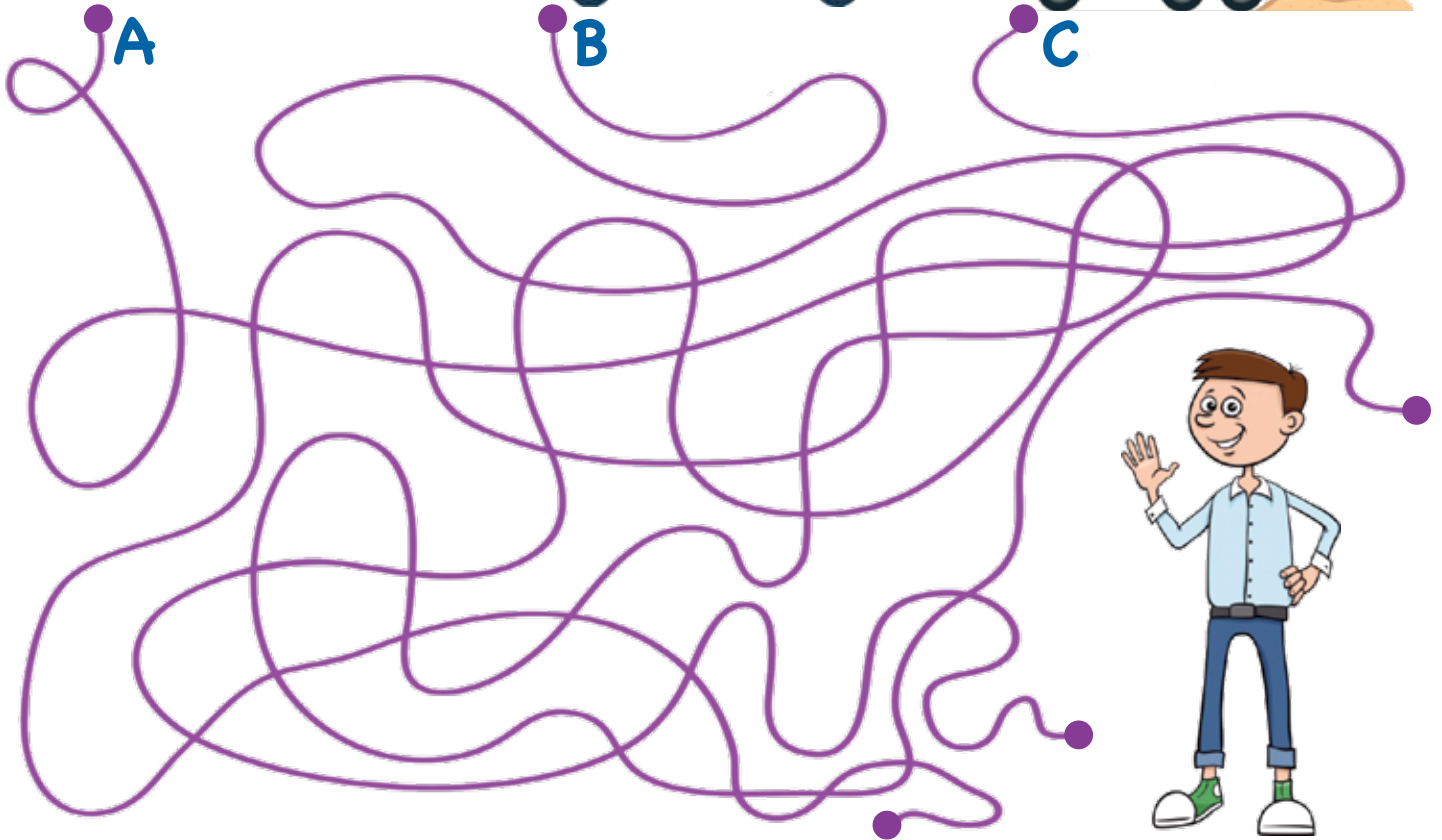
A



B



C



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

Sudoku!

