[BIOMATRIX]

NEWS

DEDICATED TO MAKING A DIFFERENCE

SUMMER 2019
VOLUME 14 | ISSUE 3

> **Rise above the storm and you will find the sunshine.**
> **— Mario Fernández**

VOLUME 14| ISSUE 3
SUMMER 2019

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

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.

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:

Can you believe 2019 is already half over? Where have the days gone! These last few months have had me traveling around the country. I have been fortunate enough to spend time with many of you in a few very unique settings from relaxing candle painting to exhilarating ax throwing. It's been a blast hearing your stories, laughing, commiserating, and getting to know every one! I hope to meet many more of you in the months to come.

This issue of our newsletter highlights the musical gifts of just a few of our talented community members. For many people with a bleeding disorder or other chronic condition, music has been an inspiration, a source of self-esteem, accomplishment and motivation, a positive way to reduce stress, a distraction from pain, and an encouraging way to increase relaxation. Read on to meet our featured impressive performers and learn their stories. Talent flourishes in our community!

By the way – check out our brand-new logo – pretty sleek and modern, wouldn't you say!

Enjoy this issue and have a happy and safe summer!

Maria Santucci Vetter
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WASHINGTON DAYS

The National Hemophilia Foundation held Washington Days, the annual event of advocacy and unity, March 28-29, 2019. The host hotel was the Hyatt Regency, but the real action took place in the hallways and offices on Capitol Hill, one family and one story at a time. NHF brought together 439 advocates representing 49 chapters from across the country and yes, they took the Hill by storm. Although we were all there to advocate for our own families and communities, BioMatrix employees offered a strong helping hand with an impressive advocacy presence. After all, it's at the core of what we do.

By Terry Stone and Felix Garcia

We had a plan thanks to a comprehensive NHF training agenda the night before the advocacy storm! Our message was clear: "Bleeding disorders are rare, but we are important. We need the protections that the ACA has afforded us and cannot live without them." And yet as delegates were on planes, trains and automobiles coming to this event, news media announced that The Department of Justice had agreed with the Texas district court's ruling that declared the ACA was unconstitutional, throwing the future of the healthcare law in doubt. This is a great reminder of why this patient community stays active, vigilant and engaged!

Junior VA advocates, Kiara and Matt, take their voices to the Hill.

On the docket this year were several critical items that affect not only the bleeding disorders community at large, but others fighting chronic conditions.

Stop the expansion of time on short term health plans

Short term limited duration insurance plans were created to provide a type of stop-gap coverage lasting only 3 months to serve as coverage for people between jobs and would provide a very short continuation of coverage. They typically offer little help to people with chronic conditions. Such an expansion would allow them to be effective beyond 1 year, up to 3 years.

Why is this bad? Short term policies do not have to abide by ACA regulations and protections which makes them very inadequate for anyone with a pre-existing health issue. When visiting the House Representatives, advocates asked for members to co-sponsor HR 1010 introduced by Rep. Castor (D-FL) . HR 1010 would rescind the 2018 regulation that expanded short term plans. Advocates asked their Senators to introduce companion legislation to HR 1010 which would help protect the Essential Health Benefits that the ACA provides.

Continue support of federal bleeding disorders programs

Speaking to this topic allowed advocates to share their personal journeys with a bleeding disorder. They spoke of how their Hemophilia Treatment Center (HTC) helps

them live better lives by not only caring for their unique needs regarding their bleeding disorder, but how they help with family issues, insurance challenges and securing other types of specialists and support they need. With chronic illness, it does take a village! They asked for Congress to maintain the funding for the following programs that make a difference in their lives:

- **National Institutes of Health (NIH)** Currently working on a national blueprint for research on inhibitor prevention and eradication, along with biomedical research on bleeding disorders.
- **Centers for Disease Control and Prevention (CDC)** Supports outreach and education and funds HTC surveillance.
- **Health Resources and Services Administration (HRSA)** Supports and provides funding for HTC's that allows clinics to offer multi-disciplinary services not typically covered by insurance, like the physical therapist and social worker.

Your Future, Our Mission
WASHINGTON DAYS
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Felix Garcia, Maria Santaella from NHF, community members Sophie and her son Gabriel visit with staffers from the offices of New Mexico Senator Thomas Udall (D) and of New Mexico Congressman Ben Ray Luján (D-3rd District) .

Many first-time advocates were met with open arms, understanding and concern from their legislators. Unfortunately that was not always the case. Even those of us who have been advocating for many years were met with some hesitation when we asked to keep our ACA protections. Most agreed, keeping young adults on their parents plans until they are 26 helps them become educated adults ready for the work force. However, once the conversation moved to protecting the ACA's current protection of omitting lifetime caps on insurance policies and the continued elimination of pre-existing restrictions came up, the certainty of success was not so clear.

Cody sharing his message with Rep. Benjamin Cline (R-VA 6th District)

The bleeding disorder community went out en masse to tell their stories and shed a few tears while tugging on the heart strings of legislators. It may not be enough to guarantee us our protections. This just means we need to keep tugging! We need to call our legislators back home, show up with our kids, or sit down and infuse in their office, or even show them an Explanation of Benefits (EOB) to highlight the cost of factor and what that would mean to you if you could not afford your portion of that bill. We need to let them see the courage we muster to take on the world each day. All we need is access to affordable care, comprehensive coverage that covers our medical needs properly and never having to worry about the discriminatory restrictions like pre-existing conditions and lifetime or annual caps on coverage.

With reasonable protections every citizen with or without special medical needs can thrive, contribute to society and give back. It is only with your voice, whether on a local, state or national level, that change happens. Remember that YOU as a community member are a resource to those who make our laws. They are not an expert on matters that affect your lives, your health and your future. This is a call to action to participate in future opportunities to advocate for your community!

YOUR VOICE MATTERS!

BIOMATRIX ATTENDS HFA'S 25TH ANNUAL SYMPOSIUM

Members of the bleeding disorders community traveled from points across the country to participate in Hemophilia Federation of America's Annual Symposium in San Diego April 4–7.

The Symposium's theme, "The Best of Us," gathered individuals, families and industry members for the largest community-centered educational event in the bleeding disorders community.

This year, HFA celebrated its 25th year of service to the community. To mark the occasion, a very exciting announcement was made. The history of the bleeding disorders community is one to honor, remember and never forget. During the symposium, it was announced HFA has partnered with the Smithsonian Institute's National Museum of American History in Washington, D.C. to preserve the history of the bleeding disorders community. An initial donation of historical artifacts has been made and more information on this very exciting project will be shared by the Federation soon. HFA also featured an interactive history exhibit on site. Attendees had the opportunity to learn and reflect on the history of the community from the earliest mentions of bleeding disorders in ancient religious texts, to milestones defining the community in the 21st century.

There were numerous educational sessions and tracks specific to hemophilia, von Willebrand, inhibitors, rare bleeding disorders, Spanish speakers, families, advocacy, the Blood Brotherhood and Sisterhood, and a track specific to member organizations of HFA. With a wide array of topics and a mass of new information, attendees had plenty of opportunities to learn, network and expand their knowledge of bleeding disorders.

During the *Awards Luncheon*, HFA recognized the extraordinary contributions of individuals making an impact on the community. Award categories

included the *Charles Stanley Hamilton Lifetime Achievement* award won by Kathleen Byrne, *It Takes a Village* award won by Trudy Stringer, *Michael Davon Community Service* award won by Joslyn Olsen, *Ron Niederman Humanitarian* award won by Laurie Kelley, *Member Organization Spotlight* award won by the Bleeding Disorder Foundation of Washington and *Volunteer of the Year* won by Murali Pazhayannur. Congratulations to all award recipients!

The exhibit hall brought attendees together to learn the latest and greatest from specialty pharmacies, pharmaceutical partners and other industry stakeholders. BioMatrix Regional Care Coordinators Kelly Gonzalez, Eva Kraemer and Justin Lindhorst were joined by Region Managers Dave Burgeson, Lisa Miller and Joe Piscitello at the BioMatrix booth. We brought back a favorite toy from the 90s, the "Tamagotchi" as a nod to HFA's 25-year anniversary. Individuals had the opportunity to learn more about our services, the 2019 Memorial Scholarship Program and our new children's book, *This Is My Something*.

It was great to make new connections and see old friends in the bustling exhibit hall. Also new this year was the *Research Poster Exhibit*. Researchers had the opportunity to share their work with the community, who voted on the first ever "People's Choice Award," recognizing the researcher whose work was found to be most valuable. Carletha Green Gates, PhD, HS-BCP, received the People's Choice for best poster award for her presentation entitled, "Gender Differences in Parenting Stress and Social Support in Hemophilia Families."

The *Final Night Event* was a truly memorable experience. Hosted on the deck of the retired aircraft carrier turned museum - the USS Midway, attendees boarded the iconic vessel for an evening of good food, music, dancing and fireworks! With 30 restored naval aircraft, virtual reality simulators and gorgeous views of the San Diego skyline, it was the perfect close to an unforgettable symposium.

BioMatrix is proud to support the Hemophilia Federation of America and we look forward to next year's symposium April 23-26, 2020 in Baltimore, Maryland. Hope to see you there!

CONGRATULATIONS TO HFA'S 2019 AWARD RECIPIENTS

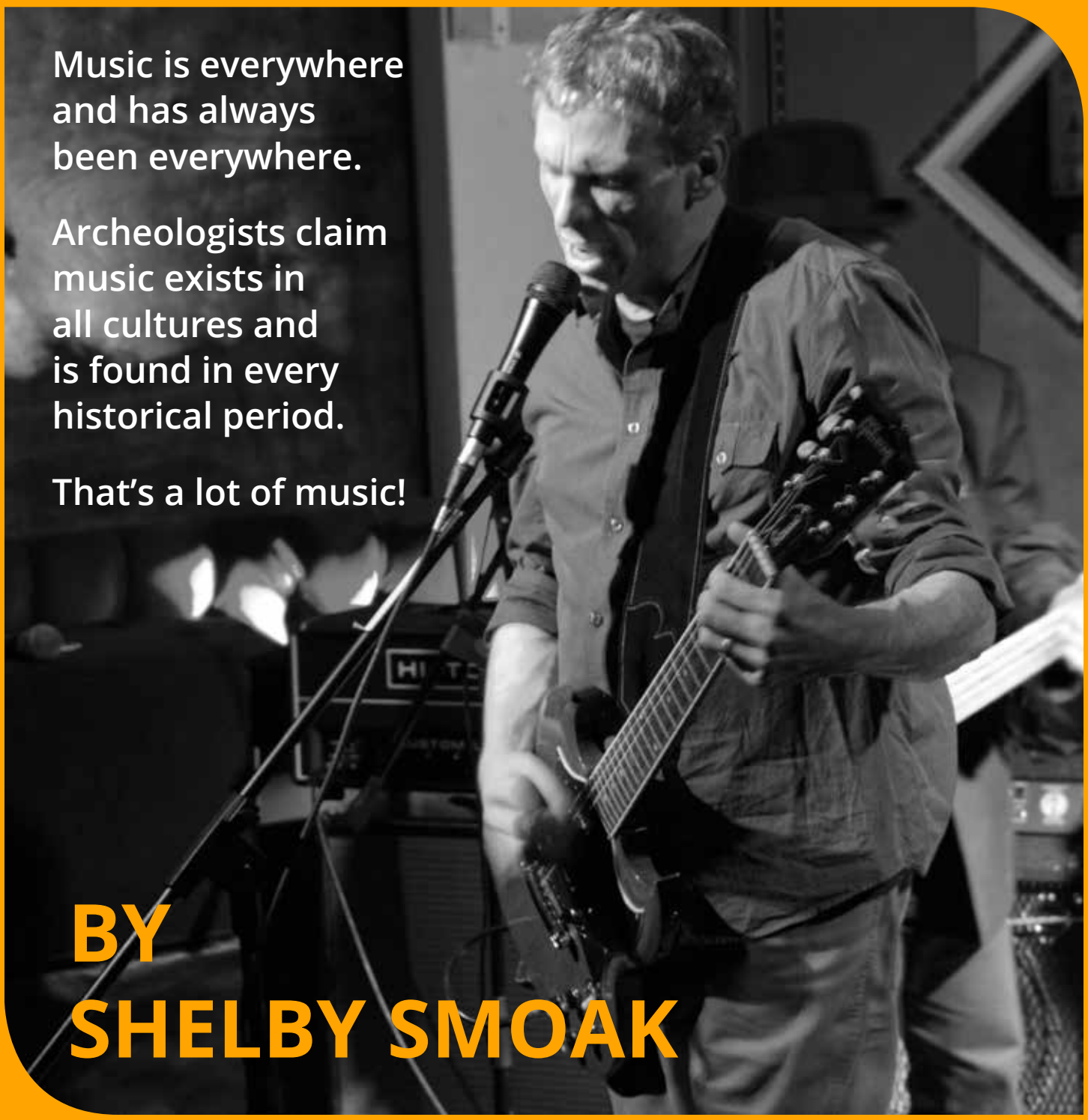
- The Bleeding Disorders Foundation of Washington, Member Organization Spotlight
- Murali Pazhayannur, Volunteer of the Year
- Joslyn Olsen, Michael Davon Community Service Award
- Kathleen Byrne, Charles Stanley Hamilton Legacy Award
- Trudy Stringer, It Takes a Village Award
- Laurie Kelley, Ron Niederman Humanitarian Award

RED TIE CHALLENGE

BIOMATRIX PARTICIPATES IN RAISING AWARENESS!

March was Bleeding Disorders Awareness Month. Throughout the month, the National Hemophilia Foundation encouraged our community members to take the "Red Tie Challenge," raising awareness and funds for research, advocacy and support initiatives. According to the official webpage of the Red Tie Challenge, the tie was designated as a symbol for the community because, "The red tie reflects the fact the blood ties – embodied in the color red and the tie – are what bind the community together." This year, community members and other supporters from across the country took the challenge, and NHF reached their $35,000 fundraising goal. Check out these photos of BioMatrix team members participating in the Red Tie Challenge!

INFUSED WITH MUSIC



Music is everywhere and has always been everywhere.

Archeologists claim music exists in all cultures and is found in every historical period.

That's a lot of music!

BY SHELBY SMOAK

One of the oldest artifacts is a primitive bone flute dating from over 42,000 years ago, somewhere between Neanderthals and Homo sapiens. These same researchers even claim that music developed before speech, perhaps in the coos or pre-historic warbles of mother to infant. So then, maybe in the beginning there was—music? More interesting than any of this, however, is that music—while ubiquitous to all cultures, all persons, in all times—is not essential to survival. It is not the sustenance our bodies need, nor the shelter we require to live. But don't tell that to someone like me who cannot imagine a day without music.

Music has always been there for me. The first time it came to mean something more than just background noise was the winter I was 11 and in the hospital for my second knee synovectomy. To keep me company at my bedside for what would be an 8-week hospital recovery, my father bought a tiny cassette player/radio. Each time he visited at the end of his workweek and relieved Mom, he'd have a new cassette in hand. There was Kenny Rogers—okay. Eddie Rabbitt—a miss. Duran Duran—getting hot.

> **"It is a rich orchestra of emotion that plucks pain from my hemophilia–worn body."**

But then came Billy Joel's "An Innocent Man." How ironic that title seems now as I think about it echoing against the sterile walls of that tiny hospital room, my surgery leg hooking in the newly-invented constant motion machine. This was 1983, before hepatitis C, before HIV. An innocent man. Even today, it always comes back to "An Innocent Man" and that feeling: at once happy, then melancholy, sad, then break-neck joy.

That spring, still in a brace and on crutches, I started piano lessons. In high school, the guitar found me. In college and after, I joined bands (too many to name), started projects, toured, recorded albums, and played stages up and down the East Coast. At this point, I probably have performed on over 20 albums and 500+ stages, from coffeeshop spreads to college town clubs to New York dives to outdoor festivals. Music has always been there. It is a rich orchestra of emotion that plucks pain from my hemophilia-worn body.

Unlike other art forms—writing and painting—music differentiates itself by actualizing more parts of the brain. That is, music is not a Left Brain/Right Brain artform. It is All Brain. It involves sound in the auditory cortex; language (lyrics) in the frontal lobe, rhythm and movement in the motor cortex, memory (who doesn't flashback when hearing an old favorite?) in the temporal lobe, sight (don't you see pictures when you

hear songs or closely listen to the lyrics?) in the occipital lobe, and, lastly, emotion (oh those feelings!) in the sensory cortex.

The health benefits of music are endless. Journals like The Lancet, Music & Medicine, Journal of Music Therapy and more report on the benefits music provides: improves sleep, improves cognitive function, reduces pain, reduces stress and anxiety, affects heart rate, and improves quality of life. It even improves venous access! (See JAMA Pediatrics and their infusion study for that one!).

In any regard, my passion for music has always guided me. I now lead Bleeder, a project of original music, and am a guitarist/singer in The Bleeders, a cover group who has more or less become the house band at The Coalition for Hemophilia B symposiums. I also present our BioMatrix sponsored program "Singing to Heal," which is a part-research, part-open mic, part lyric writing workshop. These things brought me into contact with other community member musicians who channel music's therapeutic value in various ways. I was honored and humbled to meet so many talented individuals, and to immediately bond over not just our communal enthusiasm for music, but our struggles with a bleeding disorder. There was something to this, I said. There was something here worth sharing.

With that, I am more than pleased to introduce these athletes of music, those who have the dedication, sweat and tears equal to any NBA All-Star or fledgling soccer goalie. Please read their stories and check out their music at the provided links.

You can stream my music at shelbysmoak.com. And if you are a person with a bleeding disorder who is actively performing and/or recording music, please let me know for a future article: shelby.smoak@biomatrixsprx.com.

TREVOR GRAHAM

Bands like Insect Warfare, Napalm Death, 80K, Captain Cleanoff, Deathtoll and Extreme Noise Terror may not be on repeat on the typical stereo, but these heavy-metal/punk bands inspire New Jersey rocker and hemophiliac Trevor Graham to perform with his own grindcore outfit, Organ Dealer. Grindcore fuses the fast and aggressive music of metal with the brief song length and political discontent stylings of punk. Organ Dealer began with two of Trevor's friends in 2014, when Trevor donned the bass guitar to add the undercurrent and punch such music depends upon.

Trevor started playing piano at five before joining his school band and making noise on trumpet, flute, clarinet and trombone. But at thirteen he found the guitar and hasn't looked back. It was probably a good decision since that passion has carried Trevor all over the US and the world. In addition to US tour dates, Trevor has been lucky enough to play shows in France, Germany, England, Wales, Switzerland, and even the Czech Republic, and is currently booking more dates in Europe as well as Australia.

> **"There's not much I love more than playing live music and recording."**

In talking with Trevor, he recalls a high point in his life when playing the Obscene Extreme Festival 2018 in the Czech Republic. "Never in a million years did I expect to be at that fest," he says, "let alone sharing the same stage with some of the bands I grew up idolizing. The crowd and energy were insane and the biggest event we've ever played being it's the largest grindcore fest in the world."

Trevor is also lucky that his hemophilia hasn't held him back. In fact, he remarks that the only annoying thing about his hemophilia is having to cart around his portable sharps container. "So the loss of some luggage space has been the biggest inconvenience thankfully so far. But he adds that "the occasional conversation reassuring people you're not shooting up dope in the van" is also a concern for this "legal" intravenous drug user.

Ultimately, music means everything to Trevor. "Everything else I do throughout the week is just so I have the means to do this," he enthuses. "There's not much I love more than playing live music and recording." And for the budding musician out there, Trevor has this advice: "Do it. I am of the firm belief everyone should be playing music at some level. It's very important to life. Plus, if you're someone who gets bleeds often it's not like you're not going to be sitting around a lot - pick up an instrument and make that time productive!"

For passionate music lovers, Trevor has this advice: "I encourage all [persons with a bleeding disorder] to at least listen to as much music as you can. No matter how you're feeling, music can always help make things better." So, drop the needle. Listen to music. Go over to Spotify or iTunes and listen to Organ Dealer and feel better!