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



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

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bleedingdisorders.biomatrixsprx.com 

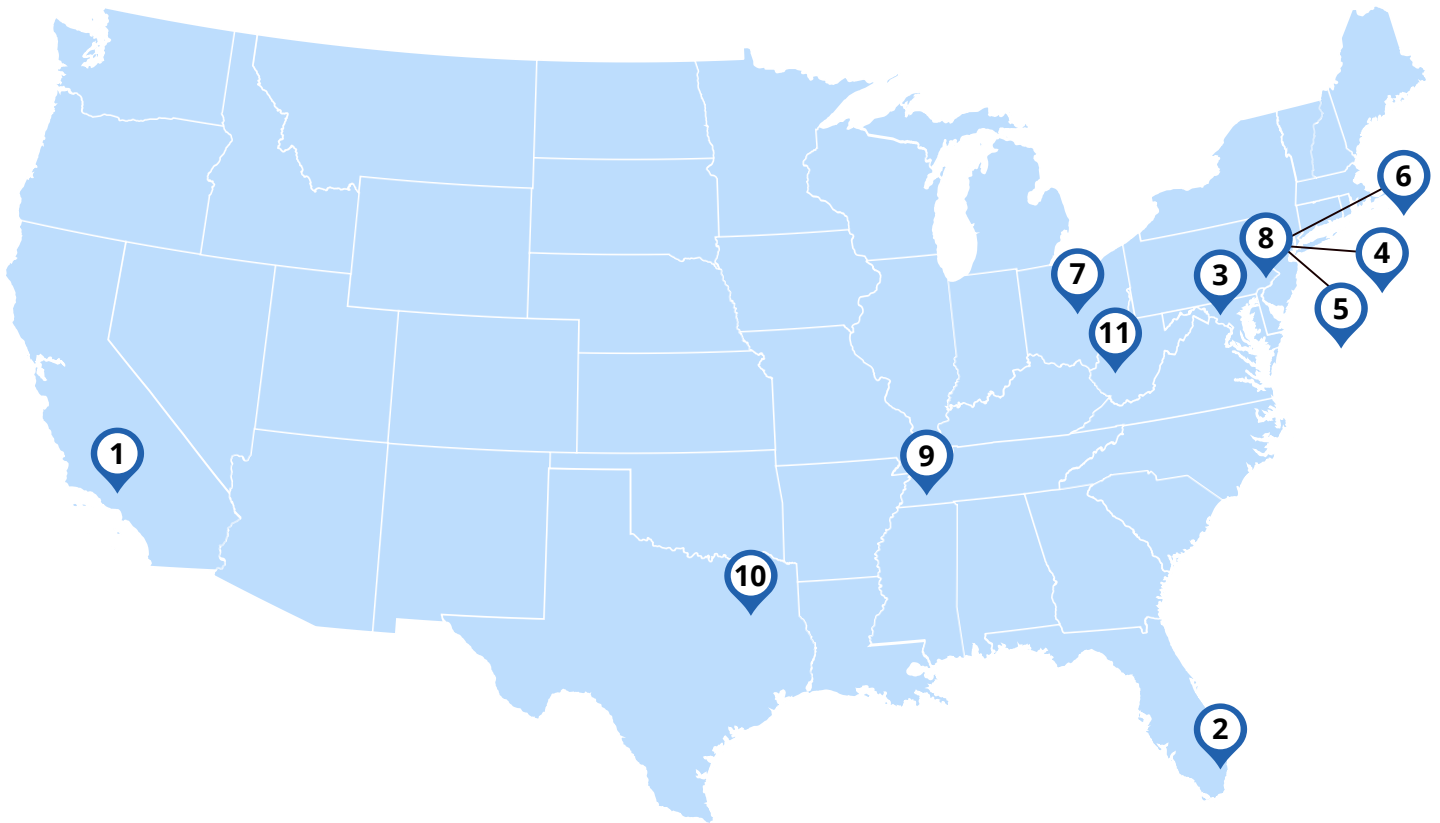
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Specialty Pharmacies



1. Canoga Park, California
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