To hear Trevor's song, visit:
https://organdealer.bandcamp.com/

ELIZABETH VANSANT

While she may be a bit too shy to take the stage with her musical talent, Elizabeth VanSant is not shy to bring music therapy to people's doorstep.

Along with the rigorous demands of a college degree, Elizabeth recently finished her B.M. in Music Therapy at University of Kansas with over 1,200 clinical hours completed. She pulled up her mid-western roots and struck out for the rainy marine climate of Seattle where she has already started working.

"I've actually gotten three music-related jobs since moving to Seattle six weeks ago," Elizabeth explained. One of the jobs includes working with special needs children and young adults, holding weekly social groups and using music to improve their social skills. Another job includes working with infants and toddlers as a music specialist. And a final job offer is so new she is still awaiting details. Certainly, it's an exciting time for this twenty-something college grad.

Elizabeth's passion for music started with dance, but the perils of having hemophilia B soon took away that opportunity. "From all the ballet, tap and jazz I was doing," she says, "I got a stress fracture in my left ankle and was unable to continue dancing." Enter then the piano, which she has now been playing since third grade. Along the way she has learned flute, guitar and a variety of percussion instruments. She also loves to sing. All these things are made obvious when watching Elizabeth play: she can fluidly sight read music without missing a note and can match the vocal with near pitch-perfection on any song.

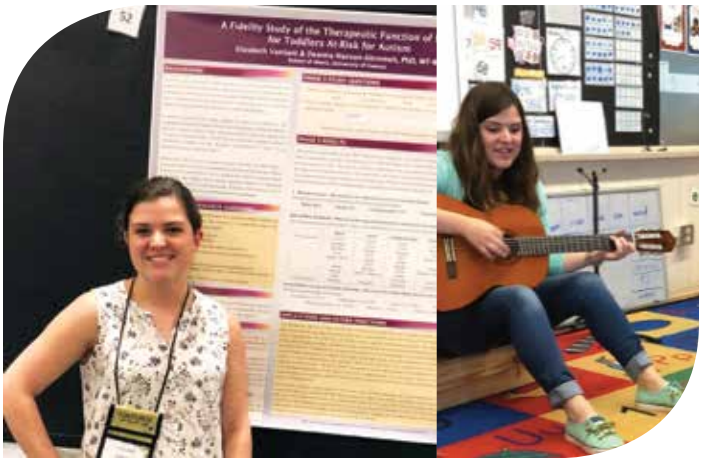
> **"...if I can help people with music in the same way that it helped me, I would be incredibly happy."**

After high school Elizabeth sought an avenue to have a career in music and began studying music therapy. She shares, "I immediately connected with it because I realized that I had used playing piano to express my emotions when learning how to self-infuse. I thought to myself, if I can help people with music in the same way that it helped me, I would be incredibly happy."

Music therapy however, isn't just listening or playing music. "While listening to music when you're having a bleed or are not feeling well is therapeutic, it is not music therapy," Elizabeth says. Music therapy is working with a trained professional and using music as an intervention tool to accomplish a specific goal for

healing or personal development. All persons receiving degrees in Music Therapy must attend an approved university and, before they can practice, must be board certified by The American Music Therapy Association.

The American Music Therapy Association's website details several of the therapeutic advantages that music therapy can provide: alleviating pain, enhancing memory, managing stress, promoting physical rehabilitation and others. Therapy is also proven in treating conditions such as Alzheimer's, autism, pain management, mental health issues and PTSD. Moreover, music therapy can be covered by certain insurances: Medicare under their Partial Hospitalization Program (PHP); Medicaid in certain states; and private insurers like Blue Cross Blue Shield, Aetna and Cigna.



Elizabeth's own struggles with hemophilia, she says, likely pushed her into music therapy. Because of her bleeding disorder, she gravitated toward playing more guitar and piano as she was growing up. "It was a release for my anxiety," she says, adding "and playing piano and guitar certainly helps veins grow right before infusing."

Now, hemophilia is only sometimes limiting: "One of my target areas is my right shoulder muscle, so sometimes it can be difficult to play guitar, which is the easiest way for me to accompany myself during music therapy sessions." But that isn't stopping her. "Thankfully, this hasn't happened in a while, but it's something to always be mindful of."

In closing, Elizabeth advocates for persons to incorporate music in their lives. "Music can help you be more self-aware," she says, "and it can be an excellent way to express, and even redirect, your emotions."

In addition to her work in Seattle, Elizabeth takes her passion on the road, running Music Therapy workshops at various hemophilia events and sometimes overcoming her shyness for a few cameo appearances in The Bleeders, a hemophilia-inspired cover band.

More information on Music Therapy can be found at The American Music Therapy Association's website: https://www.musictherapy.org/

SHAWN DECKER

When Shawn Decker finally finds some time in his busy life to chat, it is the Monday after the wildly fun 80's Prom Dance Party event he organizes and performs at in his hometown of Charlottesville, Virginia. Not unsurprisingly, this 40-something hemophiliac is suffering from an ankle bleed, the battle wounds of being married to music. "I can deal with this," he says, because ultimately for Shawn music is beneficial. It heals and "brings you peace of mind and calms you down."

Shawn is perhaps more widely known through his bizarrely funny memoir *My Pet Virus* wherein cutting humor he adopts his HIV—a result of tainted plasma products—as a pseudo-pet and narrates how to move forward in life and not dwell on the past. It also is a sort-of love story where his future wife Gwenn plays a central role. Additionally, Shawn is a contributor to POZ magazine where he continues to be a vessel of humorous support to the HIV community.

But Shawn is also a musician. When he was a kid, he fell in love with 80's synth-pop bands like Pet Shop Boys, Eurythmics, A-ha, and especially Depeche Mode who Shawn got to meet as part of the Make-a-Wish Foundation. Since then, Shawn has channeled that passion into cover songs and original music which he files under his band name Synthetic Division.

The humor that infused *My Pet Virus* is making its way into his music. Take for example the morbidly funny "I Wanna Be Cremated," Synthetic Division's spin on a classic Ramones song: "Twenty, twenty-four hours to go / I wanna be cremated / Just put me in the fire / turn me into smoke / you don't have to worry / for once I will not choke." Who wouldn't die laughing at that? (Two can play at this morbid humor game, Shawn)

This kind of humor wasn't always the case with Synthetic Division, a band that is now approaching its 20-year anniversary. An early track "Borrowed Time" from the album Bleeding Heart Cadaver darkly asks, "Am I on borrowed time, do I have much time left? / Is it not sinking in that I am checking out." On their debut album, Tainted Goods, Shawn croons in "The Rain," "Fade away / Fade away / Who's going to fade just like the rain?" Even Shawn admits his music is taking a turn and is now more optimistic. "I feel I got the dark stuff out early," he says, "and have started letting the lighter side come in," adding, "I'm not afraid to sound cheesy."

> "I feel I got the dark stuff out early..."

In talking with Shawn, he continuously reaffirms the importance of music in his life and its ability to create a continuous "safe space" which contributes to better moods and a general feeling of fulfillment. He equates writing songs to going back to being a 13-year-old kid in his bedroom, "listening to music, getting my mind back on track, and getting away from HIV." In contrast to his more lighthearted and less serious approach to music, Shawn is taking his health more seriously. For most of his adulthood, he didn't have many bleeds, but in the last decade this has changed, and more bleeds equal more treatment center visits for his necessary infusions. So finally, Shawn "took matters into his own hands" (literally) and began self-infusing. He is also embracing care for his mental health, a thing that he treats, again, with his music—loading old patches on his drum machine, tweaking sounds on his computer synths, and doing 80's prom gigs. Ultimately Shawn is making the songs he wants to hear and to him, that is the sound of happiness.

Synthetic Division's entire catalog can be found on Bandcamp https://synthetic-division.bandcamp.com/

KAYTRIEN HALL

As budding musical songbird Katyrien Hall and almost anyone will tell you, "Bleeding disorders aren't contagious," but Kaytrien's enthusiasm and passion for musical theater is.

Only in her freshman year of high school in the remote calm of Maine, she already has a pedigree of performances and a talent to match. "I've always enjoyed playing instruments and singing when I was younger," she says, and after doing her first musical *Dear Edwina Jr.* in 7th grade, followed by another role in *The Wizard of Oz*, Kaytrien was hooked. She describes her next achievement playing the lead role Belle in *Beauty and the Beast* as "one of the greatest experiences of my whole musical journey so far." She adds, "It made me fall in love with the whole idea of musical theater."

One thing that made musical theater especially attractive to Kaytrien is that it was a "much safer place" for her than any other hobby. Kaytrien suffers from von Willebrand disease and platelet impairment and has two siblings with a bleeding disorder. While she participated in volleyball thinking it a safe "non-contact sport," she still developed bruises and damaged her arms, leading her hematologist to recommend she quit. Luckily, musical theater was there to catch her, but it's not all safe. "If I am in a scene where someone needs to grab me or do anything aggressive towards me," she says, "I have to let the bruises come because it's part of the show. It is hard having to do a scene like that over and over, but I make sure to take care of myself and keep an ice pack on my bruises."

Let's hope then her latest role in *Hemophilia: The Musical* didn't give her any bruises. When she heard about the opportunity in 2018, Kaytrien filmed almost 100 takes of her audition video before feeling satisfied enough to send it along to Breaking Through, the group coordinating the awareness-raising event. Backed by funding from BioMarin, *Hemophilia: The Musical* was a work in art therapy meant to bring teenagers together to share their stories with each other as well as with a larger audience.

For her part in the musical, Kaytrien played a young girl afraid of bullying because of her bleeding disorder. "She is shy and doesn't want anybody to know about her disorder, Kaytrien says of the part, "but she eventually overcomes the fear and shares her story with others." Certainly, the musical's message is one many in our community can relate to.

Now back at home, Kaytrien is practicing alto sax, performing in chorus and jazz band and taking a class in musical theory and composition. She labels the ability to perform "so satisfying" and "one of the greatest accomplishments anybody can have." If you have a bleeding disorder, Kaytrien advocates, "Don't let it hold you back. Even if you have to do things a bit different from others, try your hardest to do what you enjoy and be proud of it." True to form, nothing seems to be holding Kaytrien back. "Music has helped me through every rough situation I have been in," she says. "When I am 20, 30, or even 85," she adds, "I intend to keep music in my life forever."

To watch the performance of *Hemophilia: The Musical*, visit: https://www.youtube.com/watch?v=dGWqxEalxKQ

WAYNE COOK

With over 40 years of playing music, nobody is more comfortable behind the kit than Wayne Cook.

His is a steady rhythm. And his instrument of choice is uncannily fitting as Wayne is the backbone for so much more than songs. For starters, Wayne, a person with severe hemophilia B, is the current president of The Coalition for Hemophilia B. For another, Wayne is the father of four grown kids and the proud grandfather of three more. Those are a lot of big roles to fill.

Wayne began playing music in 4th grade and through school beat his drums in marching band, jazz band, summer camps and band competitions, winning the New York State Class divisions for marching and jazz bands in the late 1970s. A fond memory from this time was when his school won their state championship and the jazz band burst into the Rocky theme song with Wayne pounding out a double drum solo. "In all the places I have ever played, it will never be as rewarding as playing that event because that truly sealed it for me as a drummer," he says. At home, he listened to the greats: John Bonham in Led Zeppelin, Ringo Starr in the Beatles, and one of his favorites, Neil Peart in Rush.

Wayne passes on his love of drums to grandson, Anthony.

"I loved listening to these guys," Wayne says, "because they could put down great thunderous beats or smooth grooves to some of the greatest songs."

But life got in the way after school and the drums went silent. That is until nine years ago when Wayne dusted off the skins and began sitting in for cover, tribute, studio and original bands. More recently, Wayne jumpstarted The Bleeders cover band, a group that includes myself and other persons with bleeding disorders as its core: Phil Hardt, Rick Starks, Kevin Harris. "For years," Wayne says, "I had this dream about putting together a band with people from the hemophilia community." The Bleeders just wrapped up a 2-night show at The Coalition's Annual Symposium, but Wayne's long-term goal for the project is to perform at other hemophilia events and even work toward a recording.

In talking with Wayne, he admits that hemophilia has had its impact on his playing. Two replaced knees and arthritis settling in his hands and legs have kept him from playing as fast as he once could. "Now, I am more about keeping a good steady beat and good grooves," he says, adding that "playing drums three to four times a week for a few hours at a time has helped me with my joints." Ultimately, Wayne says he will continue playing and "keep that cool groove" and will always be a "Rocker." You can catch Wayne playing near his hometown in upstate New York and at The Coalition for Hemophilia B Music Camp in Nashville this summer.

Wayne can be heard drumming in The Bleeders live recordings, available on Bandcamp: https://thebleedersusa.bandcamp.com/

MAXWELL FEINSTEIN

When I get Maxwell Feinstein on the phone for our interview he is walking the streets of New Jersey on his way to Silver Horse Sound, the studio where Maxwell can, on any given day, be caught tracking his own music, streaming live music posts on Facebook, or working with other artists who have booked time with him.

Today he has two rehearsals, a bass tracking session, and a mix session. "Tomorrow sees us doing two more recording sessions unrelated to the session previously mentioned and I'll be meeting with a potential songwriting partner for some children's music," he adds. In a world where earning your keep with music has become an almost impossible task, Maxwell, a person with hemophilia, is able to keep things moving.

Maxwell got his first guitar at age eleven inspired by Nirvana's "Smells Like Teen Spirit," and the "teen spirit" to play music struck hard. "I had been participating mostly in choirs or theater before this," he says, "with brief flirtations

(weeks of interest at most) on violin, flute, clarinet and saxophone." But once Maxwell found the guitar, he took school hours to steal away into an unused handicapped bathroom which he transformed into his band room. "People used to use that space as a make-out room," he says, "and I would just sit there practicing." Maxwell adds, "If you wanted to get some necking in, you'd have to put up with me practicing" because nothing was getting between him and his guitar.

Now, in addition to running a studio, Maxwell dons a guitar or bass—depending on the need—in a bevy of touring bands: Jaime Della Fave (Jaimerosey), BWQ (or Project BWQ), Terra Electric, The Love Network and Debra Devi. "My policy is basically that I'll perform with anyone who asks!" he enthuses. He also writes, performs and records his own music, some of which can be heard on his solo release *Round of Sound*. In talking about *Round of Sound*, Maxwell calls it a labor of love with himself and other friends who helped him complete it. "I played most of the instruments save for the drums, and we did it in our rehearsal room just stringing microphones up and grabbing the sounds 60's style with little regard for sounds bleeding onto the tracks."

Stand-out track "Mad Dog's Promenade", released in 2012, highlights Maxwell's whimsical style with its off-the-cuff lyrical refrain, "Smile to myself as I walk." "It's a song about walking around town, going about my business while musing on how good I have it if I get to go make music when I'm done walking around," he says of the track. But not all his songs are easy-going tunes. "I've written about coping with those I've lost," he reflects, "and I've written about loves current and past. I'll often write about whatever's interesting to me at any given time."

> **"Try your best to figure out what makes you happy..."**

And then there is Maxwell's hemophilia, which, as he says, "visits me when it wants." He has lost cartilage in his elbows; played shows with ankle bleeds, knee bleeds and elbow bleeds; dealt with nose bleeds while on tour. "I had a nosebleed from two days before we left on a tour until the last tour day two weeks later," he says. But it hasn't stopped him. He takes care of his hemophilia so music can take care of him.

Before ending our interview, Maxwell offers this advice, culled from his own experiences: "Try your best to figure out what makes you happy and what builds community around you and how you can make it grow into something you can be proud of toiling for." Maxwell has done just that.

Maxwell Feinstein's music can be found at www.maxfeinstein.com/

EMILY CHAMPAGNE

After attending an orchestra concert in elementary school, Emily Champagne, who has von Willebrand Disease, knew she wanted to play the violin.

For the twelve years since that first concert, she has done so and has made it her dream pursuit. At 23, Emily's life is taking off. She is recently married, spends quality time with family and friends, enjoys reading and playing video games and holds down a steady job as a grocery cashier. But she pines for her musical break. "I hope to one day get a job as a professional violinist in an orchestra," she says.

Emily has performed in a plethora of string quartets and chamber orchestras, including the Suncoast Super Strings, conducted by violin virtuoso Itzhak Perlman, who has been the equivalent of a rock star to Emily. "Growing up, I always would listen to the music of Itzhak Perlman," she states with excitement. "He is an extremely talented violinist, and someone I really look up to!"

> **"It's an activity I know I can enjoy without having to worry about my bleeding disorder."**

When Emily got to perform in a concerto under Perlman's direction, she was "beyond excited." She says, "To be able to perform in front of my violin idol was a huge deal," and adds, "When I got the phone call stating I was accepted into the program, I remember crying out of happiness. It was such a once-in-a-lifetime experience to be able to work with a world-renowned violinist."

She has also traveled to Europe with the local youth orchestra and performed in Salzburg, Vienna, Prague and Munich. During high school and community college, Emily served as concertmaster and was appointed co-concertmaster of the University of Central Florida (UCF) symphony orchestra for the 2018-2019 school year.

If you ask Emily about her bleeding disorder, she indicates that it isn't slowing her down. "VWD hasn't really affected my music," she says. "It's an activity I know I can enjoy without having to worry about my bleeding disorder." Music helps her escape the challenges of her bleeding disorder." To her, it offers a form of expression she can't find in other places. "You can compose songs that show how you feel, or simply play music to get your mind off of things," she says."

Having just graduated with her Bachelor of Music in Violin Performance from UCF in May of this year, Emily's dream is to now perform in chamber groups and a professional symphony orchestra. Violin has been a constant in her life and is even something she can lean into if she is having medical issues. So, while Emily may not have everything figured out yet, she is certain about violin: "One thing for sure is I know I'm going to keep playing violin!"

DAVE COLVIN

After over 30 years earning a living as a numbers guy and working in accounting positions while trying to perform and write songs in the off hours, Dave Colvin, a man with hemophilia A, finally shed that day-to-day job and traded it to focus on his real passion—music.

It was a career move he had put on hold since his college days when he started Illinois State as a music major, but changed because of state funding and the increased availability of jobs in accounting and cash management. But in 2006, Dave started his own publishing company, Arnybarn Music (BMI), and began professionally recording his songs and pitching them to other artists and labels, and he hasn't looked back since.

Dave's big break came in 2011 when one of his songs, "Gently Falls," was selected for use in an episode of CBS's *Star Trek: Enterprise*. The song aired in Season 2's second episode, "Carbon Copy," and can now be streamed on Netflix, CBS All Access, Hulu, and Amazon. Catch Dave's song in the background at around the 10 minute mark. For Dave, it is an exciting time and a validation of his music. "It is so amazing to think that each month thousands of people around the world hear my voice and my song!" he enthuses. "My quarterly royalty report shows some 15,000 to 25,000 views per website!"

> **"To be successful, one needs to be able to write something that will be universally felt or understood,"**

The success continued when another song "You are Living On" was released by Ronan Parke who was runner up on the 2011 season of Britain's Got Talent. While Ronan Parke's version differs from the country-infused, laid-back delivery of Dave's own performances, the emotional tug of the song gets lifted into a pop gem. The song was born from Dave's grief at losing his parents within a few months of each other:

Just the other evening
We were talking on the phone.
Your advice was sure and steady
But your voice was not as strong.
Now that body's finally failed you,
Heaven's called you to come home.

It is at once specific, opening with a clear scene anybody can relate to, yet Dave consciously avoids a strict script after that, assuring that the lines will resonate with just about any listener. "To be successful, one needs to be able to write something that will be universally felt or understood," he says, the philosophy that likely garnered this song as a hit. "It has been humbling to see the comments [Ronan Parke] fans have posted about how my song has touched their hearts," Dave says. "It makes the years of trying and getting rejected time and again, all the more worth it!"

Those years, of course, came with the normal obstacles artists face and then the not-so-normal trials of having a bleeding disorder. "Prior to prophylaxis," Dave says, "I would often get a bleed from performing, usually an elbow from playing the guitar." In those early years, he remembers going to the hospital for cryoprecipitate before his band performed. Dave continued infusing and performing, especially at a yearly festival in his hometown of Decatur, Georgia. About a decade ago, he had to let the touring go. Things came to a head at one show where Dave tripped on the stage's drum riser and broke his elbow. "As I age, I do not perform out much anymore simply because it has gotten difficult to even go up a few stairs to get on stage," he says. "The past few years I mostly record from my home studio in Nashville."

Full of wisdom and advice, Dave advocates that to be successful in music, three ingredients are required: a love of music, patience and a thick skin, all things he owns in spades. Dave spends his other time as a father and grandfather and is thankful for singing through over forty years of marriage. He's also working on an autobiography but says he's only up to 1994 in the yearly chronicle. While waiting for that, you can enjoy Dave Colvin's music now at https://www.arnybarnmusicgroup.com/music.

BIOMATRIX ON THE MOVE

NEVADA

Kelly Gonzalez

March 16th in Las Vegas began with excitement and anticipation, and certainly didn't disappoint! One of the largest educational events hosted by Nevada Chapter of NHF, and for the youth, the most fun and enjoyable event of the year, ***Spring Education Fest 2019*** kicked off at the Circus Circus Hotel and Resort.

Stephen and Joe check out the BioMatrix booth items.

Community members gathered for industry updates and participated in an assortment of interesting and valued educational breakout sessions. While adults absorbed patient-centric education, the younger set had the opportunity to experience the excitement of The Adventuredome Theme Park located in the resort. We are grateful for the opportunity to participate in this fun and empowering event and look forward to *Spring Education Fest 2020*!

VIRGINIA

Michelle Stielper and Terry Stone

There is something familiar and comfortable when attending an annual ***Chapter Education Day*** at the same location each year: a familiar spot, warm and comfortable just like our friends who gather there to share the day. The Hemophilia Association of the Capital Area (HACA) welcomed members at the Richard J. Ernst Cultural Center at Northern Virginia Community College in Annandale Saturday, March 30th for this day of learning, laughing and fellowship among old and new friends.

But what about the kids? Don't worry, also on hand were the White House Nannies! They took care of the littles while older offspring had their own meetings with great sessions like: *Failure is an Option*, which explains that it's okay to fail since that's how we learn, *Let's Talk Bullying*, *The Road to Independence* and *Jobs, Resumes and Interviews*. Leading these sessions were both local and familiar speakers who kept our kids engaged and enlightened. Thanks to Linda Pollhammer of Pfizer, Sara Ceresa of Octapharma, Betsy Koval of Takita and community members Kirstin Drye, Will Hubbert and Matthew Stone for lessons and discussions, and making our kids glad they came out early on a Saturday! For elder folk, sessions included quality break-out talks. From *Communicating with Providers*, *Maintaining Boundaries*, to *Exploring Best Practices for Physical Therapy for Bleeding Disorder Patients*, all topics were well received. After a brief annual meeting and the election of new board members, the group had an informative *Advocacy & Insurance Update* from Miriam Goldstein of HFA (and a local mom favorite!).

The lovely Shawna with Michelle Stielper.

Thanks to all who gave of themselves to better us all. Great day, great people, great chapter!

TENNESSEE

David Tignor, LeAnn Wilson, Cyndy Coors and Maria Santucci Vetter

During the first week of April, Grifols and BioMatrix partnered to host a series of ***Educational Dinners*** sweeping the state of Tennessee. April 2nd found us at Logan's Roadhouse in Memphis, April 4th at Caney Fork River Valley Grille in Nashville, and April 5th at Calhoun's in Knoxville. At each location, Octapharma's Virginia Kraus, RN, BSN presented *An Overview of Hemophilia* and von Willebrand. Virginia discussed variances of hemophilia factor VIII and factor IX deficiencies and von Willebrand disease. She explained the genetics of how these bleeding disorders are passed along. Virginia closed each program with time for questions and open

Maxton, Magan, Kara, Dayton and Daniel

Gabi, Heidi and Cameron

Allan, Taylor and Sean

discussions. Thank you to everyone who took time out of their busy schedules to come out and spend the evening with us. It was a pleasure to visit with you!

FLORIDA

Peggy Klingmann and Marcy Foertsch

Hemophilia Foundation of Greater Florida (HFGF) held its ***Tampa Super Hero Fun Walk*** Sunday, April 7th. Approximately 80 pre-registered walkers met at Al Lopez Park in Tampa for a morning of camaraderie, goodwill, and a desire to raise funds for a great cause! Joining them were a slew of volunteers and company representatives.

Brenda Montgomery King, her son Herman, and Peggy Klingmann.

While visiting the sponsor's booths and enjoying beverages and snacks, everyone was kept pumped up by deejay Joe Sena of Aairius DJ Entertainment.

Fun activities were also on the menu with face painting, posing for pictures with Star Wars characters, and games for the young ones.

Congratulations to everyone involved, from planners to walkers, on making this annual event a huge success!

CALIFORNIA

Gabriela Griffin

April 12th – what a wonderful day to embark on a thrilling Southern California adventure! Year-after-year the *Catalina Hispanic Family Camp* brings together families from all over the US and even a family from Guatemala! This camp is special - not only recreational and educational but therapeutic too.

Elsie and her grandmother, Evangelina, stop to take a photo with Gaby Griffin (center) at the luncheon.

Meeting April 12th at Cabrillo Bath House located minutes away from the Catalina Express Terminal in the Port of San Pedro, a ***Camp Luncheon*** was where things began as everyone arrived, giddy with excitement. While the group was enjoying a tasty taco meal, the Latino Hemophilia Foundation (LHF) registered each of the 157 participants.

All the way from Villahermosa, Tabasco in Mexico, Dr. Patricia Martínez Jaimes arrived well prepared to offer a presentation on *Family Therapy* to the participants. Her goal was to help improve communication, behavior and harmony between family members. She expressed great satisfaction at having the opportunity to spend time with families of the Hispanic bleeding disorders community.

With joy and anticipation, it was soon time for everyone to leave for the port and board a boat to take them to the campgrounds on gorgeous Catalina Island – no one wanted to be left behind! Thank you to LHF President Jorge Catedral and his team for organizing this wonderful event!

On a gorgeous day, 6 year old Matais is ready for Catalina Island!

[BIOMATRIX] ON THE MOVE

ILLINOIS

Eva Kraemer

"Masquerade…every face different shade," was how the Illinois bleeding disorder community showed up in support of the Bleeding Disorder Alliance Illinois (BDAI) as they hosted their ***30th Annual Gala Black and White Masquerade Ball*** April 13th at the Itasca County Club.

Patrick, Rose, Amy, Pam, Eva Kraemer, Shari, Jen, and Jim

Intrigue and elegance filled the room as the community circulated, bidding on impressive silent auction items. Fabulous live auction prizes included a Las Vegas weekend for two to see Cher perform and stay at the MGM Grand, a foursome of golf at Chicago Highlands Club and a gorgeous tennis bracelet from Clodius & Co. Jewelers, just to name a few.

Executive Director Bob Robinson and the BDAI staff provided a phenomenal evening in support of children and adults with bleeding disorders and I was glad to be a part of such a worthy cause!

OHIO

Shelia Biljes

It was a night of magic as the Northern Ohio Hemophilia Foundation (NOHF) hosted its highly anticipated ***Black and Blue Ball*** April 26th. With over 200 in attendance at the Cleveland Ritz Hotel, NOHF raised $60,000 to support its worthy programs. This year's theme *Magic in Giving* was brought to life by magician Joe Kennedy who traveled through the tables doing street magic and then wowed the entire audience with an on stage performance.

Andrew and April enjoy their first Black and Blue Ball!

Silent auction items ranged from fashionable designer purses, sought-after sporting tickets, homemade crafts and FAO Schwartz toys, which of course, included a magic set. A live auction kept the group on the edge of their seats as bids rolled in for a Vegas trip that included front row seats for a Criss Angel show. Dinner followed with filet and salmon gracing the menu along

"Are you holding an ace card, Joe?

with a sampler tray of mouth watering pastries. With the auction complete, there was nothing left to do but dance and have fun! We rocked the floor until 11 p.m.

BioMatrix is proud to be an annual sponsor of this fantastic event. NOHF and the planning committee did a wonderful job and we can't wait to see what next year's *Black and Blue Ball* has in store for us all!

MICHIGAN

Mohammed Hoque

Hosted by the Hemophilia Foundation of Michigan (HFM) ***SpringFest 2019*** was a great weekend for Michigan families to gather, learn and have fun! With its spectacular views of Ford Lake, this 3-day event held April 26-28 at the Ann Arbor Marriott Ypsilanti at Eagle Crest was attended by over 400 members of the bleeding disorders community.

The event was officially underway Friday evening with dinner and a welcome by HFM Executive Director Susan Fenters Lerch. *Movie Night* followed with a special showing of *Bombardier Blood,* which features the amazing accomplishments of Chris Bombardier - the first person with hemophilia to summit Mount Everest.

Saturday was filled with an array of educational and interesting sessions beginning with *HFM Through the Years* and *Men's Wellness*, *The Psychological Benefits of Positive Self Talk*, *Menarche to Menopause*, *The Shifting Paradigms of Treatment for Hemophilia*, *Managing Chronic Pain*, just to name a few. Saturday evening closed with a calming *Story Time* activity, which included cookies and milk, crafts and of course, a story.

SpringFest fun! Marteice, Jordan and Natasha visit Moe Hoque at the BioMatrix booth.

SpringFest wrapped up Sunday morning with breakfast and the announcement of the raffle winners. Congratulations to HFM and all involved in organizing another incredible event!

PENNSYLVANIA

Tina McMullen

Beauty abounded as 135 ladies attended the April 27th ***"Celebration for Caring" Annual Luncheon and Fashion Show*** hosted by the Eastern Pennsylvania Chapter of NHF. In honor of the event's 40th anniversary, the founders and original co-chairs of this amazing ladies' day, Sandy Krouse and Joan Murray, came out of retirement to spearhead this year's fantastic show!

Lovely ladies! Pat, Jessica, Robin, Megan and Vickie.

Held at the magnificent Normandy Farm Hotel and Conference Center in Blue Bell, the ladies enjoyed socializing and a luncheon featuring lovely cookies made by committee members. The fashion show was soon underway beginning with junior models from the bleeding disorders community followed by BOC Productions models who promoted designs by Berta Sawyer.

Guest Speaker Elijah Nobles steals a moment on the runway!

Amazing items were available for a few lucky raffle winners including a horse-drawn carriage ride, flat screen TV, Philadelphia Sixers basketball team items and an Xbox console, to name a few. This year's guest speakers were community members Elijah Nobles and Hajar Abusief who spoke about the teen group they mentor.

Sandy, Joan, the entire Fashion Show Committee, along with Executive Director Curt Krouse and his staff did a marvelous job. We look forward to the *41st Annual Luncheon and Fashion Show*!

NEVADA

Kelly Gonzalez

Woman in the southern Nevada bleeding disorders community gathered at The Forge in the quiet, earthy community of Boulder City the weekend of April 27-28 for a special ***Women's Retreat***. Hosted by the Nevada Chapter of NHF, the group included women touched by a bleeding disorder: carriers, mothers, wives and caregivers who were invited for an educational experience geared toward their specific needs.

Emily and Samantha bring light and energy to the retreat!

Becki and Lynn pause to smile for the camera!

Woven into the schedule of informative presentations was an opportunity for the women to choose from many activities designed to inspire relaxation. Among the choices were a chair massage, various crafts, journaling and a beneficial stretching session, which aimed to improve range of motion, increase circulation and promote a sense of calmness.

At the conclusion of the weekend, the ladies were more connected, empowered and supported by each other. BioMatrix was proud to be a supporter of this fantastic get-together. Thank you to the NV Chapter of NHF, Hemostasis and Thrombosis Center in Nevada, Octapharma and Aptevo for sponsoring this wonderful event!

Thank you to event sponsors: (back row) Maureen Salazar-Magaña of of NV Chapter NHF, Kelly Gonzalez of BioMatrix, Christine Bettis of NV Chapter NHF, (front row) Lynn Barker of Octapharma, Becki Berkowitz, RN of HTC of NV, and Leo Tellez of Aptevo.

Fierce ax throwing women! (back row) Joanna, Sophie, Marissa, Lisa, Liz, and Patrina; (front row) Rylee, Ryan, Crystal, Jackie, Maria, Monica, Arlene, Jennifer and Daniela.

NEW MEXICO

Felix Garcia and Maria Santucci Vetter

We've all heard the saying April showers bring May flowers, but have you ever heard that April also brings women throwing axes? Neither have I, but boy did the woman of Sangre de Oro, Inc. (SDO) show their ax throwing skills! The ladies came together April 30th at ABQ Ax in Albuquerque for a joint program sponsored by Aptevo Therapeutics and BioMatrix. Hope Woodcock Ross, RN, BSN, and Community Educator Stormy Johnson, speakers for Aptevo, presented ***Factor in the Family***, which covers bleeding disorders in women and the challenges of being properly diagnosed.

Hope and Stormy did a fantastic job explaining how the hemophilia gene is passed and how women don't always fit that established concept. Their presentation covered having discussions with personal physicians, what questions to ask and how to properly document medical appointments.

Although many still did not have a proper diagnosis, some of the women shared stories of suffering bleeding episodes and difficult surgeries prior to being diagnosed. And as we all know, no diagnosis means no treatment. The theme of the night became "woman with a diagnosed or yet undiagnosed bleeding disorder deserve to receive the same medical attention, acceptance, and treatment as men diagnosed with a bleeding disorder."

Aptivo speaker Stormy Johnson with Hope Woodcock Ross

After the great presentation, the ladies took to the ax range and showed their power! Many thought it impossible to do, but with a little training from the instructors and encouragement from their blood sisters, everyone who tried was successful. Sounds a lot like the challenges they face regularly in life. BioMatrix is proud to have been part of such a great program!

Monica's smile says it all.

Sophie takes a swing.

Maria has great aim.

Maria gets coached.

Lisa is ready.

CONNECTICUT

Rich Vogel

Previously held in December, the Connecticut Hemophilia Society (CHS) moved their ***Annual Meeting*** to May 4th. Held at the Sheraton Hotel in Rocky Hill, the day started with breakfast and a chance for interested community members to gather information and ask manufacturers and specialty pharmacies questions about their products and services.

Angie Forsyth discusses HERO study results

Is that Arjun? Yes!

Pinata Time!

While children went off to have their faces painted and build confidence through an interactive theater experience called *Broadway Bound Mission*, adults learned the *ABC's of Financial Planning* with keynote speaker Tim Bourdon of TJB Financial Services, Inc. Tim gave a great overview of financial planning for those with a chronic illness covering everything from HSAs (health savings accounts) to mutual funds.

During lunch, CHS unveiled their newly designed and easy-to-navigate website. Afternoon sessions included *Facing Pain*, a discussion on the impact pain has on you and your family. Angie Forsyth discussed the results from the HERO study, which provided insights on patients and families living with bleeding disorders. Before dinner and a screening of *Bombardier Blood*, the kids let off a little steam celebrating Cinco De Mayo with a cactus piñata!

CHS meetings always feel intimate because of the warmth and care generated by Executive Director Maryann May and Board President Dennis Mackey. We look forward to attending again!

FLORIDA

Justin Lindhorst, Juan Bruno de la Fuente and Dave Burgeson

It was a wild day May 5th at Miami's Jungle Island! Friends and families of the bleeding disorders community in South Florida came out to show their support during the Florida Hemophilia Association's (FHA) ***9th Annual Walk in the Jungle.***

The walk raises funds critical for the programs and services offered by FHA, while also generating awareness for the bleeding disorders community. In total the walk raised over $75,000! In addition to providing corporate level support, BioMatrix had a strong showing of walk participants. Team BioMatrix placed in the top ten out of over fifty teams for fundraising efforts! We look forward to next year!

Team BioMatrix!

Justin Lindhorst, Dave Burgeson and Juan Bruno de la Fuente.

NEW JERSEY

Rich Vogel

The ***8th Annual Hemophilia Awareness Walk*** May 5th was filled with friends, family and members of the local community who came out in full force despite the rain to Raritan Valley Community College in Branchburg to show their support for persons with a bleeding disorder. Hemophilia Association of New Jersey's (HANJ) hashtag for the day was *Community is in our Blood*. I personally like to call it *Jersey Strong*!

Veteran hemophiliacs, Ray Datolli and Rich Vogel.

Due to the inclement weather, the family fun walk was held under a covered walkway and the fun activities

Team BioMatrix!

[BIOMATRIX] ON THE MOVE

Big smiles - Erin and John

were all moved indoors and included a delicious barbecue lunch, refreshments, a bouncy house, face painting, balloon making, games for children and live music by New Jersey's own community member DJ Omar. Industry manufacturers and specialty pharmacies attended in full force, offering education and bringing awareness to hemophilia.

PENNSYLVANIA

Tina McMullen

More than 400 close friends gathered at Hilton Philadelphia City Avenue Hotel May 7th to participate in Eastern Pennsylvania Chapter of the NHF's ***Annual Community Dinner***. The evening began with time to explore the exhibit hall where industry representatives were available to discuss their products and services.

Latosha and Kevin with Tina McMullen

Once the dinner program was underway, community members enjoyed hearing from several noteworthy speakers: Lisa Maiale-Howell, MSS, LCSW at CHOP and Mid-Atlantic Region III Coordinator; Allyson Pishko MD, MSCE at Penn Comprehensive Hemophilia and Thrombosis Center; Matthew Evans MD Assistant Professor of Medicine and Pathology and Associate Program Director Hem/Onc Fellowship and Nathan Schaefer, NHF Senior Policy Director.

Tina McMullen proudly displays a plaque given to BioMatrix by EPC for being a Major Corporate Sponsor.

This popular event is by far the most well attended by the Eastern PA community. It is a perfect occasion to mix it up with old friends and introduce ourselves to new members of our tight-knit and welcoming group. Thank you to Executive Director Curt Krouse and his staff, External Relations Manager Lindsay Frei and External Relations Coordinator Kat Kocsi for another remarkable evening!

OHIO

Shelia Biljes and Maria Santucci Vetter

Shelia Biljes adds a few final touches.

May is a wonderful time to get together for a fun, springtime craft. BioMatrix partnered with Aptevo in Sugarcreek for a ladies' lunch and craft time May 9th. We met at Keim Lumber Company's conference center in Charm for a lunch of soup, sandwiches and amazing cheesecake for dessert. Michelle Stielper represented Aptevo for a talk on *Factor in the Family,* speaking on her uphill battle towards a diagnosis.

Under the instruction of Michelle, who is also an art major, the ladies painted jars of candles. Laughter rolled as we painted, and we learned a little about each other. Not surprisingly, every candle was beautiful and unique, just like each of the women. The jars all looked professionally crafted and nothing is better than relaxing time for girl talk and a creative craft!

CALIFORNIA

Gabriela Griffin

On the morning of May 10th, the ballroom at Knott's Berry Farm Hotel in Buena Park was filled with community members ready for Hemophilia Foundation of Southern California's ***Family Information Day*** to begin. Executive Director Michelle Kim officially welcomed all to this special annual event.

Big smiles! Gaby Griffin with Trinidad, Maria Elizabeth

Gaby Griffin, Mesly, Andy and Angelica ready for fun!

To start, a patient-to-patient panel addressed the group. Each of the panel members was carefully selected and gave short and incredibly honest presentations of their own personal experiences of living with a bleeding disorder. There is always so much to learn from each other.

Tim Ringgold presented a session on *Music Therapy* as a way of dealing with stress. This was particularly enjoyable and helpful as he showed us how the power of music therapy can help ease depression, pain, addiction and more.

Another highlight of the day was an appearance by Josh Gordy, NFL American football cornerback. Josh left us with tips and specific exercises to be active even with a bleeding disorder.

To wrap up the day and make it even more enjoyable, each person received a ticket to experience all the roller coasters and other thrilling rides at Knott's Berry Farm Theme Park. A big "Thank You" to Michelle and her team for the hard work to make this wonderful event possible.

DELAWARE

Tina McMullen

BioMatrix and Sanofi joined together in sponsoring an evening of ***Education and Blue Rocks Baseball*** May 10th for the community of the Brandywine Valley Hemophilia Chapter. The evening started with Sanofi hosting an educational dinner at Big Fish Grill in Wilmington. Lily Gomez, Sanofi Community Relations Manager, presented a program on College and Financial Assistance. During the very interactive program, guests enjoyed delicious appetizers and main courses. A decadent chocolate ganache cake finished the meal.

After dinner, we headed across the street to Daniel S. Frawley Stadium to watch the Blue Rocks take on the Potomac Nationals. Although raining, spirits were not dampened. Mr. Celery, the Blue Rocks mascot and community favorite, regretfully only performed twice as he only makes an appearance when the Blue Rocks score.

Tina McMullen, Robert and Gail.

Mr. Celery!

Other highlights of the evening were the eye ball race, horse race and fireworks. But the greatest highlight was the bonding and camaraderie between the members of the Brandywine Valley Chapter community. Thank you to Sanofi, Chapter President Gail Novak and the bleeding disorders community for an amazing evening. I look forward to co-sponsoring again next year!

Hughie, Sammy, Starla, Abel andHarry with mom Raquel and Tina McMullen (right).

MARYLAND

Terry Stone and Michelle Stielper

I've got five words for you... All-you-can-eat-buffet! You had us at "buffet" as more than 300 hungry friends of the Hemophilia Foundation of Maryland gathered to break bread Saturday, May 11th at the UAW Hall in Baltimore. At the ***Shrimp Feast & Bull Roast***, one of the chapter's biggest and most successful fundraisers, guests were treated to all you can eat steamed shrimp, grilled meats, and plenty of hearty side dishes.

Christian with Michelle Stielper

After a hearty meal, there was time to check out the action at the gaming area. Fundraising attractions included a 50/50 raffle, a money cake and plant wheel, money boards and a silent auction rich with some truly amazing gifts and sports memorabilia. It was a real party atmosphere; lights were turned down and disco laser lights lit up the dance floor as people came up to shake and shimmy to the tunes by DJ Dan T.

What a night for the Hemophilia Foundation of Maryland. Raising money isn't fun SAID NO ONE who

attended. Having a splendid night out with delicious food all while helping fund the chapter's mission is a wonderful way to *make a difference*!

TENNESSEE

David Tignor

A very important ***Educational Dinner*** program was held May 16th at Legends Steakhouse in Smyrna covering the topic of *Microbleeds: What Are They and What Are Their Implications?* Hosted by BioMatrix and Octapharma, Martina Willis-McCullough, RN, BSN, Octapharma Nurse Educator defined microbleeds and how they occur in joints. She explained how microbleeds can often go undetected because they don't show the same symptoms of regular joint bleeds. Martina described how joint damage can occur and touched upon current studies that are evaluating the benefits of using ultra sound rather than x-rays to assess microbleeds. This high-interest topic prompted the audience to ask many questions and to continue the discussion after the program's end.

Danny and Mary

KENTUCKY

Rania Salem

It was a beautiful spring day for friends and families of the Kentucky Hemophilia Foundation to gather for the ***Family Day at the Louisville Zoo*** May 18th. Families were able to meet with industry reps to hear about all the latest happenings in the bleeding disorders community while the little ones took part in fun carnival games.

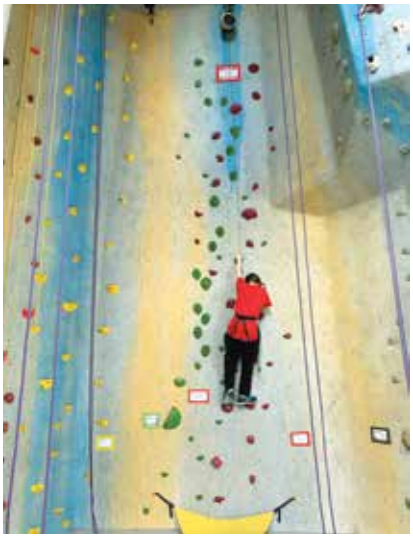
After a picnic-style lunch door prizes were awarded to lucky winners and then it was off the enjoy the beautiful Louisville Zoo. The Zoo was celebrating their 50-year anniversary so many festivities were taking place on the grounds. Spring was undeniably in the air with all the new babies including an antelope, giraffe, African lion, Komodo dragon, southern white rhino and two new little seals. Needless to say, a GREAT time was had by all! A big thanks to Executive Director Ursela Kamala, her assistant Sandy Franklin and their great group of volunteers!

Charles and Johnny enjoying their day at the zoo!

MAINE

Cheryl Ashmore

Heralding the end of a long winter, Hemophilia Alliance of Maine (HAM) held its ***Annual Meeting*** at Freeport's Hilton Garden Inn May 18th - a Saturday radiant with the first strong sunshine of spring. The unique agenda provided an out-of-the-box opportunity for families to engage in significant community building. With many members living in the rural outskirts of a large state, it is rare to get face time outside of scheduled events. HAM acknowledged the need for personal interaction by providing ample downtime for families to socialize.



Don't look down, Grace!

Knowledgeable speakers presented a broad array of topics including legislative advocacy by Joe Zamboni and Nicholas McCrae from the New England Bleeding Disorders Advocacy Coalition (NEBDAC). Deputy Director Tracey Gideon and Board President Carrie Greene successfully met their programming goal by demonstrating how to be welcoming and inclusive to persons of ALL bleeding disorders. Donnie Akers, Esq. explained the intricacies of legal tools to maintain quality of life, sharing unexpectedly hilarious and poignant personal stories to highlight key points.

HAM Executive Director Jill Packard spoke throughout the day about annual meeting nuts and bolts, adding impactful, short pieces about conversations, commitment, connection and care along with strategies

to achieve each. She left us with this powerful message: "No one should ever feel alone."

Meanwhile, the youth enjoyed the morning at nearby Wolfe's Neck Farm, "a one-of-a-kind place on the coast that connects farmers, eaters and learners to the land and animals at the core of our food systems." After hiking with goats and getting stuck in cattle traffic, the older youths headed out for indoor rock climbing, always a favorite with this adventurous group.

It was another flawless and informative event for the bleeding disorders individuals and families of Maine. Thanks, HAM!

MARYLAND

Terry Stone

In Maryland you only need to go as far as the Gaylord Hotel at National Harbor to feel as though you've stepped through the wardrobe and into a magical place. In this magical place there are friends and food and fun. Oh wait! There's a spa… and they are waiting for ME! Yes Dorothy, there's no place like home, but for the weekend of May 18-19, home was the lovely Gaylord Hotel as the women from the Hemophilia Foundation of Maryland came together for some girl time at a ***Women's Retreat***.

As ladies excused themselves for their spa appointment through the day, education and togetherness carried on for the rest of the sisterhood to educate and enrich their minds. Speakers offered discussions and insightful

There's no mystery the ladies of HFM can't solve!

reflection that taught empowerment, positive thinking and resilience. There was also a discussion about women and bleeding disorders, YES… girls bleed too!

Adding to our resume of talent, we all were able to participate in a murder mystery. It was not nominated for an academy award, but it was really fun and many ladies discovered a hidden talent not yet nurtured. We had a wonderful dinner at a National Harbor hot spot called Bond 45.

The women wrapped their weekend with fulfillment and peace and new friends. BioMatrix was one of the sponsors of this event and we were honored to provide support programming that enriches and inspires. Thanks to Emma and Jamie, HFM leaders who planned this lovely weekend for amazing women.

PS… no spouses or children or dogs were hurt or hungry while their ladies were away. They survived!

Sydney and Mason

TENNESSEE

David Tignor

Tennessee Hemophilia & Bleeding Disorders Foundation's (THBDF) helds it 2nd annual ***Blazin' for Bleeders 5k Run/Fun Walk*** at picturesque Gateway Island in Murfreesboro Saturday, May 18th. With more than 100 registered participants, everyone was excited and ready to help raise awareness and funds for THBDF services and programs.

After the race, awards were given to the top runners in their age group and door prizes were given out at the end of the event. BioMatrix sponsored breakfast and coffee for everyone on hand and we very much look forward to supporting this THBDF community fund raising event next year!

[BIOMATRIX] ON THE MOVE

MISSOURI

Maria Santucci Vetter

Where can one find an impressive group of factor IX families? At a Coalition For Hemophilia B meeting, of course! As part of the Coalition's ***Meetings on the Road*** series, families affected specifically by factor IX deficiency gathered June 1st at the Marriott St. Louis Airport for a full day of interesting sessions and camaraderie. Since those with factor IX are less common, the meeting was attended by just a few families making it an intimate and more uniquely bonding experience.

Following a warm welcome by Dr. David Clark, Chairman of the Coalition, sessions began with a presentation by Pfizer's Hemophilia Patient Affairs Liaison Joe Schuch. Joe's talk covered *Constructive Communications 2.0*, which highlighted tools to assist with effective interaction and communication. Penny Smith RN, Case Manager at the Hemophilia Treatment Center at Intermountain Healthcare in Salt Lake City Utah, followed with an overview of the B-HERO-S survey. The survey taken by 290 patients and 150 caregivers of hemophilia B patients gathered responses, showing how hemophilia B patients and caregivers feel about education, employment and quality of life.

Adorable siblings! Danny and Lilyan.

Rick Starks, fellow factor 9 hemophiliac and martial arts teacher led everyone in a *Tai Chi Movements and Meditation* session. Rick brought along his zany sense of humor as he expounded the many benefits of Tai Chi.

Dr. David Clark leads the meeting.

Big smiles from Coalition volunteer Heidi and community members Joseph and Danny.

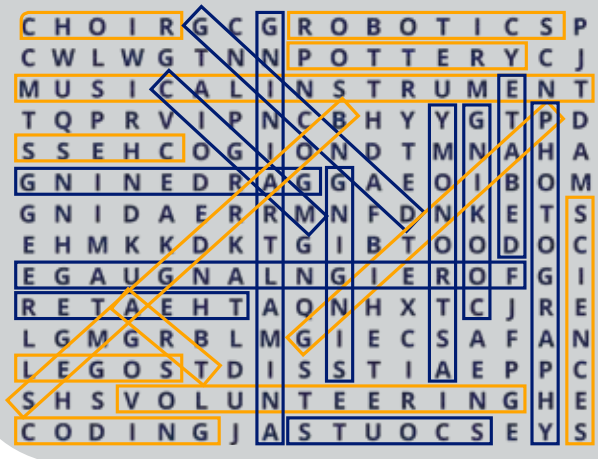
Athletic trainer Doug Stringham was up next with what was supposed to be a session on *Kinesio Taping*. However, the box of tape went missing. Doug didn't miss a beat though, improvising with a *Laugh Yoga* session that had us all belting out hardy chuckles – at what, we weren't sure, but it was hilarious! He also went on to explain, demonstrate, and have us practice exercises to help maintain range of motion.

The final session of the day had Dr. Clark covering products and treatments on the horizon for factor 9 patients. The fantastic meeting wrapped up with the drawing of raffle prizes and a delicious Italian dinner.

Many thanks to Kim Phelan, Coalition Vice President, and her amazing staff and volunteers for their dedication to bringing such high-quality and enjoyable programming to this particular group. More Coalition Meetings on the Road are scheduled. Factor IX families – make a point of attending. You won't be disappointed!

Upcoming Coalition B *Meetings on the Road*:

Oct. 19 – Columbus, OH
Oct. 19 – Knoxville, TN
Oct. 26 – Seattle, WA
Oct. 26 – Atlanta, GA
Nov. 2 – Baton Rouge, LA
Nov. 2 – Fort Smith, AR
Nov. 9 – Schaumburg, IL
Nov. 9 – Phoenix, AZ



ANSWERS FOR PUZZLES ON PAGE 39.

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

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

Now Accepting Applications for the 2019/20 School Year!

BIOMATRIX MEMORIAL SCHOLARSHIP PROGRAM

APPLY ONLINE by AUGUST 1st!

http/bit.ly/BioMatrix-Scholarship

The BioMatrix family of companies offers six $1500 educational scholarship opportunities to students diagnosed with hemophilia or von Willebrand Disease, and in the case of two of the scholarships, immediate family members may also apply.

These scholarships are in memory of several amazing individuals who brought remarkable qualities and skills together in a way that truly touched the community they were dedicated to serving. Their efforts to make a difference in the lives of people with bleeding disorders will not be forgotten and shall be carried on with these scholarship opportunities.

We have partnered with Hemophilia Federation of America (HFA) to administer our scholarship program. Partnering with HFA allows us to streamline and enhance our program with an organization that knows and understands the bleeding disorders community.

Apply online by visiting:
http://bit.ly/BioMatrix-Scholarship

The application may also be accessed by visiting:
https://matrixhealthgroup.com/scholarships/
or
scholarships@hemophiliafed.org

Joe Holibaugh (1971-2006)
$1500 Scholarship
For MEN and WOMEN with hemophilia AND an Inhibitor

Tim Kennedy (1962-2011)
$1500 Scholarship
For MEN with hemophilia

Millie Gonzalez (1953-2001)
$1500 Scholarship
For WOMEN with hemophilia or von Willebrand Disease

Ron Niederman (1950-1999)
$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mike Hylton (1945-1998)
$1500 Scholarship
For MEN with hemophilia or VWD and their immediate family members

Mark Coats (1956-1963)
$1500 Scholarship
For MEN and WOMEN with hemophilia

UPCOMING EVENTS

July 12-14, 2019 MISSOURI
Gateway Hemophilia Association
314-482-5973, gatewayhemophilia.org
Family Education Weekend
Doubletree Hotel
Chesterfield

July 18, 2019 PENNSYLVANIA
Western PA Hemophilia Foundation
800-819-0862, wpcnhf.org
Chapter Annual Meeting
Dave and Busters; Pittsburgh

July 19-21, 2019 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Northern Nevada Family Education Day
Elko Convention Center; Elko

July 20, 2019 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
First Elko Unite for Bleeding Disorders Walk
Main City Park; Elko

July 24, 2019 FLORIDA
BioMatrix and Bayer
Peggy Klingmann 864-275-0246
Educational Dinner
Roy's Restaurant; Tampa

July 26-28, 2019 FLORIDA
Florida Hemophilia Association
305-235-0717, floridahemophilia.org
36th Annual Florida Bleeding Disorders Conference
Hilton Palm Beach Airport

July 27, 2019 NEW MEXICO
Sangre de Oro, Inc.
505-341-9321, sangredeoro.org
Back to School Event
Lucy Bowl 66; Albuquerque

Aug. 2-4, 2019 CONNECTICUT
New England Hemophilia Assoc.
781-326-7645
newenglandhemophilia.org
Women's Retreat
Guest House Retreat and Conference Center; Chester

Aug. 2-3, 2019 IDAHO
Idaho Hemophilia Foundation
208-344-4476, idahoblood.org
Annual Meeting & Education Day
The Grove Hotel; Boise

Aug. 2-4, 2019 OHIO
FAMOHIO
614-344-1075, famohio.org
Family Annual Meeting of Ohio "Bleeding Disorder Safari"
Columbus Marriott NW; Dublin

Aug. 3, 2019 FLORIDA
BioMatrix and Bayer
Contact: Peggy Klingmann 864-275-0246
Educational Lunch
Hillsborough River State Park
Thonotosassa

Aug. 10, 2019 FLORIDA
Foundation Hope & Life USA
786-534-2900, www.fhlusa.org
Back 2 School Awareness
Firefighters Memorial Building
Miami

August 10, 2019 TENNESSEE
TN Hemophilia & Bleeding Disorder Found.; 888-703-3269, thbdf.org
Pitchin' for Caleb Cornhole Tournament
Centennial Park; Crossville

Aug. 16-18, 2019 TENNESSEE
Tennessee Hemophilia & Bleeding Disorder Foundation
888-703-3269, thbdf.org
Annual Meeting
Holiday Inn Downtown
Knoxville

Aug. 18, 2019 VIRGINIA
Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
HACA Chapter Picnic
The Water Mine; Reston

Aug. 24, 2019 KENTUCKY
Kentucky Hemophilia Foundation
502-456-3233, kyhemo.org
Annual Education Meeting
Hyatt Regency Hotel; Louisville

Aug. 26, 2019 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Board of Directors Annual Meeting
Crown Plaza; Burr Ridge

Sept. 6-8, 2019 VIRGINIA
Hemophilia Assoc. of the Capital Area
703-352-7641, hacacares.org
HACA Women's Retreat
Meadowkirk at Delta Farm
Middleburg

Sept. 6-8, 2019 CALIFORNIA
Hemophilia Found. of Northern CA
510-658-3324, www.hemofoundation.org
Hemophilia Found. of Southern CA
626-765-6656, https://hemosocal.com
Central CA Hemophilia Foundation
916-448-0370, www.cchfsac.org
Hemophilia Assoc. of San Diego County
619-325-3570 https://hasdc.org
www.familiadesangre.org
Familia de Sangre
Anaheim Marriott; Anaheim

Sept. 08, 2019 NEW YORK
New York City Hemophilia Chapter
212-382-2974, nyhemophilia.org
Bilingual Back to School Event
Marriott Downtown; New York City

Sept. 10, 2019 FLORIDA
BioMatrix and Takeda
Contact: Peggy Klingmann 864-275-0246
Educational Dinner
Grillsmith Restaurant; Lakeland

Sept. 10, 2019 PENNSYLVANIA
Eastern Pennsylvania Chapter NHF
484-445-4282
hemophiliasupport.org
Golf Classic
Rivercrest Golf Club; Phoenixville

Sept. 14, 2019 ILLINOIS
Bleeding Disorder Alliance Illinois
312-427-1495, bdai.org
Hemophilia Walk
Lincoln Park; Chicago

Sept. 14, 2019 NEVADA
Nevada Chapter NFH
702-564-4368, hfnv.org
Unite for Bleeding Disorders Walk
Bartley Ranch State Park; Reno

NATIONAL EVENT!

OCT. 3-5, 2019

ANAHEIM, CALIFORNIA

NHF Bleeding Disorders Conference

NATIONAL HEMOPHILIA FOUNDATION

212-328-3700
www.hemophilia.org

71st BLEEDING DISORDERS CONFERENCE
Anaheim Convention Center, Marriott and Hilton Convention Centers

TIME FOR FUN!

HI KIDS! Sports can be fun and it's healthy for kids with a bleeding disorder to be physically active. However, there are many activities and clubs for kids who aren't interested in or able to play sports. See if you can find some alternative activities listed in the Word Box in this Word Search puzzle. Search up and down, forward and backward, and diagonally. Good luck! Answers are on page 36.

WORD BOX

ART
CHESS
CHOIR
CODING
COOKING
DANCING
DEBATE
LEGOS
MAGIC
PAINTING
POTTERY
READING
ROBOTICS
SCIENCES
SCOUTS
SINGING
THEATER
ANIMAL TRAINING
ASTRONOMY
BOARD GAMES
FOREIGN LANGUAGE
GARDENING
MUSICAL INSTRUMENT
PHOTOGRAPHY
VOLUNTEERING

C H O I R G C G R O B O T I C S P
C W L W G T N N P O T T E R Y C J
M U S I C A L I N S T R U M E N T
T Q P R V I P N C B H Y Y G T P D
S S E H C O G I O N D T M N A H A
G N I N E D R A G G A E O I B O M
G N I D A E R R M N F D N K E T S
E H M K K D K T G I B T O O D O C
E G A U G N A L N G I E R O F G I
R E T A E H T A Q N H X T C J R E
L G M G R B L M G I E C S A F A N
L E G O S T D I S S T I A E P P C
S H S V O L U N T E E R I N G H E
C O D I N G J A S T U O C S E Y S

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

Sudoku!

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

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

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Weston, Florida 33331

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